ACCESS TO INFORMATION:
AN INVESTIGATION OF INFORMATION ACQUISITION BY PARENTS OF CHILDREN WITH DISABILITIES 0-6 YEARS, IN NEW SOUTH WALES.

A thesis submitted in satisfaction of the requirements for the Degree of Doctor of Philosophy

Merryl Uebel-Yan BA (Lib Sci)
Charles Sturt University
October 2007
TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>TABLE OF CONTENTS</td>
<td>3</td>
</tr>
<tr>
<td>LIST OF TABLES</td>
<td>10</td>
</tr>
<tr>
<td>LIST OF CHARATS</td>
<td>10</td>
</tr>
<tr>
<td>LIST OF APPENDICES</td>
<td>11</td>
</tr>
<tr>
<td>CERTIFICATE OF AUTHORSHIP</td>
<td>13</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>15</td>
</tr>
<tr>
<td>ETHICS APPROVAL</td>
<td>16</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>17</td>
</tr>
<tr>
<td>ABBREVIATIONS</td>
<td>18</td>
</tr>
<tr>
<td>CHAPTER ONE - INTRODUCTION</td>
<td>19</td>
</tr>
<tr>
<td>1.0 INTRODUCTION</td>
<td>19</td>
</tr>
<tr>
<td>1.1 THE AUSTRALIAN CONTEXT</td>
<td>21</td>
</tr>
<tr>
<td>1.1.1 Disability Statistics</td>
<td>22</td>
</tr>
<tr>
<td>1.1.2 Major Developments, Underpinning Legislation and Government Policy</td>
<td>23</td>
</tr>
<tr>
<td>1.1.3 Service Provision</td>
<td>26</td>
</tr>
<tr>
<td>1.1.4 Government Information Policy and Practice</td>
<td>27</td>
</tr>
<tr>
<td>1.1.4.1 Federal Government — Information Policy and Practice</td>
<td>27</td>
</tr>
<tr>
<td>1.1.4.2 NSW Government — information policy embedded in disability and related sector policy</td>
<td>30</td>
</tr>
<tr>
<td>1.1.4.3 Non-Government Organisation (NGO) Approaches to Information</td>
<td>32</td>
</tr>
<tr>
<td>1.2 INFORMATION ISSUES IN THE CHILDHOOD DISABILITY SECTOR — AN OVERVIEW</td>
<td>34</td>
</tr>
<tr>
<td>1.3 THE GAP IN CURRENT THEORY AND RESEARCH CONCERNING INFORMATION ISSUES IN THE CHILDHOOD DISABILITY SECTOR</td>
<td>38</td>
</tr>
<tr>
<td>1.3.1 Background</td>
<td>38</td>
</tr>
<tr>
<td>1.3.2 Library and Information Science Theory and Research</td>
<td>39</td>
</tr>
<tr>
<td>1.4 A PROBLEM OF PRACTICE</td>
<td>41</td>
</tr>
<tr>
<td>1.5 RESEARCH APPROACH</td>
<td>43</td>
</tr>
<tr>
<td>1.5.1 Research Design</td>
<td>43</td>
</tr>
<tr>
<td>1.5.2 Research Outcomes</td>
<td>44</td>
</tr>
</tbody>
</table>
CHAPTER TWO - LITERATURE REVIEW

2.0 INTRODUCTION

2.1 INFORMATION SEEKING, INFORMATION DELIVERY, INFORMATION ACQUISITION – REVIEW OF TANGENTIAL EVIDENCE

2.1.1 Service Factors – Program Quality, Service Needs and Satisfaction
2.1.1.1 Program Quality Indicators
2.1.1.2 Service Needs
2.1.1.3 Parental Satisfaction/Dissatisfaction
2.1.1.4 Components of Care, Measurement of Processes of Care
2.1.2 Family Factors
2.1.2.1 Stress, Coping and Information Seeking
2.1.2.2 Cognitive Information Styles

2.2 THE FAILURE OF RESEARCH TO INVESTIGATE ACCESS TO AND ACQUISITION OF INFORMATION AND THE PROBLEM OF CONCEPTUAL AMBIGUITY

2.3 INFORMATION NEED, SEEKING, DELIVERY AND ACQUISITION – REVIEW OF DIRECT EVIDENCE

2.3.1 Primary Research
2.3.1.1 Pain
2.3.1.2 Mitchell and Sloper
2.3.2 Information Research – New South Wales
2.3.2.1 Carers New South Wales (Carers NSW)
2.3.2.2 Families First

Conclusion

CHAPTER THREE – THEORETICAL FRAMEWORK

3.0 INTRODUCTION

3.1 ACHIEVING CONCEPTUAL CLARITY ABOUT INFORMATION, ACCESS TO INFORMATION AND RELATED TERMINOLOGY

3.1.1 Information
3.1.2 Access to Information
3.1.3 Information Need - recognition and awareness factors

3.2 A CONCEPTUAL FRAMEWORK FOR INFORMATION ACQUISITION

3.2.1 Information Seeking
3.2.1.1 Active Information Seeking
3.2.1.2 Information Grounding
3.2.1.3 Passive Information Seeking
3.2.2 Information Delivery
3.2.2.1 Proactive Information Delivery
3.2.2.2 Responsive Information Delivery
3.2.2.3 Passive Information Delivery
3.2.3 Serendipity

3.3 INFLUENCES/CONSTRAINTS ON INFORMATION ACCESS AND ACQUISITION

3.3.1 Awareness as a critical factor in acquisition
3.3.2 Anomie
3.3.3 Unrecognised and Latent Information Needs
3.3.4 Personal Factors – Information Styles
3.3.5 Miscalibration
3.3.6 Knowledge Calibration, Perception of Knowledge and Decisions About Ignorance

CHAPTER FOUR – METHODOLOGY

4.0 INTRODUCTION

4.1 BACKGROUND TO THE RESEARCH

4.1.1 Research Objectives
4.1.2 Research Questions

4.2 DATA COLLECTION METHODS

4.2.1 Mapping the Information Milieu
4.2.2 Parent/Carer Interviews
4.2.2.1 Pilot Study
4.2.2.2 Administration
4.2.2.3 Recruitment
4.2.2.4 The Participants
4.2.2.5 The Setting
4.2.2.6 The Interviews
4.2.3 Information Service Provider Statistics
4.2.3.1 The Array of Information Service Providers
4.2.3.2 The Role of Information Service Provider Statistics for Data Collection
4.2.3.3 Early Childhood Intervention Association (ECIA) Infoline
4.2.3.4 ECIA Infoline Data Collected

4.3 DATA REDUCTION AND ANALYSIS

4.3.1 The Information Milieu
4.3.2 Parent/Carer Interviews
4.3.2.1 Part 1
4.3.2.2 Part 2
4.3.3 Analysis of ECIA Infoline Usage Statistics
4.3.3.1 Usage Profile
4.3.3.2 Parent Information Needs
4.3.3.3 Problem Areas for Families
4.3.3.4 Information Diffusion Pattern 165
4.3.3.5 The Role of the Professional 166
4.3.3.6 Comparison of Infoline Data and Parent Interview Part 1 Data 166
4.3.3.7 Comparison of Infoline Data and Parent Interview Part 2 Data 166

4.4 PROBLEM AREAS AND POTENTIAL SOURCES OF BIAS 167

4.4.1 Maintaining Distance/Objectivity 167
4.4.2 Retrospective Analysis – Recall Bias 168
4.4.3 Length of Interviews and Saturation of Themes 169
4.4.4 Secrecy and Deception 170
4.4.5 Recruitment of Parents from EI Services 171
4.4.6 Response Bias 171

4.5 IMPROVING DATA INTEGRITY 172

4.5.1 Method and Source Triangulation 172
4.5.1.1 Method Triangulation 172
4.5.1.2 Source Triangulation 172
4.5.2 Interview Sample Size and Saturation of Themes 173

CHAPTER FIVE - RESULTS 175

5.0 INTRODUCTION 175

5.1 MAP OF THE INFORMATION MILIEU 175

5.2 THE INFORMATION NEEDS OF PARENTS OF CHILDREN WITH DISABILITIES 179

5.2.1 Information Needs – subject matter 179
5.2.1.1 Immediate Needs 179
5.2.1.2 Emergent Needs 182
5.2.2 Information – quality criteria 183
5.2.2.1 Quantity/Volume of Information 183
5.2.2.2 Timing 185
5.2.2.4 Accuracy 186
5.2.3 Information Needs – Information Access 186
5.2.3.1 Accessibility and Clarity 186
5.2.3.2 Format and Style 187
5.2.3.3 Organisation of Information 188

5.3 PARENT/CARER INTERVIEWS 189

5.3.1 Parent/Carer Demographics and Child Characteristics 189
5.3.1.1 Parent/Carer Demographics 190
5.3.1.1.1 Highest Educational Level Attained 191
5.3.1.1.2 Employment, Study and Childcare 191
5.3.1.1.3 Marital Status and Parent Age 192
5.3.1.1.4 Health Insurance Status 192
5.3.1.2 Child Characteristics 193
5.3.1.2.1 Diagnosis 193
5.3.1.2.2 Age and Gender 193
5.3.2 Modes of Information Acquisition 193
5.3.2.1 Information Seeking 195
5.3.2.1.1 Active Information Seeking 196
5.3.2.1.2 Information Grounding 200
5.3.2.1.3 Passive Information Seeking 206
5.3.2.2 Information Delivery 208
5.3.2.2.1 Proactive Information Mediation 209
5.3.2.2.2 Responsive Information Delivery 213
5.3.2.2.3 Passive/Generic Information Delivery 216
5.3.2.3 Serendipity 222
5.3.3 Issues Affecting Information Access and Acquisition 228
5.3.3.1 Modes of Information Acquisition – Frequency of Use, Use Determinants, Utility and Failure Points 228
5.3.3.1.1 Information Seeking – Active Information Seeking 229
5.3.3.1.2 Information Seeking – Information Grounding 236
5.3.3.1.3 Information Seeking – Passive Information Seeking 247
5.3.3.1.4 Information Delivery – Proactive Information Mediation 250
5.3.3.1.5 Information Delivery – Responsive Information Delivery 259
5.3.3.1.6 Information Delivery – Passive/Generic Information Delivery 265
5.3.3.1.7 Serendipity 278
5.3.3.2 Awareness of Information and Services - Quantitative Data 280
5.3.3.2.1 Demographics and Awareness of Formal Information Service Providers – Comparative Analyses 281
5.3.3.2.2 Information Style 282
5.3.3.2.3 Awareness of Benefits, Services and Entitlements 291
5.3.3.2.4 Information Style and Awareness of Benefits, Services and Entitlements 293
5.3.3.2.5 Proactive Professionals and Awareness of Benefits, Services and Entitlements 295

5.4 ECIA INFOLINE STATISTICS 297
5.4.1 Infoline Usage Profile 297
5.4.1.1 Information Seeker Types 297
5.4.1.2 Information Sought 298
5.4.1.3 Seasonal Fluctuations in Use 303
5.4.1.4 Usage Profile Summary 304
5.4.2 Parent Information Needs 305
5.4.3 Problem Areas for Families 307
5.4.4 Information Diffusion Patterns 308
5.4.4.1 Family Network 310
5.4.4.2 The Internet 310
5.4.5 The Role of the Professional 310

CHAPTER SIX - DISCUSSION 313

6.0 INTRODUCTION 313

6.1 HOW DO PARENTS ACQUIRE INFORMATION? 315
6.1.1 Information Seeking 316
6.1.1.1 Active Information Seeking
6.1.1.2 Information Grounding
6.1.1.3 Passive Information Seeking
6.1.2 Information Delivery
6.1.2.1 Proactive Information Delivery
6.1.2.2 Responsive Information Delivery
6.1.2.3 Passive/Generic Information Delivery
6.1.3 Serendipity

6.2 ISSUES AFFECTING INFORMATION ACCESS AND ACQUISITION

6.2.1 Causative Factors
6.2.1.1 Parent Information Style
6.2.1.2 Parent Knowledge Base and Effects of the Awareness Heuristic
6.2.1.3 Miscalibration of Professional/Provider Information Delivery Practices and Parent Information Behaviour, Assumptions, Expectations
6.2.1.4 The Proactive Professional
6.2.2 Associated Factors
6.2.2.1 Contextual Factors - Complexity of the Service Sector
6.2.2.2 Contextual Factors - Absence of Systematic, Coordinated Information Management
6.2.2.3 Contextual Factors - Inadequacy of Resources, Geographic Inequities and Unmet Need
6.2.2.4 Personal Factors - Parent Skills and Attributes - Perseverance
6.2.2.5 Personal Factors - Other Parent Behaviours
6.2.2.6 Family Circumstances
6.2.2.7 Parents From a Non-English Speaking Background (NESB)

7.0 INTRODUCTION

7.1 SUMMARY AND CONCLUSIONS

7.1.1 Modes of Information Acquisition
7.1.2 Issues Affecting Information Access and Acquisition

7.2 POTENTIAL AREAS FOR IMPROVEMENT IN INFORMATION ACCESS AND ACQUISITION

7.2.1 The Need for Achievable Outcomes
7.2.2 Development and Cross-Sector Implementation of Standard Working Definitions of Information and Associated Concepts
7.2.3 Development of Sectoral Information Management Standards
7.2.4 One-Stop-Shop
7.2.5 Mapping the Information Milieu - Navigational Aids
7.2.6 The Proactive Professional - Link Worker, Case Manager
7.2.7 Use of Naturally Occurring Phenomena
7.2.7.1 Reference Groups - Proximation Synchronicity

CHAPTER SEVEN - SUMMARY, CONCLUSIONS AND RECOMMENDATIONS
7.2.7.2 Value-Added Information Exchange 411

7.3 RECOMMENDATIONS 412

REFERENCES 417
APPENDICES 433
LIST OF TABLES

1.1 A Chronology of Developments, Policy and Legislation in the NSW Disability Sector 23
4.1 Participant numbers, early intervention service provider, centre, area 156
5.1 Participant numbers, early intervention service provider, centre, area 190
5.2 Children's diagnoses among participating parents 193
5.3 Infoline information seeker types 1998-2002 297
5.4 Infoline - information sought: comparison of major new categories by % of total calls (2002/3) 302
5.5 Infoline - sources of information diffusion by % of total calls 308

LIST OF CHARTS

5.1 Map of the Information Milieu of the Childhood Disability Sector (from the perspective of parent information need) 177
5.2 Educational attainment levels of participants 191
5.3 Parent awareness of information services, ratings across centres 281
5.4 Parent awareness of information services and educational level attained 282
5.5 Parent information style by centre attended 289
5.6 Parent information style and educational level attained 290
5.7 Parent information style and disability of child 290
5.8 Parent information style and age of child 291
5.9 Parent awareness of benefits, services and entitlements by centre attended 292
5.10 Parent use of information services compared with awareness of benefits, services and entitlements 292
5.11 Parent use of the Internet compared with awareness of benefits, services and entitlements 293
5.12 Parent information style and awareness of benefits, services and entitlements 294
5.13 Involvement of a proactive professional and awareness of benefits, services and entitlements 296
5.14 Infoline information seeker types: comparison across three years by % of total calls (2000-2003) 298
5.15 Infoline - information sought: comparison of four major categories across three years by % of total calls (1999-2002) 299
5.16 Infoline - information sought: comparison of four major categories across four years by % of total calls (1999-2003) 301
5.17 Seasonal fluctuations in Infoline use 303
5.18 Professional use of the Infoline on behalf of families compared with family use (as % of total calls minus administration calls) 2000-2003 311
<table>
<thead>
<tr>
<th>Appendix</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix 1</td>
<td>Parent Carer Interview Schedule</td>
<td>433</td>
</tr>
<tr>
<td>Appendix 2</td>
<td>Information Statement for Research Participants</td>
<td>437</td>
</tr>
<tr>
<td>Appendix 3</td>
<td>Information Needs of Parents of Children with Disabilities - A Comprehensive Listing by Subject Area</td>
<td>439</td>
</tr>
<tr>
<td>Appendix 4</td>
<td>Modes of Information Acquisition - Overview</td>
<td>443</td>
</tr>
<tr>
<td>Appendix 4.1</td>
<td>Modes of Information Acquisition - Information Seeking - Active Information Seeking - Information seeking in response to specific, recognised need</td>
<td>444</td>
</tr>
<tr>
<td>Appendix 4.2</td>
<td>Modes of Information Acquisition - Information Seeking - Active Information Seeking - Aware of gap or anomalous state of knowledge (actual or potential)</td>
<td>445</td>
</tr>
<tr>
<td>Appendix 4.3</td>
<td>Modes of Information Acquisition - Information Seeking - Information Grounding - Professional contact</td>
<td>446</td>
</tr>
<tr>
<td>Appendix 4.4</td>
<td>Modes of Information Acquisition - Information Seeking - Information Grounding - Networking</td>
<td>448</td>
</tr>
<tr>
<td>Appendix 4.5</td>
<td>Modes of Information Acquisition - Information Seeking - Information Grounding - Seeking out and actively using existing information resources</td>
<td>449</td>
</tr>
<tr>
<td>Appendix 4.6</td>
<td>Modes of Information Acquisition - Information Seeking - Information Grounding - Browsing parent libraries, resources centres, information services</td>
<td>450</td>
</tr>
<tr>
<td>Appendix 4.7</td>
<td>Modes of Information Acquisition - Information Seeking - Information Grounding - Browsing the Internet</td>
<td>451</td>
</tr>
<tr>
<td>Appendix 4.8</td>
<td>Modes of Information Acquisition - Information Seeking - Information Grounding - Attending information and skills development events or functions</td>
<td>452</td>
</tr>
<tr>
<td>Appendix 4.9</td>
<td>Modes of Information Acquisition - Information Seeking - Information Grounding - Membership of committees, review teams, forums, panels, parent representative functions on peak bodies, research participant</td>
<td>453</td>
</tr>
<tr>
<td>Appendix 4.10</td>
<td>Modes of Information Acquisition - Information Seeking - Passive Information Seeking - responding positively to visible/ available/known information</td>
<td>454</td>
</tr>
<tr>
<td>Appendix 4.11</td>
<td>Modes of Information Acquisition - Information Seeking - Passive Information Seeking - responding positively to what is offered without initiating the initial action</td>
<td>455</td>
</tr>
<tr>
<td>Appendix 4.12</td>
<td>Modes of Information Acquisition - Information Delivery - Proactive Information Delivery - Fellow parents, friends, family mediate information to family</td>
<td>456</td>
</tr>
<tr>
<td>Appendix 4.13</td>
<td>Modes of Information Acquisition - Information Delivery - Proactive Information Delivery - Professionals in the field</td>
<td>457</td>
</tr>
<tr>
<td>Appendix 4.14</td>
<td>Modes of Information Acquisition - Information Delivery - Responsive Information Delivery - Provider initiates Information exchange event and responds to requests for Information</td>
<td>459</td>
</tr>
<tr>
<td>Appendix 4.15</td>
<td>Modes of Information Acquisition - Information Delivery - Responsive Information Delivery - Provider responds to Parent request/s for information</td>
<td>461</td>
</tr>
<tr>
<td>Appendix 4.16</td>
<td>Modes of Information Acquisition – Information Delivery – Passive/Generic Information Delivery – Passive delivery of generic information resources</td>
<td>463</td>
</tr>
<tr>
<td>Appendix 4.18</td>
<td>Modes of Information Acquisition – Information Delivery – Passive/Generic Information Delivery – Passive delivery of information resources locally – brochures, noticeboards</td>
<td>467</td>
</tr>
<tr>
<td>Appendix 4.19</td>
<td>Modes of Information Acquisition – Information Delivery – Passive/Generic Information Delivery – Passive delivery of information resources locally – newsletters</td>
<td>469</td>
</tr>
<tr>
<td>Appendix 4.20</td>
<td>Modes of Information Acquisition – Information Delivery – Passive/Generic Information Delivery – Passive delivery of information resources – during appointments, tests, assessments, routine sessions, discussions</td>
<td>471</td>
</tr>
<tr>
<td>Appendix 4.21</td>
<td>Modes of Information Acquisition – Serendipity – Serendipitous event occurs in direct contact with another person</td>
<td>473</td>
</tr>
<tr>
<td>Appendix 4.22</td>
<td>Modes of Information Acquisition – Serendipity – Serendipitous event occurs as an unintended consequence of another action or event</td>
<td>474</td>
</tr>
<tr>
<td>Appendix 4.23</td>
<td>Modes of Information Acquisition – Serendipity – Serendipitous event occurs through exposure to formal media</td>
<td>475</td>
</tr>
<tr>
<td>Appendix 4.24</td>
<td>Modes of Information Acquisition – Serendipity – Information acquired for another purpose</td>
<td>476</td>
</tr>
<tr>
<td>Appendix 4.25</td>
<td>Modes of Information Acquisition – Serendipity – Stranger delivers information</td>
<td>477</td>
</tr>
<tr>
<td>Appendix 4.26</td>
<td>Modes of Information Acquisition – Serendipity – Information otherwise “stumbled across”</td>
<td>478</td>
</tr>
</tbody>
</table>
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* Subject to confidentiality provisions as approved by the University
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Proverbs 31:8 “Speak up for those who cannot speak for themselves”
ETHICS APPROVAL

The Charles Sturt University - Ethics in Human Research Committee approved this research. Approval protocol number 01/002.
ABSTRACT

Access to information, particularly as expressed in the acquisition of information, is of critical importance to parents of children with disabilities. Information is needed in order to obtain both a diagnosis of the child's condition, and the help and services required to support the optimal development of the child and healthy family functioning. Yet there is abundant evidence in the literature that "information problems" have beset the childhood disability sector for more than 25 years, notwithstanding fundamental changes to models of service delivery, policy and legislation. No information science perspective has been applied to the issue area.

This research sought therefore to investigate parental access to and acquisition of information from an information science perspective. Following exhaustive review of the research and sectoral documentation, together with the development of an information behaviour, need and seeking theoretical framework for approaching the problem area, a map of the information milieu was drafted. Data was then collected from 49 participants in interviews wherein a qualitative component addressed parental information access and acquisition through the employment of chronologies augmented by open-ended questions. A quantitative component recorded demographics and tested parental awareness and use of information available in the sector as detailed in the map. Statistical data was also acquired from the Early Childhood Intervention Infoline for triangulation. Data was then reduced into a conceptual framework developed by the author, detailing all the modes of information acquisition, their descriptions, defining characteristics and sample activities. The framework also yielded an analytical tool for identifying determinants of, and barriers to, the different modes of acquisition, and identification of specific failure points along with reasons for failure.

Parents acquired information through multiple mode subsets of information seeking, information delivery and serendipity, each subset represented activities from active through to passive. Significant differences in information behaviours and information acquisition were apparent among the participants. Four causative factors could be identified exerting a direct influence on parental capacity to acquire information, both in terms of theoretical access and specific acquisition activity; the first three were conceptualisations developed by the author to explain phenomena observed. They were parent information style, the awareness heuristic, and miscalibration of professional information delivery practice and parent information expectations regarding delivery. In addition, the involvement of a proactive professional with the family demonstrated a positive causal link with information acquisition. A number of associated factors were also identified that tended to exacerbate problems of information access and acquisition without being causative. They included complexity of the service sector, the absence of coordinated sectoral information management, unmet need, and parental skills and family circumstances.

Areas for improvement identified included the development and implementation of standard working definitions for information-related terminology and standardised information management, the creation of an information one-stop-shop, the development of sector navigational aids and the need for all parents to have access to a proactive professional. Further improvements would be made in harnessing the potential of reference groups and professionals value-adding to information exchanges with parents.
ABBREVIATIONS

AAP Committee on Hospital Care - American Academy of Pediatrics Committee on Hospital Care
ABS - Australian Bureau of Statistics
ACD - Association for Children with Disabilities
ADD - Ageing & Disability Department
AGIMO - Australian Government Information Management Office
AIHW - Australian Institute for Health and Welfare
Carers NSW - Carers New South Wales
CCYP - New South Wales Commission for Children and Young People
DADHC - Department of Ageing, Disability and Home Care
DCITA - Department of Communications, Information Technology and the Arts
Department of Health - New South Wales Health
DSA - Down Syndrome Association
ECIA - Early Childhood Intervention Association
ECICP - Early Childhood Intervention Coordination Project - Ageing and Disability Department
EI - early intervention
HSC - Higher School Certificate (NSW secondary schooling final examination after year 12)
ICF - International Classification of Functioning, Disability and Health
IFSP - Individual Family Service Plan
NOIE - National Office for the Information Economy
NSW - New South Wales
NSW CCYP - New South Wales Commission for Children & Young People
NSW Health - New South Wales Department of Health
OCYP - Office of Children and Young People
PADP - Provision of Appliances for People with Disabilities (a scheme of assistance in the provision of items, including nappies)
RTA - Roads and Traffic Authority (New South Wales)
SC - School Certificate (NSW secondary schooling external examination after year 10)
SDI - selective dissemination of information
SNSS - Special Needs Subsidy Scheme (a scheme funding pre school organisations to enable them to support children with disabilities in local preschool settings)
Techn. - technical education following secondary education taking place in a Technical and Further Education (TAFE) venue
WHO - World Health Organisation
CHAPTER ONE - INTRODUCTION

1.0 INTRODUCTION

One of the few characteristics common to most parents of children with disabilities is that they have never been the parent of a child with a disability before. They are in, what is for them, uncharted territory, an “unknown domain”. The diagnosis, and indeed the often tortuous times leading to a diagnosis, of a child with a condition that cannot be eliminated by medical intervention, presents parents with a set of novel predicaments (Gallagher, Beckman & Cross 1983; Pearson et al 1999). Seligman and Darling (1997, pp. 42, 43, 49) have described the “anomie” or normlessness parents experience upon discovery that their child has a lifelong disability. There is a sense in which the known world abruptly ceases, leaving the parents not knowing how to “be” – in this case the parents of a child with a disability. “When the diagnostic announcement is made, the world, as it was previously understood, becomes suddenly and inexorably transformed. It has, in effect, ruptured...The taken-for-granted world abruptly ceases to exist...” (Cohen 1993, pp. 82f.) The impact is enormous.

Child-focussed therapeutic and educational interventions, such as occupational therapy, physiotherapy, speech therapy and special education, are designed to be commenced in the early childhood intervention period (0 – 6 years) or at the time of diagnosis. They are intended to ameliorate symptoms and foster development (Larson 1998), improving outcomes for the child. Yet positive outcomes for families and their children with disabilities have been recognised as requiring more broadly based family support, rather than services that focus solely on the child (Sloper 1999).

Access to information, per se, is seen as a powerful socio-ecological resource (Beresford 1994), without which it is difficult, if not impossible, to gain entrée to the services, facilities and supports needed by the family and their child. Indeed, the literatures of child development and special education, psychology, social science, nursing and medicine uniformly agree on the importance of information to parents of children with disabilities. Information is seen to serve a range of functions and uses, including facilitating parental adjustment to the disability and coping emotionally (Pain 1999; Hopson 1986); decision making and taking action (Baine, Rosenbaum & King 1995); accessing benefits, services and resources (Pain 1999); enabling parents to act as
effective liaison between professionals working with the child (Tracy 1994) and advocating for the rights of the child as necessary (Dean 1975); ensuring the child has access to the optimal environment for his/her growth and development (Smith, Chung & Vostanis 1994); and enabling effective management of the child in terms of health, education, social adjustment etc (Pain 1999). Yet “information” is a significant issue area within the childhood disability literature. While “information” is often used in research as a “measurement of care” highly valued by parents (Baine, Rosenbaum & King 1995; King, Rosenbaum & King 1997; Rosenbaum, King & Cadman 1992), it is also commonly cited among parents as a source of dissatisfaction, and as an unmet need (Case 2000; Hall 1996; Kosciulek 1999; Larson 1998; Pearson et al 1999; Sloper 1999; Stallard & Lenton 1992).

It appears that a devolution in responsibility for information acquisition that has not yet been recognised may have occurred in the sector. As models of service delivery have shifted in emphasis from expert through consumer to family-centred practice (Case 2000) there has been a correlative shift in the role of parents from passive receptors of professional expertise to “experts about their child and family” (ADD 1997, p. 2). In turn, responsibility has subtly devolved to the parent to “become informed” such that he or she is in a position to play the role of expert, without this ever being properly understood or articulated. It is also the case that the focus of childhood disability research has tended to shift away from “the problems” to ways of coping with the problems, and in particular effective problem-focussed ways such as information seeking. This has had the effect of reifying the subtle shift onto the instrumental role of the parent in acquiring information.

Given the increasing emphasis on the instrumentality of parents in the acquisition of information, the research which is the subject of this thesis has sought to investigate how parents of children with disabilities acquire information, whether in seeking or other modes, and the points at which they fail to acquire and why this occurs. Particular issues that have an impact upon access and acquisition have thus been identified along with possible areas for improvement therein. The research focussed on four inner and northern suburbs of Sydney, and two rural areas on the South Coast of New South Wales to develop an understanding of the issues within the Australian context.
The research has taken a primarily qualitative approach as the most appropriate for an investigation where “descriptive data [were] gathered and analysed in order to ‘see’ the setting or activity from the participant(s)’ point of view” (Weingand 1993, p. 19), that is the parental experience of information access and acquisition. An important precursor to data collection among parents was a mapping of the information milieu, to identify what was potentially “knowable” to parents. Against this backdrop parents were interviewed regarding their information acquisition and their awareness of information. This yielded an understanding of the efficacy of parents’ acquisition modes and enabled the identification of failure to acquire and the reasons this occurred. The role of formal information service providers in the sector was also investigated.

This thesis presents the research as follows. Chapter 1 introduces the problem area and the research aiming to investigate it. Chapter 2 reviews the childhood disability sector literature pertaining to the information problem area. Chapter 3 presents a theoretical framework addressing the information problem area from an information behaviour, information need and information seeking perspective.

Chapter 4 details the methodology followed within the research and the reasons for its use. Chapter 5 presents the results of the data collection and Chapter 6 provides a detailed discussion of the problem area, synthesising the research findings with previous research and theory. Chapter 6 also includes new conceptualisations developed by the author to address a gap in current theory related to the awareness of information. Chapter 7 presents a summary of the research, conclusions and recommendations for action and further research.

1.1 THE AUSTRALIAN CONTEXT

The Australian disability sector enjoys no comprehensive one-stop-shop, as to both the complexion of disability in Australia and the services, resources and supports theoretically available. Indeed, the Australian Institute of Health and Welfare (AIHW 2004, p. 1) has recently observed that “research, practice and policy relating to children [with disabilities] have often been conducted in ‘silos’... meaning that information about children with disability is often difficult to find...”. The following information has thus been drawn together from an array of documents, including both those reporting
statistical analyses and interpretive commentaries, government policy papers, reports and reviews.

1.1.1 Disability Statistics

The Commonwealth and New South Wales governments are not currently in a position to identify accurately the number of children with disabilities in New South Wales, the nature of their disabilities and their service needs.

The 2001 Australian Census omitted data categories elucidating the numbers of people with disabilities in Australia, along with their specific impairments and service needs. A pre-trialled “Disability Question” was used in the 2006 Census (ABS 2003b), results from which will start to become available in 2007. Much current reporting tends to rely on the ABS Surveys of Disability, Ageing and Carers (SDAC), 1998 and 2003 (ABS 1999a, b, c, 2003a) which derived estimates of people with disabilities. There is however no statistical category covering the early intervention period (0-6 years) and the New South Wales females 0-4 years category has been subject to such high relative standard errors “as to detract seriously from their value for most reasonable purposes” (ABS 1999b, p. 20). The oft-quoted prevalence rate for children with disabilities is the Australian Bureau of Statistics (ABS) figure for all children with disabilities 0-4 years, reported as 4% in both 1998 and 2003 (ABS 1999a, p. 5, ABS 2003a, p. 5). In fact the figures, when not rounded, were 3.7% in 1998 (ABS 1999a, p. 15) and 4.3% in 2003 (ABS 2003a, p. 16), yielding a 0.6% increase. This may however relate to definitional changes. The ABS 2003 SDAC (ABS 2003a) used new definitions of disability as proposed by the World Heath Organisation (WHO) in the International Classification of Functioning, Disability and Health, ICF 2001 (ABS 2002). Although this has been said not to affect comparisons with earlier surveys, the AIHW (2004) has observed the significant problems attaching to the consistency of data collection around childhood disability issues. Such problems are not unique to Australia. Ehrenkrantz (2001) has made similar observations of the United States.

Under the Commonwealth State/Territories Disability Agreement (CSTDA) (see 1.1.2) the Commonwealth allocates funds to the States to support disability services. Statistics on disability are therefore also available from the CSTDA – Minimum Data Set (MDS) collections (AIHW 2001). However these data sets measure only those receiving
services, and not those who meet eligibility criteria, namely the "disabled population". The latter would include those for example on waiting lists, those either unaware of their eligibility for services or not having tested it, and those for whom appropriate services are not available. Hence CSTDA – MDS statistics cannot be used to establish the numbers of children with disabilities and their functioning, impairments and needs.

The significance of these points for this research, apart from knowing how many families may potentially be affected by the issues investigated, lies in the context they establish. For it is within the context of this population sub-group and its needs being imprecisely defined that parents of children with disabilities acquire or fail to acquire information about supports and services they may need.

1.1.2 Major Developments, Underpinning Legislation and Government Policy

There has been a series of developments having a fundamental impact on the functioning of the childhood disability sector, starting with the International Year of the Disabled in 1981. The progression of events, significant legislation and government policy are summarised in the table below, along with key points.

<table>
<thead>
<tr>
<th>Year</th>
<th>Development</th>
<th>Key Points</th>
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<tbody>
<tr>
<td>1981</td>
<td>The International Year of the Disabled</td>
<td>• Landmark in the development of public disability policy.</td>
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<tr>
<td>1984</td>
<td>Handicapped Programs Review</td>
<td>• Led to the Commonwealth Disability Services Act (DSA) 1986</td>
</tr>
<tr>
<td>1986</td>
<td>Commonwealth Disability Services Act (DSA) 1986</td>
<td>• Services agreeing to meet the needs of people with disabilities in more appropriate ways were provided with extra funding.</td>
</tr>
<tr>
<td>1991</td>
<td>Commonwealth State Disability Agreement (CSDA)</td>
<td>• Detailed Commonwealth and State responsibilities in policy structuring and disability services across Australia.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Each State required to enact legislation paralleling the Commonwealth Disability Services Act (DSA) 1986, in order to receive its allocation of Commonwealth funds under the Agreement.</td>
</tr>
<tr>
<td>1991</td>
<td>Early Intervention Coordination Project (EICP) commissioned</td>
<td>• To identify and assess the planning and delivery patterns of Early Intervention services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• To promote a consistent family centred approach to service planning and delivery</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• To develop a state-wide response to improve the planning, delivery and accountability of early intervention services and in particular</td>
</tr>
<tr>
<td>Year</td>
<td>Event/Act/Initiative</td>
<td>Description</td>
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| 1992 | Commonwealth Disability Discrimination Act (DDA) 1992 | - To recommend future directions for the planning and delivery of early intervention services throughout the State  
- Conducted trials in three pilot areas |
| 1993 | NSW Disability Services Act (DSA) 1993 | - Made discrimination on the grounds of disability unlawful.  
- Required all public and private sector educators and providers of services to make whatever adjustments necessary to allow people with disabilities to use those services to the same extent as other people. |
| 1993 | NSW Community Services (Complaints, Appeals & Monitoring Act) (CAMA) | - Only those services meeting the Aims, Objectives, Principles and Applications of Principles of the DSA were to receive funding. |
| 1994 | Early Childhood Intervention Coordination Project (ECICP) reviewed: Disability Direction: tomorrow's blueprint | - The goals of ECICP – the introduction of family-centred practice, based on information, accessibility and family decision making.  
- The need for “improved information” at crucial times. |
| 1995 | ECICP extended state-wide | - Used together with the DSA. |
| 1995 | NSW Ageing and Disability Department (ADD) formed | - Took lead agency role on ECICP  
- Child Disability Services remained in the remit of DoCS |
| 1997 | ECICP McRae evaluation | - Constraints to progress included uncertainty about the purpose and status of the Project  
- renamed “Early Childhood Intervention Coordination Program” (ECICP) |
| 1998 | 2nd CSDA | - Commonwealth responsibility primarily income support and employment assistance  
- States and Territories responsible for all other specialist disability services, including accommodation support, community support, community access and respite  
- Advocacy and information services were a shared responsibility. |
| 1998 | NSW Government Disability Policy Framework, developed by ADD | - Whole of government approach to ensuring community services accessible to people with disabilities.  
- State Government agencies required to develop Disability Action Plans setting out how services would be adjusted to make them accessible to people with disabilities. |
| 1998 | Families First commenced | - NSW government priority strategy, the Office of Children and Young People (within
<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
<th>Details</th>
</tr>
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<tbody>
<tr>
<td>2001</td>
<td>Department of Ageing, Disability and Home Care (DADHC) formed</td>
<td>DADHC-funded Local Support Coordinator role commences</td>
</tr>
</tbody>
</table>
| 2001 | | • Absorbed the functions of ADD  
• Removed Child Disability Services from DoCS |
| 2002 | DADHC new policy *Living in the Community: Putting Children First* | Documents DADHC’s directions, strategies and actions to support children with disabilities and their families/carers over the next five years  
• Articulates with NSW Health, NSW department of education and Training (DET) and NSW DoCS policies and practices and the ECICP |
| 2002+ | *Families First* expanding to include further regions | Focus is children 0-8 years, aiming to support parents/carers to solve problems before they become entrenched  
• Field of Activity 3 – Families Who Need Extra Support covers children with disabilities and children environmentally at risk, with emphasis on the latter |
| 2003 | DADHC undergoing massive restructuring | Regional focus with increased autonomy of regions |
| 2004 | ECICP review | Found Families First and ECICP confusion regarding the role, purpose and interface of each |
| 2004 | DADHC developed *Children’s Standards in Action* | Service standard requirements designed to support policy *Living in the Community: Putting Children First* |
| 2004 | *3rd CSTDA covering 2002-2007* signed off | New policy priorities included: strengthening access to mainstream services; collaboration and coordination across services; focus on individual needs |
| 2005 | DADHC introduce Integrated Monitoring System | To measure whether service providers provide the services, qualitatively and quantitatively, that they have been contracted to provide |

Table 1.1 A Chronology of Developments, Policy and Legislation in the NSW Disability Sector
1.1.3 Service Provision

In Australia, specialist support services are provided to:

Young children who are either at risk or who have developmental disabilities and delays, and to their families... At the child level, support services are designed to maximise the child's developmental and functional adaptation to their family and community environments. At the family level, the aim is to provide families with the support, knowledge and skills they need to meet the needs of the child and other family members. (Moore 1996, p. 20)

Porter and McKenzie (2000, p. 47) have described a set of issues parents of children with disability encounter, in the early childhood intervention period (0-6 years) in particular:

- Obtaining an accurate diagnosis
- Informing siblings and relatives about the child's disability and needs
- Locating services
- Seeking meaning in the exceptionality
- Clarifying a personal ideology to guide decisions
- Confronting social stigma
- Identifying positive contributions of the child's disability
- Setting high expectations
- Negotiating the involvement of professionals in the family
- Participating in early intervention services.

Health, medical, therapeutic, educational and ancillary supports and services can be seen to play a fundamental role as parents deal with these issues. Yet the location of, and negotiation to acquire, satisfactory services and professional involvement is rarely an easy process. The title of an Australian childhood disability sector publication informing parents and carers of benefits and services available, Through the Maze (ACD 2001a), eloquently reflects the status quo:

The mix of services and organisations varies from region to region, so the types of services available ... will depend on where [a family lives]. In some regions ... some services may be in short supply, or not available at all. It may not be fair but the fact is that often, to get the best services ... [a family will have] to fight very hard. (ACD 2001a, Using the Service System section, para. 2)

Although these comments were made by the Victorian Association for Children with Disabilities (ACD - VIC), they apply equally to NSW as is evident in the soon to be published NSW version of Through the Maze.
Indeed the problems of complexity and inequities in service distribution have been remarked on for some years. In 1994 a review of early intervention in New South Wales described the system as "a mosaic of disparate services" (Disability Direction 1994, p. 9). The most recent review of the ECICP affirms that the problems have continued, apparently unabated.

The field of early childhood intervention services is characterised by multiple players/providers across government, NGO and the private sectors, multiple and complex eligibility criteria, an environment that is constantly changing, diminishing resources, and complex and sometimes distressing issues for families. Families report that it is a maze; one for which there is rarely a readily available map. (DADHC 2004b, p. 26)

1.1.4 Government Information Policy and Practice

Since the mid-1990s, governments’ information policies have been formularised as never before, due in large part to the exponential growth of developments in communications and information technology. This section presents an overview firstly of the Commonwealth Government policy specific to information management and recent practice, followed by New South Government information policy embedded in disability and related sector documents.

1.1.4.1 Federal Government – Information Policy and Practice

An early report on the management of government information as a strategic resource stated that “Greater availability of information also allows citizens to become more active participants in government – better informed and better equipped to demand high standards of service” (NOIE 1997, Executive Summary and Recommendations - Our Reasons section, para. 4). A Steering Committee proposed an information management framework that would enable improved information management and thus access to information. (NOIE 1997, Executive Summary and Recommendations - The Information Management Framework section, paras. 1, 2).

The Working Group on Government Information Navigation, also convened around 1997, made recommendations for improving management of and access to Commonwealth government information based on principles such as: visibility, which “implies that agencies have a responsibility to actively make their information resources
known” and accessibility, which “implies that this information can be easily discovered by appropriate users” (Working Group on Government Information Navigation 1997, Background section, paras. 2, 3).

However, what has ensued in the intervening years has been a raft of objectives, policies and frameworks whose primary focus has been the utilisation of communications and information technology to achieve whole of government information management objectives. Broader issues arising in information management, for example how the information service principle of “access to government information” is actually achieved by communications and information technology, is assumed as a given rather than explored in the context of the variables. Any notion of information management as, for example, a “body of systematic principles governing the information environment” (Roberts 1996, p. 30) has been primarily anchored within the ambit of communications and information technology. Indeed it seems likely that the adoption of communications and information technology is being driven, at least in part, by a desire to reduce costs of service delivery and administration (NOIE 1997, Executive Summary and Recommendations - Our Reasons section, paras. 3, 6, 7). This has meant that information management strategies have not addressed broader issues of information access and acquisition in any comprehensive way.

Access to information by those with disabilities, and presumably their carers, was specifically identified by the National Office for the Information Economy (NOIE):

Australians will be able to use the information economy to make social and business contact; gain knowledge, information, education, assistance and income; access government services; and go about their everyday business with much more speed and convenience. These benefits will be profound for Australians whose disabilities or disadvantage make such transactions difficult. (NOIE 1998, ECONOMY Context section, para. 1)

The NOIE itself became defunct, superseded by the Australian Government Information Management Office (AGIMO) in 2004 (AGIMO 2004). Functions related to broader policy and research were transferred to the Department of Communications, Information Technology and the Arts (DCITA), although notably the absence of a broader information management perspective has continued (DCITA 2004). The Federal Government’s Online Strategy outlined in 2000 specifically recognised that a “challenge faced by users of large collections of information like the Commonwealth’s is to easily locate information” and that understanding of the Government’s structure
itself can inhibit access (NOIE 2000, Specific Action – Principles and Standards (iv) Metadata standards section, paras. 1,2). Yet the access and acquisition issues beyond those pertaining to the online environment have not been addressed.

In practice, the Australian Government’s approach to disability and service information delivery specifically, can be seen in the 2001 implementation of an Australia-wide network of Commonwealth Carelink offices. As at 2005 there were “65 ‘walk-in’ shopfronts throughout Australia” (Commonwealth Carelink Centres 2005a, Welcome to the Commonwealth Carelink Centres website section, para. 2). An introductory brochure states:

There are [sic] a wide range of services to support independent living in the community, but finding out about them or accessing them has been time consuming, difficult and confusing. Commonwealth Carelink Centres now provide a single point, nationally, for anyone to access this information quickly. (Commonwealth Carelink Centres 2005a, How Can a Commonwealth Carelink Centre Help Me section, para. 1)

This is managed at the regional level, whereby each region is operated by a local organisation which maintains databases pertaining to local services only, deriving from the local knowledge and expertise of the organisation. Access to information pertaining to another geographic locality is achieved by transferring inquiries to the appropriate Carelink Centre (Commonwealth Carelink Centres 2005a). A Commonwealth Carelink online services directory has also recently been implemented, which may be accessed via the Internet (Commonwealth Carelink Centres c. 2005b).

The Commonwealth Carer Resource Centre specifically distinguishes itself from Carelink. The Carer Resource Centre only serves carers, through information and referral, emotional support, counselling programs, a free carer support kit and other resources, and, in being able to provide information about services out of region. (Carers NSW 2005)

This research will ascertain the role of Commonwealth/State funded information services in the experience of parents of children with disabilities.
1.1.4.2 NSW Government – Information Policy Embedded in Disability and Related Sector Policy

The NSW Disability Policy Framework details priority action areas to be incorporated into agencies' Disability Action Plans, including the development of "ways of providing information about their services so that the information is accessible to people with a wide range of disabilities" (ADD 1998a, p. 23). This is in recognition of the fact that "Services will only be used if people know about them. And people will only know about them if information is provided in appropriate ways" [emphasis added] (ADD 1998a, p. 22).

The notion of awareness of information regarding available services and resources is also central to DADHC's policy Living in the Community: putting children first, noted earlier (see 1.1.2). "Families with a child/young person with a disability should have a clear understanding of the scope of support and assistance available to them" (DADHC 2002, p.12). A series of strategies underpin the DADHC policy. Of particular note to this research is the "Quality Communications" strategy in which DADHC undertakes to:

- Standardise information for families and carers about services available, service access points, roles and responsibilities etc
- Make information available in formats appropriate to the cultural and linguistic diversity of people interacting with the Department
- Make information available via the Internet, a phone information line, local offices, schools, hospitals and other appropriate community locations including shared service centres...
- Set up communication protocols with other NSW Government agencies involved in the support, care and education of children and young people with a disability (DADHC 2002, p. 26)

The ECICP Procedures Manual (ADD 1999) envisaged information exchange as one of the most important benefits of its program. Good information flow was seen as "the absolute key to the success of the Program" (ADD 1999, p.11). The Manual further observes: "Effective strategies need to be put in place to ensure this occurs. It doesn’t just happen" (ADD 1999, p. 11). The ECICP’s Local Network Committees have responsibility:

- To provide information that helps families to identify areas of concern about their child’s development and therefore access services as early as possible
- Clarify and record what services are available, eligibility criteria and referral processes
- Provide and promote accurate information about services available

Each representative of the committee has a responsibility to disseminate all relevant information to individual services, networks and the community. (ADD 1999, pp. 20f.)

The Families First strategy, noted at 1.1.2, further reveals NSW State government information policy affecting the disability sector, stating:

Through Families First, parents will receive support and information to help them foster their child’s growth and development. This information and support will be provided by a service network ...Families First will ensure that parents know how and where to get information about services so that they are in a better position to decide what help they would like for their families. [emphasis added] (Families First 2002b, pp. 3, 6)

The means of achieving the kind of access to information envisaged is not however made explicit. One of DADHC’s (2004c) recent publications Supporting Children and Young People with a Disability and Their Families describes the “Information and Referral” services provided by DADHC. It gives an interesting insight into the NSW State Government’s understanding of access to information.

DADHC is committed to providing relevant and quality information to children and young people with a disability and their families. Timely information can play an important role in ensuring children, young people and families are aware of supports available to them.

DADHC provides information and referral through the Regional contact numbers for information and assistance, available on the DADHC website. Through these contact points, DADHC provides information on supports available from a range of agencies [emphasis added] (DADHC 2004c, p. 6)

The salient fact here is that at the time parents are becoming aware that their child may have problems requiring investigation and most need to make contact with such “agencies” for support and service, they would be most unlikely to be aware of DADHC and its functions. Furthermore, such parents would not then have the capacity to make an informed search of the Internet for information which in all probability they would not know to exist. The regional contact numbers for information and assistance do not appear to be available in any other format.
This section looks briefly at Standards in Action: practice requirements and guidelines for services funded under the DSA, the more recently released Children's Standards in Action and Recommended Practices in Family-Centred Early Intervention, as they pertain to information access and delivery. These documents are significant in terms of information policy. The first has functioned as the industry standard in terms of service practice requirements and the second seeks to apply those same standards specifically to services working with children and young people. The third is significant as an implementation model for family-centred practice among early childhood intervention services. It is with early childhood intervention services that families of children with disabilities have the most contact during the child’s 0-6 years of age period.

Standards in Action (ADD 1998b) details NSW government practice requirements of services with respect to NSW Disability Services Standards. Information delivery can be seen to underpin much of the practice requirements. This starts with “Standard 1: Service Access” (ADD 1998b, p. 1.0.1ff) and continues throughout the Manual. Clients and their families are intended to be provided with information at every point; indeed an informing process prior to service entry is also envisaged.

It is also worthy of note that “Standard 3: Decision Making and Choice” as a Minimum Standard requires that “The Agency informs each service user of other services that might meet his/her needs” (ADD 1998b, p. 3.0.1). This research ascertains whether parent participants experienced this standard in practice.

The DADHC 2004 Children's Standards in Action (DADHC 2004a) was developed to support the Living in the Community: Putting Children First policy (DADHC 2002) and is intended to be used in conjunction with the Standards in Action (ADD 1998b). The 2004 standards were implemented after the data collection of parent interviews took place and therefore care has been taken not to measure actual service delivery reported by parents against these standards. However a review of these standards reveals little capacity to measure aspects of services’ information performance at all. The primary reference to what is conceptually information delivery occurs in “Standard 1 Service Access” (DADHC 2004a, p. 9), consistent with Standards in Action, as described above. This states:
Families should be provided with detailed information about their child’s disability and relevant community supports and services and have access to assessment as soon as possible once concern about development has been identified... Strategies to promote this include:

- Providing timely and user-friendly information in appropriate formats to children, young people and their families...
- Making available current information about appropriate services and supports (mainstream and specialist disability services, including therapy, early childhood services, local council services, education, recreation and sports...)
- Providing information about other families or relevant parent support groups.

(DADHC 2004a, pp. 9f.)

The poor quality of the standards in relation to information delivery is encapsulated in the statement “information should be provided on a range of issues” (DADHC 2004a, p. 10), where the standard of information delivery required, as to both mode and content, is not specified. Individual service providers are able to interpret what constitutes “providing information” and “making information available” and the nature and content of that information and its delivery. Significantly differing practices will inevitably emerge, or indeed continue, if for no other reason than conceptual ambiguity.

The final report of the NSW Government’s Early Intervention Coordination Project established eight standards governing best practice in early intervention. Of particular relevance to this research is the best practice aimed at ensuring families of children with special needs “have access to detailed information about their child’s disability and relevant services” (ADD 1997, pp. 21). Again, the crucial significance of these standards for this research lies as much in what is not stated as what is. While access to information and services is clearly central, the means of achieving access to information and its centrality to each of the standards is not made explicit. A largely responsive mode of information delivery can be inferred from some of the practices, yet it is also the case that there appears to be some expectation of acquisition of information through the instrumental actions of parents delivering information to each other:

it is recognised that there are many times when families find interactions with other families more useful than interactions with professionals. The similarity of family circumstances affords exchange of highly relevant information. (ADD 1997, p. 2)
Recommended Practices in Family-Centred Early Intervention (ADD 1997), which incorporates these standards, encourages services to “provide access to information”, “provide information for families” and to have “information made available”. (ADD 1997, pp. 14-16, 50) What these statements mean in terms of practice is open to interpretation by the provider.

Hence it is possible to identify an array of information-related policies, standards and best practice statements that ought properly to have a direct impact on information access and acquisition among parents of children with disabilities. The question then becomes whether they have had, and indeed have, the capacity to address the information issues raised consistently throughout the literature across more than 25 years, as overviewed below.

1.2 INFORMATION ISSUES IN THE CHILDHOOD DISABILITY SECTOR – AN OVERVIEW

A review of the literatures of child education, health and welfare, nursing and medicine, social science and psychology reveals considerable research effort within the childhood disability sector. A detailed Literature Review is found in Chapter 2. While early research tended to focus on disabilities and their impact, the movement away from a medical model of service delivery toward family-centred practice has opened various lines of research aimed at understanding and developing individual/family functioning, and, family/social support. In the context of these developments therefore, it is interesting to observe that a core set of information issues has consistently arisen or been reported throughout more than 25 years.

In 1975 Dean stated that there was a “lack of information on where to turn for appropriate educational services after diagnosis [of disability]... and a lack of information on how to change laws, rules and regulations which exclude handicapped children from needed services” (Dean 1975, p. 527). While Dean’s (1975) commentary pertained specifically to children in educational settings, it has been echoed through successive years in early childhood intervention generally. One might reasonably have assumed that years of changing policies, procedures, and indeed changes within the very models of service delivery toward more family-centred practice ought properly to have
resulted in some appreciable changes in parental experience of access to information within the childhood disability sector. This is especially the case given that one of the central tenets of family-centred practice is “sharing honest and unbiased information with families on an on-going basis and in ways they find useful and affirming” (AAP Committee on Hospital Care 2003, Core Principles of Family-Centred Care section, principle 6). This “support enables the family to assume power and control to make informed decisions and to be self-directed in their child’s care” (Epps & Jackson 2000, p. 90). However, the evidence is to the contrary, as the following overview demonstrates.

In 1983 Gallagher, Beckman and Cross reported that parents experienced problems as they attempted to obtain information about their child and services and in 1986 Mittler, Mittler and McConachie found the main parent complaint in special education was “lack of information” (cited in Mittler 1995, p. 31). Baxter (1989, p. 22) referred to considerable evidence of parental “dissatisfaction about such things as the extent and focus of information received”, while Stallard and Lenton (1992) also reported families as clearly dissatisfied with the amount of information they received. Sloper and Turner found in 1992 (pp. 271f) that “the greatest area of unmet need [among families of children with disabilities] related to the provision of information”. The same authors reported in 1993 “difficulties in obtaining access to and information about services” (p. 185) as a constant theme. Fyffe, Gavidia-Payne and McCubbery (1995 p. 36) found in research among families in rural Victoria that “Respondents consistently reported a lack of information”.

A review of research conducted between 1987 and 1997 on the needs of parents of chronically sick children by Fisher (2001, Discussion section, para. 6) concluded inter alia that “parents are still not satisfied with the information they receive”. Subsequently, Mitchell and Sloper (2000, p. 1) also referred to a number of studies finding “a substantial proportion of parents report that their needs for information remain unmet”. Watson, Townsley and Abbott’s (2002 Barriers to Information section, para. 1) review concurred, finding “evidence suggests that many [families] are neither getting the information they need, nor are satisfied with its quality and quantity”. Furthermore, in 2002 Mitchell and Sloper (Introduction section, para. 1) found it “unsurprising that many unmet financial, emotional and information-based support needs persist.” In 2003 Miller, Colligan and Colver (2003, Parents’ views on their need for general information
section, para. 2) found in research among families of children with cerebral palsy that parents believed "information sharing by professionals with each other and with families was inadequate." And indeed as recently as 2004 Damiani et al. found in research into the determinants of the use of respite services that difficulty in finding information was one of the most commonly cited barriers to use.

"Information" as a significant problem area has clearly beset the childhood disability sector for more than 25 years. Research specifically comparing the experiences of families of children with disabilities born 15 years apart confirms the contention that even in areas where "improvements would have been expected" (Pearson et al. 1999, Conclusions section, para. 1), such as in the delivery of relevant information at diagnosis, problems have continued unabated. It is noteworthy that these problems have been raised consistently in the literature over an extended period that has encompassed significant changes in policies, procedures and practices both locally and internationally (see 1.1.2).

It is also worthy of note that no information science perspective has been brought to bear on the problem area. When the literature is reviewed from an information science perspective a number of factors become immediately apparent. There is an extraordinary consistency in the general dissatisfaction reported with information delivery and in the experience of problems surrounding information content. Notwithstanding this, these matters have never been investigated as information problems per se, and generally arise within research either tangentially or as one of a number of characteristics functioning as a measurement or indicator. Mitchell and Sloper's recent works (2000, 2002) focusing specifically on information in terms of best practice is the first major research to give primacy to "information" within an investigation. They do not seek, however, to understand whether there may be underlying reasons for the on-going nature of the problems, beyond that they are by inference evidence of poor practice. (See Chapter 2)

Furthermore, such conceptual ambiguity attaches to the use of the term "information" and related terminology that considerable care must be taken in reviewing the literature. Inconsistent and often arbitrary use of terms such as information, advice, education, support and information delivery, provision, acquisition, seeking etc is widespread within the field. It has been further complicated by research participant (usually parent)
allusion to clearly information-related phenomena through the use of expressions such as “knowing about”, “being told about” and “being aware of”, frequently without explicit recognition by either the researchers or the parents that these do indeed reflect information phenomena. It is also the case that where researchers use information-specific terminology parents may take a particularly narrow definition of information (such as information in a book or brochure) and not consider that their experiences of not being able to find things out, or get advice or support, are information issues. Together these factors have clearly influenced parents’ capacity to identify and articulate the nature of information problems they have experienced and the reporting of those experiences. The professional response to information issues evidenced over the years, in research, policy and practice, has reflected the same ambiguity.

It is therefore important both to consider the information problems beyond those reported using information-specific terminology, and, to judge carefully what is actually in view when such terminology is used. This practice is applied in the Literature Review at Chapter 3, and, within data collection among parents in this research itself.

When the information problems arising as reported in the literature are reviewed, applying an information science perspective, there is a considerable degree of coherence and consistency. The problems can be seen as pertaining to information access and acquisition, in terms of both process and content.

Parents are failing to acquire information as and when needed, in styles and formats that are appropriate and meaningful. Lack of, or insufficient, information is a constant theme in research among parents of children with disabilities (Kerr & McIntosh 2000, Kosciulek 1999, Mittler 1995, Sloper & Turner 1993, Smith, Chung & Vostanis 1994, Watson, Townsley & Abbott 2002). Furthermore, the parental dissatisfaction reported in the literature seems to relate to two distinct subject content areas, namely:

- Lack of or insufficient information about help, services and assistance available
- Lack of or insufficient information about the individual child – the diagnosis, prognosis and all related information.
Access to information, used in the sense of information being accessible in process, form and content such that, all other things being equal, the acquisition of information results or has the greatest probability of resulting, thus underpins success or failure in the acquisition of information.

Mitchell and Sloper (2001, pp. 243f) reported in the “Sharing Value” Project that parents struggled to find information about available services largely because of the absence of a national strategy or system that offered accessible information. Centralised organisation of information as a significant facet of access, and in particular centralised in a type of one-stop-shop, is clearly in view. Indeed, Sloper (1999, p. 90) had reported earlier that “fragmentation of support” and the lack of an overall view of families’ needs had been exacerbated by “the lack of a single point of contact and coordination for families”. There is also abundant evidence across the literature of parents reporting the need for a central point of collection and delivery of information, such as a “one-stop-shop” (Dean 1975, Fyffe, Gavidia-Payne & McCubbery 1995, Mittler 1995, Stallard & Lenton 1992). In any event, coordinated, systematic organisation of the sector’s information resources, to increase the probability of access, appears to be occurring only in an ad hoc fashion at the micro level, and not occurring at all at the macro level in either Australia or the UK.

1.3 THE GAP IN CURRENT THEORY AND RESEARCH CONCERNING INFORMATION ISSUES IN THE CHILDHOOD DISABILITY SECTOR

1.3.1 Background

A significant theoretical and research gap became evident in the early stages of literature searching and review. No information science perspective had been sought or brought to bear on what were clearly identified as information issues in the early childhood disability sector, over very many years, as detailed above. The research effort in the sector has tended to be focussed within the disciplines of child education, health, welfare and development, nursing and medicine and social science and psychology. Inasmuch as it has been theoretically grounded, the theories generally applied in the sector (of potential relevance to information research) pertain to stress, adaptation and coping, within which information seeking or search is seen as a characteristic of
adaptive, vigilant or problem-focused coping (Folkman and Lazarus 1988). This may have some potential in attaining an understanding in part of the nature and causes of the information issues, since the literature itself inherently recognises that active information seeking is not a characteristic coping strategy all parents share or share equally (Beresford 1994). However, as attaining this understanding is not the purpose of those writers in any event, the information corollaries flowing remain uninvestigated. For example, what happens when parents are not characteristically active information seekers, or when they are not aware of the availability of potentially relevant information to seek?

Thus, as observed, while a considerable volume of research has, directly or indirectly, identified information as a problem for parents, it has not been possible to identify any research seeking to investigate the information issues per se. Even research on best practice in information delivery (Mitchell & Sloper 2000) has not been anchored in any theoretical understanding of the issues, but has as its starting point “what do we do now?” The net result is that there is no clear understanding of these information issues, their nature and scope and the reasons they have continued unaddressed through years of both research and changing policies and practices.

1.3.2 Library and Information Science Theory and Research

Library and information science itself as a discipline has not conducted any investigations in the early childhood disability area, and there are some problems in applying particular library and information science theories. There are many potentially relevant library and information science theories, among them those about information behaviour, information need and information seeking, which seem most relevant to the information issues described at 1.2. The detailed review in Chapter 3 does, however, expose some problems in applying the theories to the sector. The reasons for these application problems inform the design of this research, in the sense that no existing theory could be applied unamended to address the research problem.

Three characteristics in relation to information acquisition set the experiences of parents of children with disabilities apart from the everyday life experiences of other parents and community members generally. Firstly, the childhood disability sector is an unknown domain for almost all parents of children with disabilities. As they enter the
domain they are attempting to navigate unknown waters with virtually no extant knowledge base. Secondly, there is a chronicity of crisis dimension, sometimes called chronic sorrow (Krafft & Krafft 1998), whereby parents chronically re-enter the unknown domain with each new crisis or transition phase. Thirdly, there are frequently extremely high attendant stress levels (Cameron 1997) that may exert a direct influence on parents' information behaviour through the coping process (Beresford 1994; Folkman & Lazarus 1988).

The impact of these characteristics, in terms of the application of theory, is significant. Firstly, because parents are moving in an unknown domain, there is a high likelihood of failure to be aware of potentially relevant information because of inadequate knowledge base. This in turn may affect information literacy, the first step of which is the recognition of information need. Secondly, with the chronicity of crisis dimension, the problem of inadequate knowledge base constantly recurs. That is to say, there is no point at which the information need/delivery loop is finalised. Thirdly, the extreme levels of stress experienced carry high degrees of uncertainty and the information behaviours that flow may either be adaptive or maladaptive in nature. Hence theories pertaining to everyday life information seeking and community information, which would usually be applied in the non-technical user sector, have limited heuristic value in the childhood disability sector because they do not address the fundamental characteristics raised above.

Furthermore, as noted, Library and Information Science as a discipline is devoid of any direct research or theory pertaining to the childhood disability sector. Whilst some of Chatman's work (1986, 1991, 1996) among the poor has some relevance, for example, Gratification Theory applied to information seeking behaviour, and, Diffusion of Innovations Theory applied to information diffusion, it is not possible simply to transplant her adaptations into the sector. The defining, information-impacting characteristics of the poor are not fully analogous with those of parents of children with disabilities, though sharing some similarities. (See 2.3.1.2.).

It is necessary to turn then to Library and Information Science theories of information behaviour, need and seeking generally, to see a broad spectrum of approaches. These are analysed in detail in Chapter 3 for their utility to the childhood disability sector. However, none of the theories and core conceptualisations reviewed address the
childhood disability sector specifically nor, more importantly, make allowance for its defining characteristics.

1.4 A PROBLEM OF PRACTICE

As already observed, the movement from expert through consumer to family-centred models of service delivery (Case 2000) has seen a shift in the role of parents from passive recipients of professional expertise to that of “experts about their child and family” (ADD 1997, p. 2). Indeed the Local Support Coordinator role funded in a growing number of areas by DADHC, as also discussed earlier, is specifically premised on the understanding that individuals/families are best placed to identify their own needs (DADHC c. 2001). Indeed family-centred practice is seen to be:

based upon a collaborative partnership between parents and professionals based on a mutual recognition and valuing of their respective expertise, building on family strengths, and responding to family priorities. [emphasis added] (Moore 2003, p. 11)

However subtle, the instrumentality for family acquisition of information and services being vested in parents is seen here in the responsive stance taken by professionals. Parents must necessarily become initiators. The effect of the practice of family-centred service delivery, however unintended, has been to accord an importance to the capacity of parents to identify and articulate need for information and service. Yet it would seem this is exacerbating the information problems experienced in the sector by parents:

People ask you what help you want but you don’t know what you are entitled to and what is available... [emphasis added] (parent quote from Soper & Turner 1993, p. 185)

Professionals kept asking me what my ‘needs’ were. I didn’t know what to say. I finally told them, “Look I’m not sure what you’re talking about. So let me just tell you what happens from the time I get up in the morning until I go to sleep at night. Maybe that will help.” (quoted in Moore 2003, p. 13)

McCreadie and Rice (1999a, p. 64) yield an important insight from an information science perspective: “to gain access to information, a user must be aware that the means of addressing the situation are available” [emphasis added].
The practice of the family-centred model may well be assuming a degree of awareness that is simply not present. Moore has stated (2003, p. 12):

Despite family-centred practice being accepted as best practice in early childhood intervention service for a decade or more, there is often a considerable gap between the rhetoric of what professionals and services think and say they are doing and the reality of what they are actually providing.

This may have resulted, in part, from the failure of professionals to understand fully the nature of the information delivery required to support such practice and render it workable. It may well be that the changing models of service delivery have subtly shifted the responsibility for parental information acquisition, and hence awareness, from information delivery by providers onto information seeking by parents. This would certainly appear to be consistent with the changing research focus in the childhood disability sector literature from stressors toward stress, adaptation and coping, with the aim of fostering factors related to more effective coping, in particular problem-focussed coping strategies such as parent information seeking.

Thus the information behaviours required of both professionals and parents to render the model workable may be neither properly recognised nor practiced by either professionals or parents. For it is apparent that all parents do not share the same coping strategies and resources. Therefore, necessarily, inasmuch as there is information activity, such as seeking, there is also information inactivity or inaction, notwithstanding both information need and theoretically available information.

This leads to questions such as:

- How do parents acquire information? Does this occur through information seeking? What happens when parents do not seek information? Does acquisition occur in other modes?
- When parents do not acquire information what are the reasons? Is the information available? Is there an identifiable delivery and/or seeking failure? Do parents recognise their need for the information? Do parents recognise the relevance of the information?
- What other factors influence parental acquisition of information?
1.5 RESEARCH APPROACH

Clearly current childhood disability sector research and theory has failed either to investigate directly, or to explicate, the information issues raised in the sector over more than 25 years. Furthermore, changing models of service delivery toward more family-centred care would appear to be implicated in exacerbating some of the information issues. It was important therefore that these failures not impinge on the capacity of this research to explore what was in fact happening. The researcher therefore decided against utilisation of any pre-existing approach to understanding and interpreting parental experiences and instead took the following approach.

1.5.1 Research Design

The researcher was concerned to conduct sound information science research, informed by information science theory, within the childhood disability sector. Certain factors aided the design and conduct of the research. Firstly, no assumptions were made about the content of information activity among parents and there was no expectation of intersection with any information delivery systems. Furthermore, what the researcher took to constitute information activity/inactivity embraced the notion of information as that which informs.

Secondly, no assumptions were made about the information literacy capabilities of parents, and in particular, the capacity of the individual to recognise his or her own information need and to take action. All activity and, importantly, inactivity was investigated.

Thirdly, no attempt was made to “force” information issue exploration upon parents within the data collection. Parents were asked to give detailed chronologies, which revealed an array of information activity and inactivity, which they themselves described in terms of: knowing/not knowing, being/not being aware, and having/not having information, resources, data, knowledge, advice, support and help. By maintaining a broad view of information it was possible to identify themes that would almost certainly have been lost in a solely quantitative research design employing restrictive information terminology.
Fourthly, the researcher developed conceptualisations to bridge the gap in theory capable of explicating parental experiences in information access and acquisition. These conceptualisations have been incorporated with the Theoretical Framework at Chapter 3.

1.5.2 Research Outcomes

In his draft executive summary of the Strategic Framework for the Information Economy Kennedy identified as a key strategy “removing barriers and promoting enablers” (NOIE 2003, p. 7). Research on issues of information access and acquisition among parents of children with disabilities feeds directly into this strategy. If parents acquire information, what are the enablers? If parents fail to acquire information, what are the barriers?

Thus this research developed an original conceptual framework for analysing the acquisition of information among parents of children with disabilities, detailing all the modes of information acquisition, their descriptions, defining characteristics and sample activities. The framework also yielded an analytical tool for identifying determinants of, and barriers to, the use of the different modes of acquisition and identification of specific failure points along with the reasons for failure. In scoping parental information acquisition in this way, it became possible to identify specific issues affecting parental acquisition of information, together with appropriate means of addressing the barriers and failure points.
CHAPTER TWO - LITERATURE REVIEW

2.0 INTRODUCTION

This chapter reviews the childhood disability sector literature pertaining to the information problem area. As this body of literature provides no theory with the capacity to explicate the information problem area, Chapter 3 presents an information science-derived theoretical framework addressing the information problem area from an information behaviour, need and seeking perspective. Chapter 3 also includes new conceptualisations developed by the author to address a gap in current theory related to awareness of information.

The childhood disability sector literature uniformly agrees on the significance of access to information for parents of children with disabilities. Access to information is seen as a powerful socio-ecological resource (Beresford 1994), without which it is difficult if not impossible, to gain entrée to the services, facilities and supports needed by the family and their child. Dunst, Trivette and Jodry (1997, p. 499) described social support in the broadest sense as "resources — potentially useful information and things — provided to an individual or group" [emphasis added]. Certainly the family-centred practice and the professional collaboration which underpins family/social support and empowerment literature, presents information delivery to families as a core principle of family-centred practice (AAP Committee on Hospital Care 2003, Core Principles of Family-Centred Care section, principle 6; Epps & Jackson 2000, p. 90). This is also affirmed in the Australian sector, through key documents such as "Recommended Practices in Family-Centred Early Intervention" (ADD 1997, pp. 2, 5, 13).

There has been on-going development of indicators of service need and attributes, satisfaction and dissatisfaction, as described in research reviewed at 2.1.1. While this research has validated the importance of information to families, often as an unmet need, it has largely failed to specify all the information processes and outputs associated with needs and satisfaction. This lack of specificity renders addressing the information problem area far more difficult. The focus of some research does seem to be moving toward parent factors, reviewed at 2.1.2, especially those efforts to identify needs and to acquire help, including information. This is particularly evident in the stress and coping subset of the literature. This too is problematic, as parental information seeking is the
only aspect of the information problem area in view. Some research has begun to identify the need for proactive information delivery (Case 2000, 2001) and a link worker or care coordinator (Mitchell & Sloper 2000). However this has neither derived from an overall understanding of access to information and its acquisition (of which delivery is a subset), nor is it premised on any theoretical or evidentiary basis. Indeed this chapter demonstrates that the modes of information acquisition have neither been comprehensively explored nor systematically documented. Furthermore, no childhood disability sector research has sought specifically to understand barriers to access and acquisition of information, apart from stress and coping research observing that non-seeking can result in non-acquisition and the role of unhelpful professionals in failing to deliver.

After considering key service-related research at 2.1.1 and parent-related research at 2.1.2, this review outlines the failure of research to investigate adequately information access and acquisition among parents in the sector at 2.2. The small body of research specifically investigating various aspects of information and families of children with disabilities is reviewed at 2.3. It will become apparent that while adding to the understanding of particular aspects of the problem area, this body of research also does not yield a comprehensive understanding of information access and acquisition among parents of children with disabilities.

2.1 INFORMATION SEEKING, INFORMATION DELIVERY, INFORMATION ACQUISITION – REVIEW OF TANGENTIAL EVIDENCE

It will be apparent from the review at 2.3 that there is very little research seeking to investigate information issues specifically within the sector and virtually none from the perspective of information access and acquisition. Hence this section deals with aspects of information access and acquisition arising largely tangentially from research whose purpose was not the investigation of information issues per se.

Information seeking and information delivery are two fundamental aspects of access to information comprising modes of information acquisition. If information acquisition has occurred it must be possible to identify either some form of information seeking or
information delivery process at work. (Serendipity is in fact a third mode; see 5.2.1. However this phenomenon has rarely been reported in the childhood disability sector literature and never as a mode of information acquisition). This perspective has been helpful in identifying research that is relevant to the subject of information access and acquisition, whether information terminology is in use at all, or, used inconsistently and inappropriately. It has been necessary to approach the problem from this perspective because of the considerable conceptual ambiguity attaching to the use, and non-use, of information-related terminology within the literature.

Research around families of children with disabilities, with the greatest potential relevance to exploration of information issues, has tended to investigate either service-related factors or family-related factors. Service-related factors (see 2.1.1) have looked both at parental satisfaction/dissatisfaction and the elements of need that constitute variables in quality of service and care. The investigation of family-related factors (see 2.1.2) has tended to synchronise with the shift of emphasis from stressors and their deleterious effects toward parental adaptation and coping. The resultant focus has been on parent factors related to effective adaptation and coping.

Key research within each of these areas is explored below to identify their contribution to the study of information access and acquisition in the sector.

2.1.1 Service Factors – Program Quality, Service Needs and Satisfaction

Program quality indicators, service needs and satisfaction would seem to have some potential for exploring information access and acquisition, aspects of which ought properly to function as indicators of program quality and as variables in service needs and satisfaction. Parents frequently identify failure to acquire information as a stressor and source of dissatisfaction, as accurate and timely information remains to a great extent an unmet need (Case 2000; Hall 1996; Kosciulek 1999; Larson 1998; Pearson et al 1999; Sloper 1999; Stallard & Lenton 1992). Yet analysis reveals that this body of research also appears to replicate the stress and coping research failure to identify and utilise information-related concepts adequately.
2.1.1.1 Program Quality Indicators

Beamish and Bryer (1999a, b) report classic research on "recommended practices or programme quality indicators (PQI) ... [including] service delivery patterns, organizational structures, programming principles and values, and instructional strategies." (Beamish & Bryer 1999b, p. 461) This research sought to develop a valid set of program quality indicators not reliant on overseas measures but developed in the Australian context using a participatory action research model. An indicator listing was initially developed by "Key teachers [who] generated practices and collaboratively determined indicators of quality..." (Beamish & Bryer 1999b, p. 461). Stage 2 validation entailed critique of existing categories, measuring level of acceptance, rate of current use and barriers to implementation. The final stage sought to generalise the indicators across early intervention services throughout Australia by a questionnaire aimed at establishing levels of acceptance of the 31 indicators of program quality that had been developed. The program quality indicators, as they currently stand, must be set aside for the purposes of this research as they do not incorporate indicators that would enable satisfactory analysis of information access and acquisition and their role in the measurement of quality in programs.

2.1.1.2 Service Needs

Service needs research seeks to investigate parents' experiences of services from the perspective of service needs. Again there is some potential for exploration of aspects of information access and acquisition. Were parents within this body of research to be defining their service needs in relation to information more broadly than just in terms of the subject content of information, then issues such as ease of access to information and modes of acquisition could clearly be explored as information-related service needs. The latter is important because parents may have differing experiences of need depending on information acquisition preferences, whereas needs studies actually tend to look at common information subject content needs.

Sloper and Turner (1992) reported service needs research among 107 families of children with severe physical disabilities. This research was reported elsewhere as an investigation of risk and resistance factors (Sloper & Turner 1993, see 2.1.2.1). Children with severe physical disabilities and their families often experience needs for a complex
array of services. Recognising that there is some evidence of a significant mismatch between parent perceptions of need and professional perceptions, this study sought to identify family views on service help needed and the degree to which needs were met (Sloper & Turner 1992, pp. 260f). The psychological sequelae to met and unmet needs were subsequently reported in Sloper and Turner (1993). "Sequelae" is used in the sense of consequences, effects, results or implications.

The research utilised a predetermined list, namely the Perceived Needs Scale, thus parents were limited in what they could express as needs. It is noteworthy that when parents, in the open-ended part of the interview, were able without constraint to give their reasons for rating professionals as helpful, the majority (73%) reported "a combination of approachability, openness and honesty, giving information and listening to parents." [emphasis added] (Sloper & Turner 1992, p. 270) This contrasts with other aspects of helpfulness which were rated at figures such as empathy 19%, expert knowledge 14% and giving practical help 12% (Sloper & Turner 1992, p. 270). Clearly the primacy of information-related variables to parents is not reflected in the measuring instruments, (such as the Perceived Needs Scale).

The finding that high levels of unmet need were associated with, among other things, high maternal use of a coping strategy of passive optimism (Sloper & Turner 1992, pp. 274f.) is a cause for some concern. Sloper and Turner (1992) conclude that the connection between a passive coping strategy and unmet needs appeared to derive from mothers taking a less active approach to getting help and hence receiving less help in turn. This happened irrespective of actual need. Yet the research identified information itself as the highest area of unmet need. Given the high rate, this must have been the case irrespective of whether some families employed a passive coping strategy.

Sloper and Turner observe that the highest areas of unmet need occurred in areas for example “where services were not perceived by most parents to be available at all”, “where services were available but parents encountered difficulties and delays in obtaining help”, and “where parents were unaware of where help could be obtained or had attempted and failed to obtain appropriate help” [emphasis added] (Sloper & Turner 1992, p. 276). In fact each of these areas clearly reflects a problem with awareness of information, from specifics such as actual services available, to broader issues such as
overcoming waiting lists and taking political action to have needs met. Sloper and Turner (1992, p. 277) themselves observe:

It was not always apparent to parents where they should turn for help in meeting these needs and the information which would help them locate the appropriate service provider did not appear to be easily available.

Sloper and Turner (1992, p.277) conclude from this that if parents were passive in their coping strategy they would be less likely to obtain help. The research seems to suggest that to overcome the inherent problems of complexity and shortages of resources in the sector, parents need to be active in their coping strategy. This raises the question of what may happen were information delivered effectively to families, who may or may not have a passive coping strategy? Yet the emphasis in this paper is clearly on helping parents to become more active seekers of help. Sloper and Turner (1992, p. 277) state, in relation to families employing a passive approach who may be less likely to obtain help, “this raises the question of how such families can be helped to obtain appropriate and sufficient help and to take a more active role in dealing with problems.”

The research also reiterates the need for a “link person to facilitate the family’s contact with services” (reviewed under 2.1.6) but ultimately this role is seen also as:

aimed at encouraging the family in more active coping strategies in making use of the information to obtain help appropriate to problems as they arise. (Sloper & Turner 1992, pp. 277f.)

Yet the literature itself recognises that parents have differing capacities, strategies and resources (Beresford 1994). These would have a direct impact on behaviours in relation to information, whether seeking, delivery and acquisition of information or indeed application of information.

Sloper and Turner (1992, p. 278) do comment that “another aspect which would help parents to take an active approach to obtaining appropriate help is the provision of information …” [emphasis added]. This inherently recognises that information itself may trigger help seeking behaviours. It is also true that the majority of parents in this study seemed to want information, they certainly identified information as the greatest area of unmet need. However the research focusses upon getting parents to adopt active behaviours rather than the failure of information delivery mechanisms and the impact of that on families as expressed in unmet need. Indeed if the sector wishes to address
information acquisition failure among parents, problems in relation to which parents clearly report, not only do parents own information behaviours need to be examined, in every aspect not just seeking, but so too does information delivery. Any other factors affecting access to information ought also to be investigated.

The research of Perrin et al. (2000, Conclusion section, para. 2) into unmet needs among paediatricians committed to serving families of children with chronic health conditions, inherently recognises delivery failures and leaves the door open to the possibility of seeking to improve information exchange:

A mechanism must be found to integrate regular communication among parents and physicians about children’s and families’ long-term needs into the general health care supervision of children with chronic health conditions.

Perrin et al. (2000) were investigating the degree of concordance between parents and paediatricians in relation to unmet needs, using a needs index derived in part from Sloper and Turner’s (1992) work. Of particular relevance to parent information access is the analysis of differences between parent and physician perceptions of family needs in information delivery. The research does not however seek to understand parents’ differing modes of information acquisition and the role of the physician as a part of an overall process. Notwithstanding this, this is an important piece of research for the lack of concordance it reveals in relation to perceptions of need in information delivery. This is even more noteworthy when one considers that the physicians participating in this research were a group of those dedicated to serving the needs of children with chronic health conditions. Perrin et al. (2000) actually make the point that the data cannot reflect current standards among paediatricians because of the sample. It goes without saying that if information delivery is problematic among those dedicated to serving the needs of the group then general standards in information delivery are likely to be considerably lower.

The lack of concordance in key areas concerning information needs may go some way to explaining failures in information delivery from the parent perspective. Perrin et al. observe that “physicians noted significantly fewer needs with regard to both information and specific help than did either mothers or fathers” (Perrin et al. 2000, V. Concordance Between Parents and Physicians section, para. 4). This was particularly the case in relation to information about managing the child’s condition day-to-day, help for mothers in facilitating social contact and importantly “the parents’ need for help in
coordinating the child's overall health and developmental circumstances” (Perrin et al 2000, V. Concordance Between Parents and Physicians section, para. 5). It must be said however once again that families were restricted in the information-related needs they could report because of the use of a predetermined needs list. It is noteworthy that the latter category does parallel the care coordinator or link worker role recommended in the non-medical childhood disability sector research literature. The information access and acquisition factors that validate the importance of this role become evident in the analysis of Mitchell and Sloper’s (2000) work below (2.3.1.2). However these have not been identified per se in the literature nor been the subject of research.

Fyffe, Gavidia-Payne and McCubbery (1995) conducted family needs research in the Australian context. This is particularly interesting research as it questions whether the rhetoric of family-centred practice so readily adopted by professionals is actually understood and implemented in the sector. To this end the study looked at the characteristics of services families found the most and the least helpful. The findings in relation to access to information are noteworthy.

Families eligible to receive early intervention services in rural Victoria were eligible to participate, although it was not clear how those families were determined. Families of children with a range of disabilities volunteered to participate. Fyffe, Gavidia-Payne and McCubbery (1995) used three instruments to collect data, namely, the Family Needs Scale, the Family Support Scale and a structured questionnaire designed to elicit information regarding family and child characteristics, and, services used. The first two instruments comprised a self-report questionnaire completed by the 50 participants. Fifteen parents elected to participate in the follow-up interview. While 84% of the families responding actually received services, 40% received services only twice per month and 32% received less frequent service. This is in contrast to most Sydney-based early intervention services where service would be expected at least once per week. There are however significant waiting lists for services in many areas of New South Wales (DADHC 2004b, p. 17).

The problem of conceptual ambiguity arises again within this research and is most directly related to the use of Dunst, Trivette and Deal’s (1998) Family Needs Scale and Family Support Scale (Dunst, Trivette & Deal 1998 in Fyffe, Gavidia-Payne & McCubbery 1995). Variables from the scales were distilled into themes. The theme
"access to information and options" was used to report lack of information (Fyffe, Gavidia-Payne & McCubbery 1995, p. 36) especially in the early stages of finding out about the diagnosis and services. What is unclear is whether the lack of information arises from a failure of information delivery on the part of professionals or a lack of parent skill to seek available information, or indeed a combination of both. A subsequent parent quote, “I wouldn’t have known if it hadn’t been for other mums” (Fyffe, Gavidia-Payne & McCubbery 1995, p. 36), strongly suggests a failure of information delivery by professionals, as the parent would have been unable to seek information the existence of which she was unaware.

The theme “expectations of appropriate and coordinated services” was used to report the need for a central registry, referral point or key contact person (Fyffe, Gavidia-Payne & McCubbery 1995, p. 36). This is consistent with other research calling for a link worker or care coordinator, and indeed a one-stop-shop. Yet the access to information underlying this theme is simply not recognised, even though a parent is actually quoted saying: “If I hadn’t been introduced to the mum of another disabled child I would never have known what was really available and what it was fair to ask for” (Fyffe, Gavidia-Payne & McCubbery 1995, p. 36). Clearly this quote derived from a parent interview, which seems to suggest that the Scales used cannot adequately address the information issues parents wished to express. Furthermore, the researchers themselves have not recognised the information nature of this quote. Two highly significant information content needs are apparent, which have a direct bearing on family-centred practice. The cornerstone of family-centred practice is fully informed families articulating their needs for service. Yet in reality it is often only as parents become aware of what services other parents are receiving that they begin to realise what is available and what they can ask for. From this position parents can move to identifying what they really want. The starting point however is information, which provides awareness as to service possibilities and the means of both acquiring and coordinating them.

A third theme “the need for affordable services”, ostensibly non-information in nature, is also used to report an information acquisition problem. “Families reported ... difficulty obtaining knowledge about subsidy, funding etc” (Fyffe, Gavidia-Payne & McCubbery 1995, p.36). And again within a fourth theme, “the need to be respected by professionals”, the failure to acquire information directly relating both to personal
information seeking/negotiation skills and to professional information delivery failure, is not identified. Hence:

Parents felt "jobbed off" by professionals, especially in the early stages of seeking out information and services, and particularly from medical practitioners. (Fyffe, Gavidia-Payne & McCubbery 1995, p. 36)

This study is interesting as the participants acknowledged the importance of those aspects of service needs associated with family support models, yet identified many problems in areas associated with family-centred service delivery (Fyffe, Gavidia-Payne & McCubbery 1995, p. 38). Aspects of information, its access and acquisition, were clearly paramount among the problems described, although not always reported thus by the research, due to conceptual ambiguity. The highlight of the research lies in the family identified need for a key worker:

who can assist with access to information, services and resources. The key worker should know the family and service system well, facilitate identification of family needs, and promote relevant supports. [emphasis added] (Fyffe, Gavidia-Payne & McCubbery 1995, p. 38)

This is one of the few pieces of research recognising and articulating the families' need for assistance in identifying their own needs. Families are almost always, under the family-centred model, described as the expert in their own needs. Yet the key worker, in knowing the family and the sector well, is able to recognise need within the family, of which the family may not be aware, and mediate information to them on that basis. This is not responsive delivery to an articulated need by the family as expert, but proactive mediation of information in the context of relationship. The distinction is crucial to understanding parent access to and acquisition of information but the research itself does not explain why families have this need.

This research is nevertheless also very useful in identifying information-related flaws in the practice of family-centred service delivery. Particularly noteworthy is the recognition of meta-information issues in family-centred practice and its failure to find expression in families' daily-lived experience; for the role of awareness in information processes has great significance which is unremarked. Yet however useful the insights into family-centred practice, Fyffe, Gavidia-Payne and McCubbery's (1995) study does not yield a comprehensive understanding of information access and acquisition because of the failure to investigate the underlying reasons for access problems and failure to acquire.
2.1.1.3 Parental Satisfaction/Dissatisfaction

Satisfaction/dissatisfaction studies measure parents’ responses to professionals and services as they work with families. The factors contributing to satisfaction and dissatisfaction ought also potentially to provide useful insights into information access and acquisition were parents to define the nature and causes of dissatisfaction.

Case is a significant researcher in the field of parental service needs and dissatisfaction, and parent-professional relationships. In research among parents of children with disabilities Case (2000, 2001) sought to determine whether there are differences between what families need and what professionals provide, the latter study also exploring whether there have been improvements over time. The research emphasises the need for parents to define their own need rather than respond to research-driven categories.

Case (2000) observes that the bias introduced by the self-selecting nature of the sample (i.e. parents who contacted CATCH, a parent self-advocacy group, for help) precludes generalisation of the findings to all parents of children with learning disabilities. However it is worth observing that the findings are consistent with the dissatisfaction reported by parents in other studies, such as Hasnat and Graves (2000b). What makes these studies particularly noteworthy is that both of the samples used by Case (2000, 2001) comprise parents who are extremely active problem focussed copers (as evidenced by their action in contacting an advocacy organisation). Yet these parents report experiencing great difficulty acquiring satisfactory information from professionals, where difficulty is specifically defined as “professionals fail to ensure that parents have all the information they need” [emphasis added] (Case 2001, p. 843).

This casts considerable doubt on the potential efficacy of Sloper and Turner’s (1992) concern to assist parents to become more active in seeking information and support, with the aim of increasing the levels of help acquired. If parents who are active seekers experience difficulties acquiring information then this points to a problem within information delivery processes. The criticism voiced by parents in Case’s study (2001, p. 843) that professionals “Fail to ensure...” strongly suggests parents have an underlying expectation of, and need for, proactive information delivery. That is to say, the professional does not wait for parents to identify and articulate a need for
information, but delivers information according to an understanding of the family’s situation and potential need for information. This mirrors Quine and Pahl’s much earlier research (see 2.1.2.1) wherein they held, inter alia, that “Professionals who are in contact with families with mentally handicapped children should make sure that they are receiving all the financial benefits to which they are entitled” [emphasis added] (Quine and Pahl 1985, p. 516). Clearly this statement requires a type or mode of information delivery that is not merely the handing over of a brochure or the giving of a contact telephone number – proactive delivery of information in the context of relationship is the only possible way such a standard could be achieved. Yet the meta-structures of information acquisition are simply not recognised here, nor indeed in any of the childhood disability sector literature.

Pearson et al (1999) conducted research among parents of children diagnosed with learning disabilities to determine whether satisfaction with disclosure of diagnosis had improved over time. High levels of parental dissatisfaction with disclosure of diagnosis have been reported over many years (Pearson et al 1999). This research is reviewed because disclosure of diagnosis is itself delivery of information, albeit not described thus in the literature. (Indeed a specific distinction is often made between disclosure of diagnosis and delivery of information at disclosure of diagnosis.) This research, in common with other research (for example, Sloper & Turner 1992), emphasises the delivery of written information at the time of disclosure.

Pearson et al (1999) compared the perceptions of 23 sets of parents with children 0-5 years with those of 16 sets of parents with children 15-20 years, in relation to disclosure of disability. A questionnaire based on a model of disclosure of disability, covering delays, form and content of information given, follow-up service and satisfaction, was administered in parents’ homes. Pearson et al (1999) express some concern at the accuracy of recall of those parents for whom disclosure of disability occurred up to twenty years prior. Further research has been designed to overcome the “potential difficulties with using a retrospective method” by comparing parent perceptions of the younger children with parent perceptions of a newly diagnosed group (Pearson et al 1999, Discussion section, para. 1). However, both Foreman and Neilands (1991, p.256) and Taanila, Jarvelin and Kokkonen (1998, Discussion section, para 1) while recognising the need for caution, have pointed to an array of research indicating high degrees of accuracy in recall even 20 years after diagnosis.
Of particular note within the research of Pearson et al (1999) is the finding that while there appear to have been appreciable improvements in satisfaction with style of disclosure, one highly significant area has not seen expected improvements. That area was the quality of information delivered. Pearson et al (1999, Conclusions section, para. 1) observe "Some areas where improvements would have been expected, such as the provision of relevant information, seemed not to have changed". It is important to note that the study had considerable limitations deriving from its use of a benchmark model. That is to say, parents were required to respond according to a predetermined model of good practice in disclosure of diagnosis. Thus only those information acquisition problems addressed by the model could be explored. Issues such as the problem of awareness of information and its effects on information seeking efforts could not for example be canvassed.

Hasnat and Graves' study (2000b) of satisfaction with disclosure of disability, and the determinants of satisfaction, is especially interesting because it was conducted among parents in Australia. The study demonstrates the same conceptual ambiguities in relation to information as overseas studies, the same type of reliance on predetermined scales and variables and similar findings on the importance of information to parental satisfaction with disclosure of disability. The schedule of determinants of satisfaction was based on Sloper and Turner's (1993) study. Hence, as has been the case in the earlier reviewed studies, parents were immediately restricted in what they could report in relation to information issues. Of direct relevance to the study of information access and acquisition were the disclosure interview variables of:

- information received (amount, ease of understanding, ease of remembrance, use of 'technical' language, written information) ... and follow up (nature, opportunity to ask questions, opportunity for ongoing contact with disclosing professional) (Hasnat and Graves 2000b, Methods section, para. 6)

It is likely that follow-up, from an information science perspective, is a form of value-added information delivery, where there is structured potential for information exchange, information revisiting and information uptake assessment and so on.

The study found satisfaction to be related to "the manner of the disclosing professional and the information received" (Hasnat & Graves 2000b, Discussion section, para. 2). A statistically significant association was found between satisfaction with disclosure and
"the amount of information received" (Hasnat and Graves 2000b, Determinants of Satisfaction with Disclosure section, para. 1).

It is difficult to derive a greater understanding of parent information access and acquisition from this study. Yet it is Hasnat and Graves’ (2000a) parallel study into paediatricians’ disclosure practices that gives a remarkable insight into the reasons paediatricians may not deliver information. These have a direct impact on parental access to information and may be one of the foundational reasons for parents’ failure to acquire information, although it must be said that information issues were not being investigated from this perspective. Using a model of good practice in disclosure of disability, paediatricians’ practices in disclosure were quantified in a disclosure practice index, measuring 9 elements of good disclosure. These elements covered predetermined areas pertaining both to the conduct and content of the disclosure event and information delivery. Seventy-three per cent of the paediatricians responding claimed to deliver broad-based information (which would incorporate in addition to diagnosis, information on benefits, services and entitlements), yet only 31% indicated referral of parents to community services, suggesting conceptual ambiguity. This leads to the question of what exactly paediatricians understand by the term broad-based information.

Yet what is particularly relevant to this thesis are the reasons paediatricians gave for influences and constraints on their disclosure practices, which in reality presaged the failure to deliver information.

All paediatricians in the study reported that their disclosure practices are affected by parent characteristics... Most commonly, paediatricians mentioned that the intelligence or education [sic] level of the parents and the emotional state of the parents as influences on practices; both of these factors were mentioned by half of the paediatricians. (Hasnat & Graves 2000a, Reported Influences and Constraints on Disclosure Practices section, para. 1).

Paediatricians reported that parent intelligence affected the complexity and amount of information paediatricians delivered. This dovetails neatly with Hasnat and Graves’ (2000b) parallel study where parents’ satisfaction with disclosure was significantly associated with the amount of information delivered. Paediatricians also reported that the parents’ emotional state affected the pace at which news was broken:

the possibility of a disability in their child [was] introduced more slowly to parents who were perceived as not being able to cope with this information
This finding also dovetails with Hasnat and Graves’ (2000b) parallel study wherein parents’ satisfaction was significantly associated with the amount of information received. There is likely to be a connection between pace of delivery and parents’ perception of volume of information received. A parent quote elucidates this:

I don’t think it’s the responsibility of the paediatrician or neurologist to judge what parents can and can’t handle. If I’m sitting there and saying “give it to me” and I cry when they tell me, that’s my problem … it should be up to the parents to say how much information they want and it should be freely given. (Hasnat & Graves 2000b, Discussion section, para. 3)

While Hasnat and Graves’ (2000a, b) studies do not seek specifically to explore information access and acquisition among parents of children with disabilities, their work does give an important insight into a foundational reason for information access and acquisition failure among parents. The finding supports Baxter’s much earlier work (1989) looking specifically at parental access to community services as related to social status and the age of the child/adult.

These studies all point to the significance of professionals’ perceptions of parent characteristics, both as to intelligence and need, as having a profound impact on information delivery processes and hence parents’ access to and acquisition of information.

### 2.1.1.4 Components of Care, Measurement of Processes of Care

Some aspects of parent needs have been operationalised into processes or components of care. This body of research derives from an underlying concern regarding increased mental health problems and social disadvantage among families of children with disabilities. Rosenbaum, King and Cadman (1992, p. 103) state that “Since not all children and parents experience these mental health and social problems, it is reasonable to consider factors that minimise the risks for these problems”.

Rosenbaum, King and Cadman (1992), Baine, Rosenbaum and King (1995) and King, Rosenbaum and King (1997) conducted further studies exploring parent perceptions of caregiving, with a view to encouraging those aspects of services promoting parental
well being. In Rosenbaum, King and Cadman (1992) and Baine, Rosenbaum and King (1995) parents responded to a researcher-derived set of components of care (COC). Parents both assessed the validity of each item and reported its actual efficacy in terms of their own stress reduction. However the specific role of parents in developing the original list of components of care is not obvious. King, Rosenbaum and King (1997, p. 49) developed an instrument Measure of Processes of Care (MPOC) “with extensive input from families”. The differences between the two instruments are noteworthy. Aspects of the information process appear among the 22 COCs as “education/information”, “advice on development” and “anticipatory guidance” (Rosenbaum, King and Cadman 1992, pp. 109, 111f.). In contrast, the MPOCs include 9 items relating to “providing general information” and 5 items relating to “providing specific information about the child” (King, Rosenbaum and King 1997, p. 52). There is nevertheless within King, Rosenbaum and King (1997) a failure to recognise the information base of the other items, in particular “enabling and partnership”, which cannot occur if parents are not fully apprised of meta-information.

Findings from the earlier two studies strongly suggest that families consistently endorse the significance of “education/information” as an important aspect of caregiving (Rosenbaum, King & Cadman 1992; Baine, Rosenbaum & King 1995). The third piece of research, seeking specifically to address family-centred aspects of caregiving, accords far greater significance to information-related categories (King, Rosenbaum & King 1997). Its flaw, as already observed, lies in the failure to recognise the information base to all the processes of care, and in particular “enabling and partnership”.

Two of these studies make explicit the importance to families of information for example in reducing stress (Rosenbaum, King & Cadman 1992; Baine, Rosenbaum & King 1995) and the third provides evidence of parent support for aspects of the information process as valid components for measuring service family-centredness. Yet in terms of attaining to an understanding of information access and acquisition among parents of children with disabilities, the conceptual ambiguity regarding information-related factors is significantly problematic. King, Rosenbaum and King (1997) do refreshingly define “providing general information” and “providing specific information” in terms of “behaviours such as...”. This level of specificity and delineation in relation to information process matters appears to be unique in the research literature and is similar in some aspects to key practice documents such as the
Australian “Recommended Practices in Family-Centred Early Intervention” (ADD 1997). The specific activities that comprise these behaviours or practices, however, are not elucidated further and it may well be here that another problem area in the failure of information access and acquisition sets in.

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Information is clearly identified as a significant factor in program quality and components of care, service need and satisfaction. However, the body of research does not yield a coherent, systematic and comprehensive understanding of information access and acquisition. This is partly because it was not the intention of such research to do so. Yet even where information access and acquisition factors have clearly arisen as underlying parameters of service need and quality, satisfaction and dissatisfaction, and caregiving, they have still not been the specific subject of investigation. Furthermore, the failure to identify and address the problem of conceptual ambiguity in relation to the use of much information terminology can be seen to affect the degree to which the information problem area can be defined within the extant literature.

2.1.2 Family Factors

In contrast to service-related factors (see 2.1.1), which look both at parental satisfaction/dissatisfaction and the elements of need that constitute variables in quality of service and care, family-related factors look at those family-specific factors related to effective adaptation and coping. Several common models and approaches to family adaptation, functioning and need are reviewed below, both because they have some weight in the sector and their theoretical relevance to information-related research. The question is whether they are able to explain satisfactorily access to information and information acquisition among parents of children with disabilities.

2.1.2.1 Stress, Coping and Information Seeking

A useful starting point in considering family factors are some pieces of research investigating families of children with disabilities from the perspective of stress and coping. Within the literature of stress and coping, information seeking is used as a characteristic or indicator of adaptive coping. Folkman (1984, p. 840) presents the definition of stress as:
a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and as endangering his or her well-being.

The theoretical approach to coping is described in more detail at 3.3.2.2.

Sloper and Turner (1993) conducted largely quantitative research among 107 families of children with severe physical disabilities to identify adaptational outcomes associated with specific risk and resistance factors. (see 2.1.1.2 which notes the qualitative aspect of the research comprising parent interviews, reported in Sloper and Turner 1992.) Their research posited that parental resources and coping strategies may prove to be resistance factors, ameliorating the impact of stressful situations and providing resources for the coping process. The resources included the material (socio-economic), the social (support systems) and the psychological (including problem solving and help seeking skills and strategies).

Indeed the research reported an assemblage of variables or factors significantly related to parent outcomes, measured by a Satisfaction with Life index, the Malaise Inventory (measuring parental distress) and an Adaptation to the Child scale (Sloper & Turner 1993, pp. 175f.). Neither information as a resource, nor information seeking as a coping strategy, nor indeed failure to acquire information as a stressor, were reported.

Sloper and Turner (1993, p. 179) state that the results support the model of stress and coping, as the predictor variables the model uses - stressors, resources and coping strategies - "contributed to parent outcome". Yet significantly, as observed, it appears neither information as a resource, nor information seeking as a coping strategy, nor indeed failure to acquire appropriate information as a stressor, were tested as discrete variables, notwithstanding the strength and consistency with which parents have reported these issues over many years (see 1.2). While a coping strategy of seeking support was positively correlated with outcomes, it was not clear which aspect of support seeking was being considered and whether it included information seeking.

Sloper and Turner (1993, pp. 184f) use commentary from parent interviews to highlight the significance of information in addressing risk factors such as access to services: for example, "59% of the sample felt they had insufficient information about services". Yet the research does not appear to recognise that information access and acquisition, and
information itself, may well be significant risk and resistance factors in their own right. This is all the more extraordinary as their earlier article on the same research (Sloper & Turner 1992, p. 271) specifically stated “The greatest area of unmet need related to the provision of information...”, which is significant because unmet need was significantly positively related to maternal psychological distress and negatively related to adaptation to the child.

This research eloquently demonstrates the limitations of stress and coping models for explaining information acquisition. While it may be argued that it was not the purpose of such research to do so, the failure to account for information acquisition in terms of stressors, resources and coping strategy, strongly suggests a failure to appreciate the real significance of information, its processes and behaviours, for families.

Quine and Pahl’s (1985) work is one of the earlier examples of this type of design flaw. This research examined the causes of stress in 200 families of children with disabilities. Again the Malaise Inventory was used to measure parent outcomes, in terms of stress, but in this case against parent reports at interview of variables concerning the nature of the child’s impairments, the problems these presented and the family’s use of and satisfaction with statutory services. Lack of recognition of the significance of information-related variables becomes apparent at the one point where this study almost approaches the information delivery-information acquisition nexus. In a closing statement Quine and Pahl (1985, p. 516) hold, inter alia, that

Professionals who are in contact with families with mentally handicapped children should make sure that they are receiving all the financial benefits to which they are entitled... [emphasis added]

Clearly this would require information exchange, the professional would need to be aware of the family’s circumstances and in order for the family to receive all the benefits to which they were entitled, information delivery will also have been required. In fact something greater than information delivery must be in view in this scenario, as both proactive mediation of information and evaluation of information uptake, along with any necessary information revisiting, would be required to ensure application of the information. The choice to access or not to access relevant benefits and entitlements would then demonstrate effective application of the information. That is to say, the professional would only then be in a position to “make sure that they are receiving all the financial benefits to which they are entitled”, or exercising an informed choice not
to do so. It seems feasible that given the absence of information-related variables within the research, the role of information processes in this scenario is simply not recognised.

Kirkham et al (1986) report that their work, seeking to improve parental outcomes through an intervention targeting coping styles and social support networks, found measurable improvements following the intervention. Yet again, aspects of the work that were clearly information-related were not specifically identified.

Research such as Friedrich, Wiltiner and Cohen's (1985) also fails to give appropriate weighting to information factors, in this case as a resource. Their investigation considers the interaction of individual parent's coping resources and measures of stress and adaptation, yet the role of information as a "utilitarian resource" (Friedrich, Wiltiner & Cohen 1985, p. 137) is not tested. The research concludes that the better-educated individuals of the sample were people with greater utilitarian resources than less well-educated people, which they also conclude explained the lack of significance for any of the utilitarian resource variables in the regression analysis of stress and adaptation (Friedrich, Wiltiner & Cohen 1985, p. 137).

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It is apparent then that the stress and coping body of research, as it investigates parental adaptation, strategies, resources and so on, has not itself developed any means for properly investigating access to and acquisition of information.

The particular validity of the stress and coping research for this thesis is in evidence suggesting that emotion-focused coping is more likely to be used in situations appraised as being out of the individual's control, "not amenable to change" (Folkman 1984, p. 844). If one applies an information perspective to this contention an interesting possibility emerges. What may appear to be an unchangeable situation leading to an appraisal by the individual of having no control, and thus employing emotion focussed coping, may indeed be a situation that is amenable to change, were the individual only aware of relevant information. That is to say, an incorrect appraisal may have been made, not because of a coping style or other coping factors, but because of basic awareness of information. This circumstance may well arise each time the individual is unaware of information that pertains to his or her situation – the situation may well appear to be unchangeable.
Applying the same logic to the information seeking component of adaptive coping, it becomes immediately evident that there is a possibility awareness/non-awareness of information itself to some degree triggers the coping strategy response, of either problem solving through seeking or emotion-regulation, rather than the other way around. Unfortunately, investigations have focussed on information seeking only as an expression of problem focussed coping.

Yet it may well be that efforts to foster more effective coping through problem focussed strategies, in failing to investigate the issues from an information perspective, have missed a vital component. Access to and acquisition of information may well play roles as initiating conditions to coping strategy response. Attaining to a right understanding of information access and acquisition and the impact these are having on coping strategy, may well reveal that information delivery structures and processes are as much responsible for individual coping strategies in individual situations, as the individual’s typical coping style. This remains to be investigated however.

2.1.2.2 Cognitive Information Styles

Miller (1990, p. 97) has identified “individual differences in information-seeking preferences under threat”. The Monitoring and Blunting hypothesis “postulates that there are two main modes for coping with aversive events” (Miller 1990, pp. 98f). Monitoring pertains to alertness or approach to threat-relevant information; blunting to avoidance of threat-relevant information (Miller 1990, p. 99). The Miller Behavioral Style Scale (MBSS) seeks to provide a ready means for dividing individuals into coping style groups, based on their preferences for information. The rationale is that if an individual is forced to adopt a non-preferred cognitive information style his/her stress will increase.

However, the utilisation of cognitive coping styles is somewhat more complex. It appears that individuals utilise different aspects of monitoring/blunting in various combinations at different times; high monitoring/low blunting, high blunting/low monitoring and so on. It seems that appropriate choice of strategy according to the situation is the key to effective coping, as Miller (1990, p. 121) states:
the ability to cope effectively with threat and frustration appears to depend not only on the ability to avoid cognitively and/or seek information, but also is determined by the individual's ability first to discriminate the relevant situational factors, and then to execute the cognitive strategy appropriate to the particular situational contingencies.

Variations in cognitive information style and the individual parent's capacity to discern the style appropriate to the circumstances may yield some understanding of parents' information access and acquisition. This is not only because of the potential impact of the individual's basic orientation toward information, which effects both parent information seeking efforts and parent response to professional information delivery efforts. It also seems that perceived locus of control must have a considerable impact. If the individual perceives that nothing can be done to alter an aversive situation, then continuing to monitor may only result in frustration and greater stress. However, failure to monitor when that perception is incorrect, that is to say the appraisal that the situation cannot be changed is incorrect, which may have arisen from absence of awareness of information, cannot be rectified by high blunting. It seems that it is important to understand why individuals have adopted a particular approach and whether it is based on an informed appraisal of the situation.

It is unfortunate that there does not appear to be any research applying Miller's work on cognitive information styles within the childhood disability sector. Van Zuuren and Wolfs' (1991) research specifically refers to the locus of control and styles of information seeking under threat, that is when coping is required. Van Zuuren and Wolfs (1991) used the MBSS initially on 47 psychology students and subsequently on 55 general population volunteers to investigate personal and situational aspects of monitoring and blunting. They found that monitoring was associated both with internal locus of control and problem focussed coping. It is important to understand here that internal locus of control is "The appraisal of being able to change the situation... whereas not being able to achieve this corresponds to an external locus of control" (van Zuuren and Wolfs 1991, p. 142). This has considerable potential significance to the childhood disability sector, in terms of awareness of information affecting appraisal of control and parents' consequent information behaviour, as reviewed above in the stress and coping research.

The first sample revealed a significant correlation between monitoring and problem focussed/help seeking, and, between blunting and wishful thinking/escape (van Zuuren
and Wolfs 1991, p. 145). This is consistent with the analysis of stress and coping research above, and seems to correlate with the problem-focused – emotion-focused dichotomy of coping style. It may indeed be that efforts to encourage parents to become more active in coping strategies ought properly to be directed at information-avoidant individuals. Those who wish to have information but are not able to acquire it, for reasons of lack of awareness of information or lack of information literacy skills, need appropriate information delivery mechanisms, rather than training to become more active problem solvers.

2.2 THE FAILURE OF RESEARCH TO INVESTIGATE ACCESS TO AND ACQUISITION OF INFORMATION AND THE PROBLEM OF CONCEPTUAL AMBIGUITY

A pattern indirectly emerges across the literature of multiple modes of information acquisition; however, it is neither systematically recognised nor explored and is subject to considerable conceptual ambiguity.

In summary, there have been two significant failures within the childhood disability sector research. Firstly, the problem of conceptual ambiguity in the use of information-related terminology is all-pervasive, throughout the literature and also the services and their foundational policy documents otherwise intended to support families. Secondly, the failure to recognise and account for significant information-related variables (such as access to and acquisition of information) as either critical variables in their own right, or, underlying many of the variables under investigation is common throughout the literature.

Section 2.1 suggests that a number of important issues pertaining directly to information access and acquisition arising from the childhood disability sector research have not been addressed.

- What happens in information terms to parents who do not seek either as a general information behaviour or in relation to particular issues?
- Do parents acquire information in ways that mean they do not need to seek, such that for some parents there is non-acquisition and concomitant stress but
for others a sense of support derived from information acquired without needing to seek?

- What are all the possible modes of information acquisition?
- Does the mode of information acquisition affect parent outcomes? For example, would serendipity increase stress?
- Is information seeking always related to coping style or are there significant interactive effects with awareness?
- Is awareness of information a trigger to information seeking such that coping efforts may be facilitated by awareness rather than necessarily being a function of a problem focussed coping style? Is awareness of information triggering information seeking sometimes falsely understood as indicative of adaptive coping?
- Is it feasible that some individuals take action to increase the probability of becoming aware of information, such that the actions are indicative as much of information skill as coping style?
- Are negative appraisals of control falsely generated when there is a lack of awareness of information that would have a direct impact on the situation? Do parents consequently perceive situations as not amenable to change and as a direct result fail to employ problem solving and/or information seeking?
- If parents fail to seek information because of an incorrect appraisal of “no control”, arising from lack of awareness of information, do they acquire information in some other way? If not, is there a total failure to acquire help or do other factors intervene?

The first question to arise from this body of research, and bearing the above questions in mind, is - do parents seek to acquire information? A significant distinction must be drawn between seeking and acquiring. The difference between seeking and acquisition can be demonstrated by plotting the array of modes of information acquisition, and information seeking becomes immediately apparent as a subset (see 5.2.1). Even if the stress and coping model were adequate to explain information acquisition, by its own de facto definitions it could only do so among those parents employing active seeking and it is obvious from research premised on the stress and coping model that many parents do not do so. Furthermore even among those employing active seeking, information is clearly acquired in many different ways.
A series of questions addressing these issues and unanswered questions are investigated in this thesis. How does the broad spectrum of parents actually acquire information? Do they utilise an array of modes? Are those parents preferentially using one mode more than others, more or less likely to acquire information? Alternatively, is the use of multiple modes more effective? Is parent information behaviour influenced by information delivery? Does parent information behaviour influence delivery? Is seeking sometimes prompted by a failure of delivery? How does that influence outcomes? Do the parents' information skills have an impact on information acquisition? Are there attenuating effects of good information delivery? Is it possible to identify other factors having an impact on acquisition?

2.3 INFORMATION NEED, SEEKING, DELIVERY AND ACQUISITION - REVIEW OF DIRECT EVIDENCE

The body of research reviewed below accords an importance to information apparent in the research design itself and indeed seeks to explore aspects of the information process specifically. The most significant research in the field is presented firstly, followed by research specific to New South Wales, Australia.

2.3.1 Primary Research

2.3.1.1 Pain

Pain's work (1999) stands alone in specifically exploring the role of information in parent coping. This research also appears to be unique in embracing a more holistic understanding of information, inherently recognising, for example that advice-seeking is as much an expression of information seeking as specifically requesting a piece of information. In addition, Pain (1999) does not restrict the notion of information acquisition (without using the term 'information acquisition' per se) to the formats of materials, but reports on both communication and the application of information issues. The research is premised on the understanding that information is vital to parents of children with disabilities. Yet as Pain (1999, p. 300) observes "the literature does not make explicit the connection between information, the use made of it, and the psychological sequelae to that utilization".
Hence, Pain undertook qualitative research (1999) seeking to develop an understanding of the role of information in coping, sources of information, information uses and usefulness and whether there are educational level differences in information need. However given the methodology employed and the sample size (n=15), as Pain (1999, p. 309) observes, "The findings are not directly generalizable to all parents of disabled children, but should be used to assist understanding in cases to which these data are judged applicable". A number of potential points of bias may have entered with the sample. Firstly, all the children were patients of one paediatrician. Secondly, while it is true that themes may become generally saturated at around eight to nine interviews, the tiny sample may have restricted the richness of the array of data in relation to information themes acquired. Also, thirdly, the schedule used may have guided parents, "A schedule was used so that the way parents made sense of their experience and the things they felt helped or hindered them in coping could be explored" (Pain 1999, p. 302). Nevertheless, in using the schedule Pain (1999, p. 302) employed an important approach in the conduct of the interviews:

The interview began with the parent describing their child’s disabilities, then they were asked to describe any difficult periods. This approach was used to avoid focusing on information too early, so potentially missing areas that parents may not consider strictly as “information”. [emphasis added]

This is a significant insight, unique within the literature.

Pain's (1999) findings are documented in terms of sources of information, purposes of information, and, information and level of education. While Pain (1999) reported personal communication as the primary medium or source through which parents acquired information, albeit the term information acquisition was not used, it is clear that the research revealed a number of significant modes of information acquisition. The author of this thesis argues that systematically reporting the modes of information acquisition is important for two reasons. Firstly, as the array of modes is documented it becomes possible to identify both specific failure points in information acquisition, and non- or under-utilised modes. Secondly, with this identification, it becomes possible to address specific issues in information acquisition and to maximise the use of varied modes, thus improving the probability of parent acquisition of information.

Pain's (1999) data can be analysed to reveal a range of modes of information acquisition embedded within the findings:
• Proactive information delivery – "told me about the benefits, I had no idea about" (Pain 1999, p. 305)

• Responsive information delivery – Portage teacher: someone parents "could ask concerning who to approach for what" (Pain 1999, p. 304)

• Passive information delivery – leaflet racks (Pain 1999, p. 304)

• Active Information Seeking – "What should I do about this?" (Pain 1999, p. 305)

• Information Grounding – "you need the parents who have experienced the shortfalls in the system" (Pain 1999, p. 304), "knowing others in a similar situation was helpful" (Pain 1999, p. 307)

Pain’s (1999) research also identified, again unintentionally, a number of problems related to information access. The first is awareness of information. Pain (1999, p. 310) reports that "when parents do not actively seek information it may be because they do not know how to ask, or where to start". Hence, educating the parent to become more problem-focused would not then solve the problem because it is firstly a problem of awareness of information – the knowing that one is not knowing something and just what it is one needs to know. (The author of this thesis has conceptualised this problem area as the "awareness heuristic": see chapter 3.) As Pain (1999, p. 306) observed, "inability to formulate the questions did not mean information was not wanted". If information delivery efforts are premised on response to active seeking, significant problems set in for parent acquisition.

The second problem concerns the application of information, where the individual may or may not have the capacity to appraise information as relevant to personal circumstances, by virtue of situational and/or personal characteristics. These may include information literacy characteristics, knowledge base and the awareness of information, or situational characteristics such as seeing other families for example use respite. An example lies in the application of generic information to the specific circumstances of a family’s life such that the information becomes meaningful and thus accessible to the family; "generalized publications have their limitations... a professional should select [information] and give it to the parents...[indicating] what are the most important sections within it..." (Pain 1999, p. 309). Further:
The obligation lies with the health professionals to convey that information in a way the parent can understand, and the positive comments of the interviewees in this study concerning personal contact further support the concept of a key worker as an effective means of ensuring information exchange. (Pain 1999, p. 310)

The notion of a key worker can be seen to be directly relevant to each of the access issues raised. However, Pain does not make explicit the association between access issues such as awareness and application, and the role of the link or key worker. Pain (1999, p. 310) rightly observes that the "concept of a key worker [is] an effective means of ensuring information exchange" but does not explain why this is so.

Notwithstanding many insightful comments and significant data embedded within the research, Pain (1999) does not go on to develop a cogent framework for understanding information access and acquisition.

2.3.1.2 Mitchell and Sloper

The same is true of Mitchell and Sloper (2000, 2001, 2002), the most significant information researchers in the childhood disability sector. Their research does not develop a framework for understanding access to information or indeed information behaviour, from which it might be possible to pinpoint the causes of access and acquisition problems among parents. This arises because their research, notwithstanding its seminal nature, is subject to a flawed foundational premise. Mitchell and Sloper (2000, p. 2) take the view that a considerable volume of research has demonstrated parents' information needs, what those needs are and the degree to which they are met. The source of this contention can be found in Sloper (1999, p. 95) "Research over the last 25 years has provided detailed information on parents' needs and experiences". Sloper (1999, p. 95) can be seen to dictate the form of the research subsequently undertaken:

There needs to be a change in research priorities from finding out what the problems are to finding out the solutions, with full involvement of both parents and professionals at all stages of the process.

Clearly Mitchell and Sloper (2000, 2001, 2002) proceeded on the assumption that sufficient detail is known about parents' information problems and thus undertook research aimed at finding out the solution, namely a model of good practice in information delivery from the parents' perspective. Their work did not seek to
investigate the nature and causes of access and acquisition issues, rather accepting them as a given.

The research undertaken for Mitchell and Sloper's (2001) work on the Sharing Value project appears to have pre-dated the research on a model of good practice in "information provision" (Mitchell & Sloper 2000, 2002). This earlier piece of research was undertaken because families had reported that information about support services and inter-agency coordination was hard to find:

This is largely due to the absence of a national strategy or system that offers accessible information to either service agencies or families. Sharing Value seeks to address this information gap by identifying and disseminating examples of specific support services and ways of inter-agency working... [reported] as being valuable. (Mitchell & Sloper 2001, p. 244)

The research drew on the ideas and experiences of seven focus groups (n=54), comprising three groups of children and young people, two groups of parents/carers and two groups of managers/practitioners (Mitchell & Sloper 2001). The actual project design seemed to be flawed in that it sought to address the "information gap" by developing a UK-wide directory of valued examples rather than a nationally accessible information delivery system and modus operandi. While a national information system would detail all the services actually available, a national directory of good examples would serve the purpose of alerting families to what is possible in terms of quality of service.

The problem of conceptual ambiguity is also seen in this research and becomes most apparent within the findings on "Parents'/Carers' and Managers'/Practitioners' Perceptions" of "quality" in relation to "Information":

it comes as no surprise that parents and carers frequently found information seeking a confusing, stressful and erratic experience. Indeed many felt that they had received most information from other parents. [emphasis added] (Mitchell & Sloper 2001, pp. 247f.)

While the term information seeking is used, what is actually in view is information acquisition; the fact that parents had received most of their information from other parents evidences this. The distinction between seeking and acquisition is highly significant to the problems of access and acquisition. One of the reasons parents do not acquire information is that service providers respond to articulated requests, that is to
information seeking, but parents do not seek when they are not aware either that there is information to be sought, or just what it is they need to seek. What parents find confusing, stressful and erratic is acquiring information. This is one of the reasons parents constantly express the need for a “single door” source of information … ideally an individual, informing and helping families to access relevant services” (Mitchell & Sloper 2001, p. 248), although it is important to note that this connection is not made explicit in the research.

A number of key points in relation to other information concepts are embedded in the data but again not commented upon by the researchers. For example, in presenting the findings on preferences for delivery of information in accessible language, the importance of the application of information, inherent in the following parent’s statement, is not recognised:

> So many medical terms are going round in your head that even if you wanted to, you couldn’t remember one of them when you come out of there, much less what they meant, what it means for your child in the future [emphasis added] (Mitchell & Sloper 2001, p. 248)

Subsequently, under the quality in information findings, Mitchell and Sloper (2001, p. 248) report that a quality service does not stop once information is received, “but rather provides regular updates, keeping families informed”. What is in view here, using appropriate information science terminology, is either some type of selective dissemination of information (SDI) or current awareness service, and, information revisiting. Interestingly, Mitchell and Sloper (2001, p. 249) conclude that while families may value such good practice as “keeping families informed”, the “need for evidence based practice is reinforced by the very fact that many parents and carers suggest that these policy objectives are frequently not being met” (Mitchell & Sloper 2001, pp. 249f.). The irony is that none of Mitchell and Sloper’s research (2000, 2001, 2002) has analysed information access and acquisition, or developed a satisfactory theoretical framework, necessary to explicate failure and provide the evidence required to substantiate what quality or best practice is claimed to be.

Mitchell and Sloper (2002, Introduction section, para. 2) recognised both “the importance of information and the continuing problems that surround it” and that while accessible information is being advocated:
... practical issues, such as what is accessible information and how do families want to be informed and [be] kept informed, are rarely considered in any depth. This paper seeks to bridge this knowledge gap...

Yet rather than exploring information science concepts of “information” and “access to information” as a starting point, Mitchell and Sloper (2000, 2002) sought the views and experiences of 27 parents in four focus groups, to develop a model of good practice in information delivery. Parent participants were drawn from the earlier research (Mitchell & Sloper 2001), which may have tended to circumscribe the expression parents were able to give their ideas, particularly apropos of notions of quality. In the first meeting, each group considered factors they used or looked for in considering the “quality of information they received” (Mitchell & Sloper 2000, p. 10). Mitchell and Sloper (2002, Project Aims and Research Methods section, para. 4) give important additional information about the groups:

[they] were asked to discuss three key issues: where or from whom do you get information; how do you like/dislike receiving information; suggestions for improvement in information provision.

Ideas were collated into a list of quality criteria and considerations. The second meeting sought to evaluate an array of “information literature” collected by researchers, through the application of the quality criteria. Finally:

the criteria and evaluations of ‘good practice’ gleaned from many different informational sources were used to build a parentally guided model of good practice. (Mitchell & Sloper 2000, p. 11)

Notwithstanding research interest in identifying “preferred means of information delivery and information formats” and “different forms of information provision” (Mitchell & Sloper 2000, p. 3, 9), suggestive of interest in broader information delivery issues, the findings stress quality criteria as applied to specific information resources and “information provision”. Mitchell & Sloper (2002, Criteria for a Model section) summarised six key criteria for “good information provision” that, re-worded, sum up the findings for the model:

- Up-to-date, accurate, easy to read information
- Information presented in a variety of formats
- Information available at differing levels of specificity and technicality, within targeted periods for subject matter
- Information available in everyday places
- Targeted information delivery in the context of relationship
- Comprehensive information delivery, that is across agencies

It is of no small significance the researchers themselves were directly exposed to the difficulties parents face in acquiring information:

the telephoning exercise proved an important experience for the researchers, as it confirmed many problems previously noted by parents in trying to find out who to contact to get hold of information (Mitchell & Sloper 2000, p. 11)

However the research had no theoretical framework or conceptual basis from which to identify this as an awareness problem which would yield evidence for the need of “personal contact and guidance from information givers” identified under a “Delivery of Information” criterion (Mitchell & Sloper 2000, p. 15). This is accorded some importance in the “Model of Good Practice in Information Provision” where dedicated information mediators called “Information Advisers” in Mitchell and Sloper (2000, p. 19) and “Key Workers or Facilitators” in Mitchell and Sloper (2002, The Importance of Information ‘Key Workers’ or ‘Facilitators’ section) are recommended.

parents knowing how and where to contact an information giver, ideally, a designated person attached to each family, who would provide information, advice and guidance, as and when needed. (Mitchell & Sloper 2000, p. 19)

Clearly the link worker or information adviser has a central role to play in overcoming problems arising from awareness, however Mitchell and Sloper’s (2000, 2001, 2002) work cannot establish this, apart from the appeal to parent preference.

It is apparent that if parents do not have access that enables them to acquire information at all, the quality of specific information resources is virtually immaterial at that point. While issues surrounding the quality of information acquired are of paramount concern to parents, their first complaint is always the failure to acquire information in the first instance (see 1.2). Without the necessary conceptual framework for understanding parent acquisition of information and the underlying causes of failure to acquire, design of quality information delivery is at considerable danger of either reifying existing problems or not addressing them.

Mitchell and Sloper (2000, 2001, 2002) make an important contribution to understanding information issues of significance to parents. However, the failure to anchor the work in sound information theory has a considerable impact on both
conceptual acuity within the work and the capacity to validate the practices recommended, other than by appeal to parental opinion.

2.3.2 Information Research - News South Wales, Australia

Each of the pieces reviewed in this category is an unpublished consultant's report that has not been subjected to the normal rigours of peer-reviewed research. They either do, or ought, to pertain specifically to this thesis, both in terms of the subject matter and the geographic location, namely New South Wales. What becomes immediately apparent in each piece of research is that it is neither conceptually anchored within, nor informed by current theory and key thinking within the childhood disability sector literature, concerning for example coping, family support and service needs. Nor is library and information science theory related to information behaviour, need and seeking applied to the problem area.

2.3.2.1 Carers New South Wales (Carers NSW)

Commencing in 2001 the Connections Project worked with families of people with developmental disabilities in three geographic locations, including the Eastern Suburbs of Sydney, to explore service supports with an emphasis on telecommunications and information technology. In 2003 Carers NSW commissioned research on the support needs of parent carers of people with developmental disabilities, as the second phase of the Connections Project.

This research (Carers NSW 2003, p. 25), while describing information as one of several elements “making up a comprehensive package of carer support”, does not seek to explore information issues. It aimed to establish current capacities within participating organisations to support parent carers and to gauge interest in developing support capacity further. Within this research approach, information arose only tangentially, notwithstanding the fact that 10 of the 19 participating organisations had a “representation, advocacy and information” focus and information exchange was clearly identified as a barrier to parent support. The research stressed the absence of a “shared definition of what constitutes carer support”, and its findings and recommendations flowed from that perspective (Carers NSW 2003, p. iii). The failure of the research itself
to look to definitions of and research around support for families of people with disabilities is an example of one of the reasons no shared definitions were to be found.

2.3.2.2 Families First

As reported in Chapter 1, Families First in NSW is of particular significance to families of children with disabilities, and to this research. It is a NSW government priority strategy aiming to link:

- early intervention and prevention services and other community programs into a network that supports families to raise healthy children and prevent problems before they develop.

The network includes a wide range of services such as health services, general practitioners, childcare services, therapists, playgroups, schools, preschools, volunteer services and community organisations. (Families First c. 2002a, A Network of Support for Families section, paras. 1, 2)

Each region must develop an Area Plan that addresses standard Fields of Activity as appropriate for that area. The Families First Field of Activity 3 concerns “families who need extra support”. Although not formally defined, this Field of Activity clearly relates to families of children with disabilities, and families in which substance abuse, child abuse, mental health issues, domestic violence and other problems are evident (Families First 2002b). To reduce stigma attaching to targeted intervention services, more effort is put into identification of potential problem areas through universal services (such as home visiting through Early Childhood Clinics) before switching on targeted services (NSW Health 1999, pp. 36f.). The National Investment for The Early Years (NIFTeY) group “advocates targeting those at risk within a system that is available to all children” (Press & Hayes 2000, p. 61).

One of the outcomes of this approach is seen in the first two pieces of research reviewed below (Families First Inner West 2002a; OCYP 2001a, b). Aspects of information, as communication and as education and support, were initially investigated in relation to families of children 0-8 years “universally”. However it became evident to researchers, at least in the Families First Inner West (2002a) piece of research that this did not adequately address the needs of families of children with disabilities (Families First Inner West 2002b, p. i). This gave rise to the third piece of research reviewed (Families First Inner West 2002b) looking specifically at support for families of children with disabilities, but it was restricted in focus to the assessment period. It is important to note
that the second two pieces of research reviewed (Families First Inner West 2002a; Families First Inner West 2002b) arise from the Area Plans for the Inner West and that area coincides with one catchment area of parents interviewed for this thesis.

Consultants urbis keys young (OCYP 2001a, b, p.1) conducted the first piece of research to “lay the groundwork for development of a Families First Communication Strategy”. The reason this research has attracted the attention of this review lies in the stated objectives of the Communication Strategy. The objectives of relevance to this thesis are:

- To obtain advice from parents on what information and support they need, from whom and at what stage of their children’s development
- Communication for parents to help them parent children aged between 0-8 years
- Communication to help change service practice and promote service development so that it become [sic] family focused (OCYP 2001a, p. 1)

The finished research product was presented largely as a summary, reporting the results of the two methods of data collection: namely, the audit of current practices in NSW Government Department relating to the “conduct of messages about parenting”; and, the literature review related “to aspects of parent communication strategies” (OCYP 2001a, b, p. 1). There is no theoretical framework, no analysis or discussion of the findings, nor are findings presented as addressing particular elements of the communication strategy. At no point did the researchers identify the “conduct of messages about parenting” (OCYP 2001a, b, p. 1) as information delivery.

The significant qualitative and quantitative differences in the responses of departments point to the conceptual ambiguity surrounding terms such as “the conduct of messages”, “communication”, “information”, “education”, “support”, “marketing” and “information delivery”, and also the effect of those ambiguities on departmental functioning. This is highly significant to this thesis as it is often from government departments such as these, or non-government organisations funded by these departments, that parents must acquire information. For example, the Department of Community Services (DoCS), responded largely according to a marketing interpretation of communication strategies and hence referred only to the “Kids in Cars” campaign, the “Never Shake a Baby” campaign, the ATSI Calendar and parenting magazines, notwithstanding that a significantly larger volume of information is generated by the department of relevance to families.
Of particular note for this thesis is the fact that the then Ageing and Disability Department (ADD) was not approached for the audit. ADD was a “key” agency in the Families First strategy (OCYP 2001a, p. 1). Furthermore, families of children with disabilities are a specific target group within the Families First Field of Activity 3 – Families Who Need Extra Support. (Families First 2002b). The fact that the Government Department specifically intended to address the needs of these families was not defined as a “relevant government agency” (OCYP 2001b, p. 2) for the purposes of the audit, strongly indicates the poor understanding of both the OCYP and the consultants of the whole information delivery issue area, as it relates to families of children with disabilities.

The report’s literature review aimed to “review research findings related to aspects of parent communication strategies, particularly those reflecting parents’ information needs” (OCYP 2001a, p.3). This is somewhat curious since the “parent communication strategies” noted actually concern information delivery, which would be an exceptionally blunt instrument for measuring information need. The bulk of the research was reported under headings such as “Australian Research on Fathers”, “Research on Immigrant Communities”, “Social Marketing Campaigns on Child Abuse and Domestic Violence”, the “WA Parenting Communication Campaign”, the use of the Internet, print materials and media, public education programs and the use of social support networks. There was no evaluation of the research, which was accepted at face value, including a not inconsiderable number of unpublished consultants’ reports. This was problematic as the review was intended to inform development of the Government’s Communication Strategy. The potential danger of such cosmetic reporting can be seen in the claim the consultants make about the use of the Internet. Under the heading “Parenting and the Use of the Internet” appears the following statement:

An emerging element in communication strategies is the use of electronic means of reaching people. As the use of the Internet continues to expand, more families will be using this medium to obtain information on parenting. [emphasis added] (OCYP 2001a, p. 36)

The consultants apparently reached this conclusion on the basis of a Sydney Morning Herald article quoting an American survey that showed mothers with children under three were gradually replacing offline greetings with online. In fact there is direct
evidence that what the consultants claim is not the case; indeed the consultants had reported as much earlier:

Only a few parents were interested in accessing information through a recorded telephone line (8%), videos (4%) and information on the Internet (4%). [emphasis added] (OCYP 2001a, p. 31)

Even were increasing information to be made available via the Internet, “Focus group participants emphasised the need for ‘human contact’ when talking about important issues” OCYP (2001a, p. 37). The significance of this in terms of access to information is lost in the failure of the review to present a coherent picture of either information delivery strategies or parent information acquisition. In fact it is interesting to see within the OCYP (2001a, b) work, a range of access to information problems *embedded* across the literature review in both target sub-groups, such as NESB, and subject areas. However, they are neither drawn together in a cohesive picture, nor is their nexus with parent need for human contact recognised:

An Australian field study ... found that while substantial amounts of information and services for people experiencing problems with parenting exist in the community, access to these sources is problematic...Some of the problems identified by the study included lack of easy access to existing information and services. (OCYP 2001a, p. 27)

The degree to which this mirrors countless pieces of research in the childhood disability sector evidences the centrality of access to information problems. It also highlights the failure of the consultants (OCYP 2001a, b) to recognise the profound impact of access to information issues on the very communication strategy they were seeking to inform.

The second piece of Families First research to be reviewed, conducted by consultants Elliott and Apte, pertains specifically to the Inner West Area of Sydney (Families First Inner West 2002a). It sought to understand parent needs for information, education and support and was intended to inform the next project stage of developing and implementing “appropriate strategies for the provision of information to families in the Inner West...” (Families First Inner West 2002a, p. 97). While it was not the purpose of this research to investigate specifically the families of children with disabilities they were certainly identified as a discrete group with information needs and satisfaction levels at considerable variance to all other parents.
The problem of conceptual ambiguity at a sector level, in addition to the research itself, is revealed in the following quote regarding different perceptions between parents and service providers regarding information delivery products and processes:

Service providers' accounts of parents' interest in seeking or gaining information largely mirror the experiences described by parents. However service providers are more likely to emphasise their role in providing information face to face. This different perception may be because service providers are unaware of the range and types of information parents are accessing outside the service system, and may be compounded by the fact that families rarely separate the role of service provider from that of provider of information and of information 'products'. (Families First Inner West 2002a, p. 57)

In fact, there appeared to be a mismatch not only between parents' and service providers' understanding of information processes, but also between research participants and consultants, for the consultants had earlier observed:

In their descriptions of parenting, few parents distinguished between education and information, and in many instances no distinction was made between formal and incidental learning. (Families First Inner West 2002a, p. 20)

The scope of the literature review was restrictive considering the subject matter at hand, seriously limiting the potential application of the research to this thesis. This is seen specifically in claims such as:

The literature review confirmed that there had been limited consideration on the topic of parents' ideas about parenting information overall... found little research identifying preferences and view of parents from [immigrant] communities...[and] suggests that parents are able to articulate views about their needs and preferences re information. (Families First Inner West 2002a, pp. 94f.)

All of these claims are incorrect, the basis on which the claims are made is not reported, nor is any substantiating literature cited, indeed the claims derive from a consideration of resources found in one database only, namely PubMed. The health research bias this evinces does in fact carry through the entire work. Indeed the parents' own testimony, quoted in the research, at times evidences the fact that they may not be able to identify their needs because of awareness of information problems, as seen in the examples below.

I've been here eight months ... but I haven't heard of any playgroups. I heard of one, but I don't know how to get there. I haven't got no pamphlets or anything. (Families First Inner West 2002a, p. 26)
The only person who understands is a parent who's been there. People crave contact with others in the same position. I would have liked that earlier. (Families First Inner West 2002a, p. 43)

One of the important characteristics of other parents who have “been there” is that they are aware of information the other parent may not be and therefore cannot articulate as a need. This is the reason parents so frequently nominate other parents as their favoured source of information, although they do not necessarily make the awareness connection.

As a final comment on the report’s literature review, an “emerging concept” of some interest was also presented. “Health literacy” incorporates both access to information, and analysis and use of information acquired, in a health sector context. The shifting emphasis from expert transfer of information to building parent skills in developing priorities and acting “on their own individual needs for information” (Families First Inner West 2002a, p. 95) is certainly consistent with the move from a medical model to family centred service delivery. Yet it is highly likely that the concept is *derivative* of *information* literacy, which has both been established for many years and has far broader application. That being the case, and given that Elliott and Apte’s (Families First Inner West 2002a) research pertains to broad-based parenting, it really makes explicit the need this research had for relevant theories and conceptualisations from *information* science.

Parents’ views are exhaustively presented under broad subject headings, including preferences for obtaining information and what supports them. Although there are some very useful insights into aspects of parent acquisition of information, their views are not woven into a cohesive framework for understanding parent access to and acquisition of information. A conceptual framework for understanding family sources of information, described by the researchers as “four domains of sources of learning that parents draw upon” (Families First Inner West 2002a, p. 68) is given. However, the framework seems in all likelihood to have been developed first *then* the parent interviews were structured to reflect the framework rather than the other way around. As a result the consultants found what they were expecting to find. The framework is a series of concentric circles starting in the centre with the “Parent’s Own Experiences” and moving outward through “Family, Friends and Community Networks”, “Professional input via Information & Education Products & Services” out to “Education Programs & Service Interventions”.

83
When parent commentary on "sources of learning" is reviewed a conceptual flaw becomes apparent. The consultants state that "Generally, parents regard their own experience as the central source of learning." (Families First Inner West 2002a, p. 46) This seems a perfectly reasonable statement to make, until it is placed in the practical context of the framework. "The framework focuses on the sources of information and learning that parents utilise." (Families First Inner West 2002a, p. 67) Clearly parents' own experience cannot be a central source of information, firstly because of the limitations of each individual's knowledge base, and secondly because of the problem of awareness. This makes the functioning of the framework problematic, either information is not part of it or parents' acquisition of information is conceptually different to what the consultants have devised. The author of this thesis would suggest it is the latter. The research does not comprehensively define the modes of information acquisition, although the framework has some important characteristics, nor does it identify and allow for the contextual factors supporting or acting as barriers to access. If the aim is to maximise the probability of parents acquiring and using information then the first priority must be to understand all the ways in which parents acquire information, what supports their access and what inhibits it.

The final piece of Families First research to be reviewed is "Supporting Families who have a Child with a Disability" (Families First Inner West 2002b). It followed the identification of significant problems in information and service delivery to families of children with disabilities in the Inner Western suburbs of Sydney:

Parents and service providers reported a lack of information for parents of children with disabilities. This included information on their child's condition, information on services, and information on how parents could respond and cope. The extent of distress experienced by these parents, and their recognition of gaps in the system far exceeded that expressed by parents of children without disabilities... Parents reported needing more information to assist them in thinking about the future. They reported lack of coordination in information about services, and confusion about what was available to support them... significant gaps and barriers in the provision of information to families, particularly for ... parents of children with disabilities... Once children were diagnosed parents often reported confusion about service availability and identified a preference for a comprehensive resource with information about service provision. (Families First Inner West 2002a, pp. 17, 19, 42)

All the parent commentary reported by Elliott and Apte (Families First Inner West 2002a) strongly attests to serious broad based information problems that are entirely consistent with that reported in the main body of the childhood disability sector.
research, as reported and reviewed herein. However, while Tudball et al (Families First Inner West 2002b) affirm that a need for the research arose directly from family responses within the earlier Families First research, they define the need for analysis as concerning "the nature of the assessment of children with a disability or what support needs families may have specific to the assessment process.” (Families First Inner West 2002b, p. i) No satisfactory rationale is given for focussing on the assessment period. There is no reference made in Elliott and Apte’s (Families First Inner West 2002a) work to a need for analysis or research around the assessment process alone. Significant research in the field, such as that of Mitchell and Sloper (2000, 2001, 2002), does not limit addressing parents’ information problems to one time period. Notwithstanding the fact that many parents have reported problems acquiring adequate information at diagnosis, Mitchell and Sloper (2000, 2001, 2002), recognise that this is part of a larger problem in the delivery of information in the childhood disability sector generally. Such an approach cannot even be justified by claiming the assessment process presents a discrete set of information and support problems that can be researched discretely, as indeed the consultants found:

For many families, it was not always possible to separate assessment from their experience of services designed to meet on-going needs. There is not always a clear delineation between assessment and on-going support... Assessment has many purposes: to diagnose an impairment; to monitor developmental progress ...Therefore much of the information families gave relating to experiences other than assessment-based has relevance to the objective of this report. (Families First Inner West 2002b, p. 7)

This is precisely the point and raises the question why the research did not address the broader issues.

The families, services and support organisations participating all expressed the need for a “first point of contact for families to assist them in navigating the service landscape” (Families First Inner West 2002b, p. 29). This is consistent with Mitchell and Sloper’s (2000, 2001, 2002) link worker or care coordinator role, and also has an element of a one-stop-shop worth considering. This is consistent in turn with the views of service providers who earlier identified the need for the equivalent of an information one-stop-shop, reported as “a single contact point listing available brochures and their source” (Families First Inner West 2002a, p. 64). However these needs are not reflected in the model developed. The findings are all distilled into “Communicating Assessment
Outcomes”, and “Principles for Support During Assessment”. Of particular relevance are the practice guidelines on Communicating Assessment Outcomes:

1. Present brief information in the first instance
2. Give families the positive information as well as the negative
3. Give the family a fact sheet about the impairment
4. Provide opportunities for follow-up
5. Refer families to peer support agency

(Families First Inner West 2002b, pp. iv, 18f)

These findings are entirely consistent with much disclosure of disability research, such as that of Hasnat and Graves (2000b) reviewed earlier. However the model for supporting families through the assessment period contains a flaw revealing a fundamental failure to grasp one of the most significant reasons parents fail to acquire information; their extant knowledge base and awareness of information. The flaw, deriving from the family centred model of service delivery that holds the family is the expert and therefore best placed to identify their own needs, can be seen in the following quote:

The primary responsibility would be to offer current, thorough and timely explanation, information and referral when families have questions and identify their needs. [emphasis added] (Families First Inner West 2002b, p.21)

Families unaware of information may not have the necessary trigger to identify need for information and may not therefore be able to articulate a question to be answered. In the light of the above analysis this research has been a somewhat inadequate sequel to Elliott and Apte’s (Families First Inner West 2002a) work; for changing and developing practices, in the absence of a sound theoretical and evidentiary base runs the risk of not addressing or even reifying existing problems.

Conclusion

An overview of information issues in the sector, raised in the literature (see 1.2), strongly suggests that parents of children with disabilities face significant information acquisition problems and that these appear to flow as direct corollaries of specific access to information problem areas. It is evident that the research analysed for this review, to a greater or lesser degree, makes an important contribution to understanding aspects of parental access to and acquisition of information. However it does not provide a coherent, systematic and comprehensive picture of information acquisition
amongst parents and the specific issues arising that present barriers to access to information.

As observed by a parent participant in Mitchell and Sloper's (2000, p. 19) research:

If you go into any office — health, education or social work — you wouldn’t think there was any problem with information because there’s thousands of leaflets … and yet people still say they don’t get enough information. So to me that’s the starting point of the problem. It’s not simply that people aren’t getting the information, it’s why are they not getting it when they want it or in the form that they can absorb it, or in a way that they can act on it? … [emphasis added]

If parents consistently report failure to acquire information notwithstanding years of changing practices then something is happening that has not been properly investigated. What is required is an analysis of why families do not acquire information, frequently at critical times, when there is no shortage of information per se. The only way to attain to such an analysis is to model how parents acquire information and to identify the points at which they do not and why this has occurred; yielding evidence of specific access problems preventing parents from acquiring information.

This is the aim of this thesis.
CHAPTER THREE - THEORETICAL FRAMEWORK

3.0 INTRODUCTION

It is important to locate research within an appropriate theoretical framework, as this will provide a rational starting point (orientation value), a means of understanding emerging data (explicative value) and identification of potential outcomes (predictive value). Pettigrew and McKechnie (2001, p. 62) have observed that:

if fields such as information science (IS) are to delineate their disciplinary boundaries and build a central body of knowledge, then they require their own theoretical bases for framing research problems...

Yet it has not been possible to find any information science theory previously applied to the information issues raised in the childhood disability sector, as observed in Chapter 2. This Chapter therefore draws on an array of theory and core conceptualisations to provide an information science (IS) orientation with potentially explicative and predictive value to the research questions detailed in Chapter 4 (p. 146). The questions are premised on a recognition that information acquisition is multi-modal, while much practice in the sector assumes parental information seeking. Thus this Chapter explores theory around information seeking, information delivery and serendipity to form a framework from which to approach an investigation of parental information acquisition. Related theories and core conceptualisations that assist in understanding potential barriers and other influencing factors in the acquisition of information are also presented.

Given that the term information is “ambiguous and used in different ways” (Buckland, 1991, p. 351) it may well be that an effective central body of knowledge within IS is best built from what Wersig (1993, p. 237) described as an “interweaving of models and inter-concepts”. This is consistent with the building of a “statement of the relationships among theoretical propositions” Wilson (1999, p.250) sees in advanced modelling of information behaviour. Wilson (1997) has gone to some length to show the utility of interdisciplinary theory to IS study of information behaviour, and this chapter builds on the understanding that theory growth within information science can proceed from both internally generated theory and effective adaptation of relevant exo-theory. The crucial point here is that the building is coherent and logical, and achieves the aim of seamless interconnectedness. To this end, using McCreadie and Rice’s (1999a, b) work for...
orientation, this chapter weaves a range of theoretical concepts and approaches into a conceptual framework that advances IS theory.

McReadie and Rice's (1999a, b) expansive review of access to information provides sound orientation value for this thesis. The review synthesises the conceptualisations of access to information across six disciplinary research literatures (library studies, information science, information society, mass media, organisational communication, and economics of information). The authors group the conceptualisations into those addressing information, access to information, facets of the information-seeking process, and influences/constraints on access to information. Of particular relevance to this research are the conceptualisations of information itself and those facets of access to information pertaining directly to its expression in the acquisition of information, along with any precursors to information need and seeking, contextual problems and constraints.

As a starting point, McCreadie and Rice (1999a, p. 46) observe that "assumptions about information...have implications for notions of information access" [emphasis added]. Indeed, as Chapter 2 suggests, conceptual ambiguity regarding the terms information and information delivery in the childhood disability sector in N.S.W. in particular, have a profound impact on the models of service delivery in practice, and ultimately on parental information access and acquisition. It is arguable whether this has arisen because of the failure to employ an information science perspective in addressing information issues. As Bates (1999, p. 1043) has observed, "Our expertise is ignored while newcomers to information questions stumble through tens of millions of dollars of research and startup money to rediscover what information science knew in 1960."

As the focus of this research is on understanding parental access to information, particularly as expressed in information acquisition, conceptualisations of information and access to information are addressed first, followed by analysis and synthesis of literature related to information acquisition. This is presented in a conceptual framework for information acquisition. Influences and constraints on access and acquisition are considered last.
3.1 ACHIEVING CONCEPTUAL CLARITY ABOUT INFORMATION, ACCESS TO INFORMATION AND RELATED TERMINOLOGY

In order to overcome the problem of conceptual ambiguity, to which this author has attributed some responsibility for information "failures" in the sector to date (see Chapters 1 and 2), a discussion based on McCreadie and Rice's (1999a, b) synthesis follows, aimed at achieving what Taylor (1996, p. 128) described as "rigorous flexibility". From this derives the approach to achieving conceptual clarity applied in this thesis.

3.1.1 Information

McReadie and Rice (1999a) identified four basic approaches to the conceptualisation of information: information as a resource or commodity, as data in the environment, as a representation of knowledge, and as a process of communication (McReadie & Rice 1999a, pp. 46-49). No one approach yields the "correct" definition of information. It is reasonable to suggest that the most appropriate way to approach the concept of information when seeking to understand the phenomena under investigation is to embrace all the conceptualisations as providing different viewing filters of the essential concept. Each contributes an important understanding to the whole. It may well be that individuals, just as the bodies of literature McCreadie and Rice (1999) were reviewing, tend to favour one filter over the others. The author of this thesis however, consistent with McCreadie and Rice's commentary, seeks to employ all in reaching an understanding of what is under investigation, for "only by taking a multidisciplinary approach to conceptualizing access are we likely to deal with all the apparently relevant aspects of access" (McCreadie & Rice 1999b, p. 79). Dervin's (1983, Core conceptual premises section, para. 12) application of "circling reality" has particular utility here, where the concept is "a convenient way of referring to the necessity of obtaining a variety of perspectives in order to get a better, more stable view of 'reality' based on a wide spectrum of observations from a wide base of points in time-space." Indeed Solomon (1997, p. 1107) inherently recognises the impact of the multiple facets of information on the design of information systems: "information systems might better fit their associated tasks if attention is given early in information intensive tasks to issues of process and what information is in relation to the task at hand".
It is salient that from the perspective of the user or client information is often described simply as "that which informs" (Dervin 1983, Work to date section, para. 10).

If one adopts the viewing filter of information as a resource or commodity, then what one sees primarily is what Buckland (1991, p. 351) describes as "information-as-thing". It is a commodity that is produced, often in some standardised form, distributed and controlled (McReadie & Rice 1999a, p. 46). Taylor (1996, p. 93) describes this as the technological approach to information transfer, and indeed Buckland (1991, p. 352) observed that "with the expansion of information technology, the practice of referring to communications, databases, books, and the like, as 'information' appears to be becoming commoner". New South Wales government standards governing, among other things, information delivery in the sector tend to be practiced using this conceptualisation of information (see for example ADD 1997, ADD 1999, Families First 2002b). However, the notion of parents being fully "informed" and the importance of informing processes such as parent-to-parent communication (see information as process below) in parental information acquisition is specifically recognised (ADD 1997, p. 2). This points to a gap between policy and practice, arising because the practice required to achieve the standard is not specified by way of definition of information and its delivery, resulting in conceptual ambiguity.

Viewing information as data in the environment is a second approach, and yields a useful filter for identifying communication of information that occurs apropos of events, activities and other phenomena rather than as intentional information exchange. McReadie and Rice (1999a, p. 47) see in it an informing process that occurs "by perceptions of things that are communicated unintentionally". The focus is on the unintentional communication that occurs. Thus access to information is seen less from a question/answer perspective and more from a perspective of environmental availability of problem resolution. McCreadie and Rice (1999) observe that this approach is seen in Taylor's (1996, p.96) information use environments, where the "recognition of problems and the processes of seeking resolution to these problems ... define the information process". An emphasis on the acquisition of information through unintentional information exchange may well be a feature of environments in which information delivery processes enabling individual resolution of problems are not functioning satisfactorily, such as in the childhood disability sector, inducing stress as reported in Chapter 2.
A third filter through which to view the concept of information according to McCreadie and Rice (1999a, p. 48), is that of information as a representation of knowledge. Typically indexes and catalogues are tools for pursuing representations of knowledge. Taylor (1996, p. 93) describes this as the “content-driven” approach, where human representations of reality may become the reality themselves. Some of the directories of services available within the childhood disability sector tend to be constructed along these lines in an attempt to represent sectoral knowledge in terms of service delivery, for example the Association for Children with Disabilities (2001a) Through the Maze directory. If one were to maintain an “information as representation of knowledge” approach only, however, one would not reach a comprehensive understanding of what is knowable within the sector, because much of what is knowable occurs as data in the environment (discussed above) and information as communication, discussed below.

McCreadie and Rice’s (1999a, p. 48) fourth conceptualisation of information yields an information as communication process filter. This filter has particular utility in any domain characterised by information exchange in the context of relationship. Information as inherent within the communication process is very much at the heart of Dervin’s (1983, Core conceptual premises section, para. 3) work on sense making, where “information is not a thing that exists independent of and external to human beings but rather is a product of human observing”.

The significance of parent-to-parent communication in yielding the most efficacious mode of parental information acquisition is often remarked on within the sector (see for example Families First Inner West 2002a; Mitchell & Sloper 2001; OCYP 2001a, b) and bears eloquent testimony to this conceptualisation of information.

It is also important to note at this point that client groups do not necessarily use the same information terminology as professionals, either within the childhood disability sector or within the LIS field. Certainly Chatman (1986, 1991, 1996), whose investigations explored groups outside traditional information repository settings, reported information activity among the poor, for example, using terms such as news, hearing about, daily conversations, interpersonal exchange, staying informed, discussions, advice, knowing and description. Therefore in this investigation an approach to information terminology has been adopted, consistent with the multifaceted approach to the use of the term information itself, to operationalise information to include notions such as: advice, hints, material, resources, ideas, communicative devices etc as well as the information function of hearing about, knowing about, understanding, learning that, being told, being aware of, being made aware of, informed,
advised, updated, educated, kept up to date, kept in the loop, awareness raised, being assured, filled in and so on. Whenever these and related terms are used, the notion of "information" or an information function or process is understood.

3.1.2 Access to Information

McCreadie and Rice's (1999a, b) analysis and synthesis of the six research literatures' conceptualisations of access to information has considerable contextual importance for this thesis. They identify six basic approaches, namely, access to knowledge, access to technology, access to communication, access to control, access to goods and commodities and access to participation.

*Access to knowledge* is the classic approach to access to information. In this approach access derives from information as thing and information as representation of knowledge (McCreadie & Rice 1999a, pp. 49f). Much information delivery within the childhood sector adopts this approach, as there is no shortage of hardcopy information (brochures, booklets, Facts Sheets etc) and an increasing volume of directories and guides, yet clearly this does not yield adequate access per se, as observed in Chapter I (1.2).

*Access to technology* is another common conceptualisation of access to information (McCreadie & Rice 1999a, p 51). Yet technology is a tool of access, rather than the access per se. The distinction is important for, as McCreadie and Rice (1999a, p. 51) observe, technology "is not sufficient to provide access on its own". The common misconception that access to technology necessarily yields access to information can be seen in the shift of the Australian government's approach to the information management of the Commonwealth's information resources discussed in Chapter I (1.1.4.1). Clearly the widespread availability and "use" of the internet must be considered from this perspective. For example, use of e-mails and chat rooms may not yield access to the information required to resolve problems yet system access has clearly occurred and is reported in government statistics as a widespread increase in "use of the internet". Notwithstanding this, access to technology can "increase the possibilities for access to information" by intensifying an individual's information-seeking capacity or compensating for absence of capacity (McCreadie & Rice 1999, p.
and thus “overcoming physical, social, cognitive or other constraints that might otherwise block access to information”.

Of particular note is the related concept of mediation. Although McCreadie and Rice (1999a, pp. 52f) tend to focus at this point on technology as mediator, their observation that “mediation and technology can compensate also for interpersonal and structural barriers to information” does allow for an important distinction between technological and non-technological mediation. Access to information could thus be mediated by a person, with the effect of overcoming barriers that the individual may not otherwise be able to overcome. This type of mediation is clearly envisaged in the role of link worker or care coordinator, for which leading researchers in the childhood disability sector, such as Mitchell and Sloper (2000), in the childhood disability sector are calling.

Access to communication is a third conceptualisation of access to information, seen most clearly in works that focus on communication in terms of sense-making, such as Dervin (1983). Access however still requires communication relevance, which is more likely to be achieved when the information is anchored in the everyday life experience of the individual (Chatman 1991). McCreadie and Rice (1999a, p. 53) also point to the significance of interpersonal networks as part of access to communication, and this certainly reinforces the importance of reference groups in access to information and the role of the mediator of information.

Access to information can also be viewed from the perspective of access to control, which may be control over information flow itself, or metainformation or policy regarding information (McCreadie & Rice 1999a, pp. 54f). This is relevant if one considers those with increasing levels of “communication competence” skewing resources in their favour, such as the increasing polarisation seen in the so-called digital divide.

Indeed, if access to information is considered from the perspective of access to goods or resources, one immediately sees the social policy implications, as such access has an immediate effect on distribution of resources and, in the case of the childhood disability sector, of services and entitlements. McCreadie and Rice (1999a, p. 55) observe that “because of its potential as a public good, information production is frequently subsidized by the government.” Yet it is also the case, they indicate, that while
those with limited resources stand to gain more from access to information in terms of potential economic, social and political improvement than do others ... they are also less likely to possess resources such as awareness of sources of information or the ability to express clearly their needs (McCreadie & Rice 1999a, p. 56).

This is certainly seen in Chatman’s (1986, 1991, 1996) work among the poor where factors within the individuals were inhibiting access to needed goods and resources, including - importantly - information about those goods and resources.

Lastly, access to information is also conceptualised as access to participation (McCreadie & Rice 1999a, p. 56). This derives from the position that “democratic political participation requires an informed citizenry, and that to be informed we must have ready access to information” (Lievrouw 1994, p. 350). Yet ironically as the information environment has been shifting away from informing and toward involving, (Lievrouw 1994, p. 350), emphasis has also shifted away from the expert and onto the individual to become instrumental in the acquisition of information necessary for participation.

3.1.3 Information Need – recognition and awareness factors

Recognition of information need and awareness of information play a significant role in the acquisition of information. McReadie and Rice (1999a, p. 64) specifically identified awareness as an influence or constraint on access to information: “to gain access to information a user must be aware that the means of addressing the situation are available”. They cite Dervin (1980) in stating “one’s understanding that a need for information exists and the level of understanding of that gap, problematic situation or anomalous state of knowledge most certainly influence the likelihood of gaining information to address it” (McReadie and Rice 1999a, p. 63). Note that while the term “access” is being used in this context by McReadie and Rice (1999a), it is the contention of this author that information acquisition necessarily flows from access to that information as a starting point: that is (apart from serendipity), acquisition cannot occur without access, while access can be available without acquisition necessarily resulting. Yet notional access is not adequate to address circumstances - information must be acquired in order to use it in addressing those circumstances or the problem situation. Therefore, for the purposes of understanding the parental experience of information within the childhood disability sector, it is more helpful to look at access to
information as it is expressed in the acquisition of information. In the case of McCreadie and Rice’s (1999a, b) work, awareness of information and recognition of information need as influences/constraints upon access to information must necessarily therefore also be understood to influence acquisition.

The LIS information need and seeking literature is a large and diverse corpus that, of late, has tended to embrace construct theory generally and Dervin’s sense-making approach in particular, as a matter of course. According to Kuhlthau (1991, p.362) construct theory sees individuals “constructing meaning from the information they encounter”, which itself is not necessarily problematic for understanding information need unless the individual is also deemed to be constructing that need. This is in fact the position of many researchers and theorists within current information behaviour theory.

Dervin (Dervin 1983; Dervin & Nilan 1986) developed a sense-making theory and methodological approach to examine, inter alia, how individuals use information to make sense within changing reality. The sense-making model comprised the elements of SITUATION (the context), GAP (the loss of sense occasioning information need, bridged by “question/s”) and USES (the application of answer/s to question/s to reconstruct sense). Dervin holds that the information need situation is one where individual sense “runs out”. In order to make new sense, the individual builds bridges across the gap, through questions, the answers to which are used to reconstruct sense (Dervin 1983; Dervin & Nilan 1986).

Dervin’s methodological approach includes the micro-moment time line interview, which asks the individual “what happened in a situation step-by-step” (Dervin 1983, Methods of Data Collection section, para. 2). However, because the underlying theoretical perspective sees individuals “constructing” their picture of reality, their information needs and uses, as well as information itself, the focus is upon the instrumental action of the individual; what the individual did, what questions he or she asked to move from gap to reconstructed sense (Dervin 1983, Core Conceptual Premises section, paras. 6, 7).

It is not the intention of this author to de-construct this theory or its incorporation in much information need and seeking theory. It is important however in research seeking to investigate how individuals acquire information, along with factors implicated in
their failure to acquire, to identify where such an approach may be undermining the understanding of individuals' experiences of information need and seeking, which it is possible to attain.

Nowhere is the potentially undermining influence more apparent than in the study of information need. Perhaps the most revealing evidence is that seen in Wilson's movement in thinking. In his early work Wilson (1981, p.8) observed that need did not necessarily immediately trigger information seeking:

in the case of an affective need, neither the need nor its satisfaction may be consciously recognised by the actor, ... or the availability of the information may bring about the recognition of previously unrecognised cognitive need.

This is certainly consistent with the current work of Erdelez (1997, 1999, 2004) and Williamson (1998) in the areas of opportunistic information acquisition (OAI) and incidental or accidental information discovery, where the discovery of information not originally sought leads to the recognition of information need. Taylor's (1968, p. 182) early model of information seeking in libraries, described as question negotiation, also allowed for a concept of information need beyond the individual's construction, namely the “visceral” need level, wherein:

there is the conscious or even unconscious need for information not existing in the remembered experience of the inquirer. It may be only a vague sort of dissatisfaction. It is probably inexpressible in linguistic terms.

In conceptualising thus, Taylor (1968, p. 182) removed the necessity of recognition of all but a vague sort of dissatisfaction. This is important because it identifies “actual but unexpressed need”. Yet Krikelas (1983, p. 8) believed such significant difficulties attach to articulating a “relatively nebulous concept” that it is more useful “simply to define need as recognition of the existence of uncertainty and to observe the resolution (a behavior)”.

Yet this approach effectively draws a direct line between the individual's ultimate capacity to define his or her own information need (by navigating through the levels of need, albeit with the skilled assistance of the librarian), and, access to information. Yet it is of note that Taylor (1968, pp. 179f), recognised large numbers of information system users developed “their own search strategy, neither very sure of what it is they want nor fully cognizant of the alternatives open to them” and in interacting with the
librarian the user is trying to describe “something he does not know”, that is, the information need.

This resonates with Belkin’s (1986, p. 9) early assertions, including the statement that “people who come to information systems do so just because they lack some information. It seems unrealistic to ask them to specify that which they do not know”. This is evident in a typical scenario described by Belkin between a university student and a reference librarian, (1986, p. 10). In it the student asks, “Do you have any books on Shakespeare?” The underlying problem may be that the student has a paper due and has not read any of Shakespeare’s works. Belkin says “the student probably does not know that such things as cribs on plays by Shakespeare exist” (Belkin 1986, p. 10). This may in fact be what the student “needs” but they cannot articulate that need, as the existence of the information is unknown.

However, since Wilson’s earlier observation, he and others have largely ignored the phenomenon of unrecognised need, perhaps resulting from the current philosophical position that “need is a subjective experience that occurs only in the mind of the person in need and, consequently, is not directly accessible to an observer” (Wilson 1997, p. 552). From this position, “information need” only becomes a need at the point at which a person recognises it as such, whether by virtue of his or her own activities, information delivery or serendipity. Almost by definition therefore, there cannot be unrecognised information need that one could, for example, identify in another person’s experience.

Yet individuals are frequently able, retrospectively, to identify that they have had specific needs for information at particular points in time that they did not recognise. Furthermore, while they may not have recognised these needs at the time others within close proximity were in a position, by virtue of similar experience and/or expertise, to recognise objectively their information needs. The work of Mitchell and Sloper (2000, 2001, 2002), Pain (1999) and Elliott and Apte (Families First Inner West 2002a), among others, contain many embedded examples of this. (The examples are “embedded” in the sense that they were not under direct investigation as evidence of unrecognised information need by the researchers and therefore not necessarily identified as such.) Fyffe, Gavidia-Payne and McCubbery’s (1995, p. 36) work gives an insight into the parent perspective, which while not using the terminology “unrecognised information
need" bears eloquent testimony to it, and is echoed throughout the childhood disability sector literature:

I know not what and I know not where...

I wouldn’t have known if it hadn’t been for other mums...

If I hadn’t been introduced to the mum of another disabled child I would never have known what was really available and what it was fair to ask for.

I’ve been here eight months ... but I haven’t heard of any playgroups. I heard of one, but I don’t know how to get there. I haven’t got no pamphlets or anything. (Families First Inner West 2002a, p. 26)

In the case of the last parent quoted above, unrecognised, or more accurately latent, information need existed around the area of playgroups and transport to those groups. There is no presumption in identifying a need to know certain information upon which basis an individual could construct an understanding of relevance and make an informed choice about whether to utilise the information (by attending the playgroup etc). After all that is the basis of the democratic process of choice. Presumption would set in at the point someone told the person he or she needed to utilise the information.

This suggests that information need is not merely a subjective construct, resident only in the mind of the individual. Until the individual becomes aware to some degree of the panoply of possibilities, there is no sense in which he or she can effectively construct an information need: the need arises from the circumstances, rather than the individual’s capacity to construct and articulate it. Wilson’s (1981) earlier position is far more reflective with what can be observed in everyday life: that information need can and does exist prior to, and thus apart from, recognition. As observed, it is sometimes the availability of information itself, and awareness of it, that alerts the individual to previously unrecognised information need.

Wilson’s (1997, p. 554) suggestion that the stress and coping literature of psychology, (see 2.3.2.2) offering “proximate causes of information seeking behaviour”, is a potential alternative to gaining evidence of “elusive information needs”, must be cautiously examined in this regard. This literature clearly teaches that families differ greatly in how they perceive events and the personal and socio-economic resources that will comprise their own coping strategy (McConachie 1994; Sloper & Turner 1993). Coping strategies are generally understood as either emotion-focused, aimed at the
emotions arising from stressors, or problem-focused, being active and aimed at addressing the problem, encompassing among other things information seeking (Beresford 1994; Pain 1999; Van Zuuren & Wolfs 1991). Thus a family may have had a critical need for information (retrospectively identifying such need) but because theirs was a predominantly emotion-focused coping style, they might never have sought directly or indirectly, information that may have addressed their circumstances. Serendipity or proactive information mediation may be the only means by which they could have acquired such information. Hence the question arises: does the absence of recognised and articulated information need constitute an absence of information need?

There is, therefore, an inherent danger in using a stress and coping model to elucidate information need. If the model holds true, then active information seeking only occurs among those parents acting as effective copers/adapters, who are identifying what they need to know and taking action to acquire it. It says nothing regarding information awareness and needs of parents utilising emotion-focused strategies. Indeed it cannot, because families utilising primarily emotion-focused coping strategies do NOT characteristically seek information. Therefore one would either need to conclude that they have no information needs, or that there is no means of ascertaining these information needs. Thus the information awareness and needs of parents who could not identify or recognise those needs, and therefore could not seek to have them satisfied, are not addressed within the stress and coping model. This is because the model is concerned with identifying adaptive behaviour styles, not the nature and characteristics of their information sequelae.

In the light of this commentary, it is also worth considering that ethical questions must arise from the professional's philosophical orientation toward information seeking, information needs and information delivery. Consider the parent with an avoidant coping style, where there is an emphasis on the emotions arising from stressors rather than tackling the stressors directly. Should the professional assume and accept that the parent has no information needs concerning their child with a disability, on the basis that they show no behaviour evident of problem-focused coping, and in particular active information seeking? What if inaction, on the part of the parent, actually arises from a pre-existing lack of awareness of information, rather than avoidance per se? Whether the parent is avoidant or unaware, what happens if lack of knowledge of critical information pertaining to the child begins to affect the child's development? What if it
affects their quality of life? What if it affects the chances of survival? Exactly where does one draw a philosophical line between information action and inaction, and the rights and responsibilities of the parents and the professional service providers relating to information need and seeking? And what of the parent who has a largely active coping style, developing problem-solving and information-seeking strategies so effectively that service providers' resources are biased in their favour, away from those who are possibly inarticulate, information-avoidant and/or primarily emotion-focused copers? Resource allocation thence would be based not on externally identifiable, measurable need, but on the extent to which the individual could identify, articulate and demand acquisition of information and services. Erdelez' (1997, p. 417) analysis of information encounterer sub-groups, and in particular the super-encounterers, certainly suggests the capacity among a sub-group to acquire information, by virtue of their own instrumental actions, at rates far beyond that experienced by others.

Such individual differences also appear to apply within problematic situations. Miller (1987, p. 351) found results of studies investigating coping suggested that "dispositional differences in coping style are an important moderator of actual coping strategy in aversive situations" [emphasis added] (Miller 1987, p. 351). While Sloper and Turner (1992, pp. 274-276) have found a clear association between high use of a passive coping strategy and unmet needs: "mothers who did not take an active approach to obtaining help were less likely to be provided with help appropriate to their needs." Sloper and Turner (1992, p. 277) then raise the issue of how such families can be helped "to take a more active role in dealing with problems", notwithstanding evidence that variations in coping strategy may actually derive from individual differences.

If there are dispositional differences in coping strategies and hence use of information seeking, then investigating information-seeking behaviour alone to understand information need is entirely inadequate, especially where it is possible to identify a body of people who do not characteristically seek information. The author of this thesis argues that one of the reasons that there may be some discomfort within LIS theory in allowing for objective identification of information need may stem from the imperative to view need as that which is constructed by the individual (for example from a gap according to Dervin's research, from an anomalous state of knowledge according to Belkin's research, and from uncertainty in Kuhlthau's). As long as that position is maintained, any attempt to elucidate objectively what may be an individual's
information need is presumptuous, as one cannot observe the internalised construction processes. Hence research, and the theory that informs it, pulls back to a position of recognising that while there may be something vague and amorphous like “unconscious need” (Krikelas 1983, p. 8) or the “visceral need” (Taylor 1968, p. 182), there is no way of knowing what it actually is, so it becomes far more helpful to seek other means of exploring information behaviour.

In his more recent work Taylor (1996) models information use environments, which yields an interesting approach to understanding information behaviour. The focus is on:

the contexts within which ... users make choices about what information is useful to them at particular times ... These contexts being what the author has called information use environments (Taylor 1996, p. 93).

Taylor’s (1996, pp. 97-109) model suggests how information use environments can be examined under four categories: sets of people; problems; typical settings; and resolution of problems. The model appears to have potential heuristic value for mapping the information milieu (defined here as the information context in which an individual moves pertaining to a particular domain or issue area) of an array of domains. However, in defining the scope of his work, Taylor (1996, pp. 95f) states:

The user population is limited to those groups or classes of people who are active, experienced, and critical users of information. That is to say, they are aware of their problems; ... where they can find useful information; and they have a critical sensitivity to what constitutes ... a resolution of a problem in this context ... It is the recognition of problems and the processes of seeking resolution to these problems which defines the information process [emphasis added].

Hence Taylor (1996, p. 97) presents his definition of information behaviour as:

The sum of activities through which information becomes useful ... [where] activities imply active search resulting from an area of doubt or more specifically a recognised problem ... [emphasis added]

However, focussing on the instrumental actions of the individual in constructing information need and consequent information-seeking behaviour does not allow for the problems of awareness of information and unrecognised information need, as discussed above. Indeed, the effect of this position, as noted, has been to draw a direct line linking the individual’s ultimate capacity to define his or her own information need, and access to information. This is consistent with the movement in the information environment away from informing and toward involving identified by Lievrouw (1994, p. 350).
Yet factors that actively inhibit any constructive activity in recognition of need, such as awareness, do not ipso facto preclude need itself. Cole (1997, p. 63) observes of Belkin, Dervin and Kuhlthau that:

Their theories “formally” begin with the person becoming aware of a gap in understanding, or a gap in meaning or sense. When the person becomes aware of the gap, the person engages in information seeking behaviour, which is the primary focus of these theories. However, all these theories (especially Dervin’s and Kuhlthau’s) implicitly acknowledge the existence of information seeking behaviour that is “pre-awareness” and thus out of their theories terms of reference [emphasis added]

Cole’s (1997) investigation of how information modifies knowledge structures pushes further into the issue of awareness. Cole (1997, p. 56) poses the question “for someone who knows nothing about what she is looking for, who doesn’t know what she is looking for, how does she start ‘knowing’?” Under examination is the individual’s point of pickup or perception of what is available to be known within the environment (i.e. awareness). The question then devolves to one of the “initiating conditions” or triggers to the pickup. This is confirmed in his analysis of Belkin, Dervin and Kuhlthau, in which he points out that “gaps must be present in our knowledge structures about everything all the time … and yet we are not consciously seeking out information about something all the time” (Cole 1997, p. 58). He concludes that when “active conscious information seeking occurs” it may be triggered by recognition of a gap in knowledge structure, sufficient in size to breach the threshold of awareness (Cole 1997, p. 58).

Cole (1997, p. 63) believes that in extending the parameters of information he has extended information-seeking behaviour to a stage which is “pre-awareness or unconscious, [thus providing] some evidence for stage ‘zero’ – the initiating conditions where the information process actually ‘opens’”. Hence, it is not just the gap or anomaly per se but ‘becoming aware of’ the gap that triggers actions.

Clearly individuals have a large array of gaps/anomalies at any given time, of which they are unaware and therefore, apropos of which, no constructing activity can take place. Yet a great deal of behaviour and activity of an information nature must be occurring even before Cole’s (1997, p. 63) “stage zero”. This includes delivery of information and serendipity (seen in Erdelez’ 1997, 1999, 2004 work and Williamson’s 1998 work), which is clearly part of the process by which one becomes aware of a gap/anomaly. Awareness itself can also be triggered by a form of information-grounding behaviour where no particular need is in view, but according to Krikelas
(1983, p. 8) information is being gathered which is not problem-specific. Both delivery and non-specific gathering behaviours lead to the discovery of information or awareness that alerts the individual to previously unrecognised information needs. These elements may go some way to explaining Cole’s (1997) triggering mechanism more fully.

It is reasonable to conclude, therefore, that where the constructing activity envisaged by Dervin, Belkin, Kuhlthau and others pertains to a post-awareness position, this does not necessarily or logically preclude a type of information need (which the author of this thesis conceptualises as latent information need) that exists pre-awareness and is objectively identifiable by domain experts (for example other more experienced parents). Only the imperative of user construction, flowing from construct theory as it is applied to information need and seeking theory, stands in the way of this approach. The author of this thesis does not accept that constructing activity and objective reality are mutually exclusive notions and contends that the individual both constructs perceptions of reality and relates to reality as it is encountered. There is clearly a thread within LIS literature, albeit fine and not pursued as the goal of any research agenda, that indirectly attests to concepts of information need beyond that which can be constructed and articulated by a user, and associated factors such as lack of awareness of information. The work of Erdelez (1997, 1999, 2004) on information encountering and Williamson (1998) on incidental/accidental information acquisition noted above are examples.

To the degree that Dervin’s and others’ theories require the individual to construct need and take instrumental action in acquiring information relating to it, they limit the extent to which a full understanding of human information need and seeking behaviour can be developed. They also necessarily restrict the understanding of information acquisition and the factors implicated in failure to acquire, because the attendant behaviours have not been holistically mapped.

What happens when the requirement of constructing behaviour is lifted? What happens when the assumption of recognition of information need is removed? What happens when individuals are investigated within their “problem” situations and the information activities and inactivity are mapped? It then becomes possible to learn how the individual acquires information whether it arises from recognised, problem-specific information need and seeking, a more amorphous, gap-bridging exercise, or apparently apropos of nothing more specific than dissatisfaction, interest, uncertainty or a vague
desire. It also becomes possible to attain a closer understanding of why a range of people with different problems, information strategies, skills and exposure levels to an information milieu, acquire and fail to acquire information that addresses their circumstances.

All of this points to the need to challenge construct theory, and in particular its creation of a paradigmatically exclusive approach to information behaviour as sense making, ASK and ISP demonstrate. If the imperative of “user construction” is removed from the study of information behaviour, many theories and conceptualisations are opened up with a wealth of enriching features applicable to the conceptual framework for information acquisition presented below.

3.2 A CONCEPTUAL FRAMEWORK FOR INFORMATION ACQUISITION

According to Hjørland (1998, p. 618), “information science is concerned with research, which might help improve the design of information systems and services ... [as they] collect, analyse, organise, describe and retrieve information/documents in order to inform actual and potential users”. By developing a theoretical framework for information acquisition IS theory has the potential to inform system design far more effectively.

Using Krikelas’ (1983) model of “information seeking behaviour” as a starting point, the author of this thesis built a conceptual model for information acquisition that has both explicative and predictive value, and embraces the multi-faceted concepts of information and access to information identified by McCreadie and Rice (1999a, b). The following discussion is structured around the conceptual framework and allows for the expression of all the ways in which individuals acquire domain information.

The author of this thesis posits that there are three basic modes of information acquisition, namely, information seeking, information delivery and serendipity. Saunders and Jones’ (1990, pp. 42f) work on information acquisition and decision making recognises different types of information acquisition occurring but codifies them as sources and media, which does not give the necessary emphasis to the initiator of the instrumental action required in analysing information behaviour. It is true,
however, that sometimes the seeking and the delivery are two sides of the same transaction, which in a sense Krikelas (1983, p. 13) recognised in "information gathering" and "information giving" but restricted its consideration to one individual's information-seeking behaviour.

Within each mode of information acquisition there are subcategories or subsets, some of which may represent what other authors describe as sources of information (seen particularly in "user studies", for example, Nicholas & Marden 1998, pp. 43f and Pain 1999, pp. 303f) and some of which do not. For this reason the term "mode subset" is used in preference to source. For the purpose of classification into a mode or mode subset, activities or events are deemed to be seeking, delivery or serendipity, depending upon the initiator or the primary focus of activity. Hence similar activities or events can reside in different subsets of different modes, discerned by the initial impetus. As Krikelas (1983, p. 7) observed, "purpose must be ascertained whenever one observes the act, if the data are to have any meaning". Where the focus is upon the unexpected nature of the acquisition, classification would normally be within serendipity, although it should be noted that in many cases information grounding will yield unexpected information discovery. This is explained in further detail below.

3.2.1 Information Seeking

Wilson's (1999, p. 249) paper on models in information behaviour research gives a good overview of the field. In it he defines information behaviour as:

Those activities a person may engage in when identifying his or her own needs for information, searching for such information in any way, and using or transferring that information.

He goes on to say that models of information behaviour are:

concerned with, on the one hand, generalised behaviours surrounding the actual initiation of information-seeking and, on the other, with the broader perspectives of the information search than simply the use of computer-based information retrieval systems. (Wilson 1999 pp. 258f)

Wilson considers that the differing models of information behaviour "do not all attempt to describe the same set of phenomena or activities" (Wilson 1999, p. 262) and indeed may be "nested" – moving from general "information behaviour" through finer and finer layers of detail to information seeking and thence searching behaviours. Thus
Wilson (1981, 1997, 1999) implicitly recognises variable modes in information seeking. The literature of optimal foraging among scholars also suggests variations in “information-seeking activities in the search stage [that] fall along a continuum from active to passive, or from hunting-like to gathering-like strategies” (Sandstrom 1999, Prey Choice and Other Optimal Foraging Models section, para.6).

The author of this thesis posits that information seeking occurs in ‘active’, ‘non-specific purpose oriented’ and ‘passive’ modes, termed ‘active information seeking’, ‘information grounding’ and ‘passive information seeking’ respectively. Each is discussed in turn.

3.2.1.1 Active Information Seeking

Active information seeking is information seeking in response to either specific, recognised information need or an anomalous state of knowledge (Belkin 1980, 1986, Belkin, Oddy & Brooks 1982). In Krikelas’ (1983, p. 7) view, information seeking “begins when someone perceives that the current state of possessed knowledge is less than needed to deal with some issue (or problem)”. This is an interesting echo of the concept of coping which:

consists of cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person (Folkman & Lazarus 1988, p. 310)

This connection was recognised by Wilson (1997, p. 554). He suggested that rather than attempting to define information need, given the difficulties attaching to observing an “internalized process” (Krikelas 1983, p. 7), stress and coping theory could be helpful in focusing on the “proximate causes of information-seeking behaviour” (Wilson 1997, p. 554).

Major theorists such as Belkin (1980, 1986, Belkin, Oddy & Brooks 1982), Dervin (1983, Dervin & Nilan 1986), Ellis (1989), Kuhlthau (1991, 1993) and Taylor (1968) have indeed tended to direct their work at this area of information behaviour. They hold that users are in a process of moving from uncertainty to resolution through the acquisition of information actively sought and applied either to a specific recognised problem, or to the gap or anomalous state of knowledge that gave rise to the uncertainty or sense of being stopped.

108
As observed, Dervin's (Dervin 1983; Dervin & Nilan 1986) "sense making" theory and methodological approach examine, inter alia, how individuals use information to make sense within changing reality. As the underlying theoretical perspective sees individuals "constructing" their picture of reality, their information needs and uses, as well as information itself, the focus is upon what the individuals did and what questions he or she asked to move from gap to reconstructed sense (Dervin 1983, Core Conceptual Premises section, paras. 6, 7). Dervin's approach goes some way to explaining the frustration an individual may feel in not being able to construct the "right question" to bridge a gap. Sense cannot be made, or, from Belkin's perspective, the anomalous state cannot be resolved.

However, to the degree the individual is seen as an active, constructivist user, Dervin's large body of work relates primarily to the active information-seeking mode. Indeed, Savolainen (1993, p. 26) made an observation about Dervin's approach that is particularly cogent to the Australian research context generally and the childhood disability sector in particular:

In Dervin's theory, the basic values of American culture are interestingly reflected: the central position of the individual actor, the importance of making things happen and moving forward, in spite of barriers faced, and relying on individual capacities in problem solving.

Taylor (1996, p. 95) also comments that his work focuses on "the American experience in the broader context of American culture" and explicitly recognises that "there may be differences between European and American experience, education, and hence information behavior." The centrality of individual instrumentality in problem resolution, which may be premised on cultural presuppositions, does appear to be consistent with the movement from informing to involving in the information environment identified in Lievrouw (1994, p. 350).

Belkin's Anomalous States of Knowledge theory (Keefer 1993, p.336) identified the inherent problems in interrogating a system when one knows enough to recognise information is needed (the anomaly in knowledge), but not enough to specify what is required to resolve the anomaly (Belkin, Oddy & Brooks 1982, p. 299). This resonates with the experience of parents of children with disabilities who enter the childhood disability sector as an unknown domain, and therefore have little, if any, understanding of what is available to be known. Indeed, Belkin (1986, pp. 6f) presents an "information
system situation”, into which fits an array of “information systems” as diverse as advisory services, social security benefits offices and document retrieval systems. He sees the user as: having goals, problems, intentions; in a problematic situation; recognising the anomalous state of knowledge (ASK); and then going “to some information provision mechanism”, similar to the way in which Dervin’s (1983) user recognises the gap and seeks to bridge it. At this point both Belkin and Dervin are according an importance to recognition of the gap or ASK as a trigger to information seeking.

Ellis’ (1989) behavioural model of information seeking is another example. Ellis, along with Kuhlthau (1991), identifies discrete, though related, information-seeking activities. For Kuhlthau, these tend to form a sequential process, and for Ellis, they tend to be features that are utilised and combined uniquely according to individual circumstances. The focus of Ellis’ work is on the individual’s actions in seeking information known, at least to some degree, to be needed. The characteristic activities of starting, chaining, browsing, differentiating, monitoring, and extracting are not necessarily activated sequentially, and individual patterns of information seeking will depend, as noted, on the unique circumstances of the individual (Ellis 1989, p. 178).

Kuhlthau built “on both Belkin and Taylor in creating her six stage model of the information seeking process” (ISP), according to Westbrook (1993, p. 544). Kuhlthau (1993, p. 342) used the premise that “an individual is actively involved in his or her progression from uncertainty to understanding” in developing the ISP model. Uncertainty plays a significant role in triggering information seeking: indeed “uncertainty due to a lack of understanding, a gap in meaning, or a limited construct initiates the process of information seeking” [emphasis added], according to Kuhlthau (1993, p. 347). The ISP model’s six stages comprise initiation (task – to recognise a need for information), selection (task – to identify and select a topic for investigation), exploration (task – to investigate information on the general topic to extend understanding), formulation (task – to form focus from information encountered), collection (task – to gather information related to focussed topic), and presentation (task – to complete the search and present/use findings) (Kuhlthau 1991, pp. 366-368).

Hence active information seeking may be seen as the information activities undertaken by an individual who has recognised either a specific information need related either to
a “problem” (in a general sense) or an anomalous state of knowledge arising from that problem.

3.2.1.2 Information Grounding

As Krikelas (1983, pp.8ff) observes, not all information seeking is associated with immediate need and is not necessarily problem-specific. Information grounding is a term coined by the author of this thesis to identify information activities being employed that have the effect of increasing the probability of the individual becoming aware of information previously unknown, or becoming aware of the relevance or application of such information. In this mode, the information was not previously recognised as needed nor was it actively sought. It is quite distinct from active seeking generally and from specific instances such as Belkin’s ASK (Belkin, Oddy & Brooks 1982, p. 299), as there is no intentional, directed seeking and no recognition of a gap, anomaly nor necessarily any uncertainty preceding the activity or activities.

Pettigrew’s (1999) conceptualisation of an information ground is a powerful construct which is the basis of the concept of information grounding. She holds that an information ground is:

an environment temporarily created by the behaviour of people who have come together to perform a given task, but from which emerges a social atmosphere that fosters the spontaneous and serendipitous sharing of information (Pettigrew 1999, pp. 81ff).

Importantly, information exchange is not necessarily the primary functional purpose of the temporary environment and may, or may not, cease to function as the group dissipates. A typical example of the transient information ground Pettigrew (1999) envisages would be a conference or an information expo. Those attending could engage in actions within the conference of either an active information seeking or information grounding nature.

Information grounding actively takes the opportunities offered, not only by the type of information grounds envisaged by Pettigrew (1999), but also by the manifold resources latent in any individual’s environment. Hence the emphasis is more upon the instrumental action of the individual to exploit varied opportunities for acquiring information within everyday life, and less on the functional utility of a ground which is
almost arbitrarily created and therefore may be inherently unstable and unreliable. The chiropody clinic would, in the framework envisaged by the author of this thesis, constitute information grounding opportunities of professional contact taken beyond the discussion of the matter immediately at hand, with the added possibility of exploiting brochures, noticeboards, and social networking. Hence where Pettigrew (1999) sees in the clinic one information ground, the author of this thesis sees the possibility for multiple information grounding activities. It should also be observed, however, that passive information seeking and information delivery also occur within such settings or information grounds, and these are discussed below.

There are also similarities between the information grounding construct and the optimal foraging characteristics of scholars, described by Sandstrom (1999, Prey Choice and Other Optimal Foraging Models section, para.6) and the modes of environmental scanning described by Choo (1999, Modes of Environmental Scanning section, paras. 2-4):

Environmental scanning is the acquisition and use of information about events, trends and relationships in an organization’s external environment, the knowledge of which . . . [enables the organization to] develop effective responses that secure or improve their position in the future (Choo 1999, para. 1)

These modes include “undirected viewing [where] the individual is exposed to information with no specific informational need in mind . . . The goal [being] to scan broadly”, “conditioned viewing” where scanning continues but is more directed, and “informal search . . . [which] draws a profile of an issue” without being formal per se (Choo 1999, Modes of Environmental Scanning section, paras. 2-4, 7). Wilson (1997, p. 562) similarly identified the notions of “passive search”, where information search or other behaviour unintentionally causes the acquisition of information that happens to be relevant, and “ongoing search”, where a knowledge framework has been established and on-going search fills it in and updates it as necessary.

Of relevance also here is the “starting” or “surveying” feature of Ellis’ (1989, pp. 179f, Ellis & Haugan 1997, p. 395) information-seeking model, in which the individual, implicitly or explicitly, recognising the limitations of his or her current knowledge, undertakes what are in effect information grounding activities aimed at achieving awareness of gaps in his or her knowledge. In the view of the author of this thesis, this is in effect “forcing ASKs” (see Belkin above) by controlled exposure to multiple
information grounds, which may include the transient grounds regarding which Pettigrew (1999) theorised, as well as those of more lasting substance. If this analysis is correct, there may be some analogy with those individuals for whom generalised uncertainty triggers an "information grounding" response, without recognition of particular information need. This is consistent with Kuhlthau's (1993) uncertainty reduction principle, and it is certainly true that extraordinary degrees of uncertainty attach to parenting a child with a disability: "The taken-for-granted world abruptly ceases to exist" (Cohen 1993, pp. 82f). For these individuals, location on multiple information grounds will increase the probability of information discovery, recognition of need or gaps, or mediation of information by another person who is able objectively to identify their need for information.

It is also arguable whether one could construe from Ellis' model (1989, Ellis & Haugan, 1997) that the information-seeking behaviours of effective seekers (such as academic social scientists and engineers) are inherently premised on an intuitive understanding of the presence of unrecognised information need. Effective seekers may well intuit that when one enters an unknown domain (for example a new field of research), there will be information that is not known and therefore cannot be identified specifically as needed (that is to say, unrecognised information need). Steps can then be taken to elucidate what is not known, hence the various activities Ellis has described as "starting" (1989) and "surveying" (Ellis & Haugan 1997), which the author of this thesis describes as information grounding.

Erdelez' (1997, 1999, 2004) work on information encountering exemplifies the distinction between information grounding and true serendipity. Within information encountering the encounter is unexpected and yields information not originally sought. Erdelez' more recent work is concerned in particular with the opportunistic acquisition of information (OAI) at a time an individual is actively seeking other information. The individual engaged in active information seeking has by virtue of his or her own activity dramatically increased the probability of becoming aware of information and recognising information need. Hence, far from the information discovery being serendipitous, it flows as a natural consequence of what is information grounding behaviour. It is also the case that the individual who is an active agent in identifying the limitations in his or her awareness of information, and his or her own unrecognised information need, is less dependent on the information delivery activities of others. He
or she is thus exhibiting more of the constructivist, active user behaviours envisaged in Belkin, Dervin and Kuhlthau's work.

It should also be noted that as the individual's knowledge base grows through information grounding, the individual's capacity to make accurate judgments of relevance in filtering information increases. Dewdney and Harris' (1992, p. 18) work in relation to battered women suggests that to navigate the "maze of social services" women needed to be aware in advance of information available; "a very high degree of name recognition ... [is required] if people are to find [help] easily, especially in a time of crisis".

3.2.1.3 Passive Information Seeking

While active information seeking may be a natural corollary of a recognised information need, gap or anomalous state of knowledge, for many people the term information seeking "reveals an assumption of an intentional, directed search for information", whereas the "dynamic process of access to information is more ambiguous, extensive and complex than that" (McCreadie and Rice 1999a, p. 57). Even information grounding carries a real sense of action on the part of the individual. Perhaps the most ambiguous or abstract concept within this conceptual framework for information acquisition is that of passive information seeking. It would almost appear a conflict in terms, where passive is just that -- passive -- and seeking is active.

Yet the concept is robust and is supported by other theorists' work. Giannini (1998) differentiates between receiving information and seeking information. Seeking encompasses movement and directional activity on the part of the individual, whereas the individual:

receives information from his/her 'Information Environment' defined as the sum of all the ways a person receives information in the course of everyday life ... receiving is characterized by the external information environment acting upon a person with no specific information agenda, whereas in the seeking mode, a person acts upon information based on a specific information need. Thus, for example, a person buying a newspaper while waiting for a train, listening to the radio while driving to work, surfing the Web, or browsing in a bookstore, would be considered to be in information receiving mode (Giannini 1998, p. 363)
Of course there is some ambiguity at the margins and no doubt there may be some overlap with information grounding, which can best be differentiated by examining the intent and outcome of any action. If a newspaper was acquired was it read exhaustively from cover to cover (information grounding), or flicked through with the hope of noticing anything relevant (passive seeking)?

As observed earlier, the emphasis in the information seeking mode is on the activity of the individual in acquiring information. Although passive, this mode subset still requires a receptive approach on the part of the individual in order for acquisition to occur. For example, the individual must make a choice to move towards the noticeboard to read what is there, or to utilise an information exchange opportunity in which he or she is asked what he or she needs. It is important to note that this mode subset is distinct from information grounding activity where an individual actively seeks out those information grounds, such as noticeboards and information exchange opportunities, and uses them purposefully to acquire information.

Wilson (1997, p. 562) also identifies “passive attention” such as listening to the radio “where information acquisition may take place without intentional seeking”. The question then becomes how this is differentiated from serendipity. Again the answer lies in examining the intent and outcome of any action. What did the individual understand him or herself to be doing? Was the individual responding to an information opportunity with which he or she was provided, or did the information discovery occur apropos of no action at all on his or her part. For example, there is a significant difference in intent and outcome between an individual decisively ascertaining when the weather is reported on the radio and purposively listening at that time each day in order to hear the weather, an individual listening to the radio at the same time every morning and learning over time when he/she is likely to hear the weather, and an individual who flicks a radio on in the hope of hearing the weather before running out of the door to catch a train. In the latter case, if the individual actually hears the weather it would be more accurately defined as serendipitous in nature. In the case of the second example, it still remains only a passive venture, unless a specific effort is made to discover what the weather is at that particular time on that particular day.

Or take the example of a traveller following the suggestion card given with a new passport to check travel advisories before travelling. This traveller may cancel an
intended trip because of a negative advisory obtained via the travel agent, while another traveller may be told that it is unsafe to travel to Bali (his/her destination) by the taxi driver on the way to the airport. In the case of the latter, the traveller learned the same information as the former traveller without any seeking effort on his/her part; it was clearly serendipitous. In the case of the former, passive seeking is demonstrated, rather than either active or grounding modes subsets, because the individual did not set about obtaining travel advisories in the first instance but responded to what was available in his/her information environment. In this case advice made available by the travel agent.

3.2.2 Information Delivery

Best Practice standards quoted in Recommended Practices in Family-Centred Early Intervention, in particular number one, states that families must “have access to detailed information” (ADD 1997, p. 2). Indeed there is considerable emphasis on information delivery supporting the aims of family-centred practice within the childhood disability sector.

Families rely on providers to share information and clinical opinions from which they can make informed decisions. Providers are then responsible for creating opportunities for information sharing and dialogue. (Epps & Jackson 2000, p. 92)

In focusing on user situations and behaviours in response (Dervin & Nilan 1986) in order to facilitate information access and acquisition, it is important not to lose sight completely of the instrumental role of others in the individual’s acquisition of information. Indeed Dervin and Nilan (1986, p.24) observe that in focusing on application to practice, the purpose of information needs assessment approaches is “to improve the efficiency and effectiveness of information delivery”. This thesis contends that it is not enough to understand individual information seeking alone; one must also understand what is occurring as information delivery in the same domain. As Kuhlthau (1994, p. 168) observed, “a survey of the literature of the field reveals an overemphasis on product and an underemphasis on process”. Clearly equitable emphasis must apply both to information seeking and information delivery if the user’s experiences are to be properly understood.

Information delivery focuses on the instrumental activity of a professional or other person in the individual's acquisition of information. Just as information seeking is multi modal, so too is information delivery. Of particular note in understanding of
delivery is Kuhlthau's (1994, p. 175) work on the levels of library and information services; what she terms the "zones of intervention". She draws an interesting parallel with the medical practitioner's zones of treatment, which have particular application in the childhood disability sector (Kuhlthau 1994, p. 176). Five levels represent the increasing involvement of the professional in the actual delivery process: the "organizer, locator, identifier, advisor, and counselor" (Kuhlthau 1994, pp. 174). These levels of intervention mirror aspects of the modes of information delivery the author of this thesis has identified, being the passive/generic, responsive and proactive modes. They are not identical, however, as Kuhlthau still requires the user to be instrumental to some degree.

At first glance it seems that the modes of delivery ought properly to mirror the seeking modes: a person seeks information - information is delivered. However, the *sum* of information acquisition can only be represented where seeking and delivery are treated separately, because so much of what is acquired occurs either independently of expressed need, or where results (flowing from activities) are either greater or lesser than what was sought or delivered.

3.2.2.1 Proactive Information Delivery

Proactive information delivery is a "value added" mode of information delivery in that efforts made to inform clients are proactive, targeted and applied. *This mode does not require seeking on the part of the client to stimulate action.* McCreadie and Rice (1999a, p. 52) describe this as "mediation":

> Mediation occurs where our natural abilities to create, transmit, receive and process ... messages are extended, expanded or enhanced technologically by media or interpersonally by human intermediaries [emphasis added] (Ruben 1993 in McCreadie & Rice 1999a, p. 52)

McCreadie and Rice (1999a, p. 53) argue that mediation can "compensate for interpersonal or structural barriers to information". This is entirely consistent with the proactive role certain professionals are seen to play in the childhood disability sector. For example, Pain (1999, p. 300) describes the importance of a key worker to the acquisition of information among families of children with disabilities. This is mirrored in many other pieces of research in the childhood disability sector (see for example, Greco & Sloper 2004, p. 13 and Sloper 1999, p. 90). Appleton et al (1997, Care management and care coordination section, para. 6) specifically state that care
management means, among other things, \textit{proactively informing} the public and referrers about the services \textit{[emphasis added]}. 

Pain (1999) distinguishes the role of a kind of proactive professional as being able to move beyond generic one-size-fits-all information delivery, such as one might see in \textit{generalized publications}. The proactive professional may, for example, select an appropriate leaflet (appropriate because it applies to the family's circumstances), take its content, and indicate the most important sections within it, to increase the probability of parental uptake (Pain 1999, p. 309). Belkin describes the mediation of information by an information intermediary, who engages in analysis of the individual's problem area, and while he suggests that this “kicks in” at the point of the individual's \textit{recognition} of the ASK (Belkin 1986, p. 6), there is no reason not to apply it more broadly in the informing process. As he himself observes, “one of the reasons that people do not get help in, say, the social benefits office, is because the few advisors [information intermediaries] that are there are overwhelmed by the work” (Belkin, 1986, p. 8). The role of the intermediary would appear to be quite consistent with the role of, for example, a reference librarian who takes the client beyond what they know they know, and that they know they need, toward what they may not be aware of but may be useful to them. This almost parallels Kuhlthau's (1999, p. 175) level 5 zone of intervention: “zone 5 problems involve the more on-going role of the counselor” (Kuhlthau 1994, p. 177). In this zone the user “problem or task is recognized as evolving over time in the process of \textit{information seeking} requiring exploration, formulation, and construction” \textit{[emphasis added]} and just like the medical practitioner analogy diagnosis is complex and dynamic (Kuhlthau 1994, p. 176). Yet it is in the presumption of user instrumentality, which incidentally is absent from the medical practitioner's fifth zone of treatment, however, that Kuhlthau's conceptualisation diverges from that of this author.

Dervin (1989, p. 228) sees intermediaries as “responsible for making the system appealing and useful to larger numbers of diverse people ... intermediaries would ask users about their life situations” which is strongly suggestive of the context of relationship. There is a sense in which the professional seeks to enter into the life experience of the client, and in understanding their experiences is better able to identify needs of which they may be unaware, although this is well beyond the ambit of Dervin's constructivist user paradigm. Yet it is not a problem of practice. As Mitchell and Sloper
(2000, p. 4) observe, "a person facilitating information provision can also help to ascertain what information the family needs at what time." It is at this point information delivery moves beyond the responsive and into the realm of the proactive. Pettigrew (1999, p. 812) observed just this phenomenon happening in chiropody clinics, where the attending nurse entered into the life of the elderly patient, as it were, and addressed the information needs she was able to identify in that experience in the course of the interaction or "quiet exchange".

An information exchange opportunity that often functions as proactive information delivery, described in the English literature, concerns the role of the Portage teacher, who attends the family's home to assist the family to identify areas of need and how to address them (Pain 1999, p. 305). Where the teacher moves beyond addressing the needs raised by the family to advising on other areas of assistance and service that may be of interest/use to the family, proactive delivery is demonstrated.

Yet it is not only professionals who play a proactive information delivery role. Hjørland (1998, p.619) recognised that "with the development of computer technology ... there have also been tendencies to an overemphasis on information technology (IT) ... and to underestimate the virtues of traditional communication systems". Those traditional communication systems usually start with family and friends, the often favoured sources of information. Nicholas and Marden's (1998, p. 44) research among parents in the community generally found a real significance attaches to family and friends, as proactive information deliverers, "because they have been though it". As Dervin (1989, p. 224) observes, "most information 'transfer' occurs informally, between friends and colleagues, where the important collaterals are exchanged – information that means something, that is interpretable, that is culturally relevant".

Families First Inner West research conceptualised "Family, Friends and Community Networks" (2002a, p. 68) as one of parents' four domains of sources of learning: that is, the individual's immediate network was next in importance to his/her own experience. This is supported by a large body of research within the childhood disability sector and is implicit in much parent commentary. For example:

You need other parents who have experienced shortfalls in the system [to advise] (Pain 1999, p. 304)
I think if somebody could have perhaps have come to the house, and been with you in the day-to-day dealings with a child like that, to help to learn how to cope. (Pain 1999, p. 306)

If I hadn’t been introduced to the mum of another disabled child I would never have known what was really available (Fyffe, Gavidia-Payne & McCubbery 1995, p. 36)

3.2.2.2 **Responsive Information Delivery**

In this mode, the professional or other person or agency *responds* to articulated requests for information, whether they are initiated by the individual or arise in the context of an information exchange opportunity provided by the professional. The key is in the responsive stance taken by the professional. Dewdney and Harris’ (1992) work among battered women reflects the largely responsive nature of information delivery in social service settings. This is certainly confirmed in the findings of chapter 2.

A significant number of Kuhlthau’s (1994) zones of intervention actually function within this mode, as each of them involves the information professional responding in varying degrees to client-initiated seeking. In drawing an analogy with the medical practitioner’s zones of treatment, Kuhlthau (1994, p. 176) clusters zones 2 to 4 where, just as the patient’s problem is self-diagnosed and the treatment self-administered, the user’s problem requires resolution by a product or source of information, rather than the process of exploration and evolving understanding of the issue area seen in level 5. At level 2, the information professional simply functions as a locator, directing the user either to a specific piece of information or a source wherein the information would be located (Kuhlthau 1994, p. 175). Level 3 sees the information professional function as an identifier who responds to a user problem articulated in the course of a traditional reference interview, directing the user to relevant resources. In level 4, however, the information professional functions as an advisor and during the interaction a process of problem statement, assistance negotiation and recommended action sequence occurs (Kuhlthau 1994, p. 175). This mirrors the most common form of information exchange opportunity in the childhood disability sector, namely the IFSP (Individual Family Service Plan) meeting, which functions to respond to parent-articulated needs and requirements in a process of problem articulation, negotiation, recommendation.
Chatman’s (1986, 1991, 1996) work among specialised populations raises a number of points that must be considered in the context of responsive information delivery. Issues such as capacity to perceive relevance, secrecy and deception, and the concept of insiders/outsiders, amongst others, have a significant impact on the degree to which sub-groups are able to seek and receive information from others, and this is certainly magnified where the others are taking a responsive stance.

Chatman’s work applies theories from other disciplines to library and information science, for example Gratification Theory applied to information-seeking behaviour, and, Diffusion of Innovations Theory applied to information diffusion. Chatman is interesting to the childhood disability sector because her research never assumes any intersection between the individual and formal information provision mechanisms. She is seeking to explicate information phenomena, in situ, among individuals/groups who “for whatever reasons, see themselves or are viewed by others as outsiders” (Chatman 1996, p. 205). Chatman seeks to understand “why some members of our society do not benefit from sources of information that could help them” (Chatman 1991, p. 438). Indeed Chatman (1991, p. 442) states that “even though their constrained environment is fraught with information problems they do not appear to be active seekers of information that might address these problems”.

Chatman observed the significance of perceptions of relevance of sources and noted a preference for certain sources of information. This effectively restricts the range of information potentially available to be accessed. For example, population sub-groups demonstrated a preference for those with first-level direct knowledge, that is insider knowledge, as opposed to knowledge about something/s, because outsiders “don’t know” (Chatman 1991, pp. 439f). Her work on a Theory of Information Poverty, premised on the notion of insiders/outsiders, as relates to knowledge awareness, acquisition, definition and use, is drawn from the study of the sociology of knowledge (Chatman 1996, p. 194). She observes:

The idea that things can only be understood by other insiders may explain why there are informational barriers between these two worlds. A reason might be a doubt that insiders have regarding the ability of outsiders to understand their world. (Chatman 1996, p. 194)

Indeed, Chatman’s work among the “disadvantaged” has some clear analogies with the domain of parents of children with disabilities. If information professionals within the
group's information environment take a responsive stance in information delivery - do not seek to enter in the world of the user, as it were - and await the user's identification and articulation of an "information need", significant problems set in for information acquisition. In other words, where the information professional acts in a responsive rather than proactive mode, and there is no effort to demonstrate the application of available information to the unique circumstances of individuals in order to make it meaningful, then by virtue of the information professional's position as an "outsider" the user would be unlikely to perceive relevance independently. This is interesting in the light of Vakkari's (2003) commentary on relevance and utility judgments, which while document-retrieval based still affords some insight into the power of perception of relevance. "Search tactics used (including ... relevance judgments) are systematically linked to the stage of task performance" (Vakkari 2003, p. 452). In particular, users "try to infer how [information] will support task accomplishment. Thus they assess its situational relevance and utility" (Vakkari 2003, p. 443). If, however, their perceptions of relevance are flawed or otherwise inadequate to make an accurate assessment of relevance, and the information professional takes a responsive delivery stance, information acquisition is likely to fail.

Another characteristic Chatman identified is self-protection, expressed in secrecy and deception regarding personal circumstances, which has the effect of restricting mediation of relevant/appropriate information (Chatman 1996, pp. 195f). While Chatman (1996, p. 198) specifically identifies the issue that "enormous need for information ... or information that could assist the people, was missing", this seems to derive, at least in part, from their own behaviours (when understood in the context of the prevailing model of information delivery). What Chatman does not identify is the possibility that being unaware of information, the "not knowing", is an ongoing context for the other behaviours.

Whilst much of Chatman's research is among the poor and working-class, she observes that:

We are only beginning to serve the needs of other [specialised] populations. The process of understanding begins with research that looks at their social environment and that defines information from their perspective (Chatman 1996, p. 205)
3.2.2.3 Passive Information Delivery

Passive information delivery tends to be expressed as a body of information presented in a static form, requiring the individual to approach, take up and apply its contents. It may be in the form of an information repository such as a library, where the emphasis is on the user making use of the collection. This accords with Kuhlthau’s (1994, p. 175) level I zone of intervention where the information professional, as an information organiser, “provides an organized collection, but no intervention in terms of mediation or education”.

Yet while one would expect to find within a formal information repository information resources organised with a high degree of consistency and structural accessibility, the broad spectrum availability of information resources located passively within most environments would not tend to display such accessibility. Noticeboards, for example, rarely systematically present flyers and posters ordered by subject matter and currency; the individual is often confronted with a random display whose interconnectedness may be limited to physical location on the same board.

Furthermore, notwithstanding their potential utility, research among a broad population in relation to perceptions of resources available to battered women in the community failed to identify traditional information repositories such as libraries and information centres, as sources of information and referral at all (Dewdney & Harris 1992, p. 24). As Dewdney and Harris (1992, p. 6) have observed, “the programs of most such agencies tend to be system oriented, rather than client or user oriented”. They quote Barugh (1984): “proponents of the outreach approach to information provision assume that access to information is inequitably distributed in most communities” [emphasis added] (Dewdney & Harris, 1992, p. 6). Nicholas and Marden (1998, pp. 45f) found very few parents used public libraries for parenting information, as libraries are “not open when [information is] needed” and they tend to be viewed as passive “resources for printed information and not as providers of advice”. In this sense advice can be seen as the application of information held within the information repository.

The primary difficulty, then, of this mode subset of delivery seems to be in its passive nature. While information the individual may need is likely to be present in his or her environment generally, and certainly within the information repositories, it may be
inaccessible because it requires behaviour of the individual that he or she is either unable or unwilling to execute. In particular, effective acquisition appears to require instrumental action on the part of the individual. This is certainly consistent with the primary LIS theories of information behaviour, need and seeking referred to earlier, that insist on conceptualising information issues based on the presumption of a constructivist, active user. In fact, it is arguable whether current information delivery systems are being designed exclusively with the constructivist, active user in mind.

Bodies of information passively delivered or made available to clients do not only occur within information repositories. They may be either disparate or connected series of information in the form of ephemera displayed, for example on noticeboards and in leaflet racks, or grouped into directories or folders. Pain's (1999, pp. 304, 307) research among families of children with disabilities gives various examples of sources of information which are a form of passive information delivery, such as newsletters, local service provider booklets and leaflet racks. Nicholas and Marden's (1998) research among parents in the community generally did find that magazines were useful for their currency. Chatman (1986, p. 384) also identified the imperative of currency in the design of an information delivery system among the poor, noting that “freshness of the information was a critical factor in acceptance”, and she also recognised that they were often unable to utilise the information provision mechanisms available to other people. Interestingly, Chatman (1996, pp. 202,204) was studying groups of “outsiders” who were “undergoing emotional, social and psychological adjustments for which their familiar world had not prepared them”, and who did not appear to benefit from “potentially helpful sources of information … because [among other things] a source even when perceived as useful, often required too much effort”. That is to say, the individual was required to be instrumental in the acquisition of information to a degree that was beyond their capacity.

Even in the case where parents are able to approach and acquire “general printed information” as described by Pain (1999 p. 301), of the generic one-size-fits-all type, it is limited in utility in the childhood disability sector as it fails to address individual parent concerns in regard to the individual child and the family circumstances. The passive nature of the delivery, where such information is located passively within the environment, requires the parent both to perceive relevance and to apply it to the individual circumstances. Certainly Chatman (1996, p.202) argued that “the concept of
relevance provides insight as to why potentially helpful sources might be ignored”. Dewdney and Harris (1992, p. 18) found the utility of static or passive resources, such as directories, is limited for women in crisis, as information acquisition is contingent on, for example knowing the correct headings to check. They observed that the utility of such resources could be increased by improving their delivery by their internal organisation (Dewdney & Harris 1992, p. 28), a point also argued by Mitchell and Sloper (2000). Pain (1999, p. 303) considered that this type of information delivery has its role as a “backup” to what is said, rather than a primary source.

Delivery of a passive nature is also occurring where information of specific relevance to the child and family is delivered without further application. For example, Pain (1999, p. 307) identified reports, records of assessment and reviews. The delivery of the information is passive in nature where it remains for the individual to move beyond the immediate scope of the materials, or interaction, and seek to initiate further information delivery and/or application of the content. Dewdney and Harris (1992, p. 17) identified a serious problem where the professional service provider, in this case Emergency Room staff, dealt only with the immediate matter at hand and did not seek to address wider issues of information and referral. In spite of being aware of manifest injuries “physicians rarely identify these women as victims of domestic violence and rarely ask the women about violence ... physicians sidestep the issue of [domestic violence] by prescribing pain killers” (Dewdney and Harris 1992, p. 17).

Hence it would appear that passive information delivery may have efficacy among active, constructivist users who have clearly identifiable and succinctly articulated problem areas, and who have the information skills necessary to approach a sometimes amorphous and disparate body of information, perceive relevance accurately and uptake and apply information as necessary. The question is, to what extent is this “scenario” actually representative of what is occurring in the childhood disability sector? And furthermore, what of the impact of the influences and constraints operating, as detailed at 3.3?

3.2.3 Serendipity

Erdelez (1996, p. 412) has conceptualised “information encountering” as the “accidental discovery of useful or interesting information”. Here the emphasis is on the accidental
nature of the information acquisition, rather than the instrumental role of an individual in the acquisition of information (in either seeking or delivery modes). As McCreadie and Rice (1999a, p. 69) observe, “in many instances, access to information comes about serendipitously, through unplanned encounters or conversations with others”. Indeed Dewdney and Harris (1992, p. 6), reporting on Beal (1979) and Dervin (1976), state that “most people are uninformed about public and private resources for solving everyday problems, and that contact with sources of information appropriate to their needs occurs largely by chance” [emphasis added].

Williamson (1998, p. 36) has also differentiated between purposeful information seeking and incidental or accidental information acquisition. The notion of different outcomes deriving from different strategies is found in earlier research of user approaches to information utilising different strategies depending on purpose: for example, problem-specific/non-problem-specific information seeking (Childers 1975 in Erdelez 1996, Krikelas 1983) and Savolainen’s (1995) work-related/non-work-related constructs in everyday life information seeking (ELIS).

Yet a facet of information acquisition is apparent here which is not contingent upon the instrumental actions of the individual. That is to say, acquisition of information occurs despite no information-related behaviour on the part of the individual taking place. This is quite distinct from Erdelez’ (2004) opportunistic acquisition of information (OAI) which developed from her earlier work on information encountering (1997, 1999). Her more recent work is concerned in particular with the opportunistic acquisition of information (OAI) at a time an individual is actively seeking other information. Erdelez’ (2004, p. 1015) development of the term “opportunistic acquisition of information” as a technical term preferable to “serendipity” is somewhat misleading, however, as OAI always occurs in the context of the individual actively seeking other information. Serendipity, in contrast, is wholly fortuitous or accidental. Information acquisition through serendipity does not flow from any conscious information seeking activity.

This distinction is important. The individual engaged in active information seeking, whether directional or not, has by virtue of his or her own activity dramatically increased the probability of becoming aware of information and recognising information need. In contrast, the individual who acquires information serendipitously, that is to say,
through no activity on his or her own part, has not increased the probability of information discovery at all. If the individual is not an active agent in identifying the limitations in his or her awareness of information and his or her own unrecognised information need, he or she will remain helplessly dependent on the delivery activities of others and on serendipity.

The concept of information as data in the environment has particular utility in approaching this mode of acquisition, as a useful filter for identifying communication of information that occurs by virtue of events, activities and other phenomena, rather than intentional information exchange. McReadie and Rice (1999a, p. 47) see in it an informing process that occurs “by perceptions of things that are communicated unintentionally”. Overheard conversations, tangential information utility in information delivered for other purposes, and observation of information and services received by others, are examples. Pettigrew’s (1999, p. 812) chiropody clinic patients acquired information in the context of receiving chiropody services in a community clinic: “information about local resources [was] shared serendipitously without anyone expressing (or necessarily having) a need for that information”. It is important to note, however, that for some of the patients attending the “information ground”, there was a purposeful utilisation of the ground as an opportunity to acquire information (see 3.2.1.2). “Sometimes seniors seem to use these casual interactions purposefully as a segue to questioning the nurse about her knowledge of a particular area in which the senior may be experiencing difficulty” (Pettigrew 1999, p. 812). This was quite distinct from the serendipitous acquisition experienced by other patients who were more passive within the ground (Pettigrew 1999, p. 812).

As a final point, Nicholas and Marden (1998, p. 44) found that one of the reasons media was not preferred as a source among parents was that the timing of media exposure needed to coincide fortuitously with information need. Solomon (1997, p. 1107) has upheld that “information has a time value” and that “treatment of time … [is] an input to understanding why systems sometimes are used and sometimes are not”. Certainly Nicholas and Marden (1998, p. 45) found “media does not appear when [parents] need it”. This emphasises the inherent unreliability of serendipity and its potential to increase stress when it occurs.
3.3 INFLUENCES/CONSTRAINTS ON INFORMATION ACCESS AND ACQUISITION

McCreadie and Rice (1999a, b) identified six factors functioning as influences and constraints in access to information, namely, physical, cognitive, affective, economic, social and political. Of particular note is the statement:

If understanding, awareness, literacy and competence are required for one to gain access to information, it seems likely that only a small segment of the population is able adequately to understand all his or her information needs, to be aware of the possible and necessary means and the procedural knowledge to address it, and to express that need clearly enough to support the assumption that a query statement is a valid representation of the need for information. McCreadie and Rice (1999b, p. 89)

While the authors discount this approach as a means of attaining a realistic understanding of relevance as a measurement of information access, ironically it seems to depict accurately the experiences of parents of children with disabilities in the acquisition of information reflected in much of the childhood disability literature (see 1.2 and Chapter 2).

This raises the question of whether there are theoretical constructs or propositions that need to be taken into account as potential influences and constraints on parental information access and acquisition. A number of significant factors identified by the author as potentially applicable to the childhood disability sector are presented below, along with examples from the literature where available.

3.3.1 Awareness as a critical factor in acquisition

Australian governments have recognised that "Services will only be used if people know about them. And people will only know about them if information is provided in appropriate ways" [emphasis added] (ADD 1998a, p. 22). Indeed, this principle need not be restricted to information about services and can be applied across the spectrum of parental information needs.

McCreadie and Rice's (1999a) analysis of the "awareness" facet of access to information may be particularly relevant in attaining an understanding of parental difficulty in the acquisition of information (see 1.2). Those aspects identified are
awareness of the availability of information, one’s right to information, one’s need for access to/ use of information, and how to proceed (McCreadie & Rice 1999a, pp. 56, 59, 64, 70). Also, knowledge or experience of a domain is recognised as affecting one’s capacity to access information (McCreadie & Rice 1999a, pp. 56, 59, 64, 70).

To appreciate the potential significance of this analysis, it is important to understand that the concept of family-centred practice has become the underpinning philosophy of much early intervention at every level. Significantly, it mirrors the paradigm shift to a user focus within LIS settings. By virtue of its very family centeredness, in the context of a complex service system (ACD 2001a, b, c; AIHW 2001; Baxter 1989; Gravelle 1997; McConachie 1997; NSW Commission for Children & Young People 2003; Spiker et al 2000), the approach has unintentionally accorded a degree of importance to the instrumental role of parents in achieving awareness of information and recognition of information need.

Lievrouw (1994, p. 350) recognised important changes the information environment is undergoing and described the main principle that appears to underlie the changes as a:

shift from an information environment that is informing (i.e., reliant on traditional ‘mass’ media and information systems, and therefore on information ‘consumption’) to one that is involving (reliant on discursive information systems and media, and therefore on information seeking and communication).

This principle can be seen to find expression in the childhood disability sector, albeit requiring a degree of extrapolation, within the philosophical approach of family-centred practice. It can also be seen within the LIS user-focused paradigm.

Family-centred practice in early intervention settings evolved initially from moves within “health care [in] the second half of the 20th century; at a time of increasing awareness of the importance of meeting the psychosocial and developmental needs of children and the role of families in promoting health and well being” (AAP Committee on Hospital Care 2003, History of Family-Centered Care section, para. 1). Programs that were once child-focused and service provider-driven moved toward a family-focused approach where:

The professional’s sphere of expertise was seen as increasing from ‘the child’ to ‘the family’, without a thorough evaluation of the impact of this change on families’ sense of empowerment and control ... It was when practice began to
reflect an acknowledgment of parents’ rights to determine priorities and be recognised as the experts on their own families that Early Intervention became family-centred. [emphasis added] (ADD 1997, p. 1)

Porter and McKenzie (2000, p. 9) indirectly indicate the information foundation of the approach in quoting Tinworth (1994) on the family-centred model of service delivery: “In such a model, services build from family needs and ... empower the family to make informed choices and control the direction of the service” [emphasis added]. This model assumes parent awareness of information in achieving empowerment and control.

Another fundamental assumption is evident in Recommended Practices in Family-Centred Early Intervention statements such as: “Individual families determine what information they receive and when”; and, that information is given “when the family requests it” (ADD 1997, pp. 14, 16). The statements assume parent awareness or recognition of information need. Certainly such assumptions appear reasonable given Best Practice standards quoted in Recommended Practices in Family-Centred Early Intervention, in particular number one, that families “have access to detailed information” (ADD 1997, p. 2). Indeed there is considerable emphasis on information delivery supporting the aims of family-centred practice:

Families rely on providers to share information and clinical opinions from which they can make informed decisions. Providers are then responsible for creating opportunities for information sharing and dialogue. (Epps & Jackson 2000, p. 92)

Yet if this breaks down, if the practical expression required to realise the ideal is not understood, or if, indeed, service providers do not share in the family-centred approach, then access to information becomes problematic, with direct corollaries in awareness of information and recognition of information need. As Fyffe, Gavidia-Payne and McCubbery (1995, p. 35) have asked: “The rhetoric of family centred practice has been readily adopted by professionals, but is it really being understood and implemented?”

Certainly, in terms of the parent information access and acquisition corollaries, this remains to be seen. There is the question, too, of whether over-taxed service systems world-wide have the capacity to implement what is required to render family-centred practice workable.

An effective family-focused service system needs to address the individualised needs of families at various levels of the family system with increased access to information ... one is left wondering whether the structure of the service system will ever allow this to happen, since some of the concerns pointed out by families
have been the focus of professional attention for many years now. (Fyffe, Gavidia-Payne and McCubbery 1995, p. 39)

The AIHW (2002, Pressures at the Program Boundaries section, para. 1) has observed that “the overall service system for people with disabilities is under pressure”. The impact on the early intervention period, in particular, has been described by Moore (2003, p. 3):

the service system is having difficulty providing support to all families who are eligible ... services cannot meet all the needs of families they do serve ... families have difficulty finding out about and accessing services they need.

In the light of this commentary it is fair to draw two conclusions: that parent awareness of information and recognition of information need are both necessary for the proper functioning of family-centred practice, and that any failure of information delivery necessarily has a direct impact on parent access to information, increasing the significance of parent-achieved awareness of information and recognition of information need. This places a specific requirement on any theoretical framework to address issues of awareness of information and recognition of information need.

As the individual enters an unknown domain, he or she is necessarily unaware of extant information, as there is rarely recourse to a knowledge base. If, as Kuhlthau notes, thoughts tend to centre at the initiation stage on relating the problem to prior experience and knowledge (Kuhlthau 1991, p. 366), this creates a barrier or constraint to the individual with no existing knowledge base. In order to take steps to overcome a knowledge anomaly (or ASK, Belkin 1980) an individual must be aware of both the anomaly and the existence of information, if only notionally, that may overcome it. In short, one needs to be aware that one is unaware in order to take action to resolve a knowledge anomaly.

Dewdney and Harris (1992, p. 6) found that citizens may not know of the existence of information pertinent to their circumstances. Alternatively, while they may have been aware that information was needed, they may have been unaware of just what that information was and how to locate it. Interestingly these issues relate directly to aspects of information literacy. It is also important to recognise that the problem of lack of awareness also occurs among the helping agencies and professionals, as identified by Dewdney and Harris (1992, p. 27).
Anomie

Durkheim's concept of anomie appears to be broadly applicable to the childhood disability sector. Anomie is defined as the “lack of the usual social or ethical standards in an individual or group” (Illustrated Oxford Dictionary 2003, p. 43). Durkheim, writing in the latter part of the nineteenth century, was analysing periods of great social upheaval and saw how normlessness affected individuals, who no longer knew how to “be”, as it were, in the changing circumstances. Anomie was frequently expressed in deviant social behaviours including violence and suicide.

Childhood disability seems to have a similar impact on parental orientation to that envisaged in anomie. Parents frequently feel normless, not knowing how to “be” because the known world has abruptly ceased to exist (Cohen 1993, pp. 82f.). The application of anomie to the sector would certainly appear to be validated by the emotional sequelae frequently attributed to having a child with a disability. Numerous studies have demonstrated stress and adaptation problems among parents, including increased incidence of physical health complaints and high levels of depression, anxiety, anger, guilt and emotional distress generally, together with isolation and decreased mobility, increased rates of divorce and suicide (Gallagher, Beckman & Cross 1983, Pelchat et al 1999, Sloper and Turner 1993). Seligman and Darling (1997) hold that the anomie experienced by parents relate to feelings of meaninglessness and powerlessness, which are addressed over time by seeking behaviours aimed at restoring sense or meaning. They state that “parents generally continue to experience anomie to some extent until issues of prognosis have been resolved and until the child is enrolled in an intervention program” (Seligman & Darling 1997, p. 48). Seligman and Darling (1997) emphasise the significance of providing information to families who are clearly in an anomie state, without actually explaining the relationship between information and anomie.

It is feasible that when parents either give birth to a child with a disability, or, have a child diagnosed (or indeed undiagnosed) with a disability, they enter an anomie state characterised by normlessness, high attendant stress and chronic crisis. Krafft and Krafft (1998) have described this as chronic sorrow. This may find expression in, among other things, their information behaviour, as generally speaking they bring no knowledge base to the problem area, with all the attendant lack of awareness of information problems, as
identified in Chapter 2 and 3.3.1. This situation is a type of information anomie, where all the norms and ways of being, including information behaviours with which an individual has operated in the past, no longer apply.

3.3.3 Unrecognised and Latent Information Needs

The influence of awareness and unrecognised information need on information access and acquisition has been explored above (3.1.3). Yet unrecognised information need may best be described as the ‘ghost at the table’ in the current feast of information need and seeking theory. Few wish to acknowledge its presence, possibly because it challenges the philosophical presuppositions of construct theory, and yet the evidence suggests it is an integral part of lived experience. The ghost is indeed there for all to see.

If then one is to set aside construct theory and accept that the ghost is indeed at the table, there remains the question of whether it is possible to predict the occurrence of information need, whether the reason for the efficacy of proactive information delivery may lie in its capacity to recognise within another individual the need for information that the individual himself or herself has not recognised. Hence it may be more appropriate to use the term “latent information need”, as the absence of recognition may be only on the part of the individual.

Awareness of information, and/or the lack thereof, may one of the major initiating conditions of information action/inaction, where unless other factors intervene, the individual may remain in a latent information need state.

3.3.4 Personal Factors - Information Styles

McCreadie and Rice (1999a, p. 54) observed that some individuals develop a communication competence, honed by effective access to and participation in communication processes, that increases levels of participation, “increasing opportunities and skills for access in the future.” Importantly, they identified that the converse is also true, where “the impact of such deficiencies tends to compound over time” (McCreadie and Rice 1999a, p. 54).
Certainly Miller’s (1990) work on cognitive information styles in the context of stress and coping, suggests that there are discernible sub-groups whose behaviours are distinguishable by patterns of information-related activity. She developed a self-report measure, the Miller Behavioral Style Scale (MBSS), which “divides individuals into coping style groups”, based on the monitoring and blunting hypothesis which postulates that:

There are two main modes for coping with aversive events [threat]. The first mode, monitoring, is the extent to which the individual is alert for and sensitized to threat-relevant information. A second mode, blunting, is the extent to which the individual cognitively avoids or transforms threat-relevant information. (Miller 1990, pp. 98-100)

However, situational characteristics also interact with the individual disposition, such that according to Miller (1990, p. 113): “how well an individual copes is determined, in part, by the fit of his or her characteristic [cognitive information] style to the individual situation.”

The significance of Miller’s work for this thesis is in her recognition of dispositionally-related individual differences in information activity undertaken in response to a threat situation, which is not specifically addressed in the childhood disability sector literature. Nor, it seems, is it broadly embraced within the LIS literature. The problem with Miller’s (1990) work for this research is that it does not seek to investigate what actually happens in information sequelae, when an individual either avoids information or is unsuccessful in monitoring attempts. Perhaps more significantly, however, is that neither Miller’s (1990) work, nor the childhood disability sector, nor indeed LIS generally, attempts to investigate how a pre-existing lack of awareness of information and unrecognised information need may have a significant impact on the individual’s coping strategy. Both the quality and effectiveness of monitoring, and the choice itself to utilise blunting, may well derive in part from these problems.

Variations in cognitive information style and the individual parent’s capacity to discern the style appropriate to the circumstances may exert considerable influence on parents’ information access and acquisition. This is because of the potential impact of the individual’s basic orientation toward information, which affects both parent information-seeking efforts and parent response to professional information delivery efforts. Yet it also seems feasible that there may be a considerable impact of perceived
locus of control (Beresford 1994). Folkman has observed that emotion-focused coping is more likely to be used in situations appraised as being out of the individual’s control, “not amenable to change” (1984, p. 844). If the individual perceives that nothing can be done to alter an aversive situation, then continuing to monitor may only result in frustration and greater stress. However, failure to monitor when that perception is incorrect, that is to say the appraisal that the situation cannot be changed is incorrect, which itself may have arisen from absence of awareness of information, cannot be rectified by high blunting. It seems that it is important to understand why individuals have adopted a particular approach and whether it is based on an informed appraisal of the situation. If one applies an information perspective to this contention an interesting possibility emerges. What may appear to be an unchangeable situation leading to an appraisal by the individual of having no control, (i.e. external locus of control), and thus employing emotion-focused coping, may indeed be a situation that is amenable to change, were the individual only aware of relevant information. That is to say, an incorrect appraisal may have been made, not because of a coping style or other coping factors, but because of basic awareness of information. This circumstance may arise each time the individual is unaware of information that relates to his or her situation – the situation may well appear to be unchangeable.

Applying the same logic to the information-seeking component of adaptive coping, it becomes immediately evident that there is a possibility awareness/non-awareness of information itself triggers the coping strategy response, of either problem solving through seeking or emotion-regulation, rather than the other way around. Unfortunately, investigations have focussed on information seeking only as an expression of problem focussed coping.

In any event, it may well be that efforts to foster more effective coping through problem focussed strategies, in failing to investigate the issues from an information perspective, have missed a vital component. Access to and acquisition of information may well play roles as initiating conditions to a coping strategy response. A better understanding of information access and acquisition, and the impact these have on coping strategy, may well reveal that information delivery structures and processes are as much responsible for individual coping strategies in individual situations, as the individual’s typical coping style. This remains to be investigated however.
There does not appear to be any research applying Miller's (1987, 1990) work on cognitive information styles to the childhood disability sector, and where Beresford (1994) has looked at stress and coping and locus of control issues within the sector, the centrality of information has not been addressed. van Zuuren and Wolf's (1991) research does refer to the locus of control and styles of information seeking under threat, that is when coping is required, using the MBSS initially on 47 psychology students and subsequently on 55 general population volunteers to investigate personal and situational aspects of monitoring and blunting. This research found that monitoring was associated both with internal locus of control and problem-focussed coping. It is important to understand here that internal locus of control is "The appraisal of being able to change the situation... whereas not being able to achieve this corresponds to an external locus of control" (van Zuuren and Wolfs 1991, p. 142). This has considerable potential significance to the childhood disability sector, in terms of awareness of information affecting appraisal of control and parents' consequent information behaviour, as observed above.

Erdelez' (1997, p. 417) analysis of the information-encountering experiences of students and employees in an academic environment focussed on actual information activity rather than cognitive information style, and found not the "binary classification" Wilson (1999, p. 845) reports, but four discrete subsets of individuals. Each group reported discernible variations in information activities. The "superencounterer" appeared to seek out opportunities for information encountering, such as that envisaged in the information grounding mode (3.2.1.2), the "encounterer" often experienced acquisition but did not perceive how these related to their own information activities, the "occasional encounterers" simply experienced encountering as serendipity, and the "nonencounterers" reported seldom experiencing information encounters (Erdelez' 1997, p. 417). The latter group included the non-participants one would expect to equate with the "blunters" who tend to be information avoidant (Miller 1987, 1990) and those identified in stress and coping literature as adopting an emotion-focussed rather than a problem-focussed coping style (Folkman 1984).

All this is suggestive of a continuum-type array of information styles. The styles would range from the active to the passive. At one end of the continuum are those of individuals similar to superencounterers, who are actively engaged in moving toward and seeking information both in response to identified needs and anomalies and as part
of a non-directional pattern of activity. It seems feasible that in certain circumstances the superencounterers identified by Erdelez (1997) may also be the parents perceived by the professional service provider as seeking excessive information (Pain 1999, p. 305). It is interesting to note Nicholas and Marden (1998, p. 43) found that where most parents utilised four sources on average one parent used more than twice as many as others, and two parents utilised fewer than a quarter used by others. Moving along the continuum one would arrive at the information-passive individuals who may be the emotion-focussed copers Folkman (1984) identified, disinclined or unable to adopt problem-focussed strategies such as information seeking or even dispositionally information avoidant (Miller 1987, 1990). Nicholas and Marden’s (1998, p. 44) research among parents in the community certainly found discernible differences among parents’ information activities, and these appear to support of the notion of a continuum of information styles from the more vigilant superencounterer type to the more passive and avoidant types.

Kuhlthau’s (1993) “mood corollary” is also worth considering in this context. “Mood corollary” is a term Kuhlthau employs to describe “the stance or attitude that the user assumes which opens or closes the range of possibilities in a search” (Kuhlthau 1993, p. 350). Interestingly the individual chooses whether to take an invitational stance, which opens up a wide array of possibilities, or an indicative stance, which limits the possibilities to those issuing in a conclusive result (Kuhlthau 1993, p. 350). Stance may tend to be dispositional in nature, which may in turn tend to confirm an individual’s “typical” information activities and the approach to information acquisition difficulties and lack of success.

3.3.5 Miscalibration

Dewdney and Harris’ (1992, p. 8) research was designed to address the match between information need and information delivery. They observed that “clearly, there is a serious mismatch between the community’s expectations about the kinds of help available from physicians for abused women and the types of help they are likely to obtain from this source” (Dewdney & Harris 1992, p.17). This mismatch seems to be part of a broader problem of potential miscalibration in the information environment, between the expectations of the individual and the reality of the information practices of
professional providers. "In some instances the types of help that might be expected from an agency are not those which it provides" (Dewdney & Harris 1992, p.23).

The mismatch or miscalibration may arise in part because clients in general, and parents of children with disabilities in particular, and the professionals/providers who serve them, inhabit different worlds - the insider/outsider dichotomy described by Chatman (1996, p. 194). Chatman (1996) believed that insiders (who in the case of this research would be parents) may actually shield themselves from needed resources. Hence, although parents may expect proactive information delivery from professionals, they may also hold the belief, consistent with Chatman's (1996, p. 194) findings, that only "insiders can truly understand the social and information worlds of other insiders". This may impact on the degree to which information is actively sought from the professional and the stance taken in seeking, which in turn points to the importance of other parents of children with disabilities as favoured sources. It is also the case that professionals may have shortcomings in understanding parental needs and how to meet them. Certainly, given the apparent miscalibration in the social services environment, Dewdney and Harris (1992, p. 28) assign responsibility to library and information services to ensure that professionals in social services have access to an increasing body of knowledge on human information-seeking (or help-seeking) behaviour. In any event, it seems feasible that both parties to any information transaction, such as parents and professionals, may hold different perceptions of what information exchange is intended to occur and the trigger/s to that exchange, hence the potential for miscalibration between parental expectations and professional practices.

Kuhlthau's (1993, p. 351) "prediction corollary" is interesting in this regard as it reflects on the search process "as a series of choices based on predictions of what will happen if a particular action is taken": "predictions are based on expectations derived from constructs built on past experience" Kuhlthau (1993, p. 351). If, for example, parents have learned from past experience that medical practitioners provide information in relation to health problems according to the prediction corollary it would be reasonable for them to expect that doctors will provide information in relation to disability issues. However, in its reliance on construct theory, Kuhlthau's (1993) prediction corollary falls down at this point because it cannot explain why social services clients', (such as parents), expectations of information delivery are so inaccurate that significant miscalibration arises, as revealed in the childhood disability sector literature (see 1.2
and Chapter 2). The problem again is the degree to which the individual is deemed to be constructing reality and actively making choices, as opposed to experiencing, at least to some degree, dependence on the instrumental actions of others.

3.3.6 Knowledge Calibration, Perception of Knowledge and Decisions about Ignorance

A considerable body of consumer research examines the gap between what the individual knows and what the individual thinks he or she knows. This is relevant to this thesis because of the potential impact of calibration on information seeking. "Knowledge calibration" concerns self-assessed validity of knowledge, that is the "match between confidence and accuracy" (Alba & Hutchinson 2000, Full Text section, para. 1). Alba and Hutchinson (2000, V. Coda section, para. 1) consider that the concept of knowledge expertise must be expanded to include meta-knowledge - "our knowledge of our knowledge". Many years earlier, Lichtenstein and Fischhoff (1977) posed the question, "Do those who know more also know more about how much they know?" They were looking at differences in confidence, calibration and resolution between those who knew something and those who knew nothing. They found that of those who knew nothing, the "situation typically led to vast over-confidence, terrible calibration, and no resolution" (Lichtenstein & Fischhoff 1977, p. 178).

Given that the family-centred approach seeks to empower family decision making, any mismatch between what a family thinks they know and what they actually know will have significant implications for information seeking and acquisition, because "overconfidence will tend to inhibit search and under-confidence will increase search" (Alba & Hutchinson 2000, 3. Implications for Consumer Research section, para. 4). Becoming the parent of a child with a disability is for most individuals to enter an unknown domain where there is no prior knowledge, hence such individuals are not aware that they are unaware of what is available to be known. Theoretically, at least, they would be over-confident because they are unaware of the magnitude of what they do not know. It seems reasonable to assume that once parents start to acquire a little knowledge, they are able to perceive the gaps more readily and possibly become less confident and more accurately calibrated. This would then have corollaries in information seeking.
There are a number of reasons individuals have inaccurate or biased self-assessments of knowledge. Two reasons of particular relevance to this thesis are frame of reference and the importance of the topic to the individual. In the case of frame of reference, "Perceptions that one's friends are knowledgeable may unrealistically inflate perceptions of one's own knowledge. This, in turn, may decrease information search behaviour" (Radecki & Jaccard 1995, p. 131). Information inaction may in some cases derive from a common peer group assumption among parents that if information relevant to decision making were important, the service provider would deliver it, where the service provider effectively forms part of the frame of reference.

The second reason for bias relates to the importance of the topic to the individual:

The more important a topic is to an individual, the more likely it is that he or she will view himself or herself as knowledgeable about the topic area ... Higher effort in knowledge acquisition may inflate estimates of the amount of knowledge gained. [emphasis added] (Radecki & Jaccard 1995, p. 133)

Radecki and Jaccard's (1995) application of this source of bias to educational interventions has serious implications for parents of children with disabilities. Where, for example, such interventions are utilised to increase the individual's perception of the relevance or importance of certain information to their own life, there is a commensurate danger that "the interventions ultimately may lead to overestimations of one's knowledge level, thereby interfering with effective search strategies" (Radecki & Jaccard 1995, p. 133). The family-centred approach in supporting families aims to educate them to understand that they are the expert in their own family, and therefore best placed to identify and articulate their service needs. If the family is encouraged to perceive itself as "expert", there is a significant danger of inflating the individual parent's estimation of knowledge level, which may well interfere with the perceived need to seek.

Both the reasons for bias described above tend to be exacerbated by a lack of awareness of information itself and unrecognised information need, although neither is specified in Radecki and Jaccard's (1995) work.

Radecki and Jaccard (1995, p. 115) also contend that "the degree of privacy in the information acquisition situation [would] directly affect the overall amount of search".

The data:
underscore the importance of making information available to people in a non-threatening way that minimizes any fear that they will be judged negatively for showing lack of knowledge in the topic domain. (Radecki and Jaccard 1995, p. 134)

In the context of family-centred practice in the childhood disability sector, this would create problems for parents who are encouraged to perceive themselves as expert - to reveal their “ignorance” to the very people who are defining them as expert would be very threatening. The net result of these problems is that families may have quite unrealistic perceptions of their awareness of information, with a considerable impact on knowledge calibration and perceptions of knowledge. This in turn may interfere significantly with information-seeking activity.

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Having established conceptual clarity regarding information terminology, presented a conceptual framework for understanding information acquisition and provided an insight into issues influencing access to information, it remains for this thesis to document the conduct and findings of the investigation within the context of the theoretical framework.
CHAPTER FOUR - METHODOLOGY

4.0 INTRODUCTION

The purpose of this investigation was to examine an information problem area in its broader social context, thereby functioning as cross-sectoral research. Specifically, the research aimed to understand the information behaviour of parents of children with disabilities, especially as it pertained to access to and acquisition of information.

A methodological approach that would support such cross-sectoral research was therefore needed. In particular it was essential that the approach:

- did not require parental intersection with any library/information service provider but viewed parent interactions with information within their naturalistic settings, while at the same time

- allowed for the use of information science theory to explore issues arising in the sector, thus bringing a fresh perspective to a long term problem.

An investigation using primarily qualitative techniques aimed at eliciting an understanding, where “descriptive data are gathered and analysed in order to ‘see’ the setting or activity from the participant(s)’ point of view” (Weingand 1993, p. 19) was considered most appropriate, as understanding parental experience of information access and acquisition was the goal of this research.

It has thus been important to utilise data collection and analysis methods that enable the exploration of “substantive areas about which little is known or about which much is known to gain novel understandings” (Stern 1980 in Strauss & Corbin 1998, p. 11). In the case of parents of children with disabilities, much is known about issues concerning disclosure of diagnosis, stress, adaptation and coping, together with the impact generally of disability on the family. (See for example Beresford 1994; Case 2000; Mitchell & Sloper 2000.) The correlative supports and services needed by the child and family are also known, though to a far lesser degree. Little, however, is known about the exact nature of parents’ information behaviour, and the concomitant information problems as
evidenced in a great deal of research, albeit frequently tangentially, as reported in Chapter 1 (1.2) and Chapter 2.

Thus a methodology generally consistent with a grounded analytical approach (Strauss and Corbin 1998) has been adopted. This approach was particularly relevant to the subject domain for, although broad information science theory addresses information behaviour, need and seeking generally, no specific theory embraced the essential parameters of the problem area, as seen in Chapter 3. Hence the broader theories yielded a starting point from which data requiring further theoretical explication could be readily identified, and, into which framework the emerging theory could be woven.

While the research was thus primarily qualitative in nature, some quantitative data collection was found to be appropriate in the case of parent demographics along with information/service awareness and use, and usage statistics from the ECIA Infoline. The particular role of this data is detailed at 4.2.2.6 and 4.2.3.2 respectively. The purpose of method triangulation is described at 4.5.

This Chapter sets out the research objectives and questions arising therefrom that the research has sought to answer. It details the methods employed in seeking the answers, describing data collection, organisation, reduction and analysis. Potential sources of bias and the methods used to improve data integrity are also described.

Following immediately is a background to the research.

4.1 BACKGROUND TO THE RESEARCH

As an information professional, I watched myself struggle to access information, services and broad-based support, after the birth of my daughter, who has Down syndrome, more than five years ago. As a part of my own process of adaptation and coping, I became interested to understand whether this was a personal anomaly or the commonly lived experience of parents of children with disabilities. I began to ask all those with whom I was in contact, to describe what their experiences had been. All shared freely, at parent support groups, open early intervention playgroups, early intervention centres and even strangers with whom I struck up conversations in the
street. What I learned yielded a strong determination to undertake research that could be used to foster parent access to information, by developing an improved model of information delivery.

Using a proof of concept approach, some preliminary design work for an Internet-based disability information service was tested with a group of parents in a pre-research phase. What became immediately evident was that testing design elements of an Internet-based information service was thoroughly irrelevant when a significant number of parents were either not using the Internet at all, or, were using it largely for one-off, often medically-specific inquiries. Indeed, the majority of parents were simply not using the Internet as a primary tool for acquiring domain-related information, support and access to services.

The inherent assumption that the broad availability of an information technology will yield the solution to information delivery is a common mistake and is widely observable throughout the public and private sectors (see Chapter 1). Yet it seemed this was not how most parents were acquiring their most useful information and support, day by day.

Carnine (1997), in addressing the research to practice gap that exists between researchers and practitioners in special education, identified three serious issues in the quality of research: trustworthiness; usability and accessibility. He suggested that trustworthiness could be improved by, inter alia, improving the “significance” of research questions. While Carnine (1997) was concerned with the significance of research for practitioners as consumers, this thesis seeks primarily to understand the information behaviour of parents and ultimately to foster parent access to information. “Significance” in this research therefore ought properly to be approached from the perspective of parents. It is worth noting that this perspective is also consistent with both the family-centred model of practice which is currently considered best practice in the sector (ADD 1997; DADHC 2004a, c) and current library and information science user-focused practice (Dervin & Nilan 1986; Hewins 1990; Kuhlthau 1993).

It became apparent, then, that any research seeking to foster parent access to information needed primarily to investigate how parents actually acquired the information they needed, together with the circumstances surrounding any failure to acquire, whether the need for the information was recognised at the time, or in
retrospect. It would only be in understanding the nature and causes of parent access/non-access to information, particularly in its expression in information acquisition, that one could effectively design an improved model of information delivery. Such a model would have an increased probability of efficacy in addressing any information problems identified, as it would be based on the evidence of parents’ information behaviour. The importance of evidence-based practice has been increasingly recognised in the sector (Mitchell & Sloper 2001).

4.1.1 Research Objectives

The Research objectives were therefore:

4.1.1.1 To model parents’ information behaviour, with particular emphasis on information need and information acquisition

4.1.1.2 To establish whether there were any inner city/suburban/rural differences in information acquisition

4.1.1.3 To identify formal information service providers and the role they play in parents’ acquisition of information

4.1.1.4 To identify the specific nature of information problems and their cause, together with possible areas for improvement in information delivery

4.1.2 Research Questions

As the Literature Review in Chapter 2 indicates, certain questions pertaining to this research are evident. Do all parents of children with disabilities seek to acquire information? What happens, in information terms, to parents who do not characteristically seek information? Do parents acquire information in other ways? Are these modes of information acquisition reliant on parents utilising an active strategy? Does the information parents acquire satisfy their needs as to content, form, timing etc., and is there any connection between satisfaction and mode of acquisition?
Furthermore, are there issues, apart from information seeking/avoidance strategies being utilised that may have an impact on parent access to and acquisition of information? For example, are there personal or contextual issues arising from the sector itself over which parents have or do not have control? Is it possible to identify any means of improving access to information, particularly as it is expressed in acquisition, through either individual or contextual factors?

Consistent with a primarily qualitative approach to the problem area, a series of questions was developed in thinking through these issues, to satisfy the research objectives.

4.1.2.1 Do parents of children with disabilities seek to acquire information? How do they actually acquire information? Do they acquire information of the type, at the time, in the form they need it?

4.1.2.2 Do issues arise that impact on access to and acquisition of information? If so, what are they?

4.1.2.3 Are there potential areas for improvement in access to and acquisition of information that may be identified?

4.2 DATA COLLECTION METHODS

4.2.1 Mapping the Information Milieu

In order to "see" the setting (Weingand 1993, p. 19) from the parents' perspective, it was important initially to map what was "knowable" to parents within the sector. Data on the broad categories of information available in the sector, and, what was delivered by government and/or service providers, was mapped. The following sources have been utilised or consulted:

4.2.1.1 Expert witnesses:
- utilise all parent contacts - to identify all they know/know of in the sector
utilise all professional contacts (information, therapeutic, medical and other service providers) to:

- Identify what they know of benefits/services/entitlements (not technical expertise), where they refer parents, what they know is "out there"
- Document tips and advice routinely given to parents.

It should be noted that the participant interviews themselves did not yield any of the information milieu data, as the researcher needed to be fully aware of this information before interviewing, otherwise she could not have tested for awareness.

4.2.1.2 Review of the literature: childhood education, welfare, development; nursing and medicine; social science and psychology for conference papers, journal articles etc., including non-refereed journals e.g. Early Edition.

4.2.1.3 Bibliographic resources: Government and non-Government directories, handbooks, "information packs" (e.g. DADHC, Carers NSW); libraries (academic, special, parent), brochures, noticeboards, service provider meeting papers, establishment papers, submissions etc.

4.2.1.3 Internet-based resources: For example Association for Children with Disabilities www.accl.org.au “Through the Maze”, “Helping you and your family”.

4.2.1.4 Information service databases: For example the Infoline, State Library Disability Access (Information) Service, IDEAS, Carelink etc.

The researcher undertook the kind of browsing / chaining Ellis describes until instances of Belkin’s ASK were forced, to work out how far the researcher’s knowledge went and where it stopped. This continued until the researcher started finding the same information from different sources (people, databases, bibliographic resources) and then recognised that full coverage was being approached.

4.2.1.5 Expo’s, conferences: For example CHERI, ECIA, government-auspiced information sessions, service provider committee meetings, support group forums e.g. Family Advocacy, Association for Children with a Disability etc.
4.2.1.6 Commonwealth Carelink and Carer Connect, Families First Local Committees, disability-specific and carer support groups.

4.2.1.7 Healthlink data entered via local councils.

The researcher codified the information thus gathered, starting with a simple breakdown of information parents needed (derived from the literature as seen in Appendix 3) pertaining to medical and health issues, therapeutic and early intervention issues, educational issues and ancillary benefits and services. The researcher then realised an accurate representation of the information milieu in which parents moved was far more complex than categorisation by 'simple' need subject area. Indeed, the more data collected the more apparent was the need to modify the map, until one was designed that was sufficiently flexible to allow for any new data, either before the thesis was presented or any time thereafter. A particular breakthrough came with recognising that not all information need types were immediate, nor were they experienced by all parents, nor were they necessarily sequential, although there did seem to be a quality of phasing. Hence the needs framework of orientation, immediate, emergent, growing was developed, which was intended to convey a sense of growing engagement with the information available and awareness of the panoply of possibilities. While this was not sequential it was certainly phased. For example the researcher did not find any parents moving comfortably in the growing phase who had not mastered the other phases.

4.2.2 Parent/Carer Interviews

After appropriate clearance from Charles Sturt University's Ethics in Human Research Committee, interviews were conducted over a three month period with parents/carers drawn from six early intervention centres in rural/regional New South Wales, Inner Western and Inner Eastern Suburbs of Sydney and the Northern and Inner North Western Suburbs of Sydney.
The researcher conducted all interviews to ensure consistency of approach and because her credentials were already established as the parent of a child with a disability. The interviews were tape recorded to allow for total recall of all participant commentary thus enabling more extensive analysis. To ensure anonymity, all participants were given a unique code, based on the child's initials and age in months, which was determined at the beginning of the interview and thus recorded on both the interview tape and the questionnaire. The participant's name was never used or referred to during the interview, nor was it recorded anywhere on the questionnaire. The interviews were subsequently fully transcribed verbatim.

A number of the tapes were transcribed by a professional transcriber, who was made aware of the privacy issues and signed a confidentiality agreement. The remaining tapes were transcribed by the researcher and all transcriptions were subsequently checked by the researcher. At no point were participants identified on any of the tapes and participant codes were rigorously applied. These codes were stripped from participant quotes in the thesis and replaced with sequential numbers to ensure that no parent comment could be attributed to any individual. While it would be the case that a person or service provider knowing the participant may be able to determine the identity of a participant on the basis of a full transcript, no one apart from the researcher has access to those transcripts and tape recordings, which are securely held.

Interviews were conducted in two parts. Part one was a semi-structured interview, in that it sought to canvas open-ended questions detailed in a standard interview schedule (see Appendix I). However the interview was administered by asking for a detailed chronology of events from the time of either diagnosis, or suspicion of a problem. During the course of the chronology, information behaviour and problem-related issues were probed. Any open-ended questions from the schedule not arising naturally in the course of the chronology were then explored. The critical significance of the chronology was in its identification of an array of information issues which, had information-specific terminology been used, may not have been identified as such and reported by parents. This problem had become apparent in the pilot study (See 4.2.2.1).

The interviews were quite exhaustive in terms of parent knowledge of the subject content of the childhood disability sector. It was therefore possible to measure fairly accurately how much parents literally knew about within the sector and this was
confirmed by the results of the quantitative measure (Part 2), where specific awareness or knowledge of services, benefits and entitlements was measured. Awareness was thus operationalised for the purposes of the investigation as knowing sufficient information either to make an informed decision or take action to acquire information.

At the completion of Part 1, themes emergent from previous interviews were suggested to the participants to test their validity, had they not already arisen. Occasionally parents did not agree with one or more themes. This functioned as a type of dynamic “constant comparative method” as “data collection, data reduction and data analysis [blended] into one another in a cyclical process” (Blakie 2000, pp. 236, 239). For example, initial interviews showed distinct differences in the experiences of parents in acquiring information from different service providers. Early themes were drafted around failure to acquire and new parent testimony of experiences was compared with the themes. A clear sub-theme emerged related to the activities of the parents, the activities of the providers and a mismatch between the two. As new interviews took place, these themes were further refined into additional sub-themes to allow for the differences between parents in the information activities pursued and it emerged that these activities strongly suggested the existence of an individual tendency toward certain activities or groups of activities irrespective of the information yield or utility of them. Previous interviews were reconsidered in the light of the refined themes and sub-themes, developing a constant comparison. Further comparison with the literature and additional parent interviews led to the development and refining of conceptualisations around information styles.

Part 2 comprised a brief quantitative component in questionnaire form administered by the interviewer. The questionnaire looked at family demographic details, awareness and use of information service providers, and awareness and use of benefits and entitlements. These were recorded irrespective of whether the details had emerged in Part 1. On several occasions issues arose during the administration of Part 2 which gave rise to further tape recording of parent comments. For example, a number of parents, when asked if they were aware of the Home Care Service, said they were not and wanted to know what it was and whether they would be eligible. Some, upon hearing the detail, wished to record further comment about not knowing and whom they felt should have informed them (i.e. the exercise of information delivery).
A quantitative method was chosen for Part 2 as the data to be gathered was known in advance. That is to say, there were specific categories of data sought to which there was a limited array of possible answers. In the case of demographic details these concerned age, gender and disability of the child, number of other children, health insurance status, educational qualifications and employment. This data was sought to look for any connection between demographics and information access and acquisition. Certainly earlier research has suggested a link (Baxter 1989; Hasnat & Graves 2000a, b).

4.2.2.1 Pilot Study

A semi-structured interview comprising open ended questions aimed at understanding the information experiences of parents was initially tested on a pilot group of nine parents. These parents attended an early intervention service separate from the two providers/six centres from whom the formal interview participants were recruited. The pilot study revealed a problem in exploring parent experiences when participants restricted their commentary to “information specific” terminology.

The interview was then redesigned for the formal interviews to be administered as a free-flowing chronology of events from the time of diagnosis or suspicion of a problem, during which the interviewer checked the parent carer interview schedule to ensure all questions were canvassed. This obviated the need to use “information terminology” as initiating questions (rather than prompts), thereby avoiding predisposing parents to restricting their commentary to what they perceived to be information-related issues.

4.2.2.2 Administration

Approaches were initially made to the Director of each Early Intervention Service Provider to seek permission to recruit parents/carers for participation in the research project. The researcher was known personally to both Directors and discussions regarding the research occurred over a period of time. The Directors were advised that the research was being conducted according to National Health and Medical Research Council (NHMRC) guidelines for the conduct of ethical research. Participation was entirely voluntary, anonymity was assured and information from mapping of the information milieu (see 4.2.1) would be provided to each parent according to the needs evident at interview.
Each Director expressed considerable interest in the research. One Director gave immediate approval and the second approached the service’s parent management committee, which subsequently gave approval. The researcher was then free to attend centres operated by the services, meet parents and/or where practicable make arrangements to hold an information session. The researcher had attended three of the six centres from which participants were to be drawn with her own child over a three-year period. A network of contacts was therefore already in place and parents were particularly receptive to the research.

4.2.2.3 Recruitment

Eligible participants were parents or carers of children with disabilities (according to the World Health Organisation’s International Classification of Functioning, Disability and Health, WHO-ICF 2001), in the early intervention period (0-6 years). Participants were sought for recruitment from two primary early intervention service providers, namely Lifestart Cooperative and Noah’s Ark. At the time of interviews these providers were operating services in six different centres. One of the providers continued to expand operations into several other locations.

The researcher attended each centre on a number of occasions, on different days of the week, to present an overview of the research and to seek voluntary participants. Sometimes this was not possible, for example when only one group was operating in the week or when certain days of the week offered no parent withdrawal time (i.e. coffee break from children) making it difficult to present information. In this case the researcher verified with staff that the potential group was reflected in the people attending that day, that is to say their children had a range of disabilities, parents were from a variety of backgrounds and received a range of services. Any parent staff felt would particularly benefit from the interview’s information exchange was also encouraged to contact the researcher. Copies of the Information Statement were widely distributed so that any parent not in attendance could make contact for further information. If necessary, subsequent visits were made.

It was important to ensure the interview sample was spread across each service provider and not restricted to those parent/carers attending on one particular day or associated days, or those receiving one particular service style and content. In the early childhood
intervention sector parents had quite different experiences of support, information, resource and service delivery. This varied according to the service provider, centre and indeed specific member/s of staff with whom the child was connected, quite apart from the needs of the child and family. Thus an interview sample spread across each centre, as part of a recruitment program from multiple centres, both inner city, suburban and regional/rural, provided for source triangulation. (Williamson 2000, p. 36. See also 4.5)

All parents/carers whom the researcher was able to contact, either through information sessions or personal contact within the centre, were provided with an Information Statement for Research Participants (see Appendix 2). This document introduced the researcher, detailing the research, its background, purposes and conduct. The statement encouraged participation while detailing potential risks in participating, concluding with a request for participation and University contact details should questions have arisen. The researcher also gave an undertaking to provide information to parents as an incentive to participation.

Any parent/carer expressing an interest in participating was immediately requested to fill in a Consent form and contact details were recorded along with preliminary arrangements for interview where possible. In presenting the research, the researcher emphasised a number of points:

- Participation was entirely voluntary and no negative inference would be drawn from a choice not to participate by either the researcher or centre staff,

- Total anonymity was assured. No comment made by any parent would be either directly or indirectly attributed to that parent in any subsequent discussions, publication, reports or papers,

- Where details of the child’s disability, or other factors, would necessarily tend to identify the parent commentary (e.g. rarity of disorder) such detail would be stripped or changed in any subsequent reporting to preserve anonymity. Alternatively, where meaning would be lost by such action, parental consent would be sought to report identifying detail,
In the case of details of courses of action, specific programs, disputes etc. that may have tended to identify a parent, and the researcher was made aware of this by the parent, such detail would not be reported, or be reported in a way that preserved anonymity. (As it transpired no disputes, difficulties or problems were unique to any one parent.)

Virtually all parents with whom the researcher had direct contact wished to participate. Of the four parents specifically choosing not to participate (spread across the centres), one initially expressed an interest but when pressed subsequently for an interview time a friend advised she would be unable to participate because of current crises. The second provided a signed Consent but on two separate occasions failed to attend interview appointments without further explanation or contact. The third gave birth to a child around the time of the proposed interview. The fourth was absent from the country at the time interviews were scheduled for that geographic area.

4.2.2.4 The Participants

Forty-nine (49) parent/carer participants were interviewed. The participants reflected a range of ages, educational levels, employment status, number of other children and awareness and use of information and other services, within each centre. Some individuals were very active within the centre, through management, fundraising etc.; others attended only for their child’s therapy and had no other involvement. Apart from one grandparent carer, all participants were parents of children 0-6 years with a range of disabilities and impairments classified as “disability” according to the WHO-ICF 2001. These included Down syndrome, cerebral palsy, autism spectrum disorder, global developmental delay not further specified and significant language delay with behaviour disorder.

Forty-eight (48) participants were recruited directly from early childhood intervention centres in suburbs of Sydney and rural/regional South Coast of NSW, as seen in the table below. The multiple location names reflect the changing face of the services over the period of the interviews. One parent was recruited at a CHERI (Children’s Hospital Educational Research Institute) Conference.
<table>
<thead>
<tr>
<th>Area</th>
<th>Centre Location</th>
<th>E.I. Service</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rural/Regional NSW</td>
<td>Nowra</td>
<td>Noah's Ark</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Ulladulla</td>
<td>Noah's Ark</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Sub total 16</td>
</tr>
<tr>
<td>Northern Suburbs Sydney</td>
<td>Turramurra/Galston</td>
<td>Lifestart Cooperative</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Ryde/Hunters Hill</td>
<td>Lifestart Cooperative</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Sub Total 17</td>
</tr>
<tr>
<td>Inner West/Eastern Suburbs Sydney</td>
<td>Marrickville/</td>
<td>Lifestart Cooperative</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Lewisham</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Clovelly</td>
<td>Lifestart Cooperative</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Sub Total 15</td>
</tr>
<tr>
<td>Parent recruited from CHERI Conference</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>TOTAL 49</td>
</tr>
</tbody>
</table>

Table 4.1 Participant numbers, early intervention service provider, centre, area.

4.2.2.5 The Setting

Parents were able to choose their interview setting. The majority chose their own home, four chose the researcher's home office and three chose a centre-based setting.

The home-based setting chosen by the majority of participants may account, at least in part, for the parents' extraordinary candour at interview. Fear of retribution, or simply not wanting to offend (with a feared impact on service delivery to their child) prevented a significant number of parents from clearly articulating their views on service quality, quantity etc., to their service providers, as later reported at interview. This fear has been remarked by Stallard and Lenton (1992, p. 203) in relation to surveys of satisfaction with services received: "such surveys do tend to be plagued by response bias where replies are distorted by a need to please or fear of adversely affecting future treatment." Thus it was important to most parents, both in preserving anonymity and in feeling comfortable to speak bluntly, to be interviewed away from the centre with which they were connected.
All participants were asked for permission to tape record interviews and all agreed. Interviews ranged in length from 40 minutes to 6 hours; the latter was conducted over three days.

It was important in conducting the interviews to be mindful at all times of ethical considerations. While the research itself was very important, many of the parents interviewed had suffered a great deal not only by virtue of their child’s disability but, they believed, at the very hands of professionals whose role it was to help and support them. Therefore, if parents became distraught or appeared to be avoiding a subject area, the researcher would always ask if they wished the interview to be terminated, paused or moved on to another question. Parents were regularly reminded of their control of the interview. The tape recorder was turned off whenever parents became distraught, needed time to recall events or find documents, or requested a break.

Furthermore, the researcher was determined to make the interview “worthwhile” for participants. This was achieved in two ways:

- Most parents valued the opportunity to “tell the whole story”. Many had never had the opportunity to do so before and certainly never with someone who had had similar experiences, coupled with some expertise in information issues.

- The researcher made every effort to provide participants with specific information about services, resources, entitlements etc., of which they had previously been unaware. Sometimes it was more appropriate to refer parents to information providers such as Carers NSW or the ECIA Infoline, with important information on how to acquire information from these agencies, what to ask for etc. The researcher also talked to parents about how to “go about knowing” when they did not know what information they may have needed. This information and advice was generally provided at the end of the interview, as the researcher took notes of information needs arising during the course of the interview. It is important to note that parents themselves did not necessarily recognise the need until the information was delivered. They were often only
able to articulate “the problem”, from which the researcher was able to extrapolate the information corollaries.

4.2.3 Information Service Provider Statistics

4.2.3.1 The Array of Information Service Providers

Mapping the information milieu identified a complex array of information service providers in the sector. The sole criterion was that the agency, organisation or role be funded, at least in part, to provide information within the sector. This may have been by virtue of a broader information role, such as the State Library of NSW – Disability Access (Information) Service, or a specific information provision role within the sector, such as the ECIA Infoline.

There were four categories of information service provider:

**Formal.** Focus of the organisation’s role was responsive information delivery. For example:

- State Library of NSW – Disability Access (Information) Service
- Commonwealth Carelink Centres
- Early Childhood Intervention Association (ECIA) Infoline
- IDEAS (Information on Disabilities, Equipment, Access, Services)
- DIAL (Disability Information and Advice Line).

**Resources** (non-profit). Focus of the organisation’s role was information delivery plus support, advocacy etc. For example:


**Services.** Focus of the organisation’s role was service delivery plus information pertaining to the service delivered and, theoretically, relevant local service information.
For example:

- Government and non-Government organisations (NGOs), such as local early intervention service providers, respite providers or coordinators/purchasers, Families First initiatives in local areas, hospitals-outpatients departments and community health centres, private sector practitioners.

Brokers, Switching Services and “Access” points. Focus of the organisation’s role was brokering services (sometimes including information). For example:

- Sunnyside, Commonwealth Carer Respite Service, government agencies (e.g. DADHC historically provided therapeutic services such as speech therapy, these were being phased out in most regions while DADHC maintained a funding and partial information role, “switching” its clients to brokers and NGO service providers), Local Support Coordinator (LSC) role.

Some agencies fulfilled multiple roles, for example providing some services and brokering others. In one case coming to the researcher’s attention, an organisation was both the Government-appointed broker evaluating funding needs/support requirements for children with special needs in pre-school settings and distributing Government funding, as well as being a large, multi centre service provider itself in the pre-school setting.

4.2.3.2 The Role of Information Service Provider Statistics for Data Collection

Parents were tested, in Part 2 of the formal parent/carer interviews, for their awareness and use of an array of information providers operating within the sector, drawn from the categories above. As a means of increasing the reliability of data from parent interviews, partial triangulation of parent awareness/use data was sought by obtaining usage statistics from one information service provider in the sector. The aim was to cross check what parents said of their awareness and use of information service providers. In addition, valuable statistical data on the categories of information requested could also be crosschecked with themes arising from parent interviews regarding information needs and acquisition.
The choice of information service provider was not difficult. Information services such as DIRC (Disability Information and Referral Service), DIAL (Disability Information and Assistance Line) and Manly Warringah Disability Information Service tended to be geographic location-specific. IDEAS was state-wide but at the time of data collection was an Internet e-mail/fax based service and had a technological focus the researcher wished to avoid. In any event, it was virtually unknown among parents (n=0/9 in the pilot study).

4.2.3.3 Early Childhood Intervention Association (ECIA) Infoline

The ECIA Infoline was chosen for its specific responsibility for information delivery within the early childhood disability sector across New South Wales, wide advertising regime and appropriate usage statistics. Permission to acquire data from the ECIA Infoline was requested from the Early Childhood Intervention Coordination Program (ECICP). This is a Program that appears to sit with relative autonomy within DADHC (refer Chapter 1).

The Infoline, 1300 656 865, is a telephone-based information service within New South Wales, established in September 1998. It was originally developed by the then NSW government departments of Ageing and Disability, Community Services, Education and Training, and Health, in association with the Australian Early Intervention Association (NSW Chapter) with which all early intervention services in NSW are associated. The Infoline has aimed to provide information to families with concerns about their child’s development, medical practitioners, childcare workers and service providers, on services available for children with a delay in their development or a disability.

4.2.3.4 ECIA Infoline Data Collected

The Infoline usage statistics provided by the ECIA codified information seeking by mode of contact, information seeker type, category of information required, other issues raised, source of knowledge of Infoline and outcome. Of particular importance were information seeker types, which differentiated sources of call as family, professional or student/other.
The following data was obtained, in addition to the 2000 Collection Sheet Proforma for statistical information used by staff to record the statistics:

- Monthly statistics
  - July 2001 - January 2002 inclusive
  - June 2002
  - July 2002
  - August - September 2002
  - November 2002

- Cumulative statistics
  - 1 July 2000 – 30 June 2001
  - 1 August – 31 October 2002
  - 1 December 2002 – 28 February 2003
  - March – April 2003

- Annual Reports, including some statistical analysis and background information
  - July 1999 – June 2000
  - September 1998 – June 1999
  - August 2002 – twelve month cumulative report

4.3 DATA REDUCTION AND ANALYSIS

4.3.1 The Information Milieu

Data gathered in mapping the information milieu was formatted as a resource kit used to support parent/carer interviews. In addition, a document entitled “The Information Needs of Parents of Children with Disabilities” was developed listing exhaustively the information needs as derived from the literature, the information milieu and parent/carer interviews (see Appendix 3).

4.3.2 Parent/Carer Interviews

4.3.2.1 Part 1

The interviews were transcribed and coding for themes was started immediately, with notes taken during the transcription process. In a preliminary analytical measure,
strongly emergent themes coded were checked with remaining interviewees. As observed, this functioned as a type of dynamic "constant comparative method".

The step-by-step process of data reduction for part 1 of the interviews, comprising also a degree of analysis, entailed:

- Identification, coding and compilation of a list of all modes of information acquisition

- Identification and coding of:
  - core themes related to information problems
  - contextual themes directly affecting information acquisition
  - issues arising from information problems experienced
    - emotional sequelae
    - consequences, effects

- Identification and coding of sources of information.

As more detailed analysis commenced, finer layers of coding were added to specify further the sub-themes arising. These formed a useful framework for the overview of information issues presented in Chapter 1.

The coding process employed a variety of coding sheets, starting with the initial codes developed from an analysis of issues arising in the literature. Data from the literature using these codes was entered into an N.Vivo database. This was done so that any issues arising in the interviews could be readily compared with data in the literature. After the first 8-10 interviews the original codes were modified with several additions, developing a detailed coding sheet, which was used to code or mark-up each interview. It was 8 pages in length and covered both parts 1 and 2. "Saturation of themes" began to occur around interview 8, which is consistent with what has been found in the literature (p.170). The additional 41 interviews reinforced the accuracy of the basic themes, evidencing their stabilisation, while also providing refinement and definition of sub-themes. They also provided greater source triangulation.

As the refinements were developed, summary sheets of the themes were also produced that telescoped the codes. This enabled the development of a quick overview of each 162
area. Hence there was a coding sheet focussed on recurrent problem themes arising from the interviews and also a summary version of the coding sheet for data reduction covering part I and focussing on modes of information acquisition, the nature of information problems – core themes, and sources of information.

Interview data was coded manually. The actual process of data coding, mechanically speaking, was achieved through the use of coloured highlighters to mark text for different code categories and specific codes were written in red pen bracketing the relevant line/s, which were all sequentially numbered throughout each transcript. Colour-coded post-it tags were used to highlight quotes to be used in the thesis.

It should be noted that it was not possible to undertake any statistical analysis of the Part I data. Thus the use of terms such as ‘frequency’ and “significant/significance” are not intended to convey statistical concepts. Rather, common use of the terms, such as ‘extent to which’ and ‘major’ is indicated. For example in asking the interviewee to identify a ‘significant’ impact the notion of a “major” impact is intended.

With Part 2, the results were manually tabulated into one large chart that contained each of the data elements covered in Part 2. In addition a notation was made of whether the participant had a proactive professional and his/her information style, based on information grounding activity and stance taken when facing resistance. To discern between the hypervigilant and consideration was given to whether leadership, organisational and public speaking roles were played.

Data was then entered into Word graphs and charts to present the cross-tabulations. For example, parent information style and educational level. Charts and graphs were only used where their presentation in this format made the point more effectively.

Clearly not all data collected was used because some of it did not address the research questions. For example, in the course of taking each chronology a great deal of information was shared that pertained to the quality of performance of certain professionals. The area of diagnosis, for example, certainly covers important aspects of information acquisition which were reported. Complaints about doctors in making accurate diagnoses (which was a consistent theme among parents of children with autism, those without a diagnosis and those obtaining a late diagnosis) were not
however reported. In addition, where clearly few parents were acquiring information through the element being tested, such as various websites, this data was generally not reported.

4.3.2.2 Part 2

All procedures concerning Part 2 data were conducted manually due to the small sample size (n=49). Demographic data was reduced into simple charts summarising factors including gender of participant, gender, diagnosis and age of child, number of other children, hospital insurance status, employment, and educational level.

Comparative analyses were then conducted of the non-demographic data:

- Awareness compared with use in relation to:
  - Information services
  - Benefits, services, entitlements.

- Awareness and use of information services compared with:
  - Demographics
  - Geographic location of centre attended
  - Awareness and use of benefits, services, entitlements
  - Information style – derived from analysis of individual parents' information activities, using the Modes of Information Acquisition conceptual framework, as developed by the author (see Appendix 4 and Appendices 4.1 - 4.26), and stance in facing resistance or failure to acquire.

- Awareness and use of benefits, services, entitlements compared with:
  - Demographics
  - Geographic location of centre attended
  - Information style.

4.3.3 Analysis of ECIA Infoline Usage Statistics

The statistics were reviewed, cumulated and analysed to identify:
4.3.3.1 *Usage Profile*

This revealed the relative percentages of information seeker types over time, the information sought and their relative proportions. Some analysis of variations in relative proportions over time was conducted to seek patterns, such as any variations related to the time of year for example, where at the beginning of school term family inquiries were high and at the end of the year professional inquiries were low etc.

4.3.3.2 *Parent Information Needs*

The categories for the “types of inquiry” code were recorded with the relative percentages over time. In addition, changes to categories were plotted over time and analysed to determine if they reflected changing priorities in information sought or a changing understanding of parents’ actual information needs. This analysis was derived from a comparison of changes to categories with commentaries on usage trends in the Annual Reports.

4.3.3.3 *Problem Areas for Families*

Categories for which data were collected included both information-specific (e.g. “lack of information”) and information-related categories (e.g. “dissatisfaction”). This provided an interesting insight, as the figures were not consistently provided in the later monthly reports or cumulations they could only, at best, give further credence to some of the broad themes arising from parent interviews and the analysis of the literature.

4.3.3.4 *Information Diffusion Pattern*

The means by which the information seeker became aware of the Infoline gave an insight into how information regarding a service was diffused in the sector. This also suggested valued sources of information, because if a source was trusted sufficiently then their information/advice (in this case in relation to contacting the Infoline) would be followed. The act of contacting the Infoline evidenced this. Unfortunately for this research the code did not also record whether the means of diffusion resulted from information seeking (active), information delivery (passive) or serendipity (chance).
4.3.3.5 The Role of the Professional

A comparison of the “professional” and “family” categories of information seeker types over time was made. The categories of “type of inquiry” more likely to be made by professionals only (e.g. “child protection”, “brochure request” and “publicity/updating”) were teased out, as were categories more likely to relate to students (“student info”). The remaining “type of inquiry” data were analysed to estimate the degree to which professionals appeared to be obtaining information for families. These findings were then set against the commentary in the monthly, cumulative and Annual reports, to verify whether professionals appeared to be playing some kind of “information role” in relation to parents.

Comparative analyses were then conducted to aid triangulation of data.

4.3.3.6 Comparison of Infoline data and Parent Interview Part 1 data

Analysis of Infoline data and Parent/Carer interview data coding was conducted in relation to:

- Parent information needs
- Problems areas for families
- Sources of information/diffusion of information.

4.3.3.7 Comparison of Infoline data with Parent Interview Part 2 data

The statistics obtained from the Infoline differentiated sources of call, or information seeker type, as family, professional or student/other. As the Infoline was early childhood-specific, that is to say it functioned specifically in relation to children 0-6 years, it seemed reasonable to assume that close to 100% of the family calls came from families of children 0-6 years. (The Outcome category “unable to assist” strongly suggests that inquiries by persons outside the early childhood period would have been set apart.) The Infoline data on “information seeker type” (i.e. family, professional or other/student) in the “family” category was then compared with parent-reported awareness and use of the Infoline. Anomalous findings were analysed in the context of interviewed parent characteristics, to determine whether there was any readily apparent
explanation. Further explication was sought from Infoline report commentaries. Infoline data on sources of information/diffusion of information was also compared with the reported awareness and use of various information services, such as the Internet and the Infoline.

§

It must be observed that Infoline data was subject to limitations of quality, depth, consistency and degree of specificity of coding. Together these problems reduced the efficacy of comparative analysis, although some basic trends emerged so strongly they were deemed worthy of inclusion.

4.4 PROBLEM AREAS AND POTENTIAL SOURCES OF BIAS

4.4.1 Maintaining Distance/Objectivity

As the parent of a child with a disability, the researcher was uniquely placed to enter into the world of parent participants. Indeed, a considerable number of participants remarked on the ease they felt in sharing with another who was a parent and therefore able to understand and articulate many of their issues in ways they had not experienced with service providers. There was also a significant advantage in “knowing” background/contextual issues related to information and service delivery, a kind of insider knowledge (Chatman 1996). The absence of insider knowledge would tend to preclude a researcher from a thorough investigation of this field of inquiry because parents themselves were not always able to identify and articulate what this researcher could recognise as information issues.

However, there were disadvantages attaching to “parent as researcher”. In particular it was difficult to maintain objectivity at times. Parents frequently broke down and wept as they tried to detail a chronology of events. As the researcher had experienced very similar issues it was difficult to remain emotionless. At times it seemed the researcher was more a fellow parent than a researcher rising above the immediacy of the situation to look for themes and patterns. Nevertheless, to achieve the long-term goal of improving parental access to information, it remained of paramount importance to
pursue an objective understanding of the information experiences of parents and the researcher used this approach as a filter through which parent commentary was distilled.

There must also be a question of whether bias entered as a result of the researcher relating perhaps more closely to the parent participants than the service providers of whom parents were frequently highly critical. With the benefit of insider knowledge, the researcher was able to query whether parents had been delivered medical and other information and referred to appropriate services and support.

There was also a potential danger of being accused of bias against medical professionals, as almost inevitably the chronology of events led to parents critically evaluating medical interventions retrospectively. These were frequently the first events that took place (in either diagnosis or seeking a diagnosis) and most were etched in great detail in parents’ minds. Detailed examination of the information issues arising often led to strident criticisms of medical professionals.

However, it was important to remember at all times that it was not the interview questions themselves that gave rise to the concerns and complaints. The issues, concerns, complaints pre-dated the interview. The interview merely gave the opportunity for understanding the problems from an information perspective and the opportunity to express those issues, concerns and complaints.

The researcher was continually mindful of the need to maintain an information perspective. When probing, for example, misdiagnoses the researcher maintained the perspective of the degree to which parents felt informed, had access to information etc.

4.4.2 Retrospective Analysis – Recall Bias

Children of parents interviewed ranged in age from 5 months to 6 years. In the case of parents of the older children, it might be argued that the time lapse could distort parents’ perceptions of what had happened earlier. However, research has found parents of children with disabilities to have remarkably accurate recall of disclosure of disability events (Foreman & Neilands 1991, p. 256; Taanila, Jarvelin & Kokkonen 1998, Discussion section, para 1) even at considerable distance from the event. It seemed likely, therefore, that parent recall of disability-related events/issues could be trusted
over the maximum six-year period. Certainly the evidence of parents whose children were younger was remarkably consistent with those of older children. Differences between parents of younger and older children pertained more to the depth of understanding of why what had happened, had happened. Parents of older children tended to have a deeper understanding.

Another potential problem with retrospective analysis may have been that rather than talking about immediately occurring events, parents were looking at their experiences in the light of more recently gained knowledge (Pearson et al 1999). This could tend to distort their perceptions of what had happened. Certainly great bitterness attached to the commentaries of parents of older children where at some later time the parent had discovered information that they believed professionals ought properly to have shared many years earlier. This seemed unlikely to have distorted the findings, however; rather it seemed to add to parents' capacity to identify what were actually information or other types of problems. This is in contrast to the parents of some younger children who may have generally felt less supported by professionals but found it hard to articulate exactly why. When the commentary of these parents was probed further by the researcher regarding information they had been given, they were then able to identify specific areas of dissatisfaction.

Indeed, as pertains to “information need” that was exactly what happened. In the “early days” parents were usually only able to articulate their problem areas. However, in the light of subsequent knowledge/experience, parents could frequently identify that they had needed certain information that they had not recognised at the time and therefore had not been able to articulate a need in relation thereto. Only delivery of information, serendipity or retrospective analysis allowed them to recognise the information need.

4.4.3 Length of Interviews and Saturation of Themes

The parent interviews were much longer than expected, many running over two hours. Sometimes parents wanted to continue the interview although all the necessary subject matter had been covered. It was apparent that most parents had never had the opportunity to “tell the whole story” and most valued the chance. Some requested a copy of their transcript for their records, as the process of working through the chronology helped many to clarify what had happened.
Themes were saturated from about the eighth interview, which is consistent with other findings (Gravelle 1997, Sample selection and participant recruitment section, para. 1). However, concern to cover the range of locations and parent demographics meant all forty-nine participants were fully interviewed.

4.4.4 Secrecy and Deception

A significant number of parents had been advised by others, including parents and private therapists, to be very careful to whom they talked about therapy they were receiving and the information they shared. Most parents experienced a fear of losing services if they were open about what they were receiving elsewhere. Upon detailed questioning, those parents expressed the intention of practicing deception if necessary to get the best for their child, though they intensely disliked feeling it necessary to do so. While parents articulated quite pragmatic reasons for practising secrecy and deception, namely loss of services, it had the effect of establishing an “information barrier”, which as Chatman (1996, p.194) observed, had the effect in turn of shielding insiders “from needed resources”.

This necessarily gave rise to the question of whether certain parents were completely frank with this researcher. However, their candour in relation to practising secrecy and deception tended to suggest that they were willing to trust the researcher and to believe that their anonymity would be preserved regardless of their comments.

Another area of potential bias concerned those parents who were anxious in regard to DoCS Child Protection Service. Some had children who were already “clients” of the service, others were concerned at being “reported”. This was particularly noticeable among parents interviewed in the rural/regional area. As interviews progressed it became apparent to these parents that information regarding their relationship with their child was not being sought and they generally became more open. The researcher was always mindful, however, of any parental attempts to present in an unusually positive light and sought, by subtle questioning, to determine whether for example information activities claimed to be undertaken, such as using service provider resource centres, actually occurred. Extensive insider knowledge was very helpful in this regard.
4.4.5 Recruitment of Parents from EI Services

Recruiting parents from early intervention services introduced one specific area of bias. This bias was directed toward those families who had sufficient access to information to obtain a placement for their child within an early intervention service.

The considerable length of waiting lists attaching to every location of each early intervention service provider strongly suggested enormous unmet need, consistent with that reported in Chapter I. However, the early intervention service providers could not give the researcher the private contact details of those on waiting lists for reasons of privacy. In addition, for purposes of ready comparison, it was decided to stay with a sample that was homogenous in one sense only, that of being associated with an early intervention service provider.

Furthermore, it would be reasonable to conclude that whatever information issues and problems found among parents attending an early intervention centre, those on a waiting list could only be expected to have experienced the same, but to a far greater degree. This is because ALL parents went through a period of NOT being in an early intervention service and information-related issues surrounding this period were naturally canvassed in the chronology.

If the question were how representative of the total population (of parents of children with disabilities) were the views expressed in the interviews (Stallard & Lenton 1992, p. 203), the views could be said to be highly representative of parents in early intervention services because almost all parents approached agreed to be interviewed. The degree of representation of parents not in early intervention services would relate to the extent to which parents interviewed were able to describe the pre-intervention period.

4.4.6 Response Bias

Stallard and Lenton 1992 (p. 203) describe the response bias that can affect consumer research when "replies are distorted by a need to please or fear of adversely affecting future treatment". They suggest that "In order to minimize the effects of response bias, it is essential to use data collectors who are separate from the service providers" (Stallard & Lenton 1992, p. 203). The researcher as a parent, and non-service provider, was uniquely positioned to minimise response bias.
4.5 IMPROVING DATA INTEGRITY

4.5.1 Method and Source Triangulation

Two types of triangulation, of methods and sources, were used to improve data integrity through

checking... the consistency of findings by using different data collection methods

... [and]

cross checking for consistency of the information derived at different times and from different people...(Williamson 2000, p. 36)

4.5.1.1 Method Triangulation

While the research used primarily qualitative methods, some quantitative data collection was utilised, where appropriate, to improve data integrity through partial triangulation. It is important to note that the nature of the phenomena under investigation (namely parents' information behaviour and information problems) precludes direct methodological triangulation. This would require direct observation by the researcher of all the parents' crises and information sequelae. As this is not feasible within the limits of the current research project, partial methodological triangulation was achieved by mapping the information milieu (that is, mapping what information was generally accessible to parents) and data acquisition from information provider statistics, in addition to the parent interviews.

4.5.1.2 Source Triangulation

It has been possible to achieve source triangulation, by conducting interviews in different locations with parents of children of different ages (within the 0-6 year age range), disabilities, and service access. Recruiting and interviewing parents from quite different locations and service providers is described as enhancing "credibility through comparison groups" (Weingand 1993, p. 23).
4.5.2 Interview Sample Size and Saturation of Themes

The parent sample was reasonably sized (n=49) by qualitative research standards and reached a saturation of themes at around interview eight. The significant number of "additional" interviews served both to validate the themes identified and to enrich the depth of those themes.

§

This investigation's 'research process' has been presented within this chapter, wherein both 'methodology and data analysis' have been justified and described in some detail. "The research trail is clear and comprehensive." (Fisher 2001, Issues of Trustworthiness and Rigour section, para. 4)
CHAPTER FIVE - RESULTS

5.0 INTRODUCTION

The results detailed below were derived from three data collection methods: Information Milieu mapping, Parent/Carer interviews and analysis of Information Service Provider Statistics. Each is presented in turn.

5.1 MAP OF THE INFORMATION MILIEU

The research sought in the first instance to map what was “knowable” to parents of children with disabilities, in terms of the broad categories of information available in the sector and the structures and content of government/non-government service delivery; that is to say, the potential array of information theoretically available to parents. This was essential in order to explore parental access to and acquisition of that information and in turn the information behaviours and other contextual issues influencing their access and acquisition.

The mapping exercise thus mapped the information milieu from the perspective of the parent of a child with a disability. This is an important departure from much current hard copy and electronic information collation and delivery. Most disability sector directories, for example, may give exhaustive lists of services and entry criteria, under specific subject headings (such as “respite”) and these are sometimes indexed. However this information is rarely presented as part of a coherent, overall sectoral structure with which parents must interact to achieve the best outcomes for their family. The focus is generally the list of services, not the needs of the family. Internet websites frequently exacerbate this problem because of their dis-connection with those in need. The ACD (Victoria) “Through the Maze” directory is an important exception, however it is one which is known to very few parents in New South Wales. The ACD (NSW) version of the directory is still awaiting formal publication as at November 2006.

Sectoral data having been gathered, resources intended to aid further data collection (namely, parent interviews) were then developed from the data as a map (see Chart 5.1), a hyperlinked information kit and comprehensive listing of parent information needs
(see Appendix 3). The map is presented below. It seeks to provide a dynamic snapshot of the childhood disability sector from the perspective of parent information need. Moving in concentric circles outward from the family and its members’ initial need for orientation within the sector and immediate information needs, the map suggests a progression toward emergent and growing needs, and the services and resources aimed at those needs. The structure of the sector is inherent within the map, without being the focus of the chart per se.

It is important to note that the map cannot provide an exhaustive representation of all information within the milieu. It does, however, provide the significant information focal points from which it is possible for the family of a child with a disability to become aware of what may be possible in information and service acquisition.
Chart 5.1 Map of the Information Flow From the parent info

**ORIENTATION NEEDS**
Information needs arise as parents attempt to make sense of what is happening.
- Is my child O.K.?
- Do we need help?
- What do I do?
- How do I get help?

Parents seek answers to these questions in order to get their bearings.
- Family
- Friends and respected others
- Early childhood Health Centre Staff
- GP

As concerns deepen, parents move into the IMMEDIATE information needs phase, seeking to:
- Get a diagnosis
- Get help

**IMMEDIATE NEEDS**
In order to get a diagnosis and help, families must navigate the following organisations, agencies and groups:

**Health/Medical**
- Early childhood Health Centre
- GP
- Specialists including Paediatric specialists
- Area Assessment Centres
- Hospitals - Outpatients, Community clinics
- Paediatric
- Klinika

**Ancillary Supports**
- Homecare help modification
- Respite
- Community Transport: taxi vouchers
- Car modification
- Recreation Leisure
- Equipment technical aids
- Mobility parking

**Financial**
- Government benefits subsidies
- One-off payments assistance
- Health Insurance
- Other sources of funding subsidies for services etc.

**Educational**
- Preschool, Daycare etc
- Early Intervention Units (School-based)
- Autism Satellite Schools
- Local Schools for specific purposes

**Therapeutic/Early Intervention**
(Special Education, Physiotherapy, OT, Speech Therapy, Psychology, Social Work)
- Early Intervention services (NGOs)
- Early Intervention Units (School-based)
- Therapist-supported open playgroups
- Hospital Outpatients
- Community clinics
- DACMC

**Systemic Change**
Understanding Your Role as a Parent
Emotional Support
Financial Assistance
Information and Referral: Case Management
5.2 THE INFORMATION NEEDS OF PARENTS OF CHILDREN WITH DISABILITIES

Needs in relation to information arise regarding the subject content of information, the quality of information, the format of information and its sources.

5.2.1. Information Needs – Subject Matter

There is broad consensus throughout the literature on what might be described as the core information needs of parents, namely information regarding the child’s condition and the helps available. However, the core-plus needs, and even detailed aspects of the core needs themselves, are strewn throughout the literature. No comprehensive picture of information needs has emerged, largely because identification of the needs themselves has never been the purpose of research, as the needs have been assumed.

Thus no exhaustive listing has been made up to this point. (An exhaustive listing is at 2. Information Needs by Subject Area - incorporating findings from parent interviews and the literature).

The needs can be broken down into Immediate Needs, required from the time of diagnosis or suspicion of a problem, and, Emergent Needs, required as the family begins to seek more control.

5.2.1.1 Immediate Needs

The literature clearly demonstrates the immediate and most pressing need of a family is usually to obtain a diagnosis of their child’s condition and detailed information in relation thereto. Such information must address the actual condition, any tests and treatments required, its projected course, practical implications, affect on development and longer term prospects, including prognosis, anticipated progress of the child and the disability or lack thereof, and eventual outcomes. (Case 2001; Fisher 2001; Gallagher, Beckman & Cross 1983; Gravelle 1997; Hasnat & Graves 2000a; Kerr & McIntosh 2000; Krafft & Krafft 1998; Laybourn & Hill 1994; Mitchell & Sloper 2000; Rosenbaum, King & Cadman 1992; Sloper & Turner 1992; Stallard & Dickinson 1994; Stallard & Lenton 1992; Taanila et al 1998; Tracy 1994; Woolfson 1999).
One group of parents described this body of information as being given "the bad news", in the sense of being told everything pertaining to the disability/condition/impairment (McKay & Hensey 1990, p. 378).

Families also require information specific to their *individual child* with the disability (Tracy, 1994), as opposed to generic disability information. This includes both the child’s own medical or other information and files (Gallagher, Beckman & Cross 1983; Fisher 2001; Gravelle 1997; Kerr & McIntosh 2000); personal adjustment to the impairment – emotional, physical and behavioural (Rosenbaum, King & Cadman 1992) and practical tips and advice for helping in living with the child and coping (Gravelle 1997; Krafft & Krafft 1998; Taanila et al 1998). This may relate for example, to specifics such as use of medication (Laybourn & Hill 1994) or coping with the effects of the disability on their child generally (Krafft & Krafft 1998). It is also the case that parents need information on their child’s strengths and how to utilise them, learning characteristics and potential (Porter & McKenzie 2000).

The need for information regarding helps and/or services available clearly runs in tandem with the need for diagnostic information. Families need to know what assistance the medical practitioner/healthcare setting can provide (Kerr & McIntosh 2000), in addition to the broad array of interventions (therapeutic, educational, behavioural etc) and family support mechanisms available (such as respite equipment and home care) (Case 2001; Gravelle 1997; Krafft & Krafft 1998; Mittler 1995). These helps are frequently given the generic title services. (See for example Fyffe et al 1995; Gallagher, Beckman & Cross 1983; Law et al. 2003; Sloper & Turner 1992, 1993; Woolfson 1999).

It is apparent from parent commentary within the research literature that not only is information required about the array of services and support mechanisms available, what each type does and aims to accomplish (Fyffe et al. 1995; Mittler 1995), but also information on specific services and how to access/use them (Gravelle 1997; Krafft & Krafft 1998; Mitchell & Sloper 2000; Mittler 1995; Stallard & Dickinson 1994; Stallard & Lenton 1992; Woolfson 1999).
The need for information regarding the help available is greater however than services information alone. Parents also need information early on all financial and practical assistance available (Joseph Rowntree Foundation 1999; Krafft & Krafft 1998; Quine & Pahl, 1985). The financial assistance may be broad based, such as an allowance or a benefit specific to the purchase of practical aids such as equipment, or support such as respite (Gravelle 1997; Limbrick Spencer 2000 in Watson et al. 2002). As an alternative to, or in addition to financial assistance, practical assistance may be available, such as home modification, free holiday accommodation, cheap airfares etc.

Families also report a need for information on accessing generic early childhood services. This is seen particularly strongly in the need for information on early educational settings such as pre-school and day care centres, where families can face considerable difficulty accessing services.

The need for social support is recognised by parents, if not articulated in those terms, (Case 2001), and is reflected in research that identifies the need for information about social support and building networks generally, including the role of other parents. Specific information is also required about parent support groups, both disability specific and general (Case 2001; Fyffe et al 1995; Gravelle 1997; Krafft & Krafft 1998; Rosenbaum, King & Cadman 1992).

Another category of information needed by parents emerged from the literature although with a lesser degree of emphasis, and that was information that prepared families for the likely reactions of others. As a direct corollary, parents required information that could be shared for the purposes of explanation and eliciting support (Fyffe et al. 1995; Rosenbaum, King & Cadman 1992).

There is also a more amorphous type of information, sometimes labelled “advice” and “counselling”, which seems more properly to be a type of information that enables uptake of information concerning the child. It may well be information that constitutes the application of broader information to the specific child, such that it becomes meaningful to the family, enabling the information to be received.
5.2.1.2 Emergent Needs

The meta analysis suggests that certain types of information need tend to develop over time and are not always immediately considered by the family, as they have more pressing matters of diagnosis and getting help to work through.

As parents adapt to their child’s disability and its implications, they require information that enables them to have a meaningful input into their child’s treatment (Krafft & Krafft 1998) or early intervention/educational program. Such information ought properly to flow naturally from the professional’s informing role, expressed elsewhere as “sharing information and skills” (Mittler 1995, p33).

An “empowering” category of information need tends to develop naturally over time as parents experience difficulties in acquiring information and services. Empowering information may provide a “big picture”, teach parents how the system works and how to be “heard as parents” (Gravelle 1997, Seeking Information section, paras. 1, 3). Or, it may specifically assist parents to negotiate to acquire services they need because parents frequently complain about the “fight” to acquire needed services (Gravelle 1997, Negotiating section, para. 2), becoming “Parents from hell” (NSW Commissioner for Children and Young People 2003, Navigating the System section, paras.13,15).

It is sometimes within this context that parents need information on how to change laws, rules and regulations (Dean 1975) so that they can acquire the help their child or family needs. They need criteria for evaluating the quality of service they are receiving and how to change inadequate or unsatisfactory services.

At a more theoretical level, the ethical principles of beneficence and nonmaleficence cited in Epps and Jackson (2000, p.166), would seem to demand that parents ought properly to receive information as would firstly, enable them to understand fully the reality of their situation and secondly, to be empowered to do something about it should they, when fully informed, consider it to be unsatisfactory. Parents require information that enables them to understand whether they and their child are in potentially “harmful conditions” (Epps and Jackson 2000, p.166). For example, parents may be receiving services of a standard qualitatively and/or quantitatively lower than professionals know others in similar circumstances to be receiving. Parents require such information as
would enable them to understand the harmful condition they are actually in, and to follow a course of action to rectify that situation. This may be by negotiating a change to specific services to their child, changes to the service provider or to understand the range of alternative providers and information to negotiate access to them.

It is also the case that families and children change over time, as do their needs (Krafft & Krafft 1998; Porter & McKenzie 2000; Taanila et al 1998; Tracy 1994), in addition to developments occurring in the sector itself (Mittler 1995). It is important therefore that families acquire information as it becomes relevant to their current situation, as well as information regarding changes in the sector that may have an impact on them.

5.2.2 Information – Quality Criteria

The subject content of the information parents need was just one aspect of information emerging as important to parents within the literature. A discernible set of what might be called “quality criteria” arose individually across the literature. It is important to note that this expression was not itself used in the literature. Mitchell and Sloper (2000, p. vi) did state that their project “explored the criteria by which parents judge the quality of information and their idea of good practice in this area.” However research to establish “good practice” in “information provision” and described criteria for “good information provision”. These criteria address the presentation of information, the content of information, the delivery of information and the organisation of information. A detailed analysis appears in Chapter 2 Literature Review.

However, in terms of the nature and qualities of information needs, it seems more helpful to adopt the approach of many parents described in other pieces of research who identified information specific criteria, as detailed below.

5.2.2.1 Quantity/Volume of Information

At first flush quantity may not appear to be an appropriate criterion of quality. However it is important to recognise that what is in view is a quantity-content-outcomes nexus, in which there is a quality of “completeness” in the information delivered/acquired. That is to say, parents acquire sufficient information to enable them to understand their child’s
diagnosis or condition, to adjust and to make informed choices on how to proceed, including how to access helps and services.

The nexus is made more explicit in Fyffe et al.'s (1995, p.36) research, where respondents consistently reported a "lack of information" especially in the early stages of finding out about their child's diagnosis and service options. Stallard and Lenton's (1992, pp.199) study also showed parents dissatisfied with the amount of information they received on help available, financial advice, respite advice and prognosis.

Parents frequently express dissatisfaction with the "extent" of information received (Baxter 1989, p.22). Fisher's (2001) meta-analysis of the literature cites five studies finding among other causes of dissatisfaction, "insufficient" information given (The Need for Information section, para. 2).

Lack of, or insufficient, information is indeed a constant theme in the literature (Kerr & McIntosh 2000; Kosciulek 1999; Mittler 1995; Sloper & Turner 1993; Smith, Chung & Vostanis 1994; Watson et al. 2002). Furthermore, it seems to pertain to two distinct areas, namely,

- Information about help, services and assistance available
- Information about the individual child – the diagnosis, prognosis and all related information

The entire disclosure of disability area, especially in its information delivery aspects, is fraught with difficulty. Yet as one parent significantly observed

I don't think it's the responsibility of the paediatrician or neurologist to judge what parents can and can't handle. If I'm sitting here and saying 'give it to me' and I cry when they tell me, that's my problem ... it should be up to parents to say how much information they want and it should be freely given. (Hasnat & Graves 2000b, Discussion section, para. 3)

Interestingly, the need for "full disclosure" has been expressed even among those utilising health services generally (McMurray et al 1998, What People Needed or wanted from Health Services section, para. 3).
Yet among professionals there is great variation in “how much” information is considered appropriate to give to parents (Cohen 1993, p.87). Paediatricians in Hasnat and Graves (2000a) study reported that disclosure practices of many practitioners were affected by parent characteristics of intelligence, educational level and emotional state. Intelligence of parents (presumably perceived) affected “the amount and complexity of the information provided” (Hasnat & Graves 2000a, Reported Influences and Constraints on Disclosure Practices section, para.1). It is therefore of considerable interest that Hasnat and Graves (2000b) parallel study of parents’ experiences of disclosure yielded a statistically significant association between parent satisfaction and “the amount of information received” (Determinants of Satisfaction with Disclosure section, para. 1). Parent variables of country of birth, educational level and social class had no significant association with satisfaction levels (Hasnat & Graves 2000b, Determinants of Satisfaction with Disclosure section, para. 4). That is to say, a lower educational level or social class did not diminish the need for information, and, subsequent satisfaction levels were related to the volume of information received irrespective of parent demographics.

5.2.2.2 Timing

There appeared to be one particular caveat on information delivery, pertaining to timing. Information delivery requires appropriate timing and what is “appropriate” is likely to vary from family to family.

As observed above, receiving information at the time of disclosure of diagnosis, or indeed during the sometimes lengthy period of seeking for a diagnosis, is clearly very important to parents (Mittler 1995, Smith, Chung & Vostanis 1994).

Yet information related to the diagnosis and help available appears to be needed both early and continuously (AAP Committee on Hospital Care 2003, Fyffe et al 1995, Joseph Rowntree Foundation 1999). Taanila et al (1998) identified that information is needed continually, as family needs for information, support and advice change over time. Mitchell and Sloper (2000, p.15) describe this as phased information; phased both as to the volume and content delivered at any given time, and, as to progressive or variable delivery in recognition of families’ changing needs.
Given that it is also the case that some parents feel information is received too quickly (Fisher 2001), it is clear that the timing of information delivery must be appropriate to the wishes and needs of the family.

5.2.2.3 *Accuracy*

A number of facets of accuracy emerge from the literature. The AAP Committee on Hospital Care (2003) states as a Core Principle of Family-Centred Care:

Sharing honest and unbiased information with families on an ongoing basis and in ways they find useful and affirming. (Core Principles of Family-Centred Care section, para. 2)

This is consistent with parents' testimony (Krafft & Krafft 1998). Parents cite inaccurate information as a source of dissatisfaction with information received (Fisher 2001). This frequently relates to bland reassurances such as, the child “will grow out of it”, “talk when he’s ready”, or “be alright as soon as she goes to school” (Mittler 1995, p. 29) and parents not being given realistic information (Pearson et al 1999) about their child. Elsewhere parents described this as “not being told the bad news” (McKay & Hensey 1990, p. 378).

Watson et al. (2002, Lack of Information section, para. 1) cites Townsly and Robinson (2000) reporting that “information from support staff is often inadequate and sometimes inaccurate, biased or conflicting”. Indeed Scharer and Dixon (1989, p. 240) found parents went so far as to say not only had they been given insufficient and inaccurate information, they had even been given false information at times by a professional hiding their own lack of knowledge.

5.2.3 *Information Needs – Information Access*

5.2.3.1 *Accessibility and Clarity*

The term “accessible” is usually used in the childhood disability sector to denote a style of information content that parents are able to understand and apply, without requiring technical expertise. This frequently pertains to the actual language used (Mitchell &
Sloper 2001). Parents unfamiliar with medical terminology for example may find it difficult to understand the practical implications of diagnosis (Taanila et al 1998).

Another aspect of accessibility is clarity (Gallagher, Beckman & Cross 1983), which is a quality related not to terminology, but the presentation of information in a way that enables parents to receive and understand it (Limbrick-Spencer 2000 in Watson et al. 2002). Even quite technical information appropriately presented with clarity, can be received and understood by parents with no technical expertise.

5.2.3.2 Format and Style

Accessible presentation also goes to the format and style of information and its delivery. Mitchell and Sloper (2000, 2001) devoted much attention to the criteria for “good information provision”. This research emphasised, among other things, the need for a variety of formats in the presentation of information.

There are a number of distinct aspects of format parents have reported:

- While parents strongly value one-to-one communication with professionals in information delivery, it is also important that appropriate written materials support any oral communications (Mitchell & Sloper 2000, p12). This is affirmed by Tracy (1994, p434), a medical practitioner and parent of a child with a disability. She believes that it is difficult for parents to absorb all the information given at a consultation/meeting, thus written material parents can review later is valuable. It may also be helpful to parents in prompting further questions and information exchange subsequently.
- Parents also value information being made available at differing levels of specificity and coverage. This approach might also be described as the opposite of the “one-size-fits-all” approach, common to much information delivery in the sector. The types of materials described include:
  - Overview document – describing the big picture
  - Guides – containing general background information, including definitions, roles of professionals and providers, and the organisation of the sector.
- Short Directories, Informative Guides, Booklets – containing specific subject content, delimited by for example - geographic region, disability type, issue area, particular summary, introduction to ... etc and including accurate names, addresses, contact details and scope plus eligibility
- Comprehensive Directories – broad coverage with depth
- Newsletters – containing current information and updates by local area, issue area or disability type
- Videos
- Helplines
  - The Internet was not seen as a primary format for information delivery because so few parents either have access to the Internet at home, or, more significantly (given that raw numbers of Internet usage are increasing at a considerable rate), “had ever used the Internet as a source of information” (Mitchell & Sloper 2000, p.27). The reasons for this emerged in the parent interviews (Refer to 5.3 Parent Interviews).
- Link worker
  (synthesised from Mitchell & Sloper 2000, 2001)

5.2.3.3 Organisation of Information

The organisation of information is another aspect of accessibility, although not described as thus in the literature. There are two distinct aspects of organisation, micro level and macro level.

At the micro level parents want to see individual pieces of information, directories etc organised for easy retrieval. Mitchell and Sloper (2000, p.23) describe this as “referencing”, including clear contents pages, indexes and colour coding of subject matter. Some directories have also sought to include overview pages, using for example ages/stages links to pages and chapters (ACD Through the Maze). Others have taken a FAQs approach, linking frequently asked question (FAQs) to subject matter in the directory.

References to further sources of information are also considered important as it gives parents the opportunity to seek information at a greater depth if required (Mitchell & Sloper 2000). It is also the case that information for families of children with disabilities
needs to be managed at the macro level. Mitchell and Sloper's (2000, p. vi) seminal work does not address this as parents commentary on good practice in the organisation of information was limited to micro-organisation. Although unreported in Mitchell and Sloper (2000) it seems unlikely parents did not even advert to the notion of macro-organisation in for example a “one-stop-shop” or central coordination of information delivery. Mitchell and Sloper (2001) obliquely refer to this themselves elsewhere, and there is abundant evidence across the literature of parents reporting the need for a central point of collection and delivery of information, such as a “one-stop-shop” (Dean 1975; Fyffe et al. 1995; Mittler 1995; Stallard & Lenton 1992).

It is noteworthy that Mitchell & Sloper (2001, pp. 243f) reported in the “Sharing Value Project” that parents struggled to find information about available services largely because of the absence of a national strategy or system that offered accessible information. Centralised organisation of information and that in a type of one-stop-shop is clearly in view. Indeed, Sloper (1999, p. 90) had reported earlier that “fragmentation of support” and the lack of an overall view of families’ needs had been exacerbated by “the lack of a single point of contact and coordination for families”.

5.3 PARENT/CARER INTERVIEWS

Forty-nine (49) parent/carer interviews were conducted. (Parent/carers are hereafter denoted as parent/s, as only one carer participated.) A copy of the interview schedule is at Appendix 1. The quantitative data detailing parent demographics and child characteristics are presented first, followed by data addressing the research questions in particular, namely the modes of information acquisition and the issues arising that affect access and acquisition. Further quantitative data on parental awareness of information services, and, benefits, services and entitlements is also used to deepen the understanding of issues affecting access and acquisition.

5.3.1 Parent/Carer Demographics and Child Characteristics

It is important firstly to identify the characteristics of the parents who were interviewed and their partners.
5.3.1.1 Parent/Carer Demographics

Thirty-eight mothers, three fathers, six couples and one grandparent carer participated, in addition to the one mother recruited at a CHERI conference not attending a centre.

<table>
<thead>
<tr>
<th>Area</th>
<th>Location</th>
<th>E.I. Service</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern Suburbs, Sydney</td>
<td>Turramurra/Galston</td>
<td>Lifestart Cooperative</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Ryde/Hunters Hill</td>
<td>Lifestart Cooperative</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Sub-total</strong></td>
<td><strong>17</strong></td>
</tr>
<tr>
<td>Inner West/Eastern Suburbs, Sydney</td>
<td>Marrickville/Lewisham</td>
<td>Lifestart Cooperative</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Clovelly</td>
<td>Lifestart Cooperative</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Sub-total</strong></td>
<td><strong>15</strong></td>
</tr>
<tr>
<td>Rural/Regional NSW</td>
<td>Nowra</td>
<td>Noah’s Ark</td>
<td>12</td>
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<tr>
<td></td>
<td>Ulladulla</td>
<td>Noah’s Ark</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Sub-total</strong></td>
<td><strong>16</strong></td>
</tr>
<tr>
<td>Parent recruited from CHERI conference</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>TOTAL</strong></td>
<td><strong>49</strong></td>
</tr>
</tbody>
</table>

Table 5.1 Participant numbers, early intervention service provider, centre, area.
5.3.1.1.1 Highest Educational Level Attained

Interview participants provided details of the educational attainment levels of partners involved with the care of the child.

Chart 5.2 Educational attainment levels of participants

* mother total=48 differing from 49 participants because grandparent carer did not provide details of parent educational level

** father total=47 differing from 49 participants because grandparent carer did not provide details of parent educational level and 1 child had a mother only

The University figures combined with the Technical College figures indicate that the interview sample had reasonably high levels of educational attainment. 75% of mothers and 68% of fathers had higher educational qualifications at either a University or technical level. It would therefore seem unlikely that parental educational levels could be considered a major contributing factor to the information problems identified. This is further affirmed in sections 5.3.3.2.1 and 5.3.3.2.2.

5.3.1.1.2 Employment, Study and Childcare

Virtually all fathers (n=44) were in full time employment, apart from two part-time/casual and one unemployed father. The employment rate of mothers however was vastly different. Two (4%) mothers were engaged in full time employment. Thirteen mothers (27%) were engaged in part time employment and five (10%) were casually employed. Twenty-seven (56%) mothers were not employed at all and many had ceased employment due to childhood disability-related factors. The total equals two less than the participant total because one father was raising his children on his own and one
mother was not reported as the grandparent carer was participating and the mother was not involved in the child's upbringing.

Nine participating mothers were engaged in additional study at University and technical levels.

Of the 50 children (with disabilities) for whom participants were caring, 30 (60%) attended a childcare facility. Of these 30 children, 21 (70%) attended a centre that received some type of additional funding and/or training to support the child, including SNSS and SUPS.

5.3.1.1.3 Marital Status and Parent Age

Thirty-eight participants were married to the other parent of the child, 4 participants were in a de facto relationship with the other parent, 2 were separated and 1 parent had never been in a relationship with the other parent.

The age range of parents within the sample was 21-47 years for mothers and 21-49 years for fathers. The average age of mothers was 34.4 years and for fathers was 36.7 years.

5.3.1.1.4 Health Insurance Status

Of the participants 29 (59.2%) were public patients in the hospital of their child's birth, while 20 (40.8%) were privately insured patients. Health insurance status seemed slightly related to educational level. Of the 20 participants in private insurance, 90% were at a technical or University level of education. Of the 29 participants who were public patients, 68% were at a technical or higher level of education. No privately insured participants had an educational level lower than the HSC, while 5 public patients did so.

The location of the participant's home yielded slightly stronger data, suggesting that the Northern suburbs of Sydney (including centres at Turramurra/Galston and Ryde/Hunters Hill) had the highest comparative rates of private insurance and the South Coast (including centres at Nowra and Ulladulla) had the lowest. The Inner
West/Eastern suburbs of Sydney (including centres at Marrickville/Lewisham and Clovelly) had a more even spread.

5.3.1.2 Child Characteristics

The 49 parents/couples/carer participating represented 50 children with disabilities.

5.3.1.2.1 Diagnosis

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>No. of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Down syndrome</td>
<td>13</td>
</tr>
<tr>
<td>Autism spectrum disorder</td>
<td>12</td>
</tr>
<tr>
<td>Global developmental delay (lifelong impairment of multiple functions)</td>
<td>7</td>
</tr>
<tr>
<td>Developmental delay (long term outcomes not determined)</td>
<td>6</td>
</tr>
<tr>
<td>Cerebral palsy plus another diagnosis/impairment</td>
<td>3</td>
</tr>
<tr>
<td>No diagnosis</td>
<td>3</td>
</tr>
<tr>
<td>Developmental delay related to substance abuse</td>
<td>2</td>
</tr>
<tr>
<td>Rare disorders</td>
<td>2</td>
</tr>
<tr>
<td>ADHD plus speech delay plus behaviour disorder</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 5.2 Children’s diagnoses among participating parents

5.3.1.2.2 Age and Gender

The children ranged in age from 5 months to 72 months, the maximum allowable within the study. Forty-six percent of the children were less than 36 months and 54% were between 36 and 72 months. These figures are consistent with the often later diagnosis of disorders such as autism spectrum disorder and global developmental delay.

Twenty-eight percent of the children were female and 72% were male. This may appear disproportionate, however male-female disability ratios are disproportionate as revealed in the SDAC 1998, which reports 6% of boys 0-4 years with a disability and 2% of girls (ABS 2001, p. 9).

5.3.2 Modes of Information Acquisition

This research posed a number of questions, including: Do parents seek to acquire information? How do parents actually acquire information? The childhood disability research literature to date has either proceeded without an acquisition framework or has
tended to focus on information seeking, as an indicator of adaptive coping. Family-centred practice in service delivery, by placing increasing emphasis on the parent-as-expert, assumes parent capacity to identify information need (on the basis of expertise) and to seek information. Yet there is abundant evidence that parents are failing to acquire information (see Chapter 1).

It was therefore necessary to identify all the modes of information acquisition, demonstrated within the interviews, and the characteristics and utility of each. In this way a conceptual framework was built, defining the predictable array of modes of information acquisition, from which it was possible to pinpoint failure to acquire and specific issues leading to failure (5.2.3.1). An overview of all Modes of Information Acquisition is at Appendix 4.

Three broad modes of information acquisition were evidenced in parent interviews: information seeking, information delivery and serendipity. In information seeking, the focus was on the instrumental action of the parent in the acquisition of information. Information delivery, on the other hand, focussed on the instrumental action of the professional or other person in the parent’s acquisition of information. Serendipity presented quite a different focus, which was the accidental nature of the parent’s information acquisition. Interestingly, while serendipity is wholly fortuitous it too appears to occur in a predictable array of modes.

It will be apparent that the modes interact to some degree and similar behaviours or activities evinced different modes at times, depending on the purpose for which they were being used. For example, the Internet was used both in active information seeking to address specific and recognised information needs, and in information grounding where the parent browsed and followed links with no particular need in view. Furthermore, the action of information seeking would issue in information delivery at certain points, and indeed passive information seeking and delivery appeared to be two sides of the same coin. Yet the three fundamental modes of information acquisition, while interactive at certain points, were nevertheless quite distinct.

Significantly, each mode and its subsets was not equally available to all parents at all times, nor were individual parent’s attempts to employ them equally successful. The reasons for this lay in both the characteristics of the individual parent and his or her
personal and socio-ecological resources, together with unique life circumstances, events and crises, and, the contexts in which they were operating, including sector wide and local structures, philosophies, policies and practices (described in chapter 1).

5.3.2.1 Information Seeking

Parent interviews revealed that there was a considerable variation in the degrees and types of action employed in information seeking. Information seeking took three distinct forms: active information seeking, information grounding and passive information seeking. Active seeking was utilised in response either to a specific, recognised information need or awareness of an anomalous state of knowledge. Information grounding activities had quite a different purpose and outcome. They involved the parent locating him or herself in situations where there was an increased probability of information acquisition, without any particular information need in view. Significantly, grounding efforts had the effect of increasing the probability of the parent becoming aware of an anomalous state of knowledge and/or information previously unknown and unrecognised as needed. In contrast, passive information seeking rather than initiating seeking involved the parent responding to what was either available in the immediate environment or offered in some way.

Thus, while most parents did seek to acquire information in some form at various points, significant differences between parents could be seen. It became evident that these differences were indicative of parental “information styles”. Six distinct information styles were discernible among parents, as detailed at 5.2.3.2.2. Those information styles ranged from the hypervigilant to the avoidant, although the majority of parents (69%, n=34) demonstrated information behaviours within the active and receptive styles.

Among those parents clustered toward the hypervigilant/vigilant/active end of the information style spectrum (49%, n=24) could be seen the strongest use of an array of active seeking and grounding activities; these parents also used the passive mode in an adjunct fashion. Among the parents exhibiting the “hypervigilant” information style there was a determination to acquire what was needed at all costs and a refusal to “give in” either to overt professional resistance or to a general failure to acquire information and services. These parents also appeared to make slightly fewer assumptions and have lower expectations regarding information delivery by professionals.
In contrast, a distinct group of parents relied more on the passive seeking mode, together with the information delivery efforts of professionals, and tended to use information grounding only sporadically. Their grounding activities were usually limited to attending support groups and making contact with support organisations, both with varying frequency, and essential professional contact. These parents were typically clustered at the receptive/passive/avoidant end of the information style spectrum (51%, n=25). While most of these parents were receptive to information delivery (84%, n=21) they either lacked information literacy skills in a broad sense, or a certain approach to problems namely the determination to “do whatever it takes”, to seek information actively and effectively. The parents would often employ active seeking only with a very strong, specific trigger and sometimes support or guidance, where a professional would make suggestions about useful information resources the parent could acquire.

Furthermore, in the more passive approach there was not only a heavy reliance on professional information delivery, there were strong assumptions and expectations that such information delivery would be proactive in nature. Where providers required parents to articulate need for information and services to trigger information and service delivery, these parents were at highest risk of failure to acquire. Failure to acquire information in the passive mode, for these parents, would usually result in failure to acquire information barring a serendipitous event.

5.3.2.1.1 Active Information Seeking

A mode of information seeking entailing initiation of active seeking was readily identifiable among a number of parents. Two basic subsets of the active information seeking mode were discerned. Parents employing this mode were aware of either specific information need/s, or, aware of a gap in their knowledge base, an anomalous state of knowledge, and the mode subset utilised reflected this distinction.

The active information seeking in response to specific, recognised need mode subset, along with a description, defining characteristics and sample activities are summarised in Appendix 4.1

There were various triggers to the actual seeking; sometimes an event or behaviour in the child and sometimes the acquisition of information itself alerted the parent to a need
for information of which they may previously have been unaware. Depending on the parent's existing knowledge base and awareness of information, the need occurred as either a specific information need or an anomalous state of knowledge.

[You need] two things: the sort of general knowledge that things were there [information and services available]; and an [attitude], which was right from there, we’re going to be focused on getting them. (1/1196-1213)

This parent was among the very few with a pre-existing knowledge base regarding services available in the sector, which generally enabled the family both to recognise their need and to seek specific information in order to acquire services for their child.

Sometimes the acquisition of information itself alerted parents to previously unrecognised information need and they would respond with active seeking. For example:

... one day I said to the speech therapist ‘I’m sick of this’...He’s going to wake up and talk one day, he has to.’ Then she said ‘No. He’s probably got autism.’...I was so shocked...I was crying and I said ‘Well, can you give me a book?’ (2/136-147)

In this case a “hypervigilant” information style was immediately apparent at interview, and indeed the parent went on to act as an information conduit for many other parents. Yet notwithstanding her hypervigilant style, it was not until the threshold of awareness of need was breached that the mother could actively seek specific information. The mother had been aware of her son’s “symptoms” for some time and had indeed been trying to elicit information and help, but without the “label” she had been unable to direct her information seeking efforts effectively.

Indeed the significance of becoming aware, as it were, of either the actual problem, or the potential nature of the problem, to information seeking was enormous.

... it wasn’t until the physio said that I think we have a major problem here – that it’s cerebral palsy. Then all of a sudden because there was an actual word that came up, I took that back to the paediatrician and said, “What do you think?” He said, “Yes.” He thinks so too! Then he actually referred us to the Child Development Unit there. (3/402-407)

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1 Unique parent coding has been replaced with a numeric character for privacy, numbers following the slash (/) are transcript line numbers.
The mother had been attempting to "get help", which was clearly a type of information seeking, from around eight months when she could no longer accept that her son was just behaving as a "premmy baby". Yet it was not possible for most parents to maintain constant seeking efforts. High and on-going levels of vigilance were discernible among only a small number. These parents (16.3%, n=8) typically displayed the "hypervigilant" information style. Active information seeking was regularly triggered by information grounding efforts, as these efforts triggered awareness of what had been latent information need, or knowledge anomalies. For example, parents were often responsible for further medical investigations as they searched for answers to questions arising from information acquisition.

Interviewer Had there been any further investigations...?
Parent Only because of me...actually in my husband's side of the family there is epilepsy. And I'd read up that epilepsy can be a problem with autism, so I actually wanted to have an MRI scan done on him.

Interviewer So you needed to ask for that?
Parent Yes.

Interviewer Were you ever referred to a paediatric neurologist?
Parent No... (2/222-235)

Yet while the results of constant seeking and grounding efforts may have been raised awareness across a broad range of issues, there was sometimes a considerable cost. The understanding of bigger picture issues, of rights for example, occasionally led some hypervigilant parents to express their views far more strongly than other parents, which sometimes had an adverse effect on their relationships with professionals.

when you have a child with a disability...they're a human being first...I think sometimes therapists lose sight that they are a human being...one therapist said to me 'You've shown great strength in doing what you've done, in really standing your ground'...I think a child has rights. (4/1078+, 1127+)

Information seeking also occurred where parents were aware more of a generalised sense of needing to know "something" or missing "something" - Belkin's Anomalous State of Knowledge (ASK). (See Appendix 4.2.)

Parents' initial attempts to resolve knowledge anomalies were usually expressed in information seeking among family, friends and early childhood nurses or general practitioners. Irrespective of the parents' knowledge and skill levels, these attempts
were frequently fraught with difficulty, especially where the knowledge anomaly concerned the child’s health, development and/or a diagnosis. Sufficient issues with the child would often trigger information grounding efforts, which in turn increased the parent’s awareness of a knowledge anomaly in relation to the child’s “problems”. If a family was not actively information grounding a trigger was either less likely or later to occur.

One parent articulated her anomalous state of knowledge in striving to acquire a diagnosis for her child in this way:

I’m trying to find the answers. There’s a key in there with this kid, [who] just needs the door unlocked and I need to unlock it. (5/1274)

In the case below, because of the mother’s awareness of a knowledge anomaly and information seeking efforts to resolve it, a diagnosis of significant disability was subsequently made. This was not uncommon.

I knew something was wrong, something was different. I just couldn’t get any doctors to understand what I was going through. I kept thinking they thought I was neurotic, you know, every 5 minutes going down to the GP or whatever, but I knew something was wrong, but I wasn’t getting answers from anywhere. (6/135-139)

Sometimes, however, medical professionals were also experiencing a knowledge anomaly.

... every time we were seeing someone they were going “We’re not sure what it is, we know there’s abnormalities.” ... But yeah again they didn’t have any answers... “We’re going to have to keep watching...” (3/192-230)

Parents were generally far happier when professionals admitted to their knowledge anomaly.

But it’s just ... somebody not being able to say “I don’t know about this, but somebody else may be able to help you.” ... That’s the way I judge a doctor. If he’s willing to say, “I don’t know.” I love them. (7/2843-2878)

One of the problems a small number of parents (n=<5) faced in their attempts to address a knowledge anomaly was the appearance of their child. If the child did not “look disabled” it seemed that help was less forthcoming, even from medical professionals.

I went to a local doctor who I know really well ... But the problem was [my son] looked really normal. So even though I had all this official stuff [lengthy reports
and test results from an interstate paediatrician] he wouldn't refer me [to a Sydney paediatrician]... so I sort of thought, maybe I'm a paranoid Mum, maybe he's doing OK... So I sort of let it go for quite a while... (3/324-331)

This child was subsequently diagnosed with spastic quadriplegia cerebral palsy, among other disorders.

5.3.2.1.2 Information Grounding

Information grounding was a discrete category of information seeking apparent among parents (see description at p.154). Multiple subsets of the information grounding mode were apparent among parents. Hypervigilant, vigilant and active information style parents all used the wide array of information grounding mode subsets. Receptives used only one or two narrowly and with specific purpose. Passives and avoidants did not use the mode at all.

The first subset was parent-initiated medical, therapeutic and educational contacts (see Appendix 4.3). There was a significant, qualitative difference between parents using medical, therapeutic and educational appointments, sessions or other contacts as an information grounding activity and those same types of appointments, sessions or other contacts used to attend to a specific problem or routine activity only (see 1.2.3.5). In the information grounding mode, the hypervigilant/vigilant/active parent would often attend armed with multiple written questions, ideas to explore and bounce-off the professional, information acquired elsewhere for the professional to review and an almost relentless determination to be directed to other sources of information or possibilities.

Parents who attended appointments and sessions well-prepared, both in terms of background research and the determination to "be heard", always had a far higher probability of acquiring information: "You go into a specialist ... prepared, knowing what you want to talk about, what you've got...I'll try and find out as much as I can before I go" (3/949-954).

However the emphasis in successful acquisition was always on parent initiation of contact and efforts in information seeking: "The medical profession always just slips away from you. It's up to you once again to keep ringing up and making appointments, and [asking] 'Do we need to do this, this winter, do we need to do that?'" (8/21).
Although some parents recognised the role professionals could play in their information grounding efforts, it was not always easy to find the professionals who would do so.

There's all these services out there, no one has any idea where they are and how they interact with each other, if they interact at all. So until someone comes along and says "Did you go to ...?"... But that's purely talking to most parents and the occasional professional who will help you with the bigger picture rather than the specific need at the moment. [emphasis added] (6/800-808)

Networking, the second information grounding subset, was one of the most powerful modes of information acquisition (see Appendix 4.4). While almost all parents had contact of some type with other parents and organisations, those parents at the hypervigilant/vigilant/active end of the information style spectrum specifically recognised the information potential of networking. When they acquired information from other parents it was part of a deliberate approach to information acquisition by grounding activities.

However those parents at the receptive/passive/avoidant end of the spectrum often experienced fortuitous information acquisition through other people and support organisations. Hence while they also remarked that much of their valuable information came from other parents, they would often describe the acquisition as accidental.

The power of information grounding through networking for parental information acquisition is seen graphically in the following example. The parent was a nurse with a distinctly hypervigilant information style.

There was another family newly diagnosed with the same condition and I'd asked to make contact ... and the neurologist said she didn't think it ... would be in our best interest to make contact ... It so happened that that child ... was actually admitted to my ward and allocated to me. So I just made contact with this family ... I'd gone through a stage [where] ... everything we went to the doctors with they'd relate it back to the diagnosis ... 'Sorry you've got to live with it, this is part of the diagnosis'. So then being able to talk to that other mother and find out what she was doing for her son then I'd say what I was doing for my son... I think it was interesting to have two different doctors looking after us in that I'd say 'Oh we're trialling this with my son at the moment.' And she'd go and demand it from her doctor. Or I'd just try the stuff that she was trying, which worked. (9/11-39)

As parents were alerted to knowledge anomalies in the course of networking, they frequently moved specifically to active information seeking, knowing either what they
needed to know or that there was an anomaly to be resolved. "The most helpful, without a doubt, are just other parents and their experiences and what they've found out" (10/990-991).

One parent observed that while she recognised she felt more comfortable talking about issues with other parents of children with disabilities, no one had ever pointed out the importance of specifically building a support network for information and emotional support and it was not necessarily something one would know.

Parent I would feel more comfortable talking about it with [other parents of children with disabilities]...because I don't think anyone with normal kids really understands...

Interviewer ...you need to be actually told things? ...[like] what parents go through, with the uncertain diagnosis, and how important it is, to get emotional support on board early...?

Parent And how do you know that sort of thing? You don't necessarily know you need it. (11/1756-1794)

The third mode subset of information grounding was the utilisation of existing information resources (see Appendix 4.5). Sometimes parents were actively utilising the information resources naturally occurring within their environment. This may have been at home, in the form of information packs, directories, brochures etc that had been acquired previously. Most services and organisations provided parents with some type of information upon application or entry.

The utilisation of existing information resources also occurred in the multitude of settings in which parents acquired or sought to acquire services for their child. Such settings almost always had noticeboards and brochure stands, some also carried newsletters, both disability sector-general and disability-specific, and other ephemeral information resources, although the latter were frequently housed in some type of parent library or resource centre (see mode 1.1.2.4). There were considerable differences in the quality and quantity of information resources made available in this way and differences in parent approach to the resources. More vigilant parents used this mode specifically and often sought and exhaustively read the information. This was clearly distinguishable from the more passive parents who tended to respond to what was obviously available (see mode subset 1.3.1), rather than seeking it out, and flicked through at most, rather than exhaustively reading.
Most parents of children with Down syndrome had received "The Down syndrome kit" while in hospital, as per hospital protocol. However, while the kit was generally well received only the parents at the vigilant end of the information style spectrum seemed to read it with vigour.

the nurse said 'Look I've got some information from the Down Syndrome Association... When you feel ready, if you want us to, we can bring them to you.' I said, 'I really want as much information as I can [have]'...I rang [the Down Syndrome Association] direct, I rang them from hospital from the information they gave me, from the kit. (12/131-137)

Sometimes, the hospital protocol was not followed and the parent had to struggle to satisfy his or her own information needs.

One of the night-time sisters ... gave me a book and she also got hold of for me the information pack from the Down Syndrome Association, which was out of date and I wasn't able to keep it because it's the only copy they had. And I had to take notes and hand it back. ... I managed to get down to the hospital library... and had a look around there and found it. But again, I was hungry for information at that time, those first few days thinking 'Well what if he has got Down syndrome then what does it mean for us as a family?' (13/280-310)

Where such information resources and collections were not immediately apparent, only hypervigilant, vigilant and some active information style parents appeared to seek them out actively. For other parents this formed part of information acquisition by passive delivery as noted above. Hence, matters such as location and visibility were extremely important to get parents' attention.

Interviewer Noticeboards. Do you look at noticeboards?
Parent Yeah, but where?
Interviewer Some people look at them in shopping centres, libraries, Lifestart have a notice board, have you noticed it?
Parent Yeah.
Interviewer Do you ever look at it?
Parent But I don't really. I'm in there and out there, and when I'm in there, my whole focus is on the child, not sort of anything else... At Turramurra, I used to look up on the boards all the time... I could see it all. It caught my eye on a couple of things. (3/1092-1122)

Yet awareness of the existence of information resources alone did not necessarily prompt parents to use them. The fourth mode subset of information grounding, browsing parent libraries, resource centres and information services, was a typical example (see Appendix 4.6). Parents were often notionally aware, for example, of a
parent library within their early intervention service provider but frequently did not have
the time to navigate those resources to find relevant information. Indeed parent libraries
and other centralised information services often remained under-utilised resources
unless a professional was involved in the `navigation’ process. Few but the most
vigilant parents browsed such resources and services and that was frequently in the
early days or at times of crisis. “Early on, they had like a parent library, and I borrowed
some books from there to have a read.” (14/63 1-2)

§

Browsing the Internet was the fifth mode subset of information grounding (see
Appendix 4.7). High expectations are held of its capacity to “deliver” exhaustive and
wide-ranging information on a massive scale. Hence it is potentially quite unique in the
parent’s cache of potential modes of information acquisition. It should be noted that
such expectations tend to be held by government and non-government organisations
rather than parents and their support and advocacy groups (see Chapter 1).

Indeed browsing the Internet was not particularly popular because it was considered a
time-consuming activity unless the parent had a very specific need, in which case the
Internet was not browsed but searched with specific need in view (mode subset 1.1.1).

Interviewer  You tend to use it --?
Parent  When an issue arises.
Interviewer  A particular issue, rather than browsing like you might in the
library along the shelves?
Parent  … I don’t browse randomly with the websites, anyway… I don’t
have time. My husband does a little bit more, and he will tend to
search a little bit, but not hugely. (13/1928-1929)

Parents who used the Internet regularly tended to have favourite websites or specific
search terms that would be revisited for updates. They also followed hyperlinks and
webrings (connected series of websites that shared common, interlinking interests in
particular subject matter and denoted by a webring icon).

§

A sixth mode subset of information grounding was evident in parent attendance at
various information and skill development events (see Appendix 4.8). A discernible
group of parents used attendance at various functions for information grounding
purposes with the concomitant effect of networking. These included, for example,
conferences, expos, seminars, workshops and miscellaneous DADHC and other information sessions. While a subset of parents attended only disability-specific conferences, workshops and information sessions, the group with a hypervigilant/vigilant information style would frequently attend both general and specific events. These events were particularly important in raising parents’ awareness of issues they may not have considered and also in deepening the knowledge base, such that they were in a better position to discern relevance of information and to identify where knowledge anomalies were occurring in their life. Many further avenues for investigation were usually opened up by these events and hence they were a powerful tool for information acquisition.

One hypervigilant parent who was extremely active both on local committees and in attending conferences and expos heard a paper delivered at a conference regarding an organisation structure of which she herself was a part. What the professionals described and what she experienced were however different. Her awareness of professional misperception of the on-the-ground experience had only been raised by conference attendance.

I was surprised that there were these services, or the structure available [described at the conference], that was supposed to be all whiz bang, and information was [supposed to be] going to go from the local up to the regional areas...And, not [much] information was getting forwarded back...And I thought, I'd never heard about it, and then the professionals who I talked to, who did know about it, just pooh-poohed the whole thing, yet it was presented at this conference, like this is going to be the way of the future...And on the ground, just nothing is happening. (1/1336-1361)

Parents attending these conferences and being members of committees were clearly in a much better position to assess the performance of professionals and to detect the mismatch between information delivered at more bureaucratic and political levels and the reality “on the ground”. This was clearly empowering.

§

In fact membership of committees, review teams, peak bodies and so on, comprised the seventh mode subset of information grounding (see Appendix 4.9). Again the more vigilant parents almost always comprised the members of parent management committees and boards for early intervention service providers. They were often parent representatives in DADHC fact-finding sessions, local area early intervention
committees, peak bodies, regional and review committees for various government and government-funded organisations and the like, as well as tending to be those “selected” as interviewees for government-funded research etc.

Hypervigilants and vigilants were readily distinguishable from other parents in their systematic and intentional approach, and, in the case of the hypervigilants, the leadership and organisational roles they frequently assumed. These parents explicitly recognised the information potential of these activities and maximised their use for that purpose. Hypervigilants would often both organise and manage or present papers at the multitudinous array of events in the sector.

One hypervigilant parent cogently expressed the association between membership of parent, regional and other committees and Boards, and, access to information.

See now I’ve got comfort because I’m on the [early intervention service] Board and I’m on the [early intervention pre school] Board and I’m on the Area [Committee]. And I’ve got a good chance of bumping into [information]. (1/931-940)

Clearly then location within the two information grounds (conferences and committees) yielded considerable, broad ranging information exposure for parents participating and was a significant contributor to information grounding efforts. In terms of the information potential, these modes were vastly under-utilised.

5.3.2.1.3 Passive Information Seeking

Passive information seeking would almost appear a contradiction in terms. It refers to information seeking that while passive did not entail total inaction. There was some action but it was in response to what was available or offered, rather than active initiation of an information seeking process.

The key feature of these two mode subsets was receptiveness to what was offered, and the success of information acquisition relied on the ability or willingness to use the opportunity presented to acquire information. Parents utilising these mode subsets may have wanted to seek information more actively but did not have the necessary information literacy skills to do so. Alternatively, parents may have had the information literacy skills but circumstances precluded their use. Those circumstances may have
been personal or contextual, including the awareness heuristic, reluctance to "rock the boat", family circumstances such as the burden of caring, or simply the actual information displayed at a centre to which a parent could be exposed and respond.

The first mode subset of passive information seeking was the response to what was visible, obvious or known (see Appendix 4.10). Information resources were present in the multitude of settings in which parents acquired or sought to acquire services for their child. As noted under information grounding, such settings almost always had noticeboards and brochure stands; some also carried newsletters and other ephemeral information resources. However while vigilant parents used these resources specifically and often sought out and exhaustively read the information, the more passive parents tended to respond to what was obviously available rather than seeking it out. They also tended to flick through information rather than exhaustively reading. There were often issues of perceived relevance and because parents with a more passive information style tended to lack a deep knowledge base, judgements of relevance were often inaccurate. Once parents understood the relevance of the information or the utility of a particular type of resource they were more willing to respond to it, especially if the effort was considered worthwhile. The greatest probability of information acquisition through this mode, among more passive parents, was guidance by another parent or professional, or, a specific trigger (such as a media report), both of which functioned to increase the parent's understanding of relevance and interest level in the information.

Within this mode subset the parent did not actively seek out brochures or other information but responded to what was apparent. Thus, in order to acquire information in this mode, the parent needed first to be aware of the information passively available within the environment, yet this was not the case among a surprisingly large number of parents.

Interviewer: Do you look at noticeboards?...
Parent: Yes.
Interviewer: Brochures? ...
Parent: I don't think I've ever seen them having brochures, do they?
Interviewer: I just [visited Lewisham] today, you know the room at Lewisham?
Parent: Yes.
Interviewer: ... on this side there is like a brochure display cabinet.
Parent: Oh, I'll definitely have a look at that. (15/1356-1368)
Yet lack of initiative in regard to information acquisition was characteristic of the receptive information style.

Interviewer: Noticeboards, are you a noticeboard reader?
Parent: Not really.

Interviewer: What about brochures...
Parent: I did, but not any more, I used to get a lot from reading Sydney’s Child, but I don’t read that any more, because I don’t have access to it...

Interviewer: Something that [the new early intervention service provider] could probably make available?
Parent: Yeah, they do, but they only have about 5 copies, but they go.

The second mode subset of passive information seeking was quite similar to the first in that the parent responded to information being offered (see Appendix 4.11). Indeed among many parents, information passively available in the environment would only be considered if another person handed it to them, which was almost certainly influenced by judgements of relevance.

Interviewer: Do you read notice boards?
Parent: On the Internet?

Interviewer: No, no, not the Internet.
Parent: No, I'm not one for notice boards.

Interviewer: What about brochures .... when people ....?
Parent: .... hand them to me.

Interviewer: So if someone hands you a brochure, you read it from cover to cover?
Parent: Yes. I wouldn’t source that out though. (17/1565-1580)

5.3.2.2 Information Delivery

As is the case with information seeking, “information delivery” implies action. Yet again parent interviews revealed a considerable array of modes, ranging from a pre-emptive action mode where fellow parents and professionals proactively intervened to alert parents to information of which they were often unaware, to a mode that encompassed virtual inaction. In each case, however, the focus was on the professional or other person delivering information to the parent.

The single most salient feature of information delivery was its profoundly disorganised state at every level, regarding all subject matter in the sector. Whether structured settings, such as within early intervention services, or the unstructured among private
medical and therapeutic practitioners, whether government departments or charitable non-government organisations were observed, the management of information resources was in a parlous state. It would be fair to say that there was a total absence of any systematic information delivery.

In particular there were significant and irreconcilable variations in information delivery practices between different professionals/providers, within or by one professional/provider at different times and stages, between different families and professional/provider strengths in one subject area were not necessarily available in others.

It was possible to identify subsets of information delivery, with distinct variations in qualities, characteristics and efficacy.

5.3.2.2.1 Proactive Information Mediation

Proactive mediation of information was observed to entail action on the part of professionals and other people to deliver information to parents that they had neither requested nor specifically sought. Parents were almost always unaware of the actual information itself and/or its application to their own life circumstances. The professional or other person delivering the information had usually concluded either from awareness of the family's specific circumstances and need, or, extrapolating from precedent and the experiences of other parents, that the parent may have a need for the information. The professional or other person did not require a request for information to trigger information delivery and this was very important to the recipient parents. Proactive mediation of information by a "proactive professional" was described in detail by 14 parents (29%) in quite different settings, usually forming part of an on-going relationship. For the remainder of parents the proactive mediation of information was random and usually issue-specific. Information was delivered in this way by family, friends and other parents, or, professionals who did not normally function in an on-going proactive role.

The first mode subset of proactive information mediation was that which occurred among other parents, friends and family members (see Appendix 4.12). The great significance attaching to proactive delivery of information by other parents was
abundantly evident at interview. As one parent, who was an active information seeker but had experienced great frustration in acquiring information from professionals, observed: “All the health professionals in the world can’t give you what these other parents can tell you” (5/977+).

The importance of proactive information delivery by other parents was reiterated across almost all interviews:

... and again all my information really does come from mothers, it comes from other mothers because other mothers are saying ‘You should go to this paediatrician ... he does blood tests and looks at the mineral and chemical composition and so on...’ (18/698+)

Sometimes the proactive person identified issues in the child of which the family was quite unaware and because of the relationship was able to mediate that information effectively to the family, often with specific application. The relief that parents experienced when there was someone else to rely on, to relieve some of the burden of being the “expert” on their child was enormous.

Parent I think I’m very fortunate that I’ve got a friend like [name] who works with kids with a disability.
Interviewer What’s his role?
Parent He actually used to run one of the homes ...and works with DoCS and things like that... He’ll notice something ...
Interviewer He is like another set of eyes for you?
Parent Very much.
Interviewer So he has probably turned up a number of things that you wouldn’t have known?
Parent Yes, definitely. And even simple things like hands being tight at night and I would never have noticed that ever in my life...it shouldn’t be like that, that’s not relaxed. Whereas I wouldn’t know that. (3/1217-1247)

This is an important example, as it eloquently demonstrates the problem of the awareness heuristic, where the mother was unaware that she was unaware of something significant, in this case, her child’s symptom. As a result she would never have drawn the problem to a medical practitioner’s attention in any information exchange about her son’s condition, had not her friend proactively delivered information.

It seems feasible that one of the significant factors in the proactive delivery of information by other parents and friends was that these persons had the freedom not
only to speak about their own experiences, but also to proffer information and advice without fear of litigious or other consequences.

As I said the paediatrician has only just now, decided to refer me to all these different places, but it's been over a year you know! So, whether they're hesitant to label kids, whether they're hesitant to give you the information in case they're wrong, maybe they get sued, I don't know. I think there's a bit [of] hesitancy out there to help you, unless you ask a specific question. (6/692-699)

Of course, the problem many parents faced was that they were unaware that a question either needed to be asked, or what that question was. However, proactive parents and friends, in developing relationships, also built an understanding of other families' needs, which the families themselves may not have recognised because of the awareness heuristic. The proactive parents and friends were able then to apply information to other families' unique life circumstances in ways that were meaningful and unlikely to occur with many professionals.

The problem is you don’t have experience...You don’t know what to ask until other mother, already, like they [have] experience, they're ahead of you, they been through what you been through. So they know that what you should ask, so they tell you, "Go and ask them what is this". (19/2146-2154)

The second mode subset of proactive information mediation was that which occurred through professionals in the field (see Appendix 4.13). Almost all interviewed parents expressed a preference for this mode of information delivery by all professionals, however no parent enjoyed this mode of information delivery in a way that satisfied all their information needs. Some parents (n=14) certainly experienced the mode more than other parents, usually through a significant therapeutic or medical professional, or DADHC community worker.

Access to this mode appeared to have a dramatic impact both on the parent's access to information and services and to their feelings of well being.

...you're in shock, you just want someone to take you by the hand and tell you exactly where to go, 'now do this, now do that'. And you are not capable of getting on the phone and trying to ring around and find out what you're entitled to and who you should see and early intervention. We were just lucky that [the paediatrician] said straight away 'Try to get into [early intervention service provider], they do some fantastic work.' (20/627-655)
Proactive mediation of information moved beyond simple information delivery into a type of value-added delivery or mediation, where there was clearly a context of relationship and efforts were usually made to understand the family’s “whole story” and unique circumstances. Yet delivery did not end with delivery as such, there was frequently application of the information to the family’s particular circumstances.

I would like somebody who has knowledge, who has an understanding of the services in the area that might apply to us to be able to, to have an overall view and say, “This is what you can do.” [emphasis added] (13/1621-1624)

Furthermore, there was sometimes very important revisiting of information previously delivered to ensure uptake. In rare cases professionals also “tested” to ensure information uptake had occurred, but this was rare indeed.

A very small number of parents (n<4) found this approach intrusive and unwelcome. Some of their complaints pertained to one therapeutic professional in particular, whose proactive information delivery style was applauded by other parents experiencing it—hence issues beyond information delivery per se may have been in view. Nevertheless this variation in parent reaction to the mode does suggest that modes of information delivery need to be tailored to the individual family in order to increase the probability of effective delivery.

As regards professional practice, the information delivery style evident among many professionals would be best described as reticent, as if concerned not to presume to know what parent information needs may or may not have been. Other professionals may have expressed the desire to be “more proactive” but decried serious unmet need and time constraints as inhibiting this mode of information delivery.

One person caring for a DoCS Child Protection Service client-child often felt that she was not given information she may have needed but felt powerless to do anything about it.

Carer I’m still finding out what should be done, but [is] not being done...
I still wonder today, where DoCS role is as far as [child] is concerned.

Interviewer ...it’s not transparent to you...?

Carer NO! Not really, not what their role actually is. They’re there to protect the child, they keep emphasising that to me but--

Interviewer But they’ve never made clear to you what that actually means, day to day?
Parents’ largely unarticulated assumption that important information would necessarily be proactively delivered by a professional with whom they were in contact, was clearly inconsistent with the delivery approach and style of many professionals and the constraints-imposed practices of others. The most significant danger here was that the mismatch was largely unrecognised by both parties. It was only when parents, often catastrophically, discovered that they had not been proactively informed of information they had clearly needed to know, but of which they were unaware (and could not therefore seek to acquire), that the mismatch was exposed:

“I think it’s also, why didn’t someone tell me? How come I have to find out this way [serendipitous discovery]?” (18/1314-1315)

Nearly all parents (>95%) simply wanted to be assured that they would be proactively informed of information they needed, whether they recognised the need or not and whether they were able to articulate the need or not. Among these parents there appeared to be a positive correlation between the intensity with which proactive mediation of information was felt to be important and the degree of impact of the information on the child and/or family’s well being. Hence, for example, having been informed or not informed of a toy library prompted far less reaction from parents, than having been informed or not informed that they would be eligible for Carers Allowance.

All I would like to know is why in probably 12 to 15 professionals I’ve dealt with they’ve never mentioned anything like this [directory of services]? I mean how handy would that have been when I was searching for all the avenues I needed. Why didn’t my paediatrician say ‘And by the way seeing you are concerned that there is something difficult or there’s a problem with your child, have a look through this. There may be services to help you.’ (5/2327-2333)

5.3.2.2.2 Responsive Information Delivery

Parents reported that responsive information delivery was the primary mode of information acquisition by delivery, notwithstanding the fact that the proactive mode was clearly preferred. The single greatest frustration expressed by parents in relation to this mode was that they were often asked by professionals “What do you need?”, but had no real understanding of what was available other than what the professionals themselves were offering. Parent requests for information and service were similarly hamstrung. Without knowing what was available, what was “appropriate” to ask for and
Indeed, what other parents were receiving, all but the hypervigilant and vigilant parents were quite concerned not to be perceived as "greedy" or "pushy" or "wanting too much". Hence, free and open information exchange rarely occurred, especially among the active, receptive and passive information style parents.

Responsive delivery occurred in two readily identifiable mode subsets. In the first mode subset the professional or other provider provided specific opportunities for information exchange, often asking the family "What do you need?" and responding to family requests for help in that context (see Appendix 4.14).

The most common initiation of an information exchange opportunity was the IFSP – Individual Family Service Plan. The IFSP was intended to document the child and family's service needs for the following six to twelve months and how the early intervention service provider would help the family to meet those needs. In reality the focus of IFSP's was often early intervention and specific therapeutic goals. Parents were rarely made aware of the panoply of possibilities in terms of services, in order that they might fully explore their needs and make requests for service. Parents often found IFSP's were a matter of form rather than substance as it was difficult being asked what was needed when they were not aware of what was available or reasonable to request.

"if they ask is there anything else you want, can you think of any other services, it's hard because, if I don't know what's out there, how to ask for something...I don't know. And that's what I always wrote in the [IFSP forms]. I hate these IFSP's, because I just want [the early intervention service] to tell me where to go next. (20/2084-2098)"

Indeed, for many parents to be asked 'What do you need?' was a crowning frustration, whether asked by medical, therapeutic, educational or other professionals or providers. Inability to articulate need was not an indicator of an absence of need but of awareness of what was significant or what may have been possible.

"how do you know what you want... there could be huge things that I'm not even aware of, because I'm like, in the midst of it, and I don't know what I should be looking out for in the future. We just glean little bits of information, here or there. I would love to know what the next step is... how do you know what you want, if you don't know what you should be looking for? (16/948-960)"

Yet other parents were not even aware that they should be having IFSP's and that this was part of what their early intervention service provider was intended to provide. Such lack of awareness decimated the potential efficacy of another information exchange...
opportunity, that of the local support coordinator role. This relatively newly established, government-funded role was intended to assist people with disabilities and their families to link into local services. The problem was most parents had never heard of it (n=2 were aware).

Sometimes providers had specific programs aimed at ‘breaching the information gap’, such as the Connections Project of Carers NSW, which sought to get parents/carers connected with each other and mentors, for information and emotional support. However the project was not based on any analysis of how people acquire information but accepting as a given the serious information problems among parents, aimed to trial a technology-based ‘innovation’ as a solution.

Interviewer ...did they try to ascertain how most parents actually find things out?
Parent I think...they just want a computer based service...I actually think that what you need is...someone’s that actually gone through it all... and [they can] give you all the information, because that’s where you learn...
Interviewer so do you think, in terms of information services...[the problem is] you actually need to articulate the question?
Parent I don’t think you even know about any of them [information services]...even if you do [know about them], you don’t know what to do with it. (2/818-846)

The second mode subset of responsive delivery was professional or provider response to parent articulated requests (see Appendix 4.15). This was the most common operating mode of both professional and service providers evident at interview. It was not the case that most professional and service providers were unwilling to deliver information to families, it was rather that they waited until family members articulated a request for that information. This modus operandi assumed parents were aware of what was available, its relevance and potential application to their unique circumstances. It also assumed parents had the ability to translate that awareness into a need to which providers/professionals could respond, and, the willingness to articulate that need.

A wide array of providers and professionals fell into this category as their primary modus operandi, from disability parent support groups, such as the Epilepsy Association, the Autism Association, Carers NSW, through to government-funded organisations. The latter included those specifically funded to deliver information, such
as the Early Childhood Intervention Infoline and the State Library of NSW - Disability Information Service. Most professionals also operated in this mode, although there were individual differences depending upon the parent and the circumstances. The more vigilant parents acquired far less information in this mode, where the focus was upon the professional/provider’s actions in delivery. These parents were either utilising active seeking in response to identified need or information grounding to discover information and knowledge anomalies. That is to say, the focus was upon their own actions in acquisition.

Parents acquiring information in this mode were usually those who undertook little ongoing active seeking and information grounding, and would tend to contact providers such as the Down Syndrome Association, or professionals such as therapists with one-off requests. The provider or professional was very willing to deliver the information as specified but the delivery was never part of a dynamic process whereby the parent was being informed of the things they needed to know. It was also the case among parents who were more vigilant but were in a stage of their cycle where they did not know what active strategies to employ in order to become informed.

5.3.2.2.3 Passive/Generic Information Delivery

Passive/generic information delivery tended to consist of a body of information presented in a static form, requiring parents to approach, uptake and apply the contents. There was generally no targeting of information, apart from that occurring naturally in disability-specific or service-specific resources. The unique needs of individual families were not addressed by this mode of delivery.

The first mode subset of passive delivery - the delivery of one-size-fits-all, generic information packages - was one of the most common forms of information delivery and one of the least effective (see Appendix 4.16). Only hypervigilant parents were usually able to take the package and either absorb its contents at the time by active reading, or recall it later when a situation arose and apply its contents at that time. Standardised packages of information in relation to specific disorders and disabilities were one particularly common form of this mode subset. They usually contained information resources in relation to the meaning of the disorder, further or more technical reading if required, local parent contacts and support information, entitlements
such as Centrelink payment brochures and application forms and directions to websites and listservs of interest. They were in various formats including videos, sound cassettes and CD-ROMs, in addition to standard print materials. Most parents of babies born with Down syndrome received the “Down syndrome” kit within the first few days at hospital, by hospital protocol. There did not appear to be analogous protocols for the delivery of standardised information packages in any other medical settings for other disorders and disabilities, according to the parent interviews. For example, families whose children were diagnosed with other disorders at some later point were not automatically given a kit of information by the diagnosing medical practitioner. Most support groups however, such as the Autism Association, Carers NSW, NSW Council on Intellectual Disability and the Epilepsy Association had standard packages for delivery to parents on the request of the parent or a professional.

Most providers delivered some type of information kit or package upon application or entry to a service. There was virtually no revisiting of information delivered in this way by providers to ensure application and uptake, and indeed, even at the time of delivery there was rarely application of the information contents to a family’s unique circumstances. Some parents could not recall that they had been given a package, even when it was clear they had because of the provider’s standard operating procedures. Disability-specific or targeted kits had a slightly greater efficacy. The Down syndrome kit, for example, was generally well received although usually only the parents at the vigilant end of the spectrum read from cover to cover. Other parents tended either to dip in when they wanted something specifically, or felt they had it if they needed it but were actually unlikely ever to read and uptake its contents.

In addition, once a child was diagnosed with a disability, referred appropriately and met DoCS/DADHC’s entry criteria, the child’s name would be brought up to an intake meeting and entry to the service discussed. Where a service was likely to be offered at some point, a community worker would then usually conduct a one-off visit to the family’s home and present information either in a package, a kit, a showbag or simply a loose collection of brochures, handouts, lists and notes. Yet it seemed not all parents with children duly diagnosed received this body of information and there was no discernible consistency in who did and who did not acquire it. There were also significant variations between the information delivered and not delivered by DoCS/DADHC in each region. Many parents had only a vague recollection of acquiring
information in this mode. This may be in part because the information within was rarely applied to the family’s unique circumstances and it remained for the family to review and digest. If the family did not do so at the time, with the extraordinary amount of running around required in the early days, it is feasible that for those parents it is as if the information never existed.

**Interviewer** When DoCS came did they bring a show bag?

**Parent** Yes.

**Interviewer** Did they ever go back over any of that stuff and say “Do you need respite? Do you need Home and Community Care?”

**Parent** No. (10/930-944)

The second mode subset of passive delivery was the parent library (see Appendix 4.17). This was a vastly under-utilised resource in most centres. Parents at the hypervigilant end of the spectrum were most likely to use the resources but many other parents were often unaware there even was a library or parent resources collection within the centre or organisation. The only exception occurred where staff assisted the parent in accessing the information within the collection, virtually walking the parent through the collection and pointing out its relevance and applying its information.

Parent libraries and resource centres were found in early intervention services, government agencies and various support groups. They were rarely publicised in any comprehensive fashion to make parents aware of their purpose and scope.

**Interviewer** Did you know that there’s a parent library at Lifestart that has signing books and other things you can borrow?

**Parent** Yes.

**Interviewer** And also there’s a growing volume of information technology that’s applicable to our children. Is anyone making you aware of that?

**Parent** No, not really. (10/1375-1398)

The third mode subset of passive information delivery was in the provision of noticeboards, brochures and so on (see Appendix 4.18). Parents usually had a vague sense of “the noticeboard” and brochures being available at their early intervention centre or other local setting, which was often in contrast to the provider’s sense of actively delivering information by making brochures and fliers readily available. There was a mismatch between what providers thought they were doing in having a
noticeboard and brochure stand, and parents' real awareness of information available in this way.

Many parents would comment that they had never been given information, or were unaware of information, on x, y or z when it was clearly available in brochures and posters at their early intervention centre. Again it was more likely to be parents at the hypervigilant end of the information style spectrum who took the initiative to respond to information made available in this way, usually as an information grounding exercise.

Interviewer  What about noticeboards, are you a person who goes through everything that's there?
Parent 1 Yes and newsletters.
Interviewer Right. So ... you locate yourself ... on these multiple information grounds, basically --.
Parent 1 To see what's relevant to us. (1/2840-2858)

For parents at the passive end of the spectrum acquiring information in this mode was often regarded as accidental or fortuitous.

The fourth mode subset of passive delivery, newsletters, frequently contained information highly pertinent to parents (see Appendix 4.19). The newsletters incorporated disability specific, centre specific and disability/carer generic approaches. Unfortunately this mode required parental capacity both to identify relevance of the information within, and to apply it to individual circumstances. The parents deriving the most benefit were those who read from cover to cover, building a knowledge base which could be accessed at times of identified need.

One thing ... that the speech pathologist mentioned to me recently was a dentist, and I hadn't really thought of going to the dentist... So in one of the Lifestart newsletters, a mother had been to a dentist at Hornsby, which [she] said was really good, so I just brought that up, and I've got an appointment with her next month. (14/381-386)

The fifth mode subset of passive delivery occurred in the multitude of appointments, sessions and assessments parents attended with their children (see Appendix 4.20). Some of these activities were irregular, some formed part of weekly commitments, such as that to early intervention. Notwithstanding the significant differences in purpose and functioning of the activities, in terms of information delivery the outcomes were clearly
similar. The experience of many receptive, passive and avoidant information style parents in attending appointments, sessions, assessments, tests etc, was often of not being heard, of being unable to articulate the right questions, being loaded with oftentimes inaccessible information, or receiving only narrow information pertaining to the specific issue at hand.

This mode subset was commonplace among parents in the early days and they frequently experienced great resistance from professionals in their attempts to acquire information beyond what was passively delivered. Passive delivery here is taken to denote the most basic of information delivery pertaining directly and only to the specific matter at hand. Parents often experienced little support in their efforts to articulate their knowledge anomaly and often described being fobbed off or not taken seriously.

Where information was delivered, for example regarding a medical diagnosis, there was often little application to the individual child and family, and no support in applying service information. Families were often left to pursue service and support options alone and were frequently confused and dazed in their efforts to acquire the information necessary to pursue those options in any realistic way. The incredible complexity of the service sector was remarked on by most parents and when coupled with either the failure to deliver information in relation to it, or the failure to support parents in applying that information, the reason for high levels of parental distress became obvious.

Medical practitioners tended to attract the most strident criticism among parents, many of whom expected far more than simply medical intervention for their child, without ever apparently articulating this to the professional in question. Yet even where delivery of only that medical information relevant to the matter specifically at hand was concerned, parents still believed medical practitioners often failed to deliver crucial information either at all or effectively.

Parent  
We thought ‘great, she’s sleeping the whole time’...[unaware the baby was in heart failure]. She was tired because her heart was labouring, and she wouldn’t feed well...It was REALLY distressing...for the first two months. We changed paediatricians...We saw him once after leaving Hospital, and there was just no information coming from him at all. And there was no sympathy or emotional support from him...

Interviewer  
...when you asked questions were they answered satisfactorily?
It was apparent that even in situations where it would be highly unlikely that parents would have a knowledge base adequate to understand the situation fully and thus to take informed actions and decisions, some professionals continued to practice passive information delivery.

Parent... The paediatrician suggested that we had to have a CT scan at 3 months.

Interviewer Did they say what the reason for that was?

Parent Possibility of [X] syndrome... When we were told, we didn’t know what it was...

Interviewer So whilst they told you you might be looking at [X] syndrome, they didn’t say what that would mean?

Parent No. I didn’t know anything.

Interviewer The paediatrician didn’t direct you to other sources of information?

Parent Nothing. Nothing at all. But it could have been [me]... I didn’t pick up on the name properly. (26/50-82)

The important point here was that the parent identified that she may have been given some information but clearly there was neither uptake on her part nor revisiting on the part of the paediatrician. The paediatrician passively delivered the barest of information. There was no revisiting to ensure that the parent had acquired extremely important information, both as to the diagnostic possibility and its potential health sequelae. The parent was not advised of the association of epilepsy with the condition, nor the need to inform any vaccinating doctor, nor were the concerns recorded in the child’s Blue Book. (The colloquial term Blue Book is used for an individual personal health record provided to the parents of all babies born in New South Wales immediately after birth. The Blue Book provides details of vaccination schedules to be followed, routine health care checks to be conducted and recording of the individual baby’s development and health issues.)

Clearly the parent’s knowledge base was not adequate to her needs in the situation. Furthermore, she had no inherent means by which to inform herself of her knowledge anomaly and correlative information need. Firstly, because of the awareness heuristic she was unaware that she was unaware of crucial information and the importance of exchanging it with a vaccinating doctor. Secondly, being unaware of the critical importance of the information the parent did not take action to seek information actively in relation to her daughter’s possible condition. The passive nature of the information delivery meant there had been no opportunity for the kind of information exchange that
would have raised awareness of unrecognised need and may have prompted active seeking.

It was also apparent at interview that some parents continued to be unaware of the passive and inadequate nature of information delivery they had experienced in a number of different settings. They were not therefore in any position to articulate need for service to their providers.

5.3.2.3 Serendipity

Information acquisition that occurred through no intentional, information-related efforts was defined as serendipity. The individual events were wholly random and unpredictable, although as has been pointed out, they occurred in a predictable array of subsets.

Information acquisition through serendipity was clearly distinguishable from information acquisition through information grounding activities. The serendipitous events did not flow from any intentional information-related activity, such as is seen in grounding, and there was hence no expectation of information acquisition. Thus while on the surface the activity may have looked the same, for example talking to other parents, there was no sense of expectation by the parent acquiring the information that information acquisition was a likely result of the activity they were undertaking (see Appendix 4.21).

Now some of the parents [use] Kingsdene School...these parents don't get a night's sleep for ten years...so they use that option. I don't think we'd ever use that option for [our son] but you know even hearing about schools like Kingsdene and stuff, you know, is only when I heard it from them [fortuitously]. (7/943-953)

The parent here was making the point that she had just discovered information about Kingsdene School in an unsystematic, unplanned way. The school was important to the well-being of so many parents living with children who did not sleep. While she may never have used the option the mother was deeply concerned that she had only heard about it accidentally through other parents; she could not have planned to acquire information about this option systematically because she was unaware of the possibility. Were it not for the serendipitous event the parent may not otherwise have acquired the information, through the functioning of her normal information seeking and delivery
modes. The serendipitous nature of information acquisition thus created a number of problems for parents. There were often deep concerns regarding why nobody had apprised them of the information, and recognition that were it not for serendipity they may never have found out.

The impact of serendipitous events then was often to increase parental anxiety about other information that may have been out there of which they were not only unaware, but also unaware of how to become aware of its existence, other than a vague sense of needing to do more.

Interviewer: We talked a bit about chance discoveries and the impact that [has] had on you, has that affected, do you think, how you feel about access to information?

Parent: Yeah, I think it definitely does, it just makes you wonder how much you're missing, and the things you should know about, and I guess it just makes me thinking, oh I've got to start using the net more, I've got to start doing all this more... (23/1279-1302)

Sometimes parents accidentally acquired information as they joined groups and interacted with parents further along the road. They were clearly not seeking to acquire information nor did they perceive attending the group as a potential information opportunity.

I know this mother in the Chatswood playgroup, because at the time I had just been... saying that I don't know what to do. I was really stuck because I don't know what else I can give for [my son]... So she gave me her number to say, “You call me at home.” So I called her at night... And she says to me “Call Community Services. Call DoCS and tell them your problem, your concern, and they'll have an assessment for you and can tell you what kind of service.” (19/1102-1114)

Professionals also played a part in serendipitous events, often because they assumed a level of parent knowledge base that was not accurate. Knowledge anomalies were often strikingly revealed in this context.

It was almost by accident that I found out about the programme...the [OT] I'm seeing at Hornsby asked me about the Lifestart programme, and I go “Well I'm going to the playgroup.” And she says, “No, the programme,” and she said “There's some fee.” She didn't know what it was. And she photocopied a really, really old leaflet of the Galston one, which had a sort of mission statement and stuff like that. It talked through what they did, but now knowing about Lifestart it was the playgroup. So that was the first time I was given some information about Lifestart...[emphasis added] (11/2059+)
In this case the parent had not realised the difference between the playgroup and the “programme” and it was fortuitous that the OT asked her how the “programme” was, revealing the knowledge anomaly. It is worth noting that the OT worked with DADHC in the northern region but did not have current information on Lifestart, the primary early intervention service provider in the area.

Sometimes the serendipitous event occurred as an unintended consequence of another action, the second mode subset of information acquisition by serendipity (see Appendix 4.22). One parent, whose child over 18 months later was diagnosed with a very rare disorder, was concerned about her child’s lack of weight gain. In line with current thinking she was trying to establish breast-feeding, without realising that her child’s failure to thrive may have had significant causes related to the inability to establish breast-feeding. The mother attended her local early childhood health centre, then Tresillian (Family Care Centres intended to support families having difficulties establishing feeding and sleeping routines with babies) and then finally returned to her local medical practice seeking answers. A general practitioner the family would not normally have seen took the case unexpectedly and immediately identified a specific sucking problem and reflux. The event was serendipitous in the sense that while the mother was seeking to clarify her anomalous state of knowledge, its resolution was wholly fortuitous because the doctor she saw was not the doctor she would normally have seen. This serendipitous diagnosis began to build the mother’s knowledge base and eventually opened the doorway to further investigation of the child’s problems (7/115+).

A particularly striking example of serendipity as an unintended consequence of another action occurred in relation to the late diagnosis of a child with Down syndrome. The mother was attending a medical appointment for a regular check-up with her older child, taking the 6-week-old baby along. She asked the paediatrician to conduct the baby’s 6-week check-up also while she was there. The paediatrician, who was experienced in working with children with disabilities, spent a lengthy period of time checking the baby and then told the mother she wanted to take some blood and test him. The test revealed a diagnosis of Down syndrome.
Another mother's experienced a serendipitous information link to therapeutic help in a way that could be neither foreseen nor planned, nor was the information recognised as needed or intentionally acquired. The contact with the therapeutic professional was made for completely different purposes.

Sometimes the serendipitous event was more of a process of cumulating information, or the aggregation of intangible information, until the parent knowledge base was such that apparently the parent suddenly realised or knew or became aware of "something". This had all the hallmarks of being serendipitous though occurring more as a process or the result of somewhat intangible information, rather than an outstanding serendipitous event per se.

We met another family [at the Hospital] ... having an operation on the same day as us... Parallel lives basically at the Hospital just brought us together and that just made things, the whole hospital stay, just that much better. So [our daughter] had the operation, went into Intensive Care. They said probably about three days she'd be out. The other little girl was in at the same time. She was out in three days. We were still there, a long way from being out...It was good to have this other benchmark next to us, the other little baby next to us, you could see where she was going, could see where [our daughter] was going and it was a different tangent. (10/631-657)

The comparison with the other child yielded intangible information such that over time the family became more aware that something was not right. Indeed through the intangible information both of the comparison with the other baby and their own sense of their daughter's well-being, their knowledge base grew to a point where they recognised the desperate plight she was in.

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A clearly identifiable third mode subset of serendipity derived from exposure to the formal media, in what were usually one-off, unpredictable events (see Appendix 4.23). This could be distinguished from information grounding where the parent by systematically using the media recognised the potential to acquire information, for example always listening to a health program or planning to hear an interview with a person known to be an expert in a field of interest. The serendipitous media-based event was always experienced as unexpected by the parents, and accompanied by concern that "nobody told me". There was also a sense in which parents could not necessarily have planned to acquire this information in this, or indeed in any other way.
It is worthy of note that no parents from the sample used the Internet at any point as a media outlet.

One parent had a number of serendipitous events deriving from media exposure. One particular media report alerted her to the possibility of surgical intervention in epilepsy, however it was too late to be considered.

Parent
I watched Discovery Health, they had a program on Johns Hopkins and a little girl having seizure surgery, which led me to ask our neurologist whether or not seizure surgery was an option. …they looked into it after I asked the question…

Interviewer
…do you feel that lack of access to information in relation to that may have had a profound effect on the outcomes for your daughter?

Parent
Definitely! …I do now, I think that now because I'm more educated about the situation… (24/9, 22+)

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A fourth subset of information acquisition by serendipity was rather subtle, that of information acquired for another purpose. It was often seen in the sudden recognition of the relevance of information acquired for another purpose, having the effect of a serendipitous discovery because it was unintentional, unexpected and unpredictable. It could not be said to have been planned to occur (see Appendix 4.24).

One family only discovered they had been put on the wrong benefit from Centrelink when their Centrelink payments were cancelled. The acquisition of information in relation to the cessation of Centrelink payments alerted them to the fact they had been paid the wrong allowance for four months. They had attempted to acquire information in relation to appropriate payments for a child with a disability but had failed to acquire the correct information initially. They were not aware of this until acquiring information relating to having their Centrelink payments cease.

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A fifth mode subset of information acquisition by serendipity was the delivery of information by a stranger, a person with whom the family had no pre-existing relationship (see Appendix 4.25). The totally unexpected delivery of information by a stranger was not as rare as may be expected. Sometimes this delivery had the effect of alerting parents to previously unrecognised need. Other serendipitous events with strangers had the effect of either reinforcing something parents had known in a
peripheral sense earlier or applying the information in a way that made it meaningful or relevant to parents, enabling uptake, as seen in the following example.

I'd heard about respite through the pamphlets we've got, but the first time I actually heard about it practically, was just a lady who approached me in the shopping centre, who'd seen that [my daughter] obviously has downs. And we were just talking sociably, and she told me about the respite that can be obtained. (10/1282-1286)

Another parent experienced an extraordinary, serendipitous event in the middle of, but unrelated to, her on-going attempts to resolve her knowledge anomaly regarding her son's problems.

About 4 weeks ago, I walked into a shop and this woman said to me “May I ask you a question without you getting offended, because your son looks exactly like what my son looked like when he was a baby. Does your son have special needs?” And I said, “Yes.” And she said to me, “because my son has special needs, too, but he’s about 6 years old now...She said to me, “Does he walk?” I said, “No, he’s not walking yet, he’s cruising but he’ll get there I think.” She said to me, “Has he been diagnosed with anything?” I said, “No, he’s just been, we’ve just been told that he’s got global developmental delay.” She said, “That’s what they said with my son.” She said, “Has your son had hernias.” I said, “Yes.” She said, “Has he had kidney re-implantations?” I said, “Yes.” She goes, “Was he fighting for his life?” I said, “Yes.” And it was exactly what my son was going through. And I’m looking at this woman and I’m thinking, “Jesus Christ, is she reading my mind?” She goes “have you nearly gone broke, with all the intervention and stuff? It’s really expensive.” She said, “I think you’re going through what I’ve been through”...I just couldn’t believe this woman was talking to me about [my son] like that. She doesn’t even know him, and she was saying everything that we’ve been through, cos she’s been through it too... She said to me, “If you want, I’ll give you my phone number and my name and she said to me, “You can come and visit my little boy, then you’ll know that everything’s going to be alright. Because he’s just beautiful.” (25/2447-2477)

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The sixth mode subset of information acquisition by serendipity pertained to information otherwise stumbled across. This subset covered accidental acquisition not otherwise specified (see Appendix 4.26).

In the example below, the parent described a person as possibly “hinting” at certain information and it seems feasible that someone may have made a statement from which the parent was able to extrapolate that something such as occasional respite was an option. Hence the information was serendipitously acquired rather than by cognisant seeking or delivery.
[Weekend] respite services haven't been appropriate for us but intermittent, ad hoc care is ideal for us. And nobody really said that that's what they're offering...someone must have hinted at that because I did ring them up and say "Well this is what we need, is this something you can provide?" And they said "Well actually yes." (13/1669-1678)

5.3.3 Issues Affecting Information Access and Acquisition

5.3.3.1 Modes of Information Acquisition – Frequency of Use, Use Determinants, Utility and Failure Points

Having established a conceptual framework for information acquisition, that same framework is used to present issues that impact on information access and acquisition. The data is summarised at Appendices 4.1 – 4.26. Descriptions are given below along with parent interview quotes for validation.

The frequency of use figure is an approximation of the overall average for the sample: generally speaking, how often parents as a whole tended to employ the mode subset. The frequencies used are very low, low, low-medium, medium, medium-high, high and very high. The frequency is derived from an understanding of how many parents in the sample tended to use the mode subset and how often. As a general rule of thumb the more parents using the mode subset and the higher the individual rates of usage, the higher the frequency of use. The figure is balanced, however, by the availability of the mode subset. One would not expect for example to achieve very high rates of use of expos for information acquisition as so few, relatively, are held. Information grounding through attendance at conferences and expos was undertaken on a regular basis only by the hypervigilant (n=8) and vigilant parents (n=2). Active parents (n=13) attended disability specific conferences occasionally and the responsives (n=21) attended only rarely. The remainder of the parents (n=5) never attended conferences and expos. As 53% (n=26) of the sample used this mode subset either rarely or never the frequency of use across the sample was therefore adjudged to be very low.

It should be noted that the frequencies are not intended to convey “statistical statements” but to make a general observation on the extent to which the mode subset was utilised in the sector. It is meant to provide a ready comparison with the effectiveness of the mode subset, indicated by "efficacy" only. For example conferences were utilised by only a handful of parents and conferences only occur on an ad hoc basis.
therefore frequency is low, yet that frequency notwithstanding, this mode had a high level of efficacy for information acquisition among those parents utilising it.

The utility of the mode subset tells another story. This figure reflects the degree to which information tended to be acquired by utilising the mode subset. Again this is averaged across the sample, as some parents were much more effective at utilising a mode subset than others. Where very few parents utilised a mode subset, reflected in the frequency of use figure, they were always hypervigilant and vigilant parents. Clearly the fewer the parents utilising the mode subset, the more the utility rate reflects their individual success rate. Conversely, the more parents utilising a mode subset, the more the utility rate reflects an average efficacy of the mode subset generally. The utility rates used are low, low-medium, medium, high, very high and mixed. The “mixed” rate was used where there were differences in efficacy so great and clearly contingent upon parent factors an averaged rate would not have been appropriate.

Core use determinants/barriers affecting each mode of information acquisition, both as to frequency of use and utility of any given use, are detailed. These are necessarily both constraints to use and facilitators. The information literacy level of the individual parent, for example, appeared to be a determinant of the frequency and efficacy of use of many mode subsets. Parents whose information activities suggested less developed levels of information literacy faced as an initial barrier to acquisition the recognition of information need itself. This was compounded by lack of awareness of information and the means of acquiring it both in a general sense and in relation to specific matters.

The sample failure points give specific examples of the reasons that failure to acquire information occurred in the mode subset. For example, the active information seeking mode subset required recognition of information need, in order to seek. Failure to acquire information in this mode subset occurred where the parent was unaware of or did not recognise his or her information need. Failure also occurred where there was no relevant information available.

5.3.3.1.1 Information Seeking - Active Information Seeking

Parental awareness of either specific information need or an anomalous state of knowledge restricted the frequency with which the active information seeking mode
could be employed. As a result the general frequency of use was relatively low, namely low-medium. This result is informed further by factors affecting the utility of the mode, discussed below.

The first mode subset of active seeking - namely seeking in relation to a specific, identified need - required as a starting point awareness of a particular information need, yet this was not the only determinant. The frequency of use and the utility of the mode were both affected by a range of factors, detailed in Appendix 4.1. The awareness heuristic is particularly interesting because it became evident that parents frequently employing information grounding activities appeared to have significantly higher rates of success in information acquisition using active information seeking. It appeared that the wider the parents' exposure to non-specific information exchange opportunities (afforded by information grounding activities), the greater the disability knowledge base, which in turn improved information acquisition skills. Hence, as might be expected, while most parents in the very early days experienced failure to acquire information actively being sought, those employing more active grounding strategies improved acquisition rates significantly over time. This derived, firstly, from becoming aware of the information need state and secondly in having developed the necessary knowledge base to go about satisfying the need. It is arguable whether the knowledge base was either facilitating parental use of extant information literacy skills, or, facilitating the development of those skills. Certainly some parent commentary affirmed post-child acquisition of many skills. Some, but not all, parents learned to take control after building their knowledge base of the subject matter and approaches to professionals to achieve desired outcomes.

Interviewer: Were you able to self-refer to the Chatswood Assessment Centre?
Parent: Well I didn't know you could. So I did in fact wait until we got back to see the paediatrician. By this stage I'd lost that whole "I'll sit back and trust everybody". I was over all that..."I just said "Look these are the issues...I've heard about this Chatswood [Assessment Centre]. And she [paediatrician] just sat there and wrote referrals... (11/965-974)

Of particular concern was evidence of the strong mismatch between parental expectations of professional information delivery, and professional practices and policies. This was evident in both information seeking and information delivery modes. That is to say, whether parents focussed on their own efforts in information acquisition or the professional's, most parents had an expectation of delivery that was not matched
by professional practice. One would have expected to find least evidence of this among parents' employing active information seeking on a regular basis; however, their criticisms of professional information delivery failures were often the most strident. It is feasible that the heightened awareness of parents employing active seeking and grounding to the panoply of possibilities also issued in heightened awareness of any professional failure to deliver such information.

There were many powerful examples among parent interviews of the failure to acquire information even though active information seeking was being employed. In some cases the failure arose as a direct result of the awareness heuristic, where the parent while actively seeking was either not aware of an information need or of the information that would have satisfied a need of which they were aware, or how to acquire such information. They could not therefore take effective action to acquire. In the case of one parent of a child with chronic complex epilepsy, neither active seeking nor information delivery yielded what happened to be information of critical importance to the family. The parent described at interview her serendipitous discovery of the possibility of surgical intervention (24/9, 22+).

Active information seeking efforts, following identification of a problem and recognition of specific information need, were not always successful either, even within information repositories such as libraries: "I did actually go to the [public] library, but there wasn't anything in there about [Y] syndrome" (7/2917-8). The parent's lack of awareness of the many information resources potentially available from other locations, to which the library could have acted as conduit, suggests that the use of active seeking alone does not guarantee access to information. The activities themselves must be tailored to the particular information need and the individual must be aware of the range of information alternatives, both as to sources, formats and content, if one type of search is unsuccessful.

In addition to being stopped by lack of awareness of other sources of information to utilise, facing professional resistance also functioned as a failure point as it often stopped parents from further active seeking. One parent's acquisition of an oxygen tank, for use when his child stopped breathing during a seizure, demonstrated the importance of parental perseverance in the face of professional resistance (26/2020-2050). The family had clearly identified needs and were seeking to satisfy them and they
persevered in seeking until achieving the desired outcome. The father reported that
other parents were surprised to learn they had acquired an oxygen tank as they had
sought one unsuccessfully, unaware of the information that had opened the door,
namely the threat of litigation. It was also the case that success in acquiring information
actively sought from one source, such as the Internet, was often not mirrored in other
information seeking efforts. One parent whose child had a rare disorder found the
Internet helpful for acquiring general information in relation to the disorder, but not
information regarding specific services that would be appropriate and available.

In some cases failure to acquire did not stem from either seeking or delivery but because
the information the parent needed and was seeking either did not exist or was not
available. This occurred within the family of a child with a particularly rare disorder,
interviewed during the pilot study. The family was actively seeking information on the
condition and health/medical sequelae. However, information on health/medical support
and interventions was non-existent in Australia simply because it was not occurring.
Furthermore, the rarity of the disorder was such that there were no support groups in
Australia and hence no broader information base from which the family could draw.
Also the Internet did not, at the time, yield information the family were confident was
trustworthy. They were aware that they needed expert guidance to assist them
developing criteria for evaluating information, but there were simply no experts in
Australia at the time.

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The second mode subset of active seeking, that of seeking in relation to an anomalous
state of knowledge (summary at Appendix 4.2), was particularly problematic for parents
as they frequently lacked the knowledge base required to articulate the anomaly in a
way to which professionals could or would respond. This was often expressed at
interview as not being able to ask the “right question” that would open a metaphoric
doorway to needed but unknown information.

.... to get the most information you need to have very specific questions so that
you can have them answered. Another problem for parents is not often knowing,
feeling as if you don’t know quite the right question to ask that will open the door.
(27/1156-1159)

The most graphic example of lack of awareness of the “right” question pertained to the
family of a newborn baby in cardiac failure.
We didn’t know whether we had a choice of whether or not to have an intervention with the heart problems .... To let it go and let nature take its course, or if we had to stand back and just let the doctors take over...When she was one week old we said to [the paediatric cardiac surgeon] “Can we have the operation done this week, next week? Because if she’s not going to survive the operation we don’t want that bond to deepen.” We really hadn’t bonded with her at that stage, so if we were going to lose her, we wanted to lose her then. And he basically said - no he can’t do that...Ethically he’s there to provide a care for her and he’s there to basically to fix her, not to end her...It was a hard question to put to him...It was pretty emotional just asking the question and it was really hard. (10/249-252, 590-602)

In this case the family were actively seeking information, but articulating the wrong question to acquire the information they really needed. While they asked if the operation could be done immediately, what they really wanted was that their child’s sufferings not continue, but were unaware of their right to request a “not for resuscitation” (NFR) order. As a result the baby was resuscitated on many occasions, suffering enormously, which brought great distress to the family. As the family were unaware of the possibility of the NFR order they were not in a position to make informed decisions. They had been aware of their anomalous state of knowledge but due to a limited medical knowledge base had been unable to articulate a question that would have led to them being informed of the NFR order, the point of their knowledge anomaly.

Indeed there was an array of situations where parents were specifically aware of their knowledge anomaly but unable to articulate their information need in a way to which professionals could or would respond.

I really wasn’t sure exactly what early intervention was and I wanted someone to sit down and say, “This is what you do now”...like some sort of structured [informing process]...To be told “This is what you need to do.” And no one could give me those answers. (28/1142-1150)

One family, whose child was neither walking nor talking, had acquired ad hoc physiotherapy for their child but no real answers regarding his condition. Their efforts to resolve their knowledge anomaly were unsuccessful until the mother became pregnant with her second child, at which time her first child was fifteen months old.

I went for a second opinion ... because I was also pregnant, [the paediatrician] seemed to hit the panic button a little bit because he seemed to indicate that he felt there was more wrong with [my son] than just needing a bit of physio here and there. And because I was pregnant again he wanted some genetic counselling done
through Westmead Hospital. So he rushed us through an appointment down there. (8/4-30)

For over twelve months the parents had been aware of their knowledge anomaly but unable to resolve it. In this case it is important to recognise that the parents’ efforts to resolve their knowledge anomaly only became successful when the fortuitous intervention of a pregnancy triggered further professional investigation. This led to the parents’ acquisition of help and information and ultimately a diagnosis.

Another particular problem faced by parents attempting to resolve a knowledge anomaly in active seeking through professionals, was in not necessarily knowing what information to proffer. There was a sense in which the parent’s own knowledge base was precluding or restricting his or her capacity to formulate need and acquire information. Where, for example, parents were seeking to acquire a diagnosis, they did not always know what symptoms and behaviours to present to medical practitioners and therapeutic professionals. When the parent was unaware that they were unaware of something, for example the significance of a symptom, the attitude of the medical practitioner or therapeutic professional in the information exchange was pivotal to the outcome, in information terms.

I never even knew there was such a thing as autism [and] no one actually asked me “What’s he like with socialisation?”...I thought he was shy and timid but that was all I knew...I can remember filling out the forms at Tumbatim [an assessment clinic] about your concerns, and my speech therapist had actually ticked ‘how he relates to others’. And I thought, “Why is she ticking this, you know, my concern is speech?”...I said to my husband “I’m going to tick ‘fussy eating’”. And he said “What for?” So I didn’t bring that up. And then when I was at Tumbatim and they asked me about his eating habits and I told them, they said “Well that’s a classic sign of autism.” And I thought, “Well I’ve been to the Children’s Hospital about this, I’ve talked to paediatricians, I’ve talked to so many people...and everything was ignored...And I wouldn’t have even ticked ‘relating’...I would have just ticked speech, that’s all I would have ticked. (2/299-328)

A full appreciation of this problem area can only be reached by understanding that the context, in which early days’ discussions regarding symptoms and behaviours occurred, was often parents being told not to worry and that they were being over-anxious.

Parent That’s when [the paediatrician] basically suggested that maybe the attitude, I can’t remember the exact words, but it was inferring that I was being a stressed-out mother and that was somehow transferred to my daughter and she was being affected by that...

Interviewer And did you point out the observations of both the mothercraft nurse and the early childhood nurse?
This young child was subsequently diagnosed with global developmental delay.

It was therefore extremely difficult for parents to continue seeking information to resolve the knowledge anomaly, by risking further description of what may have been behaviours within the range of normal. The problem was that they literally did not know how to present the knowledge anomaly in a way that would open the door. In the case of the parent described above (2/299-328), prior to the Tumbatin assessment she had continued to seek help regarding her child’s eating, while regularly being told to “stop worrying” and “stop being neurotic”. She did not, however, present as a symptom her child’s lack of speech *at the same time*. Furthermore, the mother had no inherent means of identifying the critical significance of what appeared to her to be timid behaviours. It was not therefore information she ever brought to the attention of those through whom she was seeking to resolve her knowledge anomaly.

It was also the case that parents pursuing natural or alternative remedies did not always feel comfortable proffering that information to medical practitioners. As a result the parent’s own information seeking may have been thwarted because they were not sharing important information with the professional. For example, some paediatricians were dismissive of vitamin supplements being advocated for children with Down syndrome. These supplements and other pharmacological interventions are now the subject of large-scale multi-site research currently under way in the United Kingdom and the United States.

In other cases, the failure to acquire information arose directly as a result of professional failure to deliver in response to a clearly articulated request for information. In the following case the parents were seeking to resolve their knowledge anomaly in relation to the need for sight and hearing checks, having read much of the current literature.

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Parent 2 And so we specifically asked [the paediatrician] at the appointment.
Parent 1 And he was like “Oh you don’t really need to do that.” (28/913-929)
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This is contrary to current medical guidelines for the management of babies with Down syndrome.
As reported in the conceptual framework, information grounding activities formed a discrete category of information seeking behaviour among parents (see 5.2.2.1.2). In this mode no specific information need was in view but activities were employed which clearly had the effect of increasing the probability of the parent becoming aware of information either previously unknown of itself or its relevance or application. Information grounding often had the effect also of alerting parents to an anomalous state of knowledge.

Notwithstanding frequently high levels of this mode's utility in the acquisition of information, surprisingly few parents utilised all the modes. Those with the greatest success in acquiring information were generally those who specifically recognised the information potential of each subset and used it for that purpose. For example, while many parents may have joined support groups and developed friendships with other parents of children with disabilities, there was a clearly identifiable group (hypervigilants and vigilants) who did not join the group just for support and did not develop friendships because of mutual interest and experience alone. They specifically recognised that a great deal of information was acquired through these means and used them for that purpose.

Patterns of usage among other parents were quite different. While the active parents also utilised the wide range of grounding subsets, in contrast to the hypervigilants and vigilants it was not always with a view to their information potential. Hence, committees may have been joined, but it was often for the purpose of supporting the organisation. This had a subtle impact on information acquisition, as parents were not always alert to the information possibilities to be exploited. Among receptive parents specific grounding activities were undertaken but not across the whole range; for example, many never attended conferences and expos nor would they join committees. Receptive parents may have joined groups and made friends among other parents of children with disabilities but it was not part of any networking strategy - the patterns of usage were often ad hoc in nature. A parent may, for example, have attended Down syndrome support group coffee mornings but often it was on an irregular basis.
It was also the case that as parents were further along the information style spectrum, moving away from vigilance, there was an increasing concern not to be perceived in a negative light, which had a direct impact on information seeking and grounding efforts. For example a receptive parent may have initiated an appointment with a professional to investigate issues with their child and attended the session full of resolve to have questions answered and so on. However, as soon as resistance from the professional was encountered, or sometimes even lack of assistance in articulating around the issue area, active and receptive parents would pull back rather than force the issue. The capacity to acquire information from this stance was radically reduced. Perseverance, or the lack thereof, in this context covered both pressing on in the face of specific resistance, and continuing to seek, notwithstanding failure to acquire information in the particular mode subset.

Thus there appeared to be quite specific issues precluding use and efficacy of use of the information grounding mode subsets. The parent’s own knowledge base was a powerful determinant of use and efficacy of use at many levels. As a starting point, the influence of previous experience in perceptions of relevance was significant. Difficult experiences with medical practitioners rendered seeking information from that mode subset virtually unworkable for some parents. While there may have been relative ease of access to a general practitioner, for example, previous experience may have precluded its use. In fact the most basic access was a significant issue among rural parents who faced waiting lists among a limited number of medical professionals. The knowledge base was also significant to the parent’s own awareness of the availability of a mode subset and how to make use of it. Information literacy issues clearly dovetailed with knowledge base at this point.

Interestingly, reference group activity also appeared to exert a strong influence over parent behaviours. That reference group may simply have been a group of parents whose children happened to attend an early intervention group at the same time or, groupings by disability and/or support group involvement. The influence exerted may have occurred in part because the parents were in close enough proximity to see, and sometimes experience, the outcomes of more vigilant parents’ information grounding efforts. This often occurred in grounding activities such as attending conferences, expos and skills acquisition sessions. Had the more passive parents not been a “member” of a
reference group where active grounding was occurring, it is unlikely that they would otherwise have utilised the mode subset.

The first mode subset of information grounding was parent-initiated contact with medical and therapeutic professionals (see 5.2.2.1.3 and Appendix 4.3). One of the most significant problems for parents in using information grounding with professionals was the awareness heuristic. As previously noted, parents did not necessarily know what information was important to exchange with the medical professional, requiring a knowledge base adequate to the task.

It's like botox. There's evidence it works now but in the future who knows what it does to a child. Because it's not a long term thing, it's been a short term study... So there's a fine balance and as a mother you're expected to know that and that's been a difficult thing. Even with the medical people you're expected to know it all as well. (3/939-955)

Clearly this mode subset had very high potential for frequent use simply because parents of children with disabilities do have a constant stream of doctor's appointments, tests and assessments, as well as routine weekly therapeutic/special education sessions to attend. However there was a qualitative difference between attending these appointments and sessions with an information grounding approach, and the passive information delivery mode subset of routine conversations, tests, appointments etc (see 5.3.2.2.3). Hence this mode subset occurred with a slighter lesser frequency, because it tended only to be hypervigilant, vigilant and active parents who used these events for information grounding. They did, however, make use of every opportunity, including weekly therapeutic sessions to build their knowledge base and the frequency of use was therefore around medium-high.

The utility of the mode subset was mixed because of the tendency of many parents to pull back to some degree with resistance, however vigilant their information style. It may have required a number of visits to different professionals before the parent acquired information. The massive variation in information delivery styles of professionals also had a significant impact on the utility of the mode subset.

Even an active information seeking style was hampered when the parent was not aware of the information that could be sought and how it could be most effectively acquired. One parent actively pursuing a diagnosis for her child, through medical and therapeutic
appointments, was experiencing extreme difficulty managing his behaviour. The effects on her other children had been devastating, including witnessing public abuse of their mother by shopkeepers and threats to call the police. Apart from obtaining an accurate diagnosis, the mother needed information on behaviour management and basic advice on how to survive with her child. However, she was limited in articulating requests for assistance by her awareness of information itself. As a result she was not acquiring the information and support she desperately needed from her professional contacts. “I’ve been asking for help everywhere for behavioural management and all I got was this [psychologist’s name], who told me these techniques to use” (5/1210+).

A second significant issue affecting both the use and efficacy of use of this mode subset was the mismatch between parent expectations and assumptions of professional information delivery and the reality of professional practices. Where parents assumed proactive delivery they would either not utilise this mode subset, or not utilise it with the type of assertive determination that increased the probability of acquiring information/answers/advice. Parents assuming proactive delivery were often in fact located in the passive/generic information delivery subset of appointments tests etc (2.3.5), where only the immediate issue at hand was addressed in a minimalist style. In order to use appointments, therapeutic sessions etc as an information grounding mode, parents required a strong capacity for perseverance, which was often not the case when they were anxious not to be perceived in a negative light.

Yet the drive to get answers assumed increasing urgency for most parents. Parental instincts were almost always accurate, as evidenced particularly in interviews of the parents who had struggled sometimes for years to achieve a diagnosis of children with disabilities such as autism and global developmental delay. One of the greatest barriers faced was that of the professional’s knowledge base and competence, both in the subject expertise and the capacity to deliver information.

Now this [paediatric neurologist] examined my son...and said “[He] has mild cerebral palsy, he has developmental delay and I’m predicting intellectual delay.” ... [Looking at the same] 1999 CAT scan that the other Neurologist looked at and said “Everything’s normal.”, he showed me that [my son’s] brain was too small, he showed me that in the CAT scan, and he showed me the holes, the gaps in [my son’s] brain...So [my son] has got not enough brain and too much fluid...and I said “Well why couldn’t the other bloke tell me that in 1999?” And he said “Well, perhaps if he looked now he might change his mind...he’s made a mistake.”... I can’t believe that it is so hard to have got an answer. It shouldn’t be such a
struggle, you’re going through enough emotional problems without all of this hard, difficult drama... I ended up on anti-depressants because I... needed an answer... I needed a medical person to say “Your child is not normal” that “He has got this”... I can’t understand why it was so hard to have seen... if I could see, I can’t see why they couldn’t have seen it. (29/34-51)

Sometimes parents finally acquired information, such as the disclosure of their child’s diagnosis, in inappropriate ways. The resilience of the parents and the degree to which they adopted an active information seeking style seemed to be a factor in whether they succeeded or failed to acquire information beyond the basic diagnostic information, irrespective of the style of professional delivery.

... the respiratory doctor [had] never really heard about it. So he just told us over the phone what was suspected, not realising what he was telling us. You know, not realising how bad the news really was. ... [my partner] types it into the Internet to see what comes up... It’s like uuuggghhh! (7/840-848)

Yet given the intensity of the struggle most parents faced in acquiring the information and services for which they attended appointments, sessions and so on, it was interesting to observe how few had either taken or would consider taking political or advocacy action to acquire that information and services. Only the hypervigilant and vigilant parents appeared to be so inclined.

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The second mode subset of information grounding was “networking” (summarised at Appendix 4.4). Most parents agreed that much valuable information acquired over the years had come from other parents and parent groups. Clearly, the utility levels were unequivocally very high. Yet the mode subset still required parental action to activate, that is to say, while the first determinant was the simple availability of other parents and support groups, beyond that parent action was required to utilise the mode subset.

Interviewer Have you gone on to join any other groups, you said you had never contacted the epilepsy association, have you joined any other groups?
Parent No, I don’t know if there are any. (15/1322-1325)

As a result the frequency of use across the sample averaged out at around medium. There were parents actively utilising this subset on a regular basis but the remainder of the parents, while receptive to proactive delivery of information by other parents, did not regularly initiate the grounding action to acquire information. Hence when these
latter parents acquired information from other parents they often experienced it as serendipity because they were not initiating the action.

While networking was clearly a significant benefit to those parents utilising it, not all parents felt comfortable doing so. There were various reasons for this. For some it was simply a matter of personal preference, "I don’t know a lot of parents with kids with disabilities. In lots of ways, I don’t want that, I want to keep him as normal as possible” (3/1923-1925)

For other parents however there were family issues that tended to preclude networking. In a particularly poignant interview one mother revealed her suffering as a parent living in severely reduced family circumstances. This parent was so embarrassed she felt she could not get to know other parents for support, although she desperately needed to do so.

Parent ... it’s dreadfully embarrassing too, it’s really humiliating, by having to ‘fess up that we live with his parents, we don’t have a car, we don’t - you know. He doesn’t have a proper job...
Interviewer You just feel that they inhabit a different world?
Parent Yes, I’m just so envious, it just makes me sick. Because I know when I had my own place, the children were so different, they were so well behaved... (30/995-1010)

Many of the formalised support groups operating in the sector also functioned as information and quasi-advocacy services. Usually, however, their approach was to see parents were sufficiently informed in order to take action on their own behalf. While there were significant advantages attaching to the availability of support groups for specific disabilities and problem areas, sometimes the availability of support groups functioned in the eyes of some professionals almost as a panacea. Professionals assumed the group would or could satisfy all of the family’s information and sometimes other needs. “This assumption that we have an organisation so we’re OK. That’s a big problem” (1/348-359).

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The third mode subset of information grounding involved parent use of existing information resources (summarised at Appendix 4.5). It was certainly the case that few parents exhaustively read information resources delivered to them in a generic, one-size fits all approach. That approach may have been the delivery of standard information
packs, such as the DADHC “showbag” and early intervention provider parent information kits, noticeboards and brochure stands. While providers felt they had delivered information, in information packs, brochures and noticeboards, parents often failed to acquire the content information in any functional sense. Some parents felt that they “had information” about x, y or z, by virtue of having the resources in hand, yet had not read and applied the information. Clearly they had not acquired the information in real terms. This was a significant issue for information acquisition because it suggested that passive delivery was not sufficient to enable all parents to acquire information. Information passively delivered required parents able and willing to be active in uptake, namely by reading and application of content. Yet all parents were not able and willing to do so. Furthermore, parents who felt they already “had information” on a subject would not otherwise seek to acquire information in relation to that subject, even though they had never actually read the material nor had developed an informed sense of its content and relevance.

For some parents the delivery of a bulk pack of information rendered acquisition of that information impossible. It was considered to be too much quantitatively and irrelevant, even though they admitted that they had not actually read it.

they sent out a pack that you have for all that sort of stuff, so we had a list, but to be honest, it was so thick, like with all these different sorts of things, but it didn’t relate to us, even if it did relate to us, I probably drowned in it, because it was so intense. (3/1640-1654)

Many parents also did not see the relevance of information lying around as it were, on noticeboards or information stands. They would rarely actually read the information contained. An exception was where the brochure or other piece of information was specifically given to them; this made the information potentially meaningful.

Interviewer So if someone hands you a brochure, you read it from cover to cover?
Parent Yes. I wouldn’t source that out though. (5/1572-1580)

Time and active children also made utilisation of noticeboards impractical for some parents.

Having things on noticeboards is one of the best ways of relaying information, but people need time to actually stand in front and read a noticeboard. And I am quite happy with that arrangement, it’s just when you’ve got young toddlers, when you
can’t stand still and read a noticeboard when you’ve got your two year old flying around behind you and you worry where they are. You can’t do that. (8/30-35)

The fourth mode subset of information grounding involved utilisation of information resource collections such as parent libraries and information services (summarised at Appendix 4.6). There were two very significant factors in the utilisation of these collections. Firstly, as observed earlier, the most significant factor in poor utilisation of these collections was basic awareness of their existence and purpose, for practical purposes (that is, more than a vague sense of something there). It was also the case that parents required, as a starting point, a belief that the collections contained resources either potentially relevant to their needs or otherwise interesting in some way. Clearly the perceptions of relevance were often based on previous exposure to resource collections, such as public libraries, and there were very few parents who described themselves as library users. As a result frequency of use was low, although the resources were often very significant.

As noted above, awareness of information resource collections did not necessarily prompt parents to use them. For example, even where parents were notionally aware of a parent library or resource collection within their early intervention service provider they frequently did not have the time to navigate those resources to find relevant information. Parent libraries and other centralised information services often remained under-utilised resources unless a professional became involved in the navigation process.

Interviewer Is anyone making you aware of [the resources in the parent library]?
Parent No, not really. But I mean at the same time we don’t have time to go and read those books. (10/1375-1398)

Interestingly, parents introduced to the collection by a professional and specifically shown material of relevance did not necessarily go on to utilise the collection independently.

The fifth mode subset of information grounding, browsing the Internet (summarised at Appendix 4.7), could be clearly distinguished from searching the Internet, or other information repository, with a specific information need in mind. In browsing parents
were not looking to resolve a particular information need or knowledge anomaly, they were tending to look around to see what was available, usually by following links and webrings and looking up recommended websites.

The frequency of use of Internet browsing as a mode of information acquisition was unequivocally low. As only half of the parents interviewed used the Internet at all (frequent user n=12, occasional user n=7, rare user n=6, never use n=24) this was not surprising. Added to the relatively low usage rate generally was parent concern for the time-consuming nature of non-specific Internet use for little positive outcome. Time was considered a commodity parents did not have to spare. Only a very small number of parents (n<5) with the most active information styles used browsing the Internet as a regular information grounding strategy.

[The Internet is] like wandering into a newsagent and trying to find the best bit of information, unless you know what magazine to look for you’ll walk out with a good Aussie Post, when [what] you really want is a specialty financial. So the Internet in my line is utterly pointless...unless you know where to go, [it is valueless for] finding the information. (1/2543-2560)

When parents were seeking information using the Internet without actually knowing what they needed or where to look, they usually encountered extreme difficulty locating any information of use to them. That is to say, parents required both a clear understanding of the information they needed, and, a well-developed search strategy for success in information acquisition.

I go into Google and search for ‘Global Developmental Delay’. And then I saw all the information. Because at the time, I don’t really understand, OK, Global Developmental Delay, but what after that? When he grows up, what is he going to be? Even so far I still haven’t gotten any information about that one, I’m still looking. That’s how I bring it up...It’s all these American web pages, but nothing in Australia. I even tried to do www.developmentaldelay.com.au... It’s nothing, no. Yeah, but I think that, you know, why only US have? Why not in Australia? Such big country... (19/2303-2321)

Sometimes the Internet was used more heavily if the parent tended to be housebound by, for example, the behaviour of the child. Indeed one parent who was a very active information seeker was acquiring most of her information from the Internet at the time of the interview. The Internet provided access to a vast array of information potentially useful to issues of diagnosis and understanding her child’s disorder and had enabled the parent to make contact with another parent for support. However, her search strategies did not yield information on how to survive with the child day by day and where to get...
help in her part of Sydney. The degree to which the Internet played such an interactive role was limited to the parent's awareness of listservs and relevant chatrooms, and the more interactive websites.

The sixth mode subset of information grounding was attendance at information and skills development events and functions, such as expos and conferences (summarised at Appendix 4.8). The frequency of use of this mode subset was very low and out of all proportion to the utility. Clearly hypervigilant, vigilant and active parents did use the mode subset, although the relative rate of occurrence of expos and relevant conferences was fairly low. Other miscellaneous information sessions and workshops organised by disability specific groups, DADHC, or other early intervention service providers, were occurring at a more regular rate but parents were often either unaware of the events or their potential significance for information acquisition.

Some parents were happy to attend functions organised by other parents or parent support groups, but felt uncomfortable where professionals played more than an invited guest speaker role. As a result, while some parents attended an occasional Down Syndrome Association conference run by DSA parents, they were highly unlikely to attend events such as the Early Childhood Intervention Association (NSW chapter) annual conference.

One parent expressed frustration at interview in not being able to attend autism courses, believing them to be the exclusive preserve of the professionals. The parent was unaware that both certain professional conferences and disability-specific short courses not only welcomed parent participants but frequently set a budget aside to enable parent participation: “and even the autism courses – they should run limited courses for parents. Most of them are directed at professionals that you can’t have access to” (5/2348+).

Other parents were aware of both the conferences and provision of means to attend them because of the proactive information delivery of a professional.

If autism week’s coming up and there’s some places available for parents at a conference or whatever, and there might be some funding for a scholarship or something, she’ll advertise and say, come on, let’s get some funding. (16/1000-1003)
However even when proactively apprised of events and offered support to attend, some parents would not do so. Other parents, including receptives, may have been interested to attend such events and had indeed experienced positive information acquisition in the past in this way. However, they did not appear to have the means of acquiring information that would trigger their awareness of the upcoming event. Parents who did not have a DADHC community worker, case manager or proactive professional were reliant on the passive and non-systematic delivery of information through flyers etc.

I did go to... a little expo day...I went along to that and grabbed a lot of information at the time. Things that were appropriate at the time, which I was starting to think about...I would attend that, if they had that every year. I don’t know if they do. (23/1159-1165)

It was also the case that there were increasing numbers of private sector groups operating in the disability sector offering to run courses and information sessions that were very expensive and parents had no real means of measuring their value. Some parents appeared to be unaware of the differences between non-profit making groups providing services and charging fees to cover their costs, and private groups whose purpose was to generate income.

The seventh mode subset of information grounding, membership of committees etc (summarised at Appendix 4.9), also demonstrated a clear disproportion between frequency of use (very low) and utility (very high). Frequency was not influenced by regularity of occurrence (unlike conferences etc.) as most committees with which parents were involved met at least on a monthly basis.

Frequency of use (where use was a measurement of membership, not frequency of attendance at actual meetings) appeared to be influenced by parents’ awareness of the potential information value of committee membership. However, it was also the case that parents often felt they just had “too much on their plate” and possibly did not believe that the outcomes would justify the expenditure of effort. Hence potential information value was tempered by perception of the effort to acquire among parents with a less vigilant information style. Hypervigilant and vigilant parents appeared to have no qualms regarding the effort/outcomes quotient. Their own experiences justified the continued use of the mode.
Passive information seeking required simply a response by the parent to information either passively available in the local environment or offered to them. It was the nature and quality of that parental response that distinguished this mode from similar modes. There was a degree of engagement with the material that was nevertheless often inadequate to the task of information acquisition.

Parents were often unaware of the information potential of resources passively within their environments and their desultory approach stemmed in part from perceptions of relevance. This also occurred when parents were passively directed to bodies of information with comments such as: “Here look at these” and “Have you looked in our resource folder?” While the parent may have responded by moving toward the information, it was not necessarily with an expectation of acquisition or followed by active reading.

The first mode subset of passive information seeking was in the response to information, often in the form of brochures or handouts (summarised at Appendix 4.10). That response itself was often receptive yet passive, in the sense that there was often no active reading in order to acquire the information content, yet too this did not stem from avoidance. Many parents were clearly receptive to information but unwilling or unable to engage with it at a sufficiently deep level to acquire the information independently. Indeed this mode could be clearly distinguished from information grounding through active reading of noticeboards, brochures etc., in the degree of parent initiation of seeking which in turn had an impact on information functionally acquired. Parents engaged in active acquisition and reading of brochures etc. for information grounding purposes were expecting to find potentially useful information. In contrast, parents responding to information passively in their environment, for example occasionally flicking through a brochure lying around, did not have an expectation of useful information discovery; hence when they did so it was often experienced as serendipity.

In fact, sometimes it was the passive nature of the parent’s response to information passively delivered that resulted in failure to acquire information. The flicking through rather than active reading clearly characterised this mode subset and was significant in acquisition failures, notwithstanding a receptive orientation toward the information.
In any event parents required, as a starting point visible, available or otherwise known resources, to which they could choose to respond or not respond. There was a surprisingly high incidence of reported lack of awareness of resources that were clearly (in the interviewer's direct observation) available in the parent's early intervention environments. The specific reasons for this are unclear, although when the interviewer drew attention to particular, readily visible posters, or resource racks, parents would tend to respond with: “Oh yeah, I have noticed that” or “Haven’t really paid it much attention” or “Keep meaning to look at that.”

Parents needed both a breach to their threshold of functional awareness and to be motivated to take action. Why some did and some did not was not a simple matter of information style, nor was the response always the same. There were many contributing factors such as family circumstances and particular needs at the time, the characteristics of the information display, which either caught their attention and held it or did not, and the actions of their reference group. If parents observed and/or experienced other members of their group acquiring useful information in this way, they were more likely to do so themselves. It was also the case that the information passively available to parents and acquired by them was sometimes inadequate to the task of fully informing them. Again this occurred across the broad array of settings and subject matter. Parents were usually unaware that they were not fully informed, apropos of information they had acquired.

In the following case the parent had joined an organisation and passively acquired standard information in relation to its functioning, including fees charged. However the information she acquired had not clearly detailed the fact that service would never be withheld if the parent could not afford to pay. Unaware of this the parents struggled to pay the fees, the mother returning to work to do so, notwithstanding the fact that she was fully engaged at the time in attempting to seek a diagnosis for her son.

Parent: ...we paid for that.
Interviewer: You paid $250 per term?
Parent: And I didn’t actually know that it wasn’t a compulsory thing because it wasn’t written like that.
Interviewer: Because if you can’t afford to pay it—
Parent: But I didn’t know that at all. Absolutely didn’t know that at all. And we’ve struggled to come up [with the money], but the reality is it was the only thing that helped me to get moving with [son], so I did it.
Interviewer: [You made] sacrifices to do that?
Parent: That’s why I’ve had to go back to work... (3/1943-1958)

The fact that the parent was unaware of the information must evidence either a delivery failure or an uptake failure. Although information regarding the ethic of service delivery irrespective of parental capacity to pay was indeed in the information pack delivered to new parents joining the organisation, delivery of the information still failed as there was no uptake. In the final analysis information acquisition by parental response to available information failed because there was never an information exchange opportunity that would have revealed the family’s circumstances, and in particular their inability to pay.

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The second mode subset of passive information seeking was seen in the response to information offered to the parent (summarised at Appendix 4.11). It might be expected that because the offer would normally be made by a professional or provider there may be the opportunity for information exchange, which would have the potential to reveal unrecognised parent information needs and increase perceptions of relevance. There was some degree of importance therefore attaching to the quality of the professional/parent relationship. Yet in this mode subset parents were responding to information offered to them without any qualification or application to their unique life circumstances. While parents’ stance may have been receptive, without an adequate knowledge base their functional acquisition of information was variable and dependent on other factors, including those influencing response to information passively in the environment: family circumstances and particular needs at the time, the characteristics of the information display and the actions of their reference group. In many cases parents required some knowledge base to aid acquisition of information. Even those parents who were receptive to information handed to them required some anchor points within their own knowledge base to enable acquisition. This may have been simply a perception of relevance or a sense that a piece of information was worthwhile.

In the case of one parent, her child who was non-verbal and unable to walk remained undiagnosed at almost three years of age. The parent had been actively seeking a diagnosis for more than two years and was highly receptive to information delivered to her, but none of it had enabled her to satisfy her most basic information need – the resolution of the knowledge anomaly in relation to her son. She was not being made aware of other information she could usefully seek, or activities she could usefully
pursue. This was exacerbated by the failure of those who provided her with wads of brochures and so on to engage in any fruitful information exchange which would have revealed her needs for information and help. The mother in turn was not aware of the importance of proffering information about her own struggles to get help, to those same professionals and providers.

Parent 1: And I'm always trying to chase things... and I'm always wondering is this enough, what should I be doing here? Why is he like this, am I supposed to be doing something for him because of this?

Interviewer: Do you ever talk to anyone about feeling that?

Parent 1: No, I don't. (25/2370-2377)

One parent, who had reflected at length on her own experiences raising a child with a disability, made a particularly cogent point regarding perceptions of relevance of information offered:

When an issue arises you go asking for answers... But until that issue arises, you don’t know that that’s where you’re going to need help. In amongst that original [Down syndrome kit] that I was given in hospital... was also a folder of information as well... I actually jotted down some of the organisations and so on... I came across that piece of paper a year later, and some of those organisations would actually be useful... but I hadn’t remembered that I’d got it on the original list. So, it wasn’t at all relevant to me at the time. So that’s why you need to revisit it... So, it’s okay being handed that package of information at the beginning, but until it’s relevant, you don’t [apply it] (13/2481-2515)

In addition to relevance per se, at the time that information would otherwise become relevant the parent would either need to remember they had already been given it, or, that information would need to be re-visited with the receptive parent at that time.

In other cases, while parents were receptive to information offered to them in the sense that they were not avoidant, they would often “intend” to pursue the information further, that is, read it with a degree of engagement, but seemed never to get around to doing so.

5.3.3.1.4 Information Delivery - Proactive Information Mediation

Parents experiencing proactive information delivery from either family and friends or professionals in the field both acquired more information and were either able to apply that information more readily for uptake or were assisted in doing so. Both of these consequences had a profound impact on families, both as to general well-being and in their capacity to acquire help and services for their child and family. As previously
observed, this mode of information acquisition was favoured among parents as the only means of ensuring their access to information. This was especially so as parents experienced the awareness heuristic. The expectation occurred irrespective of whether the parent engaged in very active information behaviours or not.

Unfortunately the expectation was rarely matched by professional/provider practice. The mismatch in expectation and practice was even more dangerous than the resultant failure to deliver information because along with that assumption or expectation was a false sense of safety and often a correlative non-seeking stance. Where a parent believed the professional/provider would proactively inform them of things they could not know to ask about and the parent’s information style tended to be receptive, passive or avoidant, he or she would not routinely engage in active seeking or grounding activities.

The frequency of use figure pertains to the relative frequency with which parents enjoyed this mode of delivery and it will be apparent that this was neither a regular occurrence nor qualitatively consistent. Yet functioning well, the mode of proactive information delivery yielded high rates of utility as information was mediated to individual families, usually in the context of relationship. The relational aspect was important to the recognition of parent information need by another party, and in its enabling application of information to the family’s unique life circumstances. Clearly application was pivotal in many parents’ acquisition of information. Without mediated application, wherein the content information was interpreted and applied to the family’s individual needs, parents were likely to receive information without ever functionally acquiring it or becoming informed.

It was also the case that a relationship between the parent and the other person increased the probability of information mediation occurring in a way that was appropriate to the individual family, with sensitivity to the family’s emotional state and needs.

Yeah, [contact with other people] does it for me. I mean not everybody is like that. When they are first grieving and going through the acceptance period of having a disabled child...they tend to shut down and don’t want to communicate. For me it was a need to communicate...The pamphlet or the book may be more useful to those people [who] don’t want to communicate verbally with anyone they just want someone to hand them a book and walk away. So then, in their own time, they can look up this information, contact the services they feel they need at that time. (8/28, 30)
The first mode subset of proactive delivery was that which occurred among other parents, friends and family members (summarised at Appendix 4.12). Frequently these other persons enjoyed a degree of entrée to the family’s life that was conducive to proactive information delivery.

The problem for some parents interviewed lay in not having such a person or people in their life. Unless these parents became actively involved with a support group, or became active participants in their reference group, they were unlikely to enjoy proactive information mediation of this type. One family specifically recognised that the dynamics of the early intervention group with which they were involved were not conducive to proactive information delivery because of sheer group size, where a critical mass which almost spontaneously triggered interaction, was not reached.

[We need] contact that is different from what we’re getting at the moment, which is the group....We go to group, we’re having physio, and there’s maybe two parents there and there’s not really that interaction there about, that sharing of information and stuff like that. (28/1438-1442)

Merely joining a support group was not sufficient to fulfil this function either as this, as these groups practiced an essentially responsive mode of information delivery, which while very supportive was never proactive for the individual family. It could be argued that there was an element of proactive delivery in information resources produced by these groups, because of their potential to alert parents to issues of which they may have been unaware. The classic example would be the Down syndrome kit delivered to parents in hospital at the birth of a child with Down syndrome. However, because the individual parent needed both to read the material and to apply it to their unique life circumstances, this could not be said to be proactive because of the level of initiative required of the parent. Thus the mode subset occurred with a low-medium frequency while its utility in terms of the quality of information acquired in any particular event was usually high. Most parents experienced proactive delivery among other persons on some occasions but rarely did it cover all their information needs or occur on a consistent basis.

Proactive mediation, when it occurred, was not always effective or welcome. The capacity of the proactive person to build relationship with parents (termed ‘relational capacity’) seemed to have some significance to the efficacy of the outcomes,
irrespective of the quality of the information per se. One parent was both hypervigilant and extremely proactive in diffusing information to other parents, which was sometimes welcome and sometimes not.

Interviewer: What about those, those listservs... [name] sent out a list. Have you ever got onto those?
Parent: No. I don't know how she finds the time to do it. You know, some people probably just love sitting there, doing it. I don't, I find it a time waster. (23/1258-1261)

Some parents were both approaching and avoiding information at different times and the contact needed to be sensitive to the parent's stance. The parent below attended a meeting at the home of a hypervigilant parent who was regularly proactively delivering information. Clearly her original intent was to be apprised of information about a special program for children with autism and developmental delays. When the mother arrived, she recognised someone in the audience and pulled back from active involvement, added to which she was beginning to feel overloaded.

She had a meeting at her house one night and I went to this meeting and it was fabulous. I had to sit in the back so I didn't look like a bloody idiot. And there was a guy who went to the same school as me and I just didn't want him to see me like, "What's wrong with your kid?"...That's how I got to see a lot of other things...you hear about other things that you just don't want to take in. I've had enough. "Leave it alone" type of thing. (25/2024-2052)

Clearly proactive information delivery needed to be appropriate to the parent to whom the information was being delivered and that parent needed to be willing to receive it. Again, the quality of relationship between the parent and the contact functioned as a determinant of the appropriateness of the delivery and its efficacy. The actual quality of the information delivered also needed to be appropriate and not all proactive delivery mediated accurate information.

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The second mode subset of proactive delivery was in the mediation of information to families by a professional in the field (summarised at Appendix 4.13).

The notion of proactive information delivery by professionals was, for many parents, also associated with the coordination of services to their child and a general case management approach, where one person was responsible for overseeing all that was happening with the child and family. Much proactive delivery, however, was
fragmented and ad hoc, rather than an integral part of a professional/provider's systematic information delivery. Clearly there were individual doctors and therapists who played a significant role in the lives of parents through their proactive efforts, but these were neither exhaustive in their coverage of an individual family's information needs nor directed at all of their clients.

The following excerpts are from a parent interview transcript, augmented by a quote from a paper delivered by the same mother to a Neonatal Nurses Conference. They show the remarkable difference between information delivery by a professional who simply did not recognise the family's information need, and a professional who did. The efforts of the latter were proactive, innovative and had a significant impact on the well-being of the family.

Parent 2 We felt safe with the heart surgeon... who was spectacularly good... We didn't want someone to say, "Well, technically speaking this, this and this."... the other heart [doctor - paediatric cardiologist]... was [saying] "Technically this is very, very good."... We're not criticising [but] he took over three visits before he said "Don't worry about her. We'll be able to observe her condition change. We'll be able to book her in for the heart operation long before there's a crisis."... We needed someone to say "Don't worry she's not going to curl up and die suddenly. You can take her home"...

Parent 1... He told us how it [daughter's heart] was all going to be repaired and everything else. That's fine. That's your job... And as parents what we need to know [is how] to deal with her heart's repaired. And that's what he couldn't get his head around... (1/497-593)

"Immediately after [our daughter's] surgery, the surgeon, literally still in his surgical gown sought us out to say it was a good result. He also said that today of all days we needed a success story and introduced us to twin boys, both of whom had Down syndrome and had had the same heart complaint as [our daughter]. They had been operated on ten months earlier and were now lively one year olds bursting with the joy of life. This was a wonderful example of useful information given at the right time... a simple thumbs-up in lay persons' terms was just what we needed." [emphasis added] Extract from a paper delivered by the mother to a Neonatal Nurses Conference. Used with permission.

Many parents could in retrospect identify the proactive delivery they had needed earlier in their journey which due to the awareness heuristic they had been unable to recognise at the time.

... they must have known, they must have been able to see something because I would know from my experience... Now whether it was because they couldn't,
they didn’t want to hurt our feelings, I have no idea, but it’s not good enough. They should have hurt our feelings because that is what we needed for [our son’s] sake. Our feelings would have got over it but for [our son’s] sake we needed more [information] than we got. As I said I didn’t even know, I thought DoCS were people who looked after abused children; I didn’t know they had any form of disability support, nothing. (8/8-9, 30+)

Few parents enjoyed anything more than sporadic proactive information delivery, even where they recognised its potential significance. One of the problems that had a deep impact on parents occurred where they had enjoyed a degree of proactive delivery and then lost it because of changes in organisational or other dynamics. What appeared to occur frequently was that information delivery was not sustained over time. This resulted from information practices, for example where the focus may have been a 6-monthly IFSP, changes in priority to manage waiting lists and organisational and staff changes (which were extraordinarily frequent in DoCS/DADHC). The parent below was so affected by changes in what had been a proactive relationship with her early intervention service provider that she contemplated suicide.

I feel let down because...I really [was feeling] comfortable...I keep saying to any other mother [how much] I got from this...play group in ...only half a morning is much more than what I got from the [different early intervention service provider]...And then suddenly [not finding out about another service the family could have acquired from the provider]...why did it happen? Is it because they change...the people who run the centre, because [the coordinator is] not there any more? And is it because new people they don’t know me or something, so they just didn’t tell me, let me know about the information, all this kind of thing...I don’t get enough information. And where else can I get information, where else can I get help? That’s why I feel very depressed...then I also, I had a feeling again, that if today, if I take [my son] and go and suicide, I mean, is it going to be better? (19/2160-2201)

What also appeared to occur was that professional strengths in information delivery in one area were not available in other areas, which meant parents never found a safe information ground where they could be comfortable that “all the bases were covered”.

The following example is of the same parent as above, who had been attempting to get help for her son over a nine month period, since birth. The mother repeatedly told the early childhood nurse, her general practitioner and a paediatrician “I think something is not right.” Finally the mother asked a physiotherapist seeing her child, “Can you tell me exactly what happened to [my son]?” The therapist replied “This is called developmental delay.” (19/691-796) This event triggered the mother to seek help from a different paediatrician who immediately identified that her son required a genetic study. This paediatrician not only recognised the child’s problems and affirmed the mother’s
concerns; he went on to advise her of her son’s need for early intervention. This was something a surprising number of paediatricians did not routinely do. The mother had in fact been aware of early intervention but unable to acquire it up to that point. His commentary deepened her understanding of the significance of early intervention but he did not advise her where or how she could acquire this type of service. Indeed he directed her to an early childhood clinic for advice, the staff of which failed to make the early intervention referrals the paediatrician had intended.

Hence the professional strength in one area was not necessarily available in other areas. The mother had already encountered extreme difficulty in getting intervention for her child and while she appreciated the medical intervention was then frustrated by the lack of support in acquiring the necessary therapeutic intervention and other services deemed to be so important. The paediatrician’s strength in medical information delivery was not matched with strength in delivery of information on the acquisition of necessary services and there was no satisfactory alternative source.

The inconsistencies in information strengths covered all professions, organisations and providers. DoCS, and subsequently DADHC, were inconsistent in modes of service delivery, staff roles and practices as well as approach to parents, by both geographic area and individual performance.

I had someone when I was living in [location]...She was [my son’s] nurse. She worked for DoCS, she was his nurse. She would help me with so much information. (25/284-294)

When this family moved to another geographic location, they were still waiting after a year for their family to receive any service from DoCS, even though DoCS had advised them that their file had been “forwarded on”. The mother felt the geographic inequities particularly strongly because she had known what it was like to enjoy the services of a proactive professional.

I remember... When we came back to the [DoCS nurse] she said, “I can’t believe this area, there’s just nothing”... [At the previous location] they were helping left, right, centre. (25/1565-1578)

Some parents went on to recognise and articulate the need for a professional whose specific role was to deliver information proactively to parents. The following parents enjoyed a relationship with a physiotherapist who was instrumental in the lives of many parents (as reported at interview), in their acquisition of information. There were, however, limitations because she was only one person and her role was physiotherapy
not information delivery. Interaction with her had the effect of raising parents’ awareness of the need for this role.

Interviewer Currently where do you get most of your information, advice, support...?

Parent 2 ...from [the physiotherapist], [she] is all things!

Parent 1 [She] is a lifeline!

Interviewer ...[a] number of parents have identified her as the turning point in their experiences...is that your experience?

Parent 1, 2 Yes!

Interviewer ... And she’s quite proactive...?

Parent 1 Yes! She did that yesterday didn’t she?...There was a woman there who had a tiny little baby who’s got heart problems and she’s got a 16 month old...And I played with the 16 month old...And [the physiotherapist] said “Oh it’s really good [parent I playing with the 16 month old] it has just reminded that she needs...some extra help in the house...so I’ll organise that, I’ll talk to her”...It would be nice to have someone like [this physiotherapist and it]...was actually her job to say “There’s this, this, this, this.” (28/1449-1494)

Families who enjoyed proactive information delivery in splintered areas only, such as purely medical information from medical professionals and purely therapeutic information from early intervention services, found that there was no professional advising them of all the extras, ancillary benefits and services.

Interviewer In terms of case management though, who is letting you know about the extras?

Parent 1 No one.

Parent 2 There is no one there. No one...That’s why I said to [my wife], the doctor brought something up the other day, and said, “Look into it.”

Parent 1 I don’t know where to go to look into it! (25/1963-1977)

Many parents saw the need for a person playing something of a coordinating/overseeing role which would take the pressure off them to know things they did not or could not know.

I think as the parent of a child like this you need someone who’s going to oversee the whole thing. So you’re not chasing around, [so] you can get the best success for everything. (3/661-664)

Yet for proactive information delivery to be effective, the professional needed to be aware both of the individual family’s circumstances and of the parent’s capacity to receive and process information at the time. It was therefore surprising how few parents were ever asked to tell their “whole story”, such that the professional may have been in a position to deliver information and services appropriate to the particular family.
Interviewer: Has anyone ever sat down with you and asked you to tell your story? “Tell us from the beginning what’s happened?”

Parent: No.

Interviewer: ... So no one really knows your whole story...no one really knows where you are emotionally, where your family is ....?

Parent: No, nothing like that. (19/2250-2265)

Without this type of information exchange it is far less likely for effective proactive information delivery to occur. It is probably for this reason the following example occurred. The circumstances of one particular child’s birth were such that there was a risk of developmental delay, of which the parents were not informed. The child went on to have serious issues of feeding, sleep disorder, gross motor, fine motor, communication and cognitive delays. However, each of these was being treated as a separate issue because nobody looked at the “whole story” and the family was unaware of such a thing as global developmental delay and hence did not actively seek a diagnosis.

Issues of timing and volume in information delivery that were also significant to parents could only be properly understood by the professional in the context of relationship and understanding the family history.

The first time I went there I was still a bit overwhelmed from my last couple of weeks and they told me a lot of things about [services etc] that they can help with...And you know what it’s like when you absorb so much information that it just doesn’t stay. (5/1056-1062)

The relevance and timing issue also pointed to the critical need to revisit information to ensure that there either had been information uptake at the time, or uptake as the information became relevant. This rarely occurred.

Parent: ... the assessment [letter came] and that came with a whole heap of information.

Interviewer: Has that information ever been revisited, have they ever said, have you thought about this, have you thought about that?

Parent: No, no. (31/745-770)

The professional or provider would be unaware of any newfound relevance of information either previously delivered and not taken up by parents, or avoided, unless the relationship was qualitatively appropriate.

I remember thinking when it was all happening, “I hope they don’t offer me one of those support groups because I don’t want to go, because I’m not like those people, I don’t have those problems.” Because I was still in denial about [my
daughter]. Then a bit later I was thinking, “No one ever did offer me a support group and now I’d really like to go to one”. When I sort of moved on a bit more in my head. (15/1447-1454)

Yet it was also the case that irrespective of how proactive the professional was, the parent needed to be receptive to offers of information and help.

That’s why I didn’t want to go back to that doctor in a hurry...He said to me, this doctor...“Are you getting any help?” And I said “No.” “Are you getting anyone to come to your home?” I said, “No.” He said to me, “Are you getting anyone to clean your home, help you with your baby or anything?” I said, “No.” [He said] “That’s why you look the way you do, you need help.” (25/2577-2584)

This doctor recognised that the mother needed help, but until she was receptive to information and offers of help, nothing could be done.

It was also the case that when information was proactively delivered to parents, it was critical that it was followed by action, otherwise parents’ hopes were raised only to meet with the dawning realisation that the information delivered was rhetorical.

when we first got introduced to [the early intervention service provider], or DADHC...[they said], “We can do this, we can do that”. And then when it doesn’t come to fruition, and that’s when you learn really, that if anything’s going to happen, its because I’m going to make it happen. That, you realise, again, there is no one to, you’re responsible, and of course, as the mother, or the parent, I am responsible. (18/1825-1834)

5.3.3.1.5 Information Delivery – Responsive Information Delivery

As observed earlier, responsive delivery of information was the most common mode of information delivery across all professionals and service providers. This mode of delivery required parental recognition and articulation of need directed at a professional or provider in order to be triggered. Again, the single greatest influence upon parent information acquisition was the awareness heuristic. Awareness pertained to all educational, medical, therapeutic and ancillary supports matters, at all levels; not merely specific subject matter information, such as the notional existence of respite, but actual providers and specific services available, eligibility and conditions, and the application of that information to the individual family. In addition, awareness pertained to understanding the meta information, systems and structures and their specific influence on service delivery. It was only in knowing what was going on “behind the scenes” that families could really begin to understand what was reasonable and what was not, in
service delivery, and what they could do about it. If this were described as empowering information, then very few parents were aware of it at all, apart from the hypervigilants and vigilants. Given that the primary mode of information delivery by most professionals and providers was responsive in nature, the impact of the awareness heuristic on parental information acquisition generally was enormous.

This problem was further exacerbated by parental expectations of information delivery. If parents assumed that professionals/providers would proactively deliver information without a triggering request, they would be less likely to be requesting information on a regular basis, such that the professional/provider could practice responsive delivery. Few professionals and providers practiced proactive delivery and among those who did it was often in splintered subject areas and not consistently available to all parents. It is significant that both professionals and parents appeared to be mutually unaware of each other's actual expectations of practice in information and service delivery.

It was common for parents to be given opportunities to say what they wanted, but resource shortages meant that needs for information and services were often unlikely to be met. While most parents were unaware of this, those at the more vigilant end of the spectrum had a keen understanding: "You get to say what you want but they don't necessarily confirm what you're going to get" (7/585-586).

The first mode subset of responsive information delivery was the initiation of an information exchange opportunity by the professional/provider, at which time the professional/provider responded to parental requests for information (summarised at Appendix 4.14). This occurred on a regular basis through IFSPs and other planning and information sessions. It was also inherent in the role of the local support coordinator (LSC). Most parents were quite unaware that issues well beyond those pertaining to their child's immediate therapeutic and educational needs could be discussed at the IFSP and usually left the provider to "stage-manage" the event, which sometimes included quite a formidable array of professionals.

The single greatest frustration expressed by parents in relation to this mode was that they were often asked by professionals "What do you need?", but had no real understanding of what was available or possible other than what the service providers or professionals themselves were offering. Parents were largely unaware of what could be
achieved through an effective IFSP and only those parents at the more vigilant end of the spectrum "took the running" to accomplish what they wanted out of the IFSP. Resource constraints also meant that little proactive effort could be put into apprising parents of the panoply of possibilities, such that they could answer the question "What do you need" from an informed position.

As noted the awareness heuristic was one of the most powerful determinants of the degree to which parents could make use of responsive delivery to acquire information. The family-centred model of service delivery holds that parents are the experts and as such are best placed to identify and articulate their needs for service. Yet parents were often critically unaware of information at the specific times, or information exchange opportunities, when asked, "What do you need?" They were therefore unable to identify, articulate and acquire information, services, functions, service delivery styles etc.

Perhaps one of the most revealing facts was that most parents were quite unaware of "Recommended Practices in Family-Centred Early Intervention" (ADD 1997), according to which early intervention service providers funded by DADHC, were intended to operate. As becomes evident in the following excerpts, parents could only conceive of the early intervention service provider's service in those terms in which the provider and their services were presented to them. Very few parents were aware, for example, of the information role providers were intended to play: to deliver information about the range of ancillary benefits, services and entitlements available to parents, and the usual information exchange opportunity for this would be the IFSP. Most parents were "led" through the IFSP along a path circumscribing need in terms of particular therapeutic and educational interventions for their child, often with no reference to any of the family's other needs. The goals concerned the child's developmental and behavioural goals and as parents immediately referred to these, it became clear that this is what had primacy in each of their IFSPs. That is to say, some reference may have been made to other needs but clearly with so little impact on families that they did not recall them at interview:

"I hate these IFSP's, because I just want [the early intervention service] to tell me where to go next... Yeah, you know. You tell me" (20/2093-2098).
A number of parents explicitly recognised the problem that they had never raised a child with a disability before. It was certainly the case that parents were experts in a child with a disability up to the current point in time, because of the path they had navigated. They were not, however, in any position to know what they needed for what lay ahead — it remained uncharted territory for them.

[The therapist asked] “What do you want for [your son], what are your goals?” And I said, “I don’t know” because I don’t! I said, “My goal is to have him talk but that’s not going to happen in the next year, so what do we do before then? So I don’t know what my goals are. I just want him to progress.” And she had to then help me bring that right down...Well I do [know] now...I don’t know what to ask for [the future]...If I had another child I would know what to do from 12 months [the point at which her efforts to get help became effective], who to call, where to go...(18/1630-1646)

This issue was exacerbated by the fact that most professionals and providers were quite unfamiliar with the families’ “stories”. As observed under proactive delivery, few parents had been asked by service providers to “tell the whole story”. As a result providers were often not in a position to determine proactively whether information would be useful to a family and therefore needed to take a responsive stance. Furthermore, parents did not necessarily perceive the importance of providers knowing their whole story and did not in any event know with whom they should share it. The IFSP was not an appropriate place to “share the whole story”, yet it was one of the few formally identified opportunities for information exchange to take place.

Some parents, essentially the small number of hypervigilants, developed particular strategies for overcoming the inherent problems with the responsive mode of information delivery among professionals, especially as it pertained to IFSPs and the like.

I’ve learned not to say [specific things like] “I want” and “OT” ...I don’t pigeon-hole it because I don’t know what they’re offering...You don’t know. Well, that’s why I’ve come to [asking] questions differently ... [and] I don’t give people direct answers. (7/1855-1883, 2378-2379)

Another parent clarified the approach further:

We always say, “If she was your child, what would you do?”...And that’s the only way we can get answers, like we don’t know. We don’t know what’s out
there, you tell us what you think is best for her. That’s your decision to make.
(1/1249-1255)

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In the second mode subset of responsive information delivery, the provider responded to parent requests for information (summarised at Appendix 4.15). Parent requests for information and service were similarly hamstrung by the awareness heuristic. Without knowing what was available, what was “appropriate” to ask for and indeed what other parents were receiving, all but the hypervigilant and vigilant parents were quite concerned not to be perceived as greedy or pushy or wanting too much. Hence, free and open information exchange rarely occurred, especially among the active, receptive and passive information style parents.

Some parents explicitly recognised the problems of awareness and the limitations of their own knowledge base, but seemed unable to recognise the efficacy of information grounding activities for raising their awareness of those things they needed to know about but of which they were at the time unaware.

Again the importance of the professional/provider being familiar with the family’s “whole story” was evident, in order to facilitate parent efforts in making requests. Yet a number of parents could not see the purpose of sharing their story with professionals/providers, unless they knew something “good would come of it”. They did not recognise that they could not know this in advance.

Interviewer Has anyone sat down with you and asked you for your story, the way I’ve asked you?
Parent No, no, no.
Interviewer Would that have been helpful?
ParentOnly if something came of it. (7/2359-2366)

The parent did not recognise that she could not know in advance what the provider could help her with and circumscribing information exchange on the basis of what she thought they could or would offer was self-defeating. As the sentiment was expressed by more than one parent, it seems feasible that parent perceptions of likely outcome functioned as a criterion for deciding information exchange. The problem was the parent specifically did not know what was possible to request or the services available, and the only way of alerting the provider to a parent’s potential needs was to talk about the daily lived experiences, from which the provider could begin to extrapolate need.
Another parent expressed an expectation common to many parents that had a profound impact parent information behaviour and hence acquisition.

Interviewer Do you feel able to say to them “Well what about this and what about that and what about something else?”
Parent No, because I expect them to tell me that stuff. (5/1461-1464)

The professionals and providers were, however, largely operating under quite a different information delivery approach, that of responding to parent requests. The consequences of the mismatch are immediately evident in terms of inaccessible information and services. One parent described a parent meeting at her child’s pre-school, wherein the Director described sweeping changes to government funding of special needs support in pre-school settings, which meant the same amount of funding was to be spread over a much wider range of children. The significance of this for children with disabilities was enormous. It was certainly the case that the parent’s early intervention service provider needed to be informed because of the potentially dramatic impact on the child, and the provider’s capacity to support the parent and deliver information on courses of action that could be taken. However the parent did not intend proffering the information, and because the provider practiced responsive delivery of information it was unlikely an information exchange on the matter would occur. This clearly demonstrated a failure point of responsive delivery.

Another point of failure was where professionals/providers simply failed to respond to parent-articulated requests. The parent was then either unaware of or unable to take any further action to acquire information and concomitant help.

Parent That’s what I find, unless you’ve got a child that’s very severe you don’t get help with anything.
Interviewer Unless you keep saying, “I need your help”?
Parent But see I really did need their help at one stage. I was crying out at one stage because I couldn’t do anything. (3/1465-1472)

It was also the case that inaccurate information could be delivered in response to parents’ request for information from an “expert”. This was particularly dangerous as they sought the advice of a professional or expert for just that reason.

I spoke to a couple of people who I know in special education, and other people, like [the teacher at] the kids’ pre-school who [has] a lot to do with special
education needs. She said “Just hold off. Don’t get him assessed yet. There are things happening” (5/432-435)

This was extremely poor advice as the mother had been trying to get help for her son and was unable to do so, as he neither had a diagnosis nor an assessment of his issue areas. Without the diagnosis or assessment it was virtually impossible to get help. It is important to note in this regard that it is generally believed among professionals in the childhood disability sector that the sooner early intervention begins the better the outcomes for the child.

5.3.3.1.6 Information Delivery – Passive/Generic Information Delivery

Passive/generic information delivery occurred primarily as a collection of information resources statically delivered in the sense that parents were required to approach, uptake and apply the contents. There was no engagement with the parent regarding the information therefore the provider had no real understanding of what was actually delivered and how it was received.

Some providers appeared to rely heavily on passive delivery mode subsets to effect an “informing parents” function. There appeared to be little understanding of the extraordinary variation in parental capacity to acquire information in this way, as the following section evidences.

The first mode subset of passive/generic information delivery was in the delivery of generic, one-size-fits-all information resources (summarised at Appendix 4.16). Most organisations, services and groups offered some type of generic information upon either entry to the organisation or upon application to enter. However, that information was largely neither targeted to the individual family to whom it was given, nor was there usually any application to the family’s needs, nor was information previously delivered in this way revisited to ensure uptake. Information was “supplied” in the most basic of senses and parents were left to make of it what they could or would.

There was a medium frequency of use, as most service providers with which parents interacted delivered some type of generic information. However the utility was low-medium because in the first instance parents needed to read the material and if they actually did so, then needed to perceive its relevance to their own circumstances. There
was frequently valuable information “embedded” in the generic kits but parents of receptive, passive and avoidant information styles were unlikely to do more than “dip into” the kits, expecting they would notice anything relevant. However as often occurred they never functionally acquired the information. This became apparent at interview when certain parents were adamant they had never received certain information that the interviewer understood to be within kits they had received.

The single greatest problem common to all packages, exacerbated by the parent’s knowledge base at the time of acquisition, was that they almost always contained generic, one-size-fits-all information. This was the case irrespective of the disability (unless it was a disability-specific package), age of the child and history of diagnosis, circumstances of the parents, parents’ interests, service needs, approach to information and actual needs for information. Indeed those needs for information, frequently unrecognised by the parent, could only be identified in an information exchange where the parent had the opportunity to share their story and circumstances. When packages or kits were delivered there was often no information exchange opportunity at the time or application of the contents to the unique life circumstances of the family. Families were largely left to read and digest the material alone, often with the blanket suggestion that they get back to the organisation if they had any questions or needed help.

Parent And they gave you a little pack of information. I can’t remember what was in it, now.

Interviewer Did it mention respite care?

Parent Not that I recall, but that doesn’t mean it wasn’t in there.

Interviewer So they never actually revisited material they’d given you early, to make sure it had...

Parent No, I don’t think they’ve really got their act together. I think the idea of it’s great. But unfortunately, the sort of implementation is sadly lacking. (11/175-187)

Sometimes parents were unsuccessful in acquiring specific information they needed from the information package, as reflected in the following parent’s comments. She had received her early intervention service provider’s standard package but had not functionally acquired significant information in relation to fees. Whether this arose from a quality problem in the kit or a problem the parent experienced interpreting the information could not be determined at interview. What was clear, however, was that because of the passive nature of the delivery, the family did not acquire the information.
Other parents were simply not receptive to information passively delivered without regard for their particular circumstances and emotional needs, especially as to timing.

Only the more vigilant parents tended to read these kits exhaustively, usually immediately upon delivery. They were then in a much better position to negotiate for services for their child, but they also became more aware of frustrating anomalies within the organisation and the sector generally. This was particularly so as these parents also tended to be heavy networkers, attending social functions and information sessions within other service providers, or different services within the one provider.

Another form of passive delivery of generic information occurred when children were scheduled for formal developmental assessments (from some not all providers), including both information sheets to fill in plus information about the functioning of the assessment. Parents were intended to familiarise themselves with the information so they would know what to bring to the assessment, what happened at the assessment and to prepare both themselves and their child for it.

Interviewer  Has anyone actually told you what happens [at the assessment]? That there's a team? ...a [developmental] paediatrician, [name of a social worker] – has anyone told you?

Parent  I know about [name of developmental paediatrician]. I've got the literature. I haven't gone through it. It's just on the fridge. (25/1761-1766)

Almost certainly one of the influences on the above parent's receptivity to information from the assessment centre was negative information she had received from other parents in relation to assessment at this particular assessment centre.

Interviewer  And has someone told you what it's going to be like?

Parent 2  ...Going to walk out of there very heart broken.

Parent 1  Someone said to me “I think the best thing for [you] to do is walk in there and expect the worst.” Because I think when I walk out of there I’m going to be a bloody wreck. (25/1753-1759)

The second mode subset of passive delivery was the parent library or other resource collection for parent use, among others (summarised at Appendix 4.17). The low frequency of parent use of passive information resource collections, such as libraries,
was related in large part to awareness of their existence and awareness of the quality and potential relevance of information resources contained therein. Providers generally did very little to communicate actively the content and utility of their collections, to parent bodies. The exception to this were the parent support, disability-specific collections, such as those of the Down Syndrome Association and Family Advocacy, who frequently mail parents lists of resources available to them either separately or as part of a newsletter. This practice was by far the exception to the rule. Also, as the parent below recognised, one needed to take the initiative, to make use of the service for it to be a viable means of information acquisition.

Interviewer Did you join the Down Syndrome Association?
Parent Yes.
Interviewer And have you found they've been helpful in terms of information, advice, support?
Parent I think they're helpful. I think you probably need to make use of them more than I do. I think I initially borrowed things from their library. (23/859-867)

Of particular note was the failure of the NSW State Library in this regard. The Library did not apprise parents in the childhood disability sector of the role of their Disability Information Service. One of only two interviewed parents actually aware of the State Library’s role in this regard, was unsuccessful in getting the Library to acquire information for her. This of particular note because the State Library ought to model effective information delivery in this sector. Delivery must necessarily start with apprising potential clients of what is possible, and then to deliver what it is funded to undertake. Its model of passive delivery was certainly followed by most other resource collections.

Parents needed to perceive the collection or library as a viable mode of acquiring information. While a small number of parents were members of libraries, public and special, few seemed to actually use them for the purpose of acquiring domain information.

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The third mode subset of passive/generic information delivery was in the passive delivery of generic information resources in local environmental settings, such as the parent room of an early intervention service provider, waiting rooms in doctors’ surgeries and early childhood centre parent areas (summarised at Appendix 4.18). The 268
frequency of use was low-medium because, again, parent initiative was usually required in “moving toward” information and the uptake of that information. This was always affected by perceptions of relevance and the degree to which the information was presented in an attention-grabbing format/style.

The impact of parents’ perceptions could also be seen as emanating at least in part from their own coping style. One parent, whose early intervention service reference group included two mothers at the vigilant end of the spectrum, was experiencing some difficulty getting her child to the early intervention service. The mother had no driver’s licence and no car, no viable public transport and frequently had to walk with her disabled child when suffering a debilitating illness. The two vigilant mothers apprised her of the possibility of getting community transport and/or taxi vouchers. “See I didn’t know those sort of things existed before”, the mother commented. The mother was also unaware of her eligibility for either carers’ allowance or carers’ pension, even though those brochures were visibly available in the early intervention service. The reason for her failure to acquire much information relevant to her personal circumstances became evident at interview. “I knew there was a disability pension, but I never thought that, I just suppose I never see [my son] as a disabled child so it [carer’s allowance] never came to my attention” (32/1).

The information holdings within any setting frequently reflected information delivered to the organisation rather than the needs of the clients. Hence strengths in one area, for example in transition to solid food for infants, was not matched in other areas, such as milk, gluten, additive and preservative-free diets for babies. Baby food manufacturers supplied the former brochures and booklets in bulk to early childhood centres; the latter were often unavailable apart from nutritionists/dieticians and food allergy groups.

Parents identified the difference between information delivered passively in the environment, through brochure racks and noticeboards, and that same information delivered to them personally by a professional. Clearly the act of delivering information personally breached the parent’s threshold of awareness both of the information and also its potential relevance to them. The action of the other person seemed to act as a filter. It was also the case that, for those parents who would look at brochures and noticeboards, the information passively delivered in this way needed to be apparent in order to be noticed.
Interviewer: Are you a person who looks at everything on noticeboards?
Parent: Yes.
Interviewer: So you read all of those things that are around. (14/602-608)

Time and active children also made utilisation of noticeboards impractical for some parents: “you can’t stand still and read a noticeboard when you’ve got your two year old flying around behind you and you worry where they are” (8/30+).

Information styles clearly had an impact on the utilisation of passive resources. Whereas parents at the more vigilant end of the spectrum used active reading of noticeboards and brochures as part of their information grounding strategy, parents of a more receptive passive style tended to take the stance described by the following parent: “I glance at noticeboards; I don’t think I purposely read them” (23/1159).

Parent capacity to acquire information delivered passively was also influenced by his or her own knowledge base. One parent, who had an active information style, had been seeking help for her child for almost two years and had been attending an early childhood centre, in addition to various general practitioners and paediatricians. The centre held brochures for the Early Childhood Intervention Infoline but as the mother explained, she had no idea what “intervention” meant. As a result she did not acquire the information she clearly needed but could not recognise. Indeed, Infoline and local disability information service posters were a typical example of the failure of this mode in its delivery role. Such posters were frequently found by the researcher on walls and noticeboards in the early intervention services from which participants were recruited. Yet at interview most of those participants stated that they had either never heard of such services, or had only the vaguest awareness or were not aware of the source.

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The fourth mode subset of passive/generic information delivery was through those newsletters produced by many of the organisations and groups with whom parents were in contact (summarised at Appendix 4.19). Most newsletters were provided as a function of membership, by organisations such as the Autism Association and Family Advocacy, DADHC and the early intervention service providers. Again, there were significant qualitative and quantitative differences between newsletters that were not simply a function of subject content, scope and focus. Nevertheless newsletters were a
rich potential resource for parents, although their frequency of use was only low-medium.

Consistent with other passive/generic modes of information delivery, this mode subset required the parent to take an active role in approaching the information and applying it to their own life circumstances. In the first instance however they had to be aware of and in receipt of the newsletter or aware of how to acquire it. This was rather problematic for families waitlisted for full service within an early intervention service provider who were outside any communication channels.

The significant failure point of generic newsletters in their frequent inability to target and meet the information needs of discrete sub-groups, and particularly those parents often invisible to those more active in the sector, became evident in one poignant interview. A mother struggling to hold her family together financially, emotionally and socially, at the same time as attempting to have her child’s problems recognised by medical and therapeutic professionals, felt missed by the provider’s newsletter.

Parent They sent me the newsletter or whatever it is. “Yes, our social group, our New Year party, or our moving party”, all this. And it’s like, oh yeah.

Interviewer $50 a head dinner---

Parent That’s right, we’ll be there!! We’ll come. We can’t even take a taxi, we haven’t got a car. We’ll hitch there!! (30/1553-1561)

Sometimes the focus of the group was simply not appropriate to the family’s view of the world.

I do get their newsletter, and I read the information about the workshops they run. And it just seems the huge focus of them is to mainstream your child. It seems to ...to be what that organisation is about. (15/1793-1796)

Even though the newsletter contained other valuable information in relation to the disability sector, it was difficult for the mother to acquire the information in any real sense because of her view of the organisation.

Another problem arose by virtue of parents’ information style. Consistent with findings in other mode subsets, those parents with information styles at the more receptive passive end of the spectrum would not necessarily seek out newsletters, even those they had experienced as containing valuable information. The interview commentary below
reflects the receptive parent who, while willingly receiving information, will not actively seek it out, even when its relevance and value has been established.

Parent I used to get a lot from reading Sydney’s Child, but I don’t read that any more because I don’t have access to it...

Interviewer [Is that] something [your special education pre school] could probably make available?

Parent Yeah they do but they only have about 5 copies, but they go. (16/1020-1029)

This was in stark contrast to the vigilant parents who were constantly seeking valued sources of information.

The fifth mode subset of passive/generic information delivery occurred through a wide range of medical and therapeutic events such as routine appointments and sessions (summarised at Appendix 4.20). Unlike the parent-initiated appointments under the active information grounding mode subset used to acquire information beyond the matters directly at hand, these appointments and sessions were not used to deliver any information beyond the specific matter at hand.

The passive delivery of information in the course of appointments, routine therapeutic sessions and groups, during tests, assessments and other appointments and discussions, occurred with medium-high frequency. However, the information thus imparted was often in a neutral or even offhand manner and there appeared to be no concerted effort to impart information, other than specifying matters at hand; for example, “Do these exercises”, as opposed to explaining that when certain exercises are conducted on a regular basis the outcome can be a significant improvement in mobility because of x, y and z, plus any other information related to disadvantages.

One parent identified that while she had probably been given certain information (passively), in order to acquire it she had needed the significance of that information to be made meaningful to her – something which simply did not occur in the passive mode of delivery.

Interviewer Sibling Support?

Parent Well, I need that...somebody should have drummed that one into me. They probably did tell me. (5/2002-2009)
For those parents with active, receptive, passive and avoidant information styles this minimalist approach presented real hurdles, as they would normally pull back with resistance and felt very uncomfortable at the prospect of being perceived in a negative light. Being assertive in order to acquire more information than the passive deliverer was offering was beyond what many felt able to do. Hence the utility of this mode subset for information acquisition was quite low.

Parent: [The physio] was saying she wants me to see what the assessment people say...the DADHC [assessment]. So I rang them and they ask you a few questions and they said “You have to go before the board to see if he’s eligible..."

Interviewer: And did you ask them “Well what are the eligibility criteria?”

Parent: No, I’m, you know, not good at thinking these things. (30/319-385)

For some parents the professional expertise of the medical and therapeutic professionals was a significant barrier to challenging the minimalist information delivered and activity level. Only the hypervigilant and vigilant parents appeared able to push through either the resistance or the information delivery inertia of the professional to acquire further information or seek answers.

Parent: The GP didn’t give me any referral, didn’t advise me to go to physio, all this kind of thing...

Interviewer: And had you actually been saying, “What should I do?” “Tell me what to do”? Had you been expressing it in that way?

Parent: No, not really...I think at the time you also think that, you know, if you’re a doctor, you’re a professional and you can probably tell me something I don’t know. (19/682-743)

When professionals restricted the scope of their activity to dealing only with the issue directly at hand, parents almost always failed to acquire information of fundamental importance to them. In the case of the parent above, medical practitioners had tended to focus on the child’s head, which was always tilted to one side, and his renal reflux, among other disorders. However no one put the whole picture together until some time later, because each professional had taken the position of dealing only with the matter immediately at hand.

For some parents, notably at the vigilant end of the spectrum, this type of failure was usually in random events. Whenever these parents became aware of this type of failure, their resolve to drive information and service acquisition rather than relying on professionals’ discretion was reinforced. For the remainder of the parents, however,
failure to acquire in this mode subset was a regular occurrence of which they were frequently unaware until a serendipitous event.

Another thing I heard [fortuitously] through my special education teacher, specifically for children [on the autism spectrum] is desensitising them to, like he freaks out with rain, that there’s tapes you can buy to desensitise them. I’ve told these people that’s what he gets really stressed about and nobody else has ever said this is what you could be doing to help the problem. (5/2338-2342)

One area of particular concern was the failure of professionals to advise parents to seek further assessment or investigation of their child even when they were clearly lagging in developmental milestones. This occurred both at the early childhood centre level, which parents routinely attended for check ups with their child’s “Blue Book”, and also among medical professionals. Many parents clearly slipped through the net even when they were attending medical and health appointments and check ups, where one might have expected information to be delivered. This militates against the utility of passive information delivery. The parent of a child with a disability reflected that one almost needed to become a professional expert in order to be in a position to acquire the help needed. Where the parent was passively attending early childhood health centres and medical practitioners and the mode of information delivery of those professionals was passive, information acquisition was far less likely to occur.

I was talking to a friend, who was telling me about her friend’s son… I was asking her some questions about his symptoms. [I said] “He’s got to go and see a speech pathologist, straight away.” And she said, “Oh, do you think so?” I went, “Yes!!” I thought, “Well why hasn’t someone else told the girl this?” It’s almost like you need to become an expert in these different professions, to sort of do anything… It’s like I need to be a speech pathologist and a physio to get it!” (11/2918-2927)

Families’ most regular contacts with professionals were with their early intervention service provider, usually at least on a weekly basis. Often parents interviewed, while clearly aware of what they had been informed of, for obvious reasons were not aware of where professionals had failed to deliver information in the course of these passive delivery activities.

Interviewer Do you have equipment made by Technical Aid for the Disabled?
Parent No...
Interviewer Has anyone used those cut-out tables with you?
Parent No. (3/778-793)
Parents within the same early intervention service provider, but at a different location to the above parent, were having tables and chairs made for their children by Technical Aid for the Disabled. Also, parents within the same early intervention service provider, but at another location were having the cut-out tables used routinely during therapy and group sessions. The parent quoted above was quite of these possibilities. The passive information delivery nature of the therapeutic session meant that while the child’s capacity to be seated upright in a corner was discovered and specifically addressed, the family’s need for suitable furniture to support his sitting at home and where to obtain it was never the subject of information exchange. The parent did not know to ask and the professionals, who would have been aware of what was happening at the other locations, did not apprise the parent because she did not request the information.

Interestingly, at the latter location where the cut-out tables were in use, at least one parent was advised to get one of the tables for their daughter but was neither advised how to get it nor that they were made by Technical Aid for the Disabled.

Parent: We’ve been told things like “It would be good if she could have this table this size with the little thing cut out in it…

Interviewer: But not how to acquire it?

Parent: No. No. It’s been left up to us to go and find that. (10/1363-1367)

One parent who had been striving for help for a considerable length of time was finally able to have her child assessed by an assessment centre. The problem was, notwithstanding the child’s autistic behaviours, he was assessed as not being on the autism spectrum. Yet the follow up action recommended included work through the Autism Association and the Applied Behaviour Analysis (ABA) program, both of which required a formal diagnosis of autism for enrolment.

They assess your child without living a week in your life…all those related things that they referred us to were autism based training and intervention programs…And I rang…the first one told me that he wouldn’t get on because he wasn’t autistic…And the other one…I made the call to [the early intervention service provider] – well he can’t get in until he’s autistic… (5/571-592)

Empowering information of the type that would enable parents to make informed decisions about the modes of services delivery that would be most appropriate to their family circumstances was virtually never delivered in passive information delivery, and those few parents who did know almost always grew into the understanding.
One child had built a significant rapport with a physiotherapist in a Hospital Outpatient setting. The mother was keen to retain the service, although also seeking early intervention services through an early intervention service provider, because of all the difficulties her son had endured. However, when she talked with the early intervention service provider, which offered special education in addition to physiotherapy, she was presented with an “It’s them or us” scenario.

Interviewer Did you say, “Well can I have your program without physiotherapy?”

Parent I didn’t say that because I didn’t know.

Interviewer You didn’t know that you could negotiate that sort of thing?

Parent No.

Interviewer And they didn’t tell you, you could negotiate?

Parent No. I didn’t have experience or nothing... (19/1156-1167)

Sometimes providers seemed surprised that parents were unaware of services or modes of delivery they could have acquired, without ever having specifically delivered pertinent information. It was unclear to parents how the provider thought the parents could have known. There is a distinct possibility that the professional/providers own familiarity with their service causes a failure to recognise information need in others.

When we met with [therapist] a few weeks ago she said “Oh we’ve just started at [location]. Maybe on Mondays we could see you at [location]. And I said “I didn’t realise I could go to [location].” And she said “Oh of course you can.”...I consider I’m someone who’s very outgoing and very forward and articulate...I articulate everything I do know and the, if someone else has information on top of that, that I don’t know, if they don’t tell me, I will never know. I can never pursue it. (18/1274-1299)

A significant problem with the passive/generic information delivery mode lay in the fact that there was little, if any, information exchange that would open up exploration of what was possible and what was actually unknown to parents. In this approach the provider did not seek to develop a detailed understanding of the client, their story and circumstances and possible needs. There was no basic checklist used to determine what services, facilities and supports parents were aware of and what they were using.

One of the dangers when parents were given minimalist information in passive delivery was that it frequently led them to assume that that was all there was available, or there was nothing else of significance they also needed to know.

Perhaps I would have expected more [information] from [the assessment centre]. I think the [the assessment centre] is where I would have expected to be told, “This
is what’s available.” And since I was told that DoCS was available, I think I thought, “That’s all that’s available.” (15/1487-1494)

Medical practitioners in particular seemed often unaware of families’ circumstances, and the impact of their failure to deliver important information to families often added to the already serious difficulties they were experiencing.

Parent  
That’s when [the paediatrician] decided to put [my son] on a couple of drugs, which was Valleran Forte, was one of them, and we ... used it once and... [it cost] $40...

Interviewer  
Was that a lot of money to you?

Parent  
Yes.

Interviewer  
Did [the paediatrician] understand your financial position?

Parent  
Well I think he might have known that, you know, with me not working ...

Interviewer  
When he wrote the script for you, did he explain to you that it wouldn’t be covered and it would be expensive?

Parent  
No.

Interviewer  
So when you turned up at the pharmacy to get it, what was your feeling when you were told “This is going to cost you $40”?

Parent  
Well I was horrified ... [but] I sort of thought if it’s going to put him to sleep, well we’ll be able to sleep ourselves ... it would’ve been worth it. (33/1100-1168)

Sometimes the information delivery of the professional was seriously undermined by relational incompetence, reducing parental capacity for information acquisition.

And he came in and said “Your child has Down syndrome.” Baby wasn’t there, blood test wasn’t done, absolutely nothing... in the waiting room he came in, with, you know, people going in and out ... So that was the worst thing he could have done, the way he did it... he was so eager to race in there and tell us. (20/82-136)

This particular medical practitioner continued with his poor information delivery practices and was challenged by a number midwives. Clearly his practices were not restricted to the participant family, as the following quote evidences.

The midwives were so fantastic... the doctor was shocking... saw him as a medical case and not a child, and not us as a family ... “This is our case”, and, “What do these two want, why are they standing around?” The midwife said “That’s the mother, what the child needs most is the mother, and the mother needs the baby” ... Some of [the midwives] told him to just shut up and leave... But he would be standing at the humidicrib and he would never look at me when he told me something about [my son] he would always be looking at [my son].... And sort of mmm mmm mmm mumble mumble. And some hi-tech words and I’d be “What does that mean, in plain English?” ... But there was another friend of mine who was in at the same time, and [her son] was 7 weeks early. And when [the same paediatrician] was looking at him in the humidicrib he kept going on about
“this is wrong” and “this is wrong” and “this can happen” and “that can happen”. And she [the friend] just looked at him and said “So is he going to die?” And he went “No.” He’s got this, he goes on about all these theories and technical stuff. He just can’t talk to people... He should be in Pathology. (20/261-289)

5.3.3.1.7 Serendipity

Analysis of serendipitous acquisition of information required consideration of slightly different factors because there was no sense in which information was purposely sought or delivered. Frequency of the event was suggested by occurrence rather than use and also because there was no sense in which information was purposely sought or delivered, there were impact points rather than failure points. As frequency of occurrence, determinants/barriers, utility and impact points equally applied to all the mode subsets they are considered as one, (summarised at Appendices 4.21-4.26). Serendipitous events occurred in relation to the full spectrum of parent information needs.

Among the most difficult of paths to walk were those navigated by parents whose children either never received a diagnosis or received a generic diagnosis, such as global developmental delay, not further specified. Every one of these parents, within the sample, encountered great difficulty being heard, articulating the right question to acquire information, and getting help. The immediately following example was not exceptional, however, the accidental manner in which the parent discovered that her concerns about her child were actually quite serious, after trying unsuccessfully for some considerable time to get help, was devastating.

After [my son’s paediatrician] went away, and this doctor from the kidney research department come and talk to another doctor, the paediatrician who look after [my son] in the hospital...They were talking and I heard she was talking to the doctor that [my son’s paediatrician] say that [my son] is abnormal...I say to her, “He never mention. We went to see him and he never mention to me that he was abnormal. He just said to me that he was OK.”...And she say, “Oh.” She suddenly think that maybe she say something wrong. (19/580-631)

Sometimes the serendipitous event magnified the failure of organisations parents believed ought properly to have delivered such information. One parent reported learning by accident about other children with the same rare disability as her own child, through a parent who used a common respite service. This parent had repeatedly attempted and failed to acquire information from the disability-specific parent support
group: “things happen by chance – when you have this support organisation [and] you send them e-mails and you call and stuff, and you don’t get anything back” (7/879-880). The impact of serendipity was considerable both in terms of parent relations with professionals/providers and parents’ sense of well-being and security: “Who knows where we’d be if she hadn’t made that chance comment. It scares me. It does scare me a little bit.” (15/1008-1009)

There were clearly many occasions on which parents discovered information accidentally, for example regarding services parents in other areas were getting, yet felt powerless to use it to effect outcomes in their favour. It is arguable whether this occurred because the information acquisition was serendipitous, rather than a product of active information grounding. Parents who seemed to experience higher levels of serendipity were experiencing as serendipity what other parents experienced as the result of active information grounding. Those parents utilising active information grounding, and constantly breaching their threshold of awareness, were also those parents most likely to discover empowering information and have the fortitude to push through and use it.

One parent, speaking at a communication information session attended by parents from outside her own early intervention service provider, unintentionally precipitated a serendipitous event. A number of parents from the audience made serendipitous discoveries as unintended consequences of a discussion with her during the break, about matters well outside the ambit of her talk:

I just did my one and a half minute spiel...then at the break, one parent came up and asked me, what happened when my daughter turned 3 regarding her intervention, where did I go from 3? I said I didn’t understand what she was saying. And as the conversation transpired, the service she was using expired when the child was 3, and she had to go and access her own therapies and intervention from then.... I just said to her, well our early intervention service takes us to the first year of school and beyond now as the programme is extending, so I realised how lucky we were, to have that service, and the continuation of service. Then another lady asked me what I’d done when [my daughter] started Pre-School, with settling her into Pre-School, and is there any problems, that sort of thing. And I said to her, I’d just taken along my allocated support person from [the early intervention service provider] and she’d come with me, and we met with the Pre-School teachers and had IFSP meetings and they brought aides and what was available, and made suggestions on the phone. And that was another eye-opener for me, realising she had no support when her child started kindergarten, she had to find the kindergarten, do it all herself. (12/1831-1859)
The problem for the parents making the serendipitous discovery was that even once their awareness of the anomaly was raised, they had no immediately available means of acquiring the further information they needed.

5.3.3.2 Awareness of Information and Services - Quantitative Data

The awareness of information and services was of central significance to information access and acquisition, and awareness and usage levels among parents were specifically tested in the quantitative component of the interview. Parents participating in the interviews clearly experienced significant differences in awareness of formal information service providers and the ancillary benefits, services and entitlements potentially available. Awareness was treated as more significant than use in this investigation because parents who were aware were theoretically more able to exercise a choice in whether or not to utilise a service, assuming eligibility (see 5.2.3.1). It is therefore critical to understand the degree to which parents were aware of information services that should have yielded access to information, and their awareness of ancillary benefits, services and entitlements, such that they could exercise choice.

Each parent was rated for awareness and use of set core services plus additional services relevant to their geographic location, provider and personal experiences/involvement. Each parent was uniquely assessed according to what was “reasonably knowable” in their circumstances. For example, parents at Ulladulla had the benefit of a number of information sessions organised by the coordinator, wherein services locally available were described. As a result they were tested on a wider array of services than some Nowra parents, whose exposure to the array of potential services, apart from personal information grounding efforts, was either through passive delivery or serendipity.

It was also critically important to understand why the differences in awareness arose. Thus a range of demographics were tested, correlated with the centre attended, information style and involvement of a proactive professional. The results were unambiguous.
5.3.3.2.1 Demographics and Awareness of Formal Information Service Providers - Comparative Analyses

Extremely low rates of awareness of formal information service providers were found among parents uniformly across all centres, irrespective of geographic location. Only 8% of parents (n=4) were aware of at least 50% (n>4) of the formal information service providers available to them. Of these parents, not one approached any comprehensive awareness of the range of information services available. 24% of parents (n=12) were aware of at least 2 information service providers.

Of greatest concern was that 49% of parents (n=24) were not aware of a single formal information service provider from which they could seek to obtain information. This included the core set of providers such as the Infoline. It also included additional providers more likely to be known by certain groups (for which only those groups were tested), such as the Disability Information and Assistance Line (DIAL) on the South Coast and the (then) Disability Information and Referral Service (DIRC) in the Eastern suburbs of Sydney.

![Chart 5.3 Parent awareness of information services, ratings across centres](image)

The chart above demonstrates both the fairly even spread of awareness across all centres, and, the total absence of awareness of any information services among almost half of the parents. Given the extraordinarily low rates of information service awareness, the question then became whether it was possible to discern any factors, such as level of education attained, that may have been related to parent awareness of information services. However, as will be apparent from the chart below, university and
technical levels of education were as common relatively among those parents with zero awareness of formal information service providers in the sector, as among those with rates at .5 and higher.

Furthermore, there was no discernible association between awareness of information service providers and employment of the mother (given that virtually all fathers were in full-time employment only the mother's employment status was considered), health insurance status, or number of other children. Only participating parents over 32 years of age demonstrated the higher levels of awareness of information services, and all participant parents using the Internet (frequently, occasionally or rarely) were at least 31 years of age. However, as only 6 participant parents were actually less than 31 years old, age, while interesting, could not be considered a reliable factor. Yet when the individual parent’s “information style” was considered clear patterns emerged.

5.3.3.2.2 Information Style

It was possible to discern six distinctive information styles among parents interviewed. Each of the styles is detailed below, followed by a breakdown by the centre attended and comparative analyses with educational level, child's disability and age, and Internet use. The impact of information style on awareness of benefits, services and entitlements is then presented in the following section.
The "hypervigilant" information style was immediately apparent at interview. These parents used virtually all modes of information seeking and grounding to acquire information. Anomalous states of knowledge appeared to be either more readily identified by these parents, or clarified by constant information grounding efforts. Parents quickly learned not to assume proactive information delivery and were highly focussed on personal efforts in the acquisition of information and services. Of the parents interviewed 16.3% (n=8) practised the hypervigilant style.

While there was common usage of certain modes of information acquisition among all parents, there were quite clear points at which the differences between each of the information styles could be discerned. Hypervigilant parents, along with the vigilant and the active, for example, all utilised mode subsets 1.2.6 “attending information and skills development events/ functions” and 1.2.7 “membership of committees etc”. However, unlike the vigilant and the active parents, hypervigilant parents usually assumed leadership and organisational roles in relation to other parents for these events and committees, were parent representatives on peak bodies and presented papers at conferences, information sessions and so on.

Both hypervigilant and vigilant (n=2) parents also appeared to use all the information grounding modes advisedly, that is to say, according to their own testimony were aware of their information potential. Indeed information grounding was usually occurring constantly in the sense that parents were always vigilant to the information possibilities of any situation. One parent explicitly recognised the potential information value of this research. “Like we would agree to this research, 1 because we...have a responsibility to provide input ... [and 2] we might learn something from this as well” (1/2840-2858)

The high awareness rating for benefits, services and entitlements among hypervigilant and vigilant parents was matched only by parents with other information styles who enjoyed the services of a proactive professional or community worker. Interestingly, more hypervigilants and vigilants, relatively, also enjoyed the services of a proactive professional or community worker than parents with active, receptive and passive information styles. (The one parent participant with an avoidant information style reluctantly enjoyed the benefits of both proactive professional and reference group.)
This tends to confirm that their vigilance did result in real, on-the-ground improvements in access to services.

Hypervigilants generally appeared to have access to more information and services than other parents, unless those parents enjoyed the services of a community worker or proactive professional. However, only 9 parents (18%) who were neither hypervigilants nor vigilants did so. Furthermore, while there was some dissemination of information by hypervigilant parents among other parents, this diffusion role was by no means comprehensive or uniform across the group.

It was also the case that hypervigilant and vigilant parents demonstrated more general personal characteristics that clearly had an impact on their capacity to acquire information. These parents were results-focused and would not pull back when facing resistance from professionals or a failure to acquire using one or more modes of acquisition. While not comfortable at the prospect of being perceived in a negative light, this would not deter these parents from continuing to push forward in the effort to acquire information and services.

I put my name down on everything that I can imagine...I get on every single waiting list. And I read things, and that's how I got onto the Carers [NSW]...I’m on the Committee for [an early intervention service provider], and I go to a support group called Learning to Learn, and I’m on the autism awareness support group, and I go to a biomedical one for [my son] and his supplements...I go to Weight Watchers and I have a few mothers with kids with autism, we have a coffee afterward, and we talk about therapy...we go off to different sorts of channels as to what we can do. We talk about schools, we talk about everything...And that's how you sort it out. (2/803-834)

Vigilant parents were distinguishable from hypervigilants primarily in that they did not tend to take leadership or organisational roles in the sector, and while attending conferences and expos etc were less likely to present papers. They were, however, very similar to the hypervigilants in their determination to seek out information, and identify and resolve knowledge anomalies. They shared higher rates of awareness of benefits, services and entitlements with the hypervigilants.

Active

The “active” information style was expressed in what appeared to be very similar active information seeking and some grounding efforts to those of the hypervigilants and
vigilants, however, fundamental underlying differences were apparent. These parents (n=13), while active in information seeking efforts when specific need was recognised, frequently did not recognise anomalous states of knowledge because of assumptions about professional proactive delivery. They also demonstrated a characteristic unwillingness to rock the boat or be perceived as a nuisance, and this unwillingness would usually cause parents to pull back when facing either resistance from a professional or even a lack of validation of their efforts. Pulling back when facing resistance or even absence of overt success with a professional was more marked when the parent was experiencing an anomalous state of knowledge (ASK) rather than having a specific and recognised information need. Failure to acquire information using one mode of acquisition would not always prompt more active efforts using another mode, as it would in the case of hypervigilants and vigilants.

Furthermore, although similar modes of acquisition were used, active parents were generally seeking to satisfy recognised needs, rather than seeking actively and consciously to become aware of all that they might need to know. Hence, active parents did not necessarily adopt what has been defined as an information grounding activity, for the purpose of acquiring information. For example, some active parents were members of committees but this was more with the intention of serving/helping the organisation than deliberately seeking to undertake activities with information potential. Often information acquired in these ways was felt to be serendipitous in nature. Attending conferences and information and skills sessions was also less a part of a conscious rationale to become aware of broad ranging information than specific purpose-oriented. For example, active parents would attend information sessions regarding schooling options specifically to find out about the schooling possibilities for their individual child. Hypervigilants and vigilants would seize those same opportunities to meet local Department of Education representatives and others to find out about departmental policies and initiatives, structures and useful contacts, among other things.

Receptive

Parents with a "receptive" information style formed the majority of the participant parents (n=21, 42%). These parents used significantly lower rates of active information seeking and grounding efforts. While they were generally very willing to receive information they usually required a significant trigger for active information seeking.
Unfortunately they often lacked either the necessary information literacy skills to know where and how to seek and even what was available to be sought, or, the capacity to apply those skills in the disability sector. This arose in part because of their lack of information grounding efforts rather than poor information literacy per se. Grounding activities were usually limited to occasional specific purpose conferences and information sessions. Membership of support organisations often yielded only sporadic involvement or contact for specific problems and newsletters were either unread or scanned for relevance, in contrast to the exhaustive reading of newsletters often exhibited by hypervigilants, vigilants and sometimes active information style parents. The problem with scanning was that in order to be effective the knowledge base needed to be adequate to make a realistic determination of relevance. Often this was not the case.

Receptive parents had very low rates of awareness of benefits, services and entitlements. Along with active parents, receptives were very concerned not to rock the boat or to be viewed in a negative light and always pulled back with resistance or when facing difficulty with professionals. Receptives often had a fear of retribution, however vague or ill-formed (especially in terms of services to their child), and found it very difficult at a personal level to engage in the fight to get services for their child.

I'm not saying I'm too nice but I feel like I'm bothering people...I guess I'm the sort of person when I do find something and I'm reasonable happy with it, I stick with it. So I'm probably not the person who's searching out a lot more, unless I have a specific thing come up. So I guess I was pretty lost until I got into [an early intervention service provider] and started to make some associations with people there, otherwise yes, I would be very lost...I didn't know all the things I was supposed to know. I knew I was going to have to do all this special stuff and I didn't know what they were and I didn't know how to find out...I don't know if I was covering every angle. I knew I wasn't covering hardly any angles so how would I ever know if I was covering every angle? So I guess I found out a little bit, a little, little bit. (23/1470-1560)

Anomalous states of knowledge among receptive parents were always characterised by difficulties in clarification and articulation of the right question that would open the door. While all parents struggled with this to some degree, the receptive parents would often not continue in their efforts to achieve satisfactory clarification. It appeared that their children were at risk of later diagnosis (in the case of autism and gdd) unless other factors intervened. These parents had high levels of expectation that professionals would proactively deliver information that was important. If, for example, the parent
expressed concerns about their child's lack of language development or difficult or strange behaviours to a professional and was fobbed off, they would pull back for a period of time, assuming the professional's expertise and capacity to deliver appropriate information. These parents were far less likely to seek a second opinion or to challenge any professional's comments and were always shocked to discover information of which they had never been apprised.

**Passive**

Four participants (8%) exhibited a passive information style. Interestingly, 3 of these 4 (75%) were DoCS Child Protection Service clients. They passively received information without great interest or enthusiasm, rarely engaging in information seeking efforts at all. Active efforts by one proactive professional meant two of the parents had high to middle rates of awareness of benefits, services and entitlements. Perhaps as DoCS took over a role of linking the child in to as many supports as possible, the family may have tended to pull back, in the sense of not taking action to get help. However, it was difficult to make this determination without having known the parents before their involvement with DoCS.

**Avoidant**

Only one avoidant parent participated in the interviews. It is feasible that most avoidant parents avoided being interviewed because they characteristically moved away from overt information exchange. This parent had been well known to the interviewer and only agreed to the interview for that reason. The pre-existing relationship also enabled the interviewer to probe areas the parent did not readily reveal at interview. There were highly significant issues related to the seeking of a diagnosis for her child who had displayed autistic tendencies for a considerable time without any professionals advising the family to seek an assessment. As the parent was avoidant in information style, she readily accepted "all children are different" platitudes and was optimistic that her child would become just like other children. Therapeutic professionals working with the child would not proactively recommend further investigation, preferring rather to wait until the mother asked questions about her child's development and behaviours. However, because the mother was avoidant this was highly unlikely to occur and another parent of a child with autism intervened to make recommendations about taking the child for
assessment. After continued efforts by this parent, the mother finally had the child assessed by a paediatric neurologist with a consequent diagnosis of autism spectrum disorder.

The mother’s avoidant information style was of considerable concern because there was a possibility that drugs used to control a medical condition had been indicated in her child’s developmental problems. A number of parents attempted to intervene and proactively deliver information to the parent related to the contraindication of certain medications during pregnancy when the mother announced her intention to have another child. However, the mother strongly believed that professionals would give incontrovertible evidence to her, were that the case. It is a moot point whether the mother proffered the information necessary to trigger her own doctor to deliver that information.

Information styles were spread unevenly across centres. Turramurra/Galston’s (T/G) apparently higher rates of a receptive style may have been because they were attending a strongly established centre. Many of the parents’ needs were being met by their early intervention service and there was less need to be seeking actively. This is in contrast to Ryde/Hunters Hill (R/HH), which was a relatively new offshoot of the main Turramurra/Galston service, where parents were still jockeying for help. This may have required a more active style. Marrickville’s predominantly receptive style would appear to be anomalous in this regard, as many of the families’ needs for service were unmet.
This raised a significant question: whether information style developed with information need or was simply a capacity unique to each parent. The issue was also clouded by awareness. Parents could only “jockey” for services they were aware were available and reasonable to request. In the case of Ryde/Hunters Hill (R/HH) parents, many were aware of services being received by Turramurra/Galston’s (T/G) parents. Marrickville/Lewisham parents, in contrast, were quite isolated and unaware of other parents’ services. Hence they were less able to develop awareness other than by personal information grounding efforts which fewer than half were likely to undertake.

It was difficult to tease apart the initial development of information style from parents’ individual contexts. Questions remained about whether there was any relation between factors such as educational level and information style. The chart below suggests there was no overt relation with higher educational attainment. Along with 4 out of the 8 hypervigilants being university-educated parents, there was also a very high rate of receptives among this group (11 of 21 receptives) tending to suggest that the figures were proportional. (There were 21 university educated parents.)
The child's disability similarly seemed to have no direct relation with the information style of the parent. Parents did not seem to develop an information style in response to particular needs arising from their child's disability. No disability stood out as particularly related to any information style. It may be the case that, for some parents, increasingly active styles developed over time. While it was not the case that parents of older children had a primarily hypervigilant and vigilant style, certainly of the 8 hypervigilants 6 had children 47 months and older. Clarification would require a longitudinal study.
Parental awareness of benefits, services and entitlements was of considerable significance. Information of this nature was critically important to parents, along with medical/diagnostic information. More than half the sample (n=25) were aware of less than 60% of benefits, services and entitlements for which they may have been eligible. Only 15 parents (30%) were aware of more than 70% of benefits, services and entitlements for which they may have been eligible.

There did not appear to be a specific relation between awareness ratings and centre attended, although Turramurra/Galston had more parents with the highest awareness levels (.7+) whereas Marrickville/Lewisham had a cluster of parents with low levels of awareness (.2<.4). The other results were more scattered.
The question arose whether there were other factors that may have influenced awareness of benefits, services and entitlements. Theoretically at least, it might be expected that a person aware of the formal means of acquiring information in the sector would have an increased awareness of critical information within the sector. Thus parents aware of information services specifically established to meet the information needs of people in the disability sector would also be more likely to be aware of benefits, services and entitlements. If one knew enough to know where to find information, would not one then have more information, especially that of particular relevance? In fact, the higher the correlation between awareness of information services in the sector and awareness of benefits, services and entitlements the more this would be likely to be true.

In fact, those parents using information services did tend to have the higher rates of awareness of benefits, services and entitlements.
However, the rates of usage generally were so low, in fact primarily zero, as to suggest that rather than use of information services contributing to awareness of benefits, services and entitlements, it may be an indicator of a more active information style. Were this the case one might also expect to find a higher correlation between Internet use and awareness, and information style and awareness.

Chart 5.1: Parent use of the Internet compared with awareness of benefits, services and entitlements

The above chart is interesting for a number of reasons. Firstly, a cluster of frequent Internet users were also among those with the highest rate of awareness of benefits, services and entitlements. However, there was also a significant cluster of parents who did not use the Internet at all among those with the highest rate of awareness of benefits, services and entitlements. Secondly, 5 of the 6 frequent Internet users with the highest rates of awareness also had a proactive professional or community worker. This also held true for those 6 parents who never used the Internet but had the highest rates of awareness of benefits, services and entitlements. Information style compared with awareness of benefits, services and entitlements yielded similar results. The following two sections pinpoint two key, underlying factors which appeared to lead directly to higher rates of awareness of ancillary benefits, services and entitlements, namely, information style, and the services of a community worker or proactive professional.

5.3.3.2.4 Information Style and Awareness of Benefits, Services and Entitlements

The impact of information style was clearly profound. All parents with higher levels of awareness of ancillary benefits, services and entitlements were either hypervigilant or vigilant in information style, or had a community worker or proactive professional.
stark contrast parents with neither a hypervigilant nor vigilant information style, and with no community worker or proactive professional, had significantly lower rates of awareness of ancillary benefits, services and entitlements.

(>.7 = awareness of greater than 70% of available services, and, 0 = zero awareness)

* each of these parents with an awareness rating of >.7 had either a community worker or a proactive professional

** 3 of these parents with an awareness rating of >.7 had either a community worker or a proactive professional

Chart 5.12 Parent information style and awareness of benefits, services and entitlements

It seems likely that parent information style was related to personality characteristics, although this would need to be established through psychological testing. Certainly the themes arising from the qualitative component of the interview strongly suggest that it was the hypervigilant parents who were most likely to continue to push on, seeking for satisfactory answers. Professional resistance or failure to acquire information using one information acquisition mode subset would always trigger heightened efforts using other mode subsets. Hypervigilant parents were also the least likely to allow concerns about being perceived in a negative light to inform their seeking behaviours. This did not mean they did not have those concerns but rather chose to ignore them to get the best for their child.

Most other parents stopped at the point of resistance or failure to acquire, waiting for another trigger to prompt seeking, at which point they may start up seeking efforts again. Active, receptive, passive and avoidant parents were all very concerned not to be perceived in a negative light or to be seen as pushy, demanding, over the top, or a nuisance. This concern would shut down seeking efforts unless the original trigger was so great that its impact was perceived to be greater than the fear of being perceived in a
negative light. For example, many parents of children subsequently diagnosed with autism would reach a point where they literally could no longer live with the knowledge anomaly. The cost to the child, to family life, working life and social life was so great as to outweigh the cost of being perceived in a negative light. These parents would step up seeking efforts until resolution. Often the efforts required the parents to act in ways they felt were uncharacteristic and very difficult, experienced by some as demeaning and humiliating.

The extensive information grounding efforts of the hypervigilants, the vigilants and to a lesser extent the active, meant they were often located in a position to become aware either of information itself, or an anomalous state of knowledge which they could then seek to resolve. Yet the active parents, while having generally higher awareness levels than the receptives and the passives, did not display the same high awareness levels as the hypervigilants and vigilants. This may have been because, as previously observed, while the mode subsets utilised may have been the same, the actual information behaviours in relation to their use was often different. The hypervigilants and vigilants were always attuned to the wide information possibilities of any situation. The active parents' use of information mode subsets was often, in contrast, specific purpose oriented and therefore more limited in result. The expectation of what could be acquired by information grounding efforts may have had some impact on the outcomes.

Where parents with active, receptive and avoidant information styles enjoyed the services of a community worker or proactive professional the awareness levels were similar to hypervigilants and vigilants.

5.3.3.2.5 Proactive Professionals and Awareness of Benefits, Services and Entitlements

The chart below demonstrates that those parents enjoying the services of a community worker or proactive professional (n=14), in some cases in addition to a proactive reference group (the avoidant parent was clearly in this category), also enjoyed the highest rates of awareness of benefits, services and entitlements.
It is also important to note that every parent with a high rate of awareness (.6>.7) who did not enjoy the services of proactive professional had a hypervigilant or vigilant information style.

It would appear that the role of the proactive professional was such that the parent was able to acquire information and raise awareness levels irrespective of whether they had the information skills and knowledge base otherwise necessary to do so. Indeed in the qualitative component of the interviews, parents gave considerable commentary about the role of proactive professionals and the profound difference they had made to their lives.

Only those parents with a hypervigilant or vigilant information style achieved the same levels of awareness, no doubt due to their constant information grounding efforts. The fact that 4 of the 10 hypervigilants and vigilants also had a proactive professional does raise the interesting possibility that the “information savviness” of these parents extended to recognising the informing potential of certain professionals and others and actively utilised them for that purpose. Whilst these parents did not articulate it thus at interview, it was clear that they enjoyed more encounters with proactive people than other parents and seemed more able to maximise those opportunities.
Data pertinent to five issue areas was analysed, yielding an Infoline usage profile and information about parent information needs, problem areas for families, information diffusion patterns and the role of the professional. Comparative analyses of the Infoline data with parent interview data were then conducted. Each analysis is addressed in turn.

5.4.1 Infoline Usage Profile

5.4.1.1 Information Seeker Types

The comparative usage of the Infoline by different seeker types, since its inception in September 1998 until June 2002, can be seen in the following table.

<table>
<thead>
<tr>
<th>Seeker Type</th>
<th>% of Infoline Usage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional</td>
<td>58.1%</td>
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<tr>
<td>Family</td>
<td>33.9%</td>
</tr>
<tr>
<td>Student</td>
<td>7.7%</td>
</tr>
</tbody>
</table>

Table 5.3 Infoline information seeker types 1998-2002

This table clearly demonstrates that professionals are the primary information seekers using the service. Those classified as professionals include early intervention service providers (including both services generally and individual therapists), early childhood childcare providers, ECIA or ECICP members and government departments.

If the figures are presented as annual comparisons over three years the relative percentage of family information seeking is seen to be increasing steadily over time. It remains to be seen whether this trend continues.
The purpose of the usage profile is to give an overview of information seekers and information sought. A detailed listing of families’ information needs, reflected in the range of information sought, is found at 5.3.2.

In the period from the Infoline’s inception in September 1998 up to July 2002, the primary categories of information sought can be seen in the chart below in their relative proportions over time. The categories are:

- Early intervention services (re-named “early special education”)
- Therapy services
- Family support
- Assessment.
While no definitions of categories were supplied, and over time different staff members entered the data (see note below), some observations that can be made about these categories:

- **Early Intervention Services**
  
  This category refers to those early intervention services usually providing holistic programs in-house, with special education and therapeutic interventions including speech therapy, physiotherapy and occupational therapy. Much of the intervention is on a group basis. Each child in the service has an “Individual Family Service Plan” (IFSP) which details among other things all the interventions to be provided. They are distinct from specific therapeutic services provided by Area Health services or private practitioners.

  In the past these services have been provided by DADHC however much early intervention service provision today although funded by DADHC is provided by non-government organisations (NGOs). When parents are unable to acquire satisfactory services from a local early intervention service provider (because of waiting lists, non-availability of appropriate therapies or problems of a qualitative or quantitative nature) they may seek assistance from a therapy specific service and/or therapist supported playgroup.
Therapy services
This category refers to specific therapeutic interventions, for example physiotherapy, speech therapy, occupational therapy, that is usually accessed through Area Health services as an outpatient, or through a private practitioner. They are usually practiced one-to-one with the child, although some behaviour intervention therapies and hydrotherapy may include groups of children.

Family Support
A great deal of information can be classified under this category, including any services that enable a family to stay together and the child with a disability to remain out of care. It normally includes social work and various forms of practical, financial and psychological assistance. Prior to the dramatic increase in categories, from August 2002, this category would have included information about Home Help/Care, financial and practical assistance from for example Centrelink and Technical Aid for the Disabled, sources of support (financial and otherwise) to enable the child to remain in childcare settings (for example SNSS funding) and case management – where one link worker takes responsibility for coordinating the family’s access to assistance or informing the family of those services. The category would also include information on advocacy services that help families access assistance and services. Apart from financial assistance, these latter sub-categories and psychological assistance became categories in their own right from August 2002.

Assessment
When a child appears to have a developmental delay or disability, they may be assessed. The assessment is conducted by a multi-disciplinary team looking in fine detail at specific aspects of the child’s development. The child is graded or assessed in each functional area. A developmental paediatrician usually heads the team and gives the diagnosis.

While special education and therapeutic staff of an early intervention service may do an assessment of a child, their aim is not to give a diagnosis, but to assess what interventions the child may require. When the term assessment is used formally diagnosis is assumed, and would normally be conducted in an assessment centre, child development unit or similar.
From August 2002, as observed, the categories of information sought were dramatically increased threefold with a commensurate decrease in the recorded incidence of information sought in the “top four” categories. This was significant in the case of early intervention/early special education, as seen in the chart below.

![Chart 5.16 Infoline - information sought: comparison of four major categories across four years by % of total calls (1999-2003)](image)

It is difficult to reconcile the particularly dramatic drop in recorded incidence of information sought on early intervention services/special education (labelled “early intervention” on the chart above), which had remained constant at around 40-45% of total calls, with the unchanging purpose of the Infoline. Furthermore, there did not appear to be any particular surge in any of the other categories.
Table 5.4  *Infoline* — information sought: comparison of major new categories by % of total calls (2002/3)

<table>
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<td>8</td>
</tr>
<tr>
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<td>1.8</td>
<td>2.8</td>
<td>12.8</td>
<td></td>
</tr>
<tr>
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<td>1.8</td>
<td>-</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Early Ch Health</td>
<td>4.3</td>
<td>2.7</td>
<td>1.6</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>EI/Early Spec Ed</td>
<td>8.1</td>
<td>11.6</td>
<td>9.6</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Family Support</td>
<td>8.4</td>
<td>4.5</td>
<td>5.3</td>
<td>8.6</td>
<td>6.7</td>
</tr>
<tr>
<td>Playgroup</td>
<td>13.5</td>
<td>10.7</td>
<td>0.6</td>
<td>1.6</td>
<td></td>
</tr>
<tr>
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<td>8.9</td>
<td>8.7</td>
<td>8.6</td>
<td></td>
</tr>
<tr>
<td>Pre School Support</td>
<td>8.8</td>
<td>5.4</td>
<td>12.7</td>
<td>6.9</td>
<td></td>
</tr>
<tr>
<td>Respite</td>
<td>7.5</td>
<td>1.8</td>
<td>2.2</td>
<td>1.6</td>
<td></td>
</tr>
<tr>
<td>Schooling</td>
<td>14.6</td>
<td>5.4</td>
<td>10.6</td>
<td>8.6</td>
<td></td>
</tr>
<tr>
<td>Therapy Services</td>
<td>16.9</td>
<td>16</td>
<td>32.9</td>
<td>15.5</td>
<td>20.3</td>
</tr>
</tbody>
</table>

The results, in terms of the incidence of information sought under each category, appear to become less consistent monthly from August 2002. A "strong performer" one month may be virtually unrecorded the next. Only "therapy services" consistently remains a top performer, with an occasional high spike, and "pre-school/pre-school support" consistently remains a middle range performer, as seen in the table above.

The staff members answering the Infoline and entering the statistical data changed over time, in addition to the category changes themselves. There were no documented definitions for inclusion of data in each category. It seems likely that some variations occurred in the classification of data under the categories, especially after the dramatic increase in categories in August 2002, introduced by a new staff member. The scattered effect seen in the table above suggests it would be prudent to consider general trends, rather than attempting to establish specific statistical results for the usage profile.

Clearly "therapy services" is the primary category of information sought from the Infoline. This has remained constant over time. Information related to pre-schools that support children with disabilities and the actual supports (financial and practical) available consistently ranks in the middle range. All other categories have significant

302
peaks and troughs, such as assessments, behaviour management, casework, playgroups and schooling. There may be some seasonal connections but it is difficult to discern a consistent pattern. Certainly the March-April period sees strong growth in categories related to assessment, behaviour management, casework, early childhood health and family support. November, however, sees a significant drop-off in many of these categories, suggesting that there may be times families seek certain information more actively (either personally or through a professional service provider). From the categories described, it may well be that these families are among those having difficulties managing their child and getting help generally.

5.4.1.3 Seasonal Fluctuations in Use


Is it possible to predict the information that may be required by families at different times of the year? While it is not possible to make accurate predictions across the range of categories of information sought, a number of interesting points emerge:

- The December-February period reflect more closely direct family interest as early intervention services are either shutting down direct services or are
closed. "Therapy Services", "Schooling", "Pre School support", "Early Intervention/Early Special Education" were the primary categories.

- March-April period sees strong growth in categories related to assessment, behaviour management, casework, early childhood health and family support. November, however, sees a significant drop-off in many of these categories.

- At the beginning of schooling years families seek information related to basic therapeutic interventions and education.

5.4.1.4 Usage Profile Summary

The primary information seekers using the Infoline over time have been professionals, described by the Infoline as early intervention service providers (including both services generally and individual therapists), early childhood childcare providers, ECIA or ECICP members and government departments. Parents as information seekers have been increasing steadily over the same time period and if the trend continues at its rate of growth averaged over the last three years, will overtake professionals as the primary information seekers within one to two years.

When administrative requests are stripped from professional inquiries it becomes apparent that the majority of professional inquiries are those seeking information for families. These professionals were playing a mediation of information role. As the Infoline has become more established as a point of contact for information among families so family use of the Infoline has increased and professional use has dropped off slightly.

A realistic profile of primary information sought cannot be derived from the statistics. Significant difficulties attach to the change in categories of information sought from August 2002. Whilst the new categories clearly reflect more extensively the array of information potentially required, considerable conceptual ambiguity attaches to the change from "early intervention services" (which was the Infoline's original information delivery goal) to "early special education" and the alternative category of "therapy services". Clearly the major category of information sought is now "therapy services". Yet what this actually meant is unclear. Early intervention services combine
early special education plus various therapeutic interventions usually in group settings. The “therapy services” category relates to specific 1 to 1 therapeutic interventions, for example physiotherapy, speech therapy, occupational therapy, usually accessed through Area Health services as an outpatient, or through a private practitioner.

It seems feasible that parents seek information about early intervention in general for their child because they are either receiving insufficient services from their early intervention service provider, or, are wait-listed on that service (certainly waiting lists were frequently raised by callers as a problem area), or are indeed unaware of or unable to access early intervention services in their region. There are few early intervention service providers in each geographic area and severe limitations on places available in those services. It seems possible therefore that the Infoline now records this seeking as requests for information about “therapy services” rather than requests for information which may actually concern a need for early intervention, but for which there is no service available. This is because service providers either don’t exist in that area (e.g. the Illawarra region has no early intervention service provider and families can only receive blocks of service from DADHC) or have such long waiting lists families have no real prospect of gaining entry. As DADHC uses statistical results from the Infoline for planning purposes among other things, the extent to which the category “therapy services” is reflecting actual need must be queried.

Further detail regarding information sought may be found at 5.3.2.

5.4.2 Parent Information Needs

Categories of data recorded as “type of inquiry” for the period 1998-July 2002, with the administrative and professional-specific categories removed, function as a basic list of the service information needs of parents. The categories are:

- Early intervention services (early special education)
- Therapy services
- Family support
- Early childhood services (generic)
- Respite care services
- Toy library services
- Playgroups
- Assessment
- Schooling.
The further categories relate to information generally:

- Information - child development
- Information - other services
- Information - other

The dramatic increase in categories from August 2002 yields a far richer array of potential service information needs. However, it is important to note that the focus remains on services available rather than needs per se, with the aim being to locate a service which can address the family’s need/s. The categories, excluding administrative and professional-specific categories are:

- Advocacy
- Assessments
- Behaviour Management
- Childcare
- Crisis care
- Early special education
- Family support
- Giftedness
- Home help
- Information - child development
- Nursing services
- Playgroup
- Pre-school support services
- Recreation
- Schooling
- Therapy (Speech, physio, OT)
- Transport
- Aids/equipment
- Audiology
- Casework
- Counselling
- Early childhood health
- Family education
- Genetic counselling
- Hearing impairment
- Hydrotherapy
- Information service
- Nutrition
- Pre-school
- Psychology
- Respite care
- sibling support
- Toy/book library
- Vision impairment.

Apropos of the changing categories, it is difficult to reconcile the particularly dramatic drop in recorded incidence of information sought on “early intervention (ei) services/special education”, which had remained constant at around 40-45% of total calls from 1998-2002, to the average of 9% thereafter. Some of the new categories may have functioned as sub-categories of early intervention services or were recorded thus. As the sub-categories were teased out of the umbrella category it may have had the effect of reducing the incidence of calls pertaining to early intervention services.

The question is: what underpins the category changes? Do they reflect a growing understanding of the actual information needs of seekers in more accurate recording under more specific categories? Alternatively, do the changes reflect an increasing sophistication among information seekers with improved understanding of information potentially available to be sought? A third possibility is that there has been a dramatic
change in the basic usage profile, namely what constitutes the service information needs of parents.

The answer to what appears to be an anomaly may well lie in Infoline staff changes and the differing perceptions of information need as constructed from telephone conversations with information seekers. This researcher understands that new staff members responsible for the Infoline at the time of the changes were parents of children with disabilities. This may have triggered the category increase and possibly a change in approach to the classification and coding of data based on information sought. In any event, the lowered figures have remained firm over time. This suggests that while “therapy services” remains highly important to parents, other significant information needs must be considered. These may fluctuate over time but when taken together may more closely approximate the range of potential information needs of parents.

5.4.3 Problem Areas for Families

The range of problem areas raised over 1998-2002 includes:

- Lack of services
- Lack of information
- Lack of follow-up
- New services
- Dissatisfaction
- Accessibility.

The Infoline’s 2001/2 Annual Report (2002, pp. 3f.) provided an interesting variation to the usual categories, citing as the “top 5 issues raised in parent support calls”:

- Waiting lists
- Financial issues
- School aged support
- Children who don’t fit in the service system
- Lack of recreational programs.

Following this report, monthly reports and cumulations either use the original categories or do not report on issues of concern at all.

It is important when considering these categories to note that information seekers were not asked if they had issues to report, so data in this category was only entered when a caller volunteered such information. Callers may not have been aware that they could
raise issues that would then be reported, or indeed may not have become aware that they
had an issue until after the call was completed.

This data therefore provides a broad guide only and must be considered alongside
parent reported problem areas in this research and in the literature.

5.4.4 Information Diffusion Patterns

The means by which an information seeker became aware of the Infoline gives an
insight into diffusion of information regarding a service in the sector.

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<th>Source</th>
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# in 2001/02 the parent component was also recorded separately
* this figure shows the relative percentages for parents only
" from 2002/03 only parent figures were provided

where no figure is recorded the result is nil for that period

Table 5.5 Infoline - sources of information diffusion by % of total calls

As the results are quite scattered and appear to be changing over time it would be
difficult to pinpoint any one category as a primary means of information diffusion.
Certain broad trends may be discerned.
While the Infoline brochure has been strong in diffusion over time, this does appear to be weakening, and the 2001/02 parent only figure may be anomalous. (This may again relate to staff changes and differences in classifying raw data as either the brochure itself or the organisation providing it, or the forum in which the brochure was handed out. For example, a Disability Expo in that time period may have seen a dramatic increase in the raw numbers of Infoline brochures handed out to parent information seekers. As ‘Disability Expo’ is not used as one of the categories of sources of information diffusion, the source of diffusion would have been classified as ‘Infoline brochure’.)

The use of the telephone directory is strengthening and is particularly strong among the parent information seekers. Of some interest also is the consistently increasing role of early intervention services in diffusing information about the Infoline. Diffusion of information regarding the Infoline may be occurring as some parents seek entry into an early intervention service and are either unsuccessful, wait-listed or receiving limited/unsatisfactory service. Parents may then be referred to the Infoline by the early intervention service in order to locate alternative or additional services. Generic early childhood services, such as childcare centres and pre-schools, also seem to play a not insignificant role in diffusing Infoline information. Many of the other categories, such as ECIA, other peak organisations, government departments and ECICP, are clearly professional sources of information diffusion to the professional component of information seekers.

In summary, certain categories appear to be more strongly associated with information diffusion among parents in the sector than others, namely:

- Telephone directory
- Early intervention services
- Early childhood services, such as childcare centres and pre-schools
- Infoline brochure.

Two important categories failed to play any significant role in information diffusion. They are detailed below.
5.4.4.1 Family Network

The importance of other families of children with disabilities as both significant support and one of the most valued sources of information has been frequently reported in both research and family centred practice literature. Yet the Infoline data yields insignificant levels of information diffusion about the Infoline through family networks. This may be explained by parent interview results, showing negligible rates of awareness and use of the Infoline. If parents have low rates of awareness and use of the Infoline, one would not expect parent networks to be a source of diffusion of information in relation to it. And indeed, the low diffusion factor tends to validate parent interview results of low awareness and use of the Infoline.

5.4.4.2 The Internet

The Internet barely registered as a source of information diffusion regarding the Infoline. Even the most recent results continue to show the Internet as a negligible source of information diffusion, which does not, on the surface, appear consistent with the world-wide trend of increasing Internet usage. Yet if parents have low rates of Internet usage, as interviews evidenced, one would not expect the Internet to be a significant source of diffusion of information in relation to the Infoline. Again, the low diffusion factor further validates parent interview results of low Internet usage. As concerns the apparent inconsistency with world-wide usage trends, relevant commentary is in Chapter 7. It is worthy of note that even as increasing numbers of parents do use the Internet generally, significant difficulties attach to acquiring information of which one is unaware, in terms of formulating a search strategy that is likely to yield useful results.

5.4.5 The Role of the Professional

When the “type of inquiry” data of an administration nature (including “Admin/brochures”, “Admin/update info”, “publicity/networking” and “child protection”) is stripped from the professional as information seeker data, the remaining professional as information seeker data reveals the degree to which professionals seek information on behalf of parents. That is to say, this data suggests the extent to which professionals may be acquiring information for parents and therefore playing an
information mediation role. It remains to be seen whether the downward trend in the professional as information seeker category continues, and whether there is some association with the slowly increasing parent as information seeker trend.

In any event it is clear that professionals play a significant role in acquiring information from the Infoline for families, although this may be diminishing over time.

Chart 5.18 Professional use of the Infoline on behalf of families compared with family use (as % of total calls minus administration calls) 2000-2003

* average extrapolated from July 2001 – January 2002 inclusive figures

# average extrapolated from August 2002 – April 2003 figures
CHAPTER 6 - DISCUSSION

6.0 INTRODUCTION

By way of introduction consider two vignettes:

Gina is aged almost 3 years and has a likely diagnosis of global developmental delay, which may be related to in-utero maternal infection. She is progressing but is as yet unable to walk independently or communicate verbally and has significant behaviour disorder. She has required surgery and on-going medications for a renal condition. Aware of pre- and ante-natal complications a paediatrician referred the child for early intervention at 6 months, in addition to private physiotherapy. Gina’s mother observed:

...there’s a place on [X] Rd for children with autism and I walked past it and I thought “They’ve got a place for autism, what have they got for [my daughter]?” They don’t. There’s nothing there, nowhere I can go...and say “What do I do?” She doesn’t fit into the autism [spectrum], she doesn’t fit into the Spastic Centre, or cerebral palsy or whatever else is out there. I just feel like I’ve got to chase things. I’m always stuck in thinking, “Am I doing enough? Am I doing what she needs? What’s out there that I have to do – things I don’t know?”

At the time of interview the mother was unaware of Carers Allowance and the concomitant Health Care Card, RTA mobility parking, SNSS, respite, behaviour management programs, equipment provision through PADP and Technical Aid for the Disabled, Home Care, parent support groups and case management. At the time of interview the mother was almost immobilised with back pain and in some emotional distress. As the researcher detailed the family’s chronology of events it became apparent that the parents had never requested many services, benefits and resources simply because they were unaware of them. (Participant 25)

Jordan is 2½ years. Born at 29 weeks gestation he was a “premmy baby” who would not feed and never settled. He cried for almost two years. After repeated pleas for help his mother finally said to his paediatrician, “If you don’t do something you have him, you take him home because I’m going to throw him through the window.” Subsequent examination by a paediatric neurologist yielded a diagnosis of cerebral palsy. The neurologist also commented in passing that a drug being administered to Jordan for gastro-intestinal reflux could be stopped - indeed he had banned its use in his own hospital as he considered it a “poison”. The drug was the subject of an investigation within the hospital at the time. Within two weeks of ceasing the drug Jordan stopped crying and settled. The mother had not articulated a need for a specific “diagnosis” as, although she believed something more than “premmy baby” was in view, she was unaware his problems may have related to cerebral palsy. Similarly, the mother had not raised questions about the safety of the reflux drug being used as she was unaware it was the subject of an investigation. (Participant 29)
Each vignette demonstrates parental failure to acquire information of critical significance, in terms of both content and process, with profound effects on the well-being of the families and the children. These vignettes are not exceptional. The literatures of child development and special education, psychology and social science, nursing and medicine, uniformly agree on both the importance of information to families of children with disabilities, and, the on-going parental dissatisfaction and unmet need in relation to its acquisition. Furthermore, each of the parent participants in this research detailed information acquisition problems. They appeared to be critically uninformed during many phases of the "becoming a parent of a child with a disability" process and each of the crisis and transition phases beyond. This occurred notwithstanding the fact that abundant information as resource or commodity and as representation of knowledge (McCreadie & Rice 1999a, pp. 46, 48) was theoretically available, as mapped by the researcher in the domain’s information milieu. (Refer to Chart 5.1 map of the information Milieu of the Childhood Disability Sector.) It is noteworthy that these issues of access to information, as expressed particularly in acquisition, have continued to be problematic despite many years of research, developing practices and changing models of service delivery.

Sectoral research, for example, has shifted in emphasis from stressors to adaptation and coping in an effort to identify and foster those factors related to improved outcomes for families. Models of service delivery have also shifted in emphasis from expert through consumer to family-centred practice (Case 2000). This has seen a shift in the role of parents from passive receptors of professional expertise to "experts about their child and family" (ADD 1997, p. 2). Yet none of these developments has resulted in any change or approach, philosophical, structural or otherwise, capable of demonstrating an appreciable and lasting influence on access to and acquisition of information. Indeed specific negative information sequelae appear to be flowing from those very models and research approaches intended to build family resilience and support the whole family such that it can provide an optimal environment for the child’s development. Why is this occurring? As a parent quoted in Mitchell and Sloper’s (2000, p. 19) research so cogently observed,

...if you go into any office - health, education or social work - you wouldn’t think there was any problem with information because there’s thousands of leaflets...and yet people still say they don’t get enough information. So to me that’s the starting point of the problem. It’s not simply that people aren’t getting
the information, it's why are they not getting it when they want it, or in the form that they can absorb it, or in a way that they can act on it? [emphasis added]

It is necessary therefore to understand how parents do acquire information in daily lived experience, the points at which they fail to acquire and why this occurs. Does the parent acquire information by seeking? What does that seeking look like? Are there other modes of information acquisition? What do they look like? Is it the same for all parents? What are the differences in information acquisition and why do they occur? Are there situational, contextual and/or personal factors that influence outcomes? Discovering the answers to these questions has been the essence of this research.

Research questions 1 and 2 are therefore addressed in turn below. Potential areas for improvement addressing research question 3 are found at 7.2.

6.1 HOW DO PARENTS ACQUIRE INFORMATION?

The conceptual and analytical framework developed in the course of this research specifying Modes of Information Acquisition is presented in summary below, synthesised with relevant theory and research, and NSW Government policies and practices. It embraces the multi-faceted concepts of information and access to information identified by McCreadie and Rice (1999a, b). It is important to note that this framework models the array of information acquisition and is by no means equally available at all times to all parents. The acquisition of information by parents of children with disabilities is neither systematic nor consistent across all parents. Situational, contextual and personal characteristics all effect influences on acquisition as do the characteristics of the information itself and its management including delivery. (These factors are addressed at 6.2 Issues.)

Of particular note in understanding the modes of acquisition are parent information style and a conceptualisation the author has developed, namely, the awareness heuristic. The six information styles of parents identified by the researcher both exerted an influence on, and were predictors of, information activities undertaken by parents and their behaviours in encountering resistance and failure to acquire. These styles appear to be entirely consistent with Miller's (1990) cognitive information styles, using instead of
cognitive factors information activity parameters and increased specificity of the information style subsets. The awareness heuristic, as conceptualised by the researcher, the need to be aware that one is unaware in order to seek to resolve a knowledge anomaly, on the other hand, affected all parents, to a greater or lesser degree. It mediated the parent’s capacity to recognise need and seek information. That is to say, where parents were aware of gaps and uncertainties and specific information needs, they could take action to seek information. Where they were unaware of gaps, needs or anomalies, or indeed information itself, they had latent information needs and could not by definition specifically seek information. Yet where parents undertook information grounding activities, or proactive information delivery or serendipity occurred, the problem of the awareness heuristic could be overcome and information was often acquired.

Parents clearly acquired information in three distinct modes: information seeking; information delivery; and serendipity. In information seeking the focus was upon the instrumental role of the parent in acquiring the information. Had the parent not undertaken this role the information may or may not have been acquired. In information delivery the focus was upon the instrumental role of the professional/provider in parent acquisition of information. Had the professional/provider not delivered the information, the information may or may not have been acquired. In serendipity the focus was upon the accidental nature of the information acquisition, and clearly as the acquisition was wholly fortuitous it may or may not have occurred.

6.1.1 Information Seeking

Most parents did seek to acquire information at certain times. Yet while the expression “information seeking” implies almost uniform action, parent interviews revealed that there was a considerable variation in the degrees and types of action employed in seeking and their efficacy. This is consistent with Wilson’s (1981, 1997, 1999) implicit recognition of variable modes in information seeking, and also the variations in seeking demonstrated in research around optimal foraging (Sandstrom 1999) and environmental scanning (Choo 1999). Yet it also contrasts with the singular approach to information seeking observed in the stress and coping literature and child disability sector research premised upon it, which sees “information seeking” indiscriminately as an indicator of
adaptive coping to be encouraged, without further clarification or specification. (See 2.1.2.1 for further analysis.)

In fact information seeking was seen among parents interviewed to take a number of distinct forms, namely, active information seeking, information grounding and passive information seeking. Each of those modes demonstrated further subsets. It is important to note that a number of superficially like information activities may be indicative of quite different mode subsets of information seeking, depending upon the parental purpose or expectation behind the activity, such as use of the Internet and medical, therapeutic and educational appointments/sessions/contacts.

Each mode is presented in turn below.

6.1.1.1 Active Information Seeking

A mode of information seeking entailing parent initiation of active seeking in response to either specific information need/s or an anomalous state of knowledge (Belkin, Oddy & Brooks 1982) was readily identified among parents at interview. Where parents had a specific trigger to seek information many would do so. As these parents either became aware of a need for specific information or a discernible gap in their knowledge they would seek to clarify and/or satisfy it. This falls within the ambit of classic information need and seeking theories such as those of Taylor, Dervin, Kuhlthau, Ellis and Belkin, which require action on the part of the individual in response to a recognised need or gap.

Consistent with Dervin’s (1983) sense making approach, many parents could be clearly observed seeking to make sense, for example, of their child’s inappropriate behaviours, through seeking information, advice and guidance from professionals and other parents, although usually friends and family were consulted in the first instance. Parents often seemed to need some kind of validation from those closest to them that there was indeed a gap that could be identified. This is consistent with Chatman’s (1991) work on trusted sources or insiders. Yet it was important that parents were able to move beyond family and friends to other parents of children with disabilities in seeking information. This type of active networking was far more effective for information acquisition, however, it was more likely to be seen among parents at the vigilant end of the information style
spectrum. McCreadie and Rice's (1999a, p. 53) identification of the significance of interpersonal networks as part of access to communication reinforces the importance of these type of reference groups in access to information and the role of the mediator of information.

Yet considerable variations between parents were apparent in the specific activities undertaken to seek information and their resultant efficacy, and, parental response to resistance or lack of assistance from the professional and lack of success in initial acquisition attempts. These appeared to relate directly to the information style and knowledge base of the parent (see 6.2.1.1 and 6.2.1.2), although affects of reference group activity and a proactive professional or mediator could also be seen. Activities ranged from seeking information from friends, family, other parents, support groups and professionals to searching among information resources already held by the family or individual, and searching the Internet. Formal information service providers, such as the State Library Disability Information Service, were very rarely approached and when parents did so it was often with little success. Support groups with an information service function, such as the Down Syndrome Association, yielded far higher rates of information acquisition apropos of seeking efforts. It is worthy of note that staff and volunteers engaged in work within the support groups are virtually all parents and carers of children with disabilities.

Parents also reported seeking to resolve knowledge anomalies, as conceptualised by Belkin (Belkin, Oddy & Brooks 1982). The more tightly parents were able to “specify” the anomaly, the more effectively they could seek information. Yet often they were unable to do so. Dervin’s (1983; Dervin & Nilan 1986) sense making approach goes some way to explaining the frustration individuals felt in not being able to construct the “right question” to bridge a gap. Sense could not be made, or, from Belkin’s perspective, the anomalous state could not be resolved.

Yet as observed in Chapter 3, one of the problems in applying Belkin’s theory to the childhood disability sector may in fact be a requirement of too great a degree of specificity in Belkin’s ASK model. For example, for many parents of a child with a disability, the full extent of recognition of an ASK, may simply be having a child with additional needs, especially in the “early days”. Unfortunately, there was no information provision mechanism to which parents could address the question “tell me everything I
need to know (in relation to my child)”. Even those “information provision mechanisms” specifically funded by Governments, State and Federal, for information delivery within the sector, such as the Early Childhood Intervention Infoline, the State Library Disability Information Service, various local disability information and referral services and Commonwealth Carelink offices, played that role in the lives of very few parents interviewed. The results deduced from Infoline statistics (5.3 Infoline Statistics) and parent awareness and use of information services (5.2.3.2.3 Awareness of Benefits, Services and Entitlements) are very telling in this regard. Parents had extremely low rates of awareness of formal information service providers and negligible rates of use; they rarely played a role in parents’ information seeking activities whether active or passive.

However, where parents had triggers to recognition of specific anomalies that could be addressed by information seeking, often the process did resemble Kuhlthau’s (1993) information search process (ISP) in which parents moved from uncertainty and efforts to “specify” the information problem through to resolving it. This was rarely a fluid and problem-free process, however, and one needs to remember the attendant and on-going knowledge base, high stress and chronicity of crisis problems with which parents lived.

6.1.1.2 Information Grounding

The second mode of information seeking, namely information grounding, occurred when parents did not have a specific need, gap or anomaly prompting seeking efforts. While no specific information need was in view in information grounding, activities were employed that clearly had the effect of increasing the probability of the parent becoming aware of information previously unknown of itself or of the relevance or application of such information.

Pettigrew’s (1999) conceptualisation of an information ground is the basis of this researcher’s concept of information grounding. An information ground temporarily results from “the behaviour of people who have come together to perform a given task, but from which emerges a social atmosphere that fosters spontaneous and serendipitous sharing of information” (Pettigrew 1999, p. 811f). Information grounding actively takes the opportunities offered, not only by the type of information grounds envisaged by Pettigrew (1999), but also by the manifold resources latent in any individual’s
environment. Hence the emphasis is more upon the instrumental action of the individual to exploit varied opportunities for acquiring information within everyday life, and less on the functional utility of a ground which is almost arbitrarily created and therefore may be inherently unstable and unreliable. Hence where Pettigrew (1999) sees in the chiropody clinic one information ground, the author of this thesis sees the possibility for multiple information grounding activities. These may include networking among fellow patients, reading ephemera such as noticeboards, pamphlets and brochures and seeking to take the communication with the nurse beyond the immediate matter at hand toward broader issues.

There are similarities between the information grounding construct and the optimal foraging characteristics of scholars, described by Sandstrom (1999), and the modes of environmental scanning termed “undirected viewing”, “conditioned viewing” and “informal search” described by Choo (1999, Modes of Environmental Scanning section, paras. 2-4).

Such similarities with optimal foraging and environmental scanning appeared among more vigilant parents. Their information grounding activities had the same effect as an environmental scanning strategy, where knowledge of the external environment, namely the childhood disability sector, was constantly being built. Wilson (1997, p. 562) in seeking to identify modes of “searching” additional to active searching, identified the notion of “ongoing search”, where a knowledge framework has been established and on-going search fills it in and updates it as necessary. This seems to exhibit some similarity with the “informal search” of environmental scanning (Choo 1999) and could readily be seen among the more vigilant parents. This knowledge base building related not only to the child’s particular disability, but also to the services and resources available and importantly how to acquire them. Often this information was acquired as data in the environment (McCreadie & Rice 1999a, p. 47), where the more vigilant parents were keen observers of what other parents acquired and how they went about doing so and this information was readily built into their growing knowledge base.

Yet information grounding had the effect both of building the parent’s knowledge base and raising awareness of anomalies in that knowledge base. The significance of the growing knowledge base also lay in its function in aiding parents to make more accurate assessments of relevance of information and to identify and clarify problem areas. In
these ways information grounding increased the incidence of both intentional and unintentional information acquisition among parents. Erdelez' (2004) work on the opportunistic acquisition of information (OAI) and Wilson's (1997, p. 562 “passive search...when one type of search (or other behaviour) results in the acquisition of information that happens to be relevant to the individual”, suggest some parallels with information grounding activity.

In short, the parent engaged in active information seeking or grounding had, by virtue of his or her own activity, dramatically increased the probability of becoming aware of information and recognising information need. This was in stark contrast to the parents who acquired information serendipitously, that is to say, apropo of no activity on their own part. Parents who were not an active agents in identifying the limitations in their awareness of information and their unrecognised information needs, tended to remain helplessly dependent on the delivery activities of others, which may or may have been forthcoming. This is consistent with Sloper and Turner’s (1992) work in relation to the acquisition of support by parents of children with disabilities. They concluded that the connection between a passive coping strategy (characterised by non-information seeking among other things) and unmet needs appeared to derive from mothers taking a less active approach to getting help and thence receiving less help in turn.

Multiple subsets of the information grounding mode were identified among parents and quite distinct differences in usage patterns emerged. Hypervigilant, vigilant and active information style parents all used the array of information grounding mode subsets. Receptives used only one or two narrowly and with specific purpose. Passives and avoidants did not appear to use the mode at all. Activities parents reported undertaking included networking, browsing the Internet, parent libraries and resource centres, seeking out and actively using/reading resources such as noticeboards, information kits and newsletters, which most parents undertook to some degree at some point, whether frequently or infrequently. Activities also included appointments and routine sessions with professionals used to acquire more information than that only regarding the matter at hand, attendance at conferences and expos, and, committee membership, which far fewer parents undertook. These activities are strikingly similar to the environmental scanning activities described by Auster and Choo (1991, p. 3) and the optimal foraging characteristics of scholars, described by Sandstrom (1999, Prey Choice and Other optimal Foraging Models section, para.6).
Ellis' (1989, pp. 179f) model of information seeking would also appear to have some application here, particularly the "starting" feature, in which the individual, implicitly or explicitly recognising the limitations of his/her current knowledge, sets about grounding him/herself through means aimed at achieving awareness of gaps in knowledge. It is the contention of the author of this thesis that this is in effect "forcing" Belkin's (1986) ASKs (see Chapter 3) by controlled exposure to multiple information grounds. Thus among parents, the effect of parental exposure may have been to force an ASK specifically enabling the parent to identify what was not known; where knowledge or sense ran out as it were. If this analysis is correct, it may be that for the more vigilant parents (49%, n=24), generalised uncertainty as conceived by Kuhlthau (1993) triggered a broad "information grounding" response, without recognition of particular need. Location on multiple information grounds then increased the likelihood of becoming aware of the ASK (Belkin, Oddy & Brooks 1982) and opportunistic acquisition of information (Erdelez 2004).

Furthermore, parents frequently employing information grounding activities appeared to have significantly higher rates of success in information acquisition using active information seeking. It also seemed to be the case that apropos of their grounding activity, the more vigilant parents were often alert to upcoming issues and crises in advance of less vigilant parents. They were then able to take pre-emptive action in actively seeking information and/or services and support, consistent with Choo's (1999) commentary. It appeared that the wider the parents' exposure to non-specific information exchange opportunities (afforded by information grounding activities), the greater the disability knowledge base which in turn improved information acquisition skills. Hence, as might be expected, while most parents in the very "early days" experienced failure to acquire information actively being sought, those employing more active grounding strategies improved acquisition rates significantly over time. This derived firstly from becoming aware of the information need state and secondly, in having developed the necessary knowledge base, to go about satisfying the need.

The key role of networking, in particular with other parents, in information acquisition found in this research mirrors that of childhood disability sector research (Mitchell & Sloper 2001), as well as government-funded research, policy and practice (Families First Inner West 2002a). It is also consistent with LIS research. For example, Ellis'
work investigating information seeking among academics moving into a new or unfamiliar field found a similar pattern of behaviour, in approach to "people whom they believe are knowledgeable about a particular area...to get some guidelines and information about the topic...often they can give you tips and advice..." (Ellis & Haugan 1997, p. 395).

It seems surprising therefore that while the New South Wales government recognises the significance of parent networking, "families [often] find interactions with other families more useful than interactions with professionals. The similarity of family circumstances affords exchange of highly relevant information" (ADD 1997, p. 2), there appears to be little proactive, systematic, coordinated support or facilitation of networking. While seed funding is available to families setting up innovative family support groups, such as Family-to-Family, these rely on the instrumental actions of parents to initiate and maintain and therefore appeared to be inaccessible to parents towards the less vigilant end of the information style spectrum.

The difference between parents actively seeking out and reading information resources, for grounding purposes, and parents responding to information passively located within the environment is important to note. In the case of the former, more vigilant parents' activities were characterised by thorough reading of those resources, whereas in the latter case, more receptive and passive parents tended to "flick through" materials, expecting to notice anything of relevance. What these parents did not realise was that they were in all probability less able to make accurate judgments of relevance due to a more limited knowledge base. The more vigilant parents, while exhaustively reading materials, were constantly building their knowledge base and hence increasingly able to make accurate judgments of relevance. It is conceivable, although it would require further investigation, that the greater the vigilance the better the calibration between perceived and actual knowledge and hence necessarily capacity to judge relevance. Consumer research examines knowledge calibration, the gap between what the individual knows and what the individual thinks he or she knows. Lichtenstein and Fischhoff (1977, p. 178) found that among those who knew nothing (and a very limited knowledge base would tend to characterise the more passive parents) the "situation led to vast over-confidence, terrible calibration, and no resolution". That is to say the less well developed the knowledge base, it is feasible that the less able the individual parent
was able to make a realistic determination of how much he or she knew and what was actually available to be known, hence restricting seeking activity.

There was also a significant, qualitative difference between parents using medical, therapeutic and educational appointments/sessions/contacts as an information grounding activity and those same types of appointments/sessions/contacts being used to attend to a specific problem or routine activity only (passive/generic information delivery). In the case of the former, the hypervigilant/vigilant/active parent would often attend armed with multiple written questions, ideas to explore with the professional, information acquired elsewhere for the professional to review and an almost relentless determination to be directed to other sources of information or possibilities. Pettigrew (1999) noticed a similar distinction in the chiropody clinic.

Again parents at the more vigilant end of the spectrum were among the few to utilise actively a further two of the most effective mode subsets of information grounding. Conference and information session attendance and membership of committees yielded consistently high levels of information acquisition for participants. The more vigilant parent information style sub-groups were further differentiated here, in that only the hypervigilant parents tended to take leadership roles on committees, organise functions and information events and present papers at conferences. It was also the case that hypervigilant and vigilant parents recognised the information potential of these and other information activities and used them for that purpose. Many of the professional conference organisers, such as ECIA, specifically set a budget to support parents of children with disabilities financially to attend, though attendees are almost always hypervigilant, vigilant and active types unless a proactive professional intervenes. A number of receptive parents did attend disability specific conferences but they used the conference attendance to acquire specific information known to be needed. They did however experience OAI (Erdelez (1997, 1999, 2004) becoming aware of information unexpectedly. This did not however prompt them to attend conferences as an information grounding strategy.

The active parents, who were also utilising the wide array of mode subsets, often did so without information motivation as such. For example, committees were joined for civic responsibility rather than information potential, and conferences were attended to
acquire specific information rather than to achieve broad exposure to the state-of-the-art.

6.1.1.3 Passive Information Seeking

Passive information seeking was the third mode subset of information seeking, which while passive did not entail total inaction. Action was that of response to what was available or offered rather than active initiation of an information seeking process. The key feature of the mode subset was receptiveness to what was offered and the success of information acquisition was reliant upon the ability or willingness to use the opportunity presented to acquire information. Giannini's (1998) differentiation of receiving information and seeking information is helpful here. Seeking encompasses movement and directional activity on the part of the individual, whereas the individual:

receives information from his/her 'Information Environment' defined as the sum of all the ways a person receives information in the course of everyday life ... receiving is characterized by the external information environment acting upon a person with no specific information agenda, whereas in the seeking mode, a person acts upon information based on a specific information need. Thus, for example, a person buying a newspaper while waiting for a train, listening to the radio while driving to work, surfing the Web, or browsing in a bookstore, would be considered to be in information receiving mode (Giannini 1998, p. 363)

Although there may be some overlap with information grounding, this can best be differentiated by examining the intent and outcome of any action. If a newspaper was acquired was it read exhaustively from cover to cover (information grounding), or flicked through with the hope of noticing anything relevant (passive seeking)?

Parents utilising these mode subsets may have wanted to seek information but did not have the necessary information literacy skills to do so. Alternatively, parents may have had the information literacy skills but circumstances precluded their use. Those circumstances may have been personal or contextual, including the awareness heuristic, reluctance to “rock the boat”, family circumstances such as the burden of caring, or simply the actual information displayed to which a parent could be exposed and respond.
Parents with receptive and passive information styles were most likely to use this mode. Rather than initiating active seeking efforts they tended to respond to what was either passively located in their environment or offered to them by a professional or provider. As the focus was on the role of the parent being receptive, rather than the action of the professional in delivering, this remains a seeking mode.

Wilson's (1997, p. 562) identification of "passive search" as a mode of "searching" at first glance seems to hold potential as an analogy of passive information seeking. However, the definition Wilson provides of "one type of search (or other behaviour) [resulting] in the acquisition of information that happens to be relevant", suggests this not to be the case. This is far closer to a blend of Erdelez' (2004) OAI, which always occurs in the context of active seeking, and serendipity where non-information-related behaviours or events result in information acquisition. Passive information seeking among parents was in contrast neither active in the sense of Erdelez' (2004) OAI nor serendipitous. Parents were simply responding to information located passively within their environment. However it was the case that more passive parents often described experiencing information acquisition through this mode as serendipitous.

At heart this was a passive mode and action/response frequently stopped with failure to acquire rather than the parent adopting alternative activities. If for example the noticeboard or brochure rack was not obviously positioned, the receptive or passive parent would tend not to have sought it out, even in circumstances where such a noticeboard had been useful in the past. Further, the more passive parents utilising this mode tended to glance over or flick through resources and this had a significant impact on their capacity to perceive relevance accurately and indeed to recall raw availability of information so fleetingly perused. It was also the case that the same parents who tended to glance and flick seemed to be those whose knowledge bases were less well developed, by virtue of the failure to employ exhaustive reading as part of active information grounding. Hence they were necessarily less well positioned to make accurate relevance judgements.

The problem of perceived relevance was important in information acquisition and it is noteworthy that for many parents, information passively available in the environment would only be considered if another person handed it to them, effectively influencing their judgement of relevance. In cases where parents were "offered" information by a
professional to which they responded (in the passive information seeking mode), it is important to recognise that the professionals were not being proactive. There was a quality of parents being willing to receive and professionals passively offering rather than actively delivering specific information which applied to a family’s particular circumstances. What this “looked like” were professional comments such as “why don’t you look at the brochure racks or in our parent library, you might find something useful there.” Parents would then often respond with some type of effort to peruse those resources. The difficulties of perceived relevance and therefore uptake kicked in again at this point if the professional failed to assist with identification of need and application.

6.1.2 Information Delivery

It is important to understand that information delivery in the childhood disability sector was neither a mirror image, nor a direct correlate, of parent information seeking. As observed earlier, the modes of information delivery focus on the efforts of the professional, provider or other person in delivering information to parents. This may or may not have occurred independently of parent actions in seeking and therefore must be conceptualised separately if the whole process of parent information acquisition is to be understood fully.

The problem of conceptual ambiguity in the use of information-related terms in the sector has been addressed in Chapter 1 and in detail in Chapter 2 and was strongly evident in information delivery. “Information delivery”, or provision or dissemination - all terms commonly used - generally refers to professionals and other service providers in the sector making information available to parents. However, what that meant on the ground, what that actually “looked like”, and parental experience of it, has never been conceptualised in the sector. There was no working definition under which everyone, policy makers, parents, professionals and other service providers, operated. This also includes, significantly, DADHC’s (2004a) most recent set of standards “Children’s Standards in Action: a resource for service providers working with children and young people with a disability”. As a result of the failure to specify just what is meant by information delivery and the instrumental means of its achievement, information delivery found wildly differing expression in the marketplace. It ranged from the “passive” (e.g. a poster on a wall), to the “responsive” (responding to articulated
requests for information), right through to proactive and targeted information delivery, where the individual parent was actively apprised of information, of which they may or may not have been aware, by professionals, providers and other parents. This conceptual framework necessarily yields a comprehensive definition of information delivery, of itself.

Kuhlthau's (1994, p. 175) work on the levels of library and information services; what she terms the "zones of intervention" are an important consideration in information delivery. She draws an interesting parallel with the medical practitioner's zones of treatment, which have particular application in the childhood disability sector (Kuhlthau 1994, p. 176). Five levels represent the increasing involvement of the professional in the actual delivery process: the "organizer, locator, identifier, advisor, and counselor" (Kuhlthau 1994, pp. 174). These levels of intervention mirror aspects of the modes of information delivery the author of this thesis has identified, being the passive/generic, responsive and proactive modes. They are not identical, however, as Kuhlthau still requires the user to be instrumental to some degree.

6.1.2.1 Proactive Information Delivery

Proactive information delivery was the preferred mode of information acquisition among most parents. The author termed it proactive mediation of information as it was clearly a "value added" mode of information delivery in that the deliverer's efforts were proactive, targeted and applied. McCreadie and Rice (1999a, p. 52) similarly describe this as "mediation":

Mediation occurs where our natural abilities to create, transmit, receive and process ... messages are extended, expanded or enhanced technologically by media or interpersonally by human intermediaries [emphasis added] (Ruben 1993 in McCreadie & Rice 1999a, p. 52)

The mode was observed to entail action on the part of professionals and others, to deliver information to parents that they had neither requested nor specifically sought. Parents were often unaware of the actual information itself and/or its application to their own life circumstances. The professional or other person delivering the information had usually concluded either from awareness of the family's specific circumstances and need, or, in extrapolating from precedent and the experiences of other parents, that the parent may have had a need for the information. The professional or other person did
not require a request for information to trigger information delivery and this was very
important to the recipient parents. Proactive mediation of information was described by
quite a number of parents in quite different settings. Sometimes the mediation of
information was one-off and issue specific and at other times formed part of an on-
going relationship.

Almost all interviewed parents expressed a preference for this mode of information
delivery by all professionals, however no parent enjoyed the mode as his or her daily
lived experience. Some parents however certainly experienced the mode more than
other parents, usually through a significant proactive therapeutic or medical
professional, or DADHC community worker. Of the 49 parents interviewed 14 enjoyed
the services of a DADHC community worker or other proactive professional, of whom
4 parents were hypervigilant or vigilant. It is worthy of note that all parents
demonstrating the highest levels of awareness of benefits, services and entitlements
were either hypervigilant or vigilant and/or enjoyed the services of a proactive
professional. As one parent observed:

...you’re in shock, you just want someone to take you by the hand and tell you
exactly where to go, ‘now do this, now do that’. And you are not capable of
going on the phone and trying to ring around and find out what you’re entitled to
and who you should see and early intervention. We were just lucky that [the
paediatrician] said straight away ‘Try to get into [early intervention service
provider], they do some fantastic work.’ And it’s only because of that ... He treats
[you like]... ‘How are you going? So tell me, how has it been?’ It’s completely
different. (20/627-655)

Proactive mediation of information, of an on-going nature, moved beyond simple
information delivery into a type of value added delivery where efforts were usually
made to understand the family’s “whole story” and unique circumstances. Certainly
Dervin (1989, p. 228) sees intermediaries as “responsible for making the system
appealing and useful to larger numbers of diverse people ... intermediaries would ask
users about their life situations” which is strongly suggestive of the context of
relationship. There is a sense in which the professional seeks to enter into the life
experience of the client, and in understanding their experiences is better able to identify
needs of which they may be unaware, although this is well beyond the ambit of
Dervin’s constructivist user paradigm. Yet it is not a problem of practice. As Mitchell
and Sloper (2000, p. 4) observe, “a person facilitating information provision can also
help to ascertain what information the family needs at what time.” It is at this point
information delivery moves beyond the responsive and into the realm of the proactive. Pettigrew (1999, p. 812) observed just this phenomenon happening in chiropody clinics, where the attending nurse entered into the life of the elderly patient, as it were, and addressed the information needs she was able to identify in that experience in the course of the interaction or “quiet exchange”.

Furthermore, delivery did not end with delivery as such; there was frequently application of the information to the family’s particular circumstances and revisiting of previously delivered information.

Yet the information delivery style evident among many professionals would be best described as reticent, as if concerned not to presume to know what parent information needs may or may not have been. Other professionals may have expressed the desire to be “more proactive” but serious unmet need and time constraints inhibited this mode of information delivery.

The proactive professional seemed to be analogous to the case manager or link worker described in the childhood disability sector literature. That role has been given many names, including care coordinator, service coordinator, link worker, family support worker, information adviser or key worker. It is “a single point of contact that many families would like” (Greco & Sloper 2004, p. 13). Sloper (1999, p. 90) observed that the problem of “the lack of a single point of contact and coordination for families” would be addressed by a key worker but that less than one-third of families had one. This research also found, as observed above, that 14 of the 49 families participating enjoyed the services of a DADHC community worker or proactive professional. At just under 30% this roughly equates with the UK figures.

McCreadie and Rice (1999a, p. 53) argue that mediation can “compensate for interpersonal or structural barriers to information”. This is entirely consistent with the proactive role certain professionals are seen to play in the childhood disability sector noted above. Pain (1999, p. 300) describes the importance of a key worker to the acquisition of information among families of children with disabilities. This is mirrored in many other pieces of research in the childhood disability sector (see for example, Greco & Sloper 2004, p. 13 and Sloper 1999, p. 90). Appleton et al (1997, Care management and care coordination section, para. 6) specifically state that care
management means, among other things, "proactively informing the public and referrers about the services" [emphasis added].

There may also be some analogies in the practices of the proactive professional with the "reference interview" of the skilled librarian who supports the client, moving from uncertainty to problem definition, to review of alternatives, to problem resolution, selective dissemination of information and current awareness services. Belkin describes the mediation of information by an information intermediary, who engages in analysis of the individual's problem area, and while he suggests that this "kicks in" at the point of the individual's recognition of the ASK (Belkin 1986, p. 6), there is no reason not to apply it more broadly in the informing process. As he himself observes, "one of the reasons that people do not get help in, say, the social benefits office, is because the few advisors [information intermediaries] that are there are overwhelmed by the work" (Belkin, 1986, p. 8). The role of the intermediary would appear to be quite consistent with the role of the reference librarian who takes the client beyond what they know they know, and that they know they need, toward what they may not be aware of but may be useful to them. This parallels Kuhlthau's (1999, p. 175) level 5 zone of intervention: "zone 5 problems involve the more on-going role of the counselor" (Kuhlthau 1994, p. 177). In this zone the user "problem or task is recognized as evolving over time in the process of information seeking requiring exploration, formulation, and construction" [emphasis added] and just like the medical practitioner analogy diagnosis is complex and dynamic (Kuhlthau 1994, p. 176). Yet it is in the presumption of user instrumentality, which incidentally is absent from the medical practitioner's fifth zone of treatment, however, that Kuhlthau's conceptualisation diverges from that of this author.

Other persons also proactively delivered information to families, including parents and friends. Families First Inner West research conceptualised "Family, Friends and Community Networks" (2002a, p. 68) as one of parents' four domains of sources of learning (or information acquisition, according to the conceptualisation of information adopted in this thesis). It seems feasible that one of the significant factors in the proactive delivery of information by other parents and friends was that they had the freedom not only to speak about their own experiences, but seemed also to proffer information and advice without fear of litigation.
As I said the paediatrician has only just now, decided to refer me to all these different places, but it's been over a year you know! So, whether they're hesitant to label kids, whether they're hesitant to give you the information in case they're wrong, maybe they get sued, I don't know. I think there's a bit of hesitancy out there to help you, unless you ask a specific question. (6/692-699)

Of course, the problem many parents faced was that they were unaware that a question either needed to be asked, or, what that question was. As observed earlier, Dervin's (1983; Dervin & Nilan 1986) sense making approach goes some way to explaining the frustration an individual may feel in not being able to construct the "right question" to bridge a gap in sense as it were. However, proactive parents and friends, in developing relationships, also built an understanding of other families' needs, which they themselves may not have recognised because of the awareness heuristic. The proactive parents and friends were able then to apply information to other families' unique life circumstances in ways that were meaningful and unlikely to occur with many professionals.

The problem is you don't have experience, you don't know what to ask...You don't know what to ask until other mother, already, like they [have] experience, they're ahead of you, they been through what you been through. So they know that what you should ask so they tell you "Go and ask them what is this". (19/2146-2154)

Indeed, the importance of proactive information delivery by other parents was reiterated across almost all interviews and is consistent with the value placed upon it in the literature.

6.1.2.2 Responsive Information Delivery

Parents reported that responsive information delivery was the primary mode of information acquisition by delivery, notwithstanding the fact that the proactive mode was clearly preferred. In this mode, professionals and providers responded to parent articulated requests, whether initiated by the parent or arising in the context of an information exchange opportunity provided by the service provider or professional. This is consistent with Dewdney and Harris' (1992) work among battered women, which reflects the largely responsive nature of information delivery in social service settings. This is confirmed in the findings of chapter 2.
The most common form of information exchange opportunity was the IFSP (Individual Family Service Plan) meeting. The aim of the meeting was to detail the family's service needs over the following 6-12 months and how each of the needs (including for information) would be addressed by the primary provider and/or referral to other services or organisations. This mirrors Kuhlthau's (1994, p. 175) level 4 zone of intervention, where the information professional functions as an advisor and during the interaction a process of problem statement, assistance negotiation and recommended action sequence occurs. In reality, however, the focus of IFSP meetings was often early intervention and specific therapeutic goals. Parents were rarely made aware of the "panoply of possibilities" in terms of services within and outside the organisation, in order that they might fully explore their needs and make informed requests for service. The single greatest frustration expressed by parents in relation to this mode of information delivery was that they were often asked by professionals "What do you need?", when they were not aware of what was available or reasonable to request, other than what the professionals themselves were offering. There was a particular concern that not being able to articulate need was not an indicator of an absence of need but absence of awareness of what was significant or what may have been possible. Parents often found then that IFSP meetings were a matter of form rather than substance. As most parents were unaware of the Recommended Practices in Family-Centred Early Intervention (ADD 1997, pp. 14f), they were also unaware that service providers were intended to deliver information to them on the broad array of "agencies" and "entitlements" also available to them, not just therapeutic interventions.

Sometimes providers developed specific information exchange opportunities aimed at 'breaching the information gap', such as the Connections Project of Carers NSW, which sought to get parents/carers connected with each other and mentors with strong knowledge bases, for information and emotional support. However the project was not based on an analysis of how parents actually acquire information but, accepting as a given the serious information problems among parents, aimed to trial an Internet-based 'innovation' as a solution. Only two parents interviewed were aware of the project and neither described it as having efficacy in their own acquisition of information.

Responsive delivery also occurred simply as professional or provider response to parent articulated requests. This was clearly the most common operating mode of both professional and service providers evident at interview. A wide array of providers and
Professionals fell into this category as their primary modus operandi. From disability parent/carer support groups, such as the Epilepsy Association, the Autism Association and Carers NSW, through to non-government organisations including those specifically funded to deliver information, such as the Early Childhood Intervention Infoline and the State Library of NSW - Disability Information Service. Most professionals also operated in this mode, although there were individual differences depending upon the parent and the circumstances.

It was not the case that most professionals and service providers were unwilling to deliver information to families, it was rather that they waited until family members articulated a request for that information. This modus operandi assumed parents were aware of what was available, its relevance and potential application to their unique circumstances. It also assumed parents had the ability to translate that awareness into an information need to which providers/professionals could respond, and, the willingness to articulate that need.

Indeed research around knowledge and perceptions of knowledge, noted earlier, along with the author's conceptualisation of the awareness heuristic, suggests considerable problems for information acquisition through responsive information delivery. (See 6.2.1.2)

It was also the case that without knowing or having been apprised of what was available, what was "appropriate" to ask for and indeed what other parents were receiving, all but the hypervigilant and vigilant parents were quite concerned not to be perceived as "greedy" or "pushy" or "wanting too much". Hence, free and open information exchange rarely occurred between parents and professionals/providers with whom they were in regular contact, especially among the active, receptive and passive information style parents. Yet without such free and open exchange, an essential element of family-centred practice (DADHC 2004a, p. 4), professionals and providers could not effectively practice responsive information delivery, which is assumed in most standards and models of best practice. The concern of parents not to be viewed in a negative light has the potential to undermine family-centred practice to a profound degree, with necessary negative sequelae in the acquisition of appropriate information.
Another problem for responsive information delivery lay in the practice of secrecy and deception by a number of parents. Chatman (1996) observed precisely this phenomenon among a separate population sub-group, she found self-protection expressed as secrecy and deception regarding personal circumstances. This had the effect of restricting mediation of relevant/appropriate information (Chatman 1996, pp. 195f). This effect was magnified among parents in this research, where primarily responsive information delivery was practiced. Indeed among parents, exchange of information was traded off wherever they believed access to services was potentially in jeopardy. It was certainly the case that some parents had not been aware of the consequences of not sharing information, or indeed the benefits accruing from doing so. In the responsive mode of information delivery, these issues could never be tackled as there was no on-going attempt to understand the family and its needs beyond what parents specifically requested. (See 6.2.2.6)

Furthermore, consistent with Chatman’s (1996) work on a Theory of Information Poverty around the notion of insiders/outsiders, as pertains to knowledge awareness, acquisition, definition and use, parents of children with disabilities did appear to form an “insider” group. “The idea that things can only be understood by other insiders may explain why there are informational barriers between these two worlds.” (Chatman 1996, p. 194) It is conceivable then that all the medical, helping and service professionals, though in many ways heterogeneous, became “outsiders” to parents. Thus the real and perceived differences between “being a parent” and “helping a parent” may have developed knowledge awareness and other barriers that a responsive style of information delivery could not overcome.

Firstly, as has been observed on a number of occasions, parents did not know all that was available to be known (the panoply of possibilities), often over-estimating what they actually knew (consistent with Lichtenstein & Fischhoff 1977), yet as insiders were best placed to know what was needed to be known (albeit often retrospectively). Secondly, while professional service providers knew all that there was to be known in this domain (in terms of combined knowledge), as outsiders, they did not necessarily know what was needed by whom and when. Furthermore, both the parent and professional groups were not themselves homogenous information exchanging groups. As a result there were serious information barriers operating in the domain before any individual “triggering” event occurred, to alert the individual to a gap in their awareness
of information and/or unrecognised information need. The capacity then to request
information from a professional or provider, who could then exercise responsive
information delivery, was seriously diminished.

Chatman's work among the "disadvantaged" has further clear application within the
domain of parents of children with disabilities. If information professionals within the
parents' information environment take a responsive stance in information delivery - do
not seek to enter into their world, as it were -- but rather await parents' identification and
articulation of an "information need", significant problems will set in for information
acquisition. For where the information professional acts in a responsive rather than
proactive mode, and there is no effort to demonstrate the application of available
information to the unique circumstances of individuals in order to make it meaningful,
then, by virtue of the information professional's position as an "outsider", the parent
would be much less likely to perceive relevance independently. This is interesting in the
light of Vakkari's (2003) commentary on relevance and utility judgments, which while
document-retrieval based still affords some insight into the power of perception of
relevance. "Search tactics used (including ... relevance judgments) are systematically
linked to the stage of task performance" (Vakkari 2003, p. 452). In particular, users "try
to infer how [information] will support task accomplishment. Thus they assess its
situational relevance and utility." (Vakkari 2003, p. 443). If, however, their perceptions
of relevance are flawed or otherwise inadequate to make an accurate assessment of
relevance, and the information professional takes a responsive delivery stance,
information acquisition is likely to fail.

Responsive information delivery can thus be seen to be problematic at a number of
levels for parents as a mode of information acquisition.

6.1.2.3 Passive/Generic Information Delivery

Information delivery also occurred in a passive or generic delivery mode. Inaction
classified passive/generic information delivery as a mode of parental information
acquisition. Passive/generic information delivery tended to occur as a body of
information presented in a static form, requiring parents to approach, or receive, and
apply the content. This accords with Kuhlthau’s (1994, p. 175) level 1 zone of
intervention where the information professional, as an information organiser, "provides
an organized collection, but no intervention in terms of mediation or education”. While one would expect to find within a formal information repository information resources organised with a high degree of consistency and structural accessibility, the broad spectrum availability of information resources located passively within most environments do not tend to display such accessibility.

Furthermore, there was generally no targeting of information, apart from that occurring naturally in disability-specific or service-specific resources. The unique needs of individual families were not addressed by this mode of delivery. Information acquisition flowed directly from the capacity of the individual to perceive relevance, apply and uptake, all independently of advice or guidance.

Passive/generic information delivery occurred in a range of mode subsets, from delivery of one-size-fits-all, generic information packages to the individual, through provision of parent libraries, newsletters, noticeboards, to routine sessions, conversations, appointments etc with professionals dealing only with the matter at hand. The latter was particularly noteworthy as it was the classic form of routine sessions and appointments that receptive, passive and avoidant parents had with medical, therapeutic, educational and other professionals. These events could not be construed as the information exchange opportunities of the responsive mode of information delivery as the event was largely a “one way street”. The receptive, passive and avoidant parents did not generally use the event to seek information beyond the matter at hand and professionals were passive in the sense that they did not use the event to deliver any more information than that technically necessary. In fact, Australian research among paediatricians has found that delivery of diagnostic information by medical practitioners to parents (addressing the most basic of information needs) is frequently affected by factors such as perceived intelligence level of the parent and degree of emotion displayed (Masnat & Graves 2000a). This is consistent with parent testimony both in this research and within the childhood disability literature generally of the great difficulties encountered acquiring information from professionals. Furthermore, such professionals did not seek generally to apply any delivered information to the family’s or child’s unique circumstances to improve the capacity of parents to understand the information and as a result the probability of parent perception of relevance and uptake.
The nature of information "failures" in this mode and their consequences were as broad as the array of providers utilising the mode. Sometimes failure occurred in a number of facets as conceptualised by McCreadie and Rice (1999a, b). For example, both in the generic information product (such as the "Blue Book") and the context or process of its delivery (such as the routine appointment with the early childhood professional dealing only with the matter at hand, for example taking the baby's height, weight and head circumference but not asking how everything was progressing). Elliott and Apte (Families First Inner West 2002a, p. 94) report Australian research claiming that 93% of parents expressed satisfaction with the "Blue Book" and an extraordinary 96% had read some of the parenting and first aid advice. Earlier research presented on the same "Blue Book" reported "85% [of parents] had found the health information helpful, but recall of the health information and first aid was poor." (Families First Inner West 2002a, p. 94)

It is not without significance that the developmental milestones recorded in the same Blue Book were usually disregarded by health care workers, according to parent interviews. Those health care workers included early childhood health centre nurses and general practitioners. Many parents interviewed struggled to have their concerns taken seriously even though their children were clearly failing to meet the milestones and demonstrating behaviours themselves worthy of further investigation. However while height, weight and head circumference measurements were taken, or transition to solid food may have been discussed for example, or vaccinations given, information was only usually exchanged specifically in relation to the immediate matter at hand.

This situation was further exacerbated where parents adopted a passive modus vivendi, waiting for the health care worker to identify issues. Indeed it would seem that if health care workers do not utilise the Blue Book for the purpose for which it was intended, its role in information delivery must be questioned. For it is important to understand that the Blue Book not only provides parenting, first aid and health information but developmental milestones that are intended to have an informing function, by alerting parents to development considered to be within the "range of normal". If parents respond to a child developing outside the "range of normal" by seeking information and help, and are rebuffed as parent interviews suggest often occurs, it would seem that the Blue Book had little informative value, apart from being an immunisation and medical intervention record.
Sometimes the information failure in the passive delivery mode was life endangering and all the more surprising inasmuch as it derived from the normal professional modus operandi and thus was more than likely to recur. In one example, when potent combinations of drugs were being used to control a child's epilepsy, parents were delivered information on the administration of the drug and advice that "there may be side effects". This constituted passive information delivery, as the bare minimum necessary. The parents were not however also delivered application information, such as "side effects might look like ....", or, "if you child starts to ... then seek medical attention immediately."

...we were told [there may be side effects] but we weren't aware, when reactions happened, we weren't aware of what we were looking for...[my daughter] actually stopped walking all of a sudden...[the paediatric neurologist] didn't tell us what we were going to look for...we found that out because [my daughter] tried to walk and couldn't. She fell over... (24/16-22)

The parents did not recognise that their child was showing symptoms of liver damage and hence continued with the drug regimen until the three year old literally lost the ability to walk. At this point the parents, who had not recognised earlier symptoms as side effects, realised something was seriously wrong and was in all probability a "side effect" regarding which they had received a generic warning.

Another example occurring with some frequency related to community transport, to which young children with disabilities were theoretically entitled. Early intervention service providers would make arrangements for a child to commence attending their service often unaware of whether the family had means of transport to the location. Community transport was intended to meet this need, however early intervention and transport providers rarely apprised parents of their right to the service and how to acquire it, in the course of either initial appointments or on-going sessions. Service providers were in effect functioning in a passive information delivery mode and delivering only that information pertaining to the specific matter at hand.

In some cases a generic information kit introducing the early intervention service provider had been passively delivered to parents, containing some reference to community transport. However, it is important to note that while many of the information resources statically delivered were in fact valuable resources, in the failure to orientate the individual parent to their function and relevance, providers rendered the
information virtually inaccessible. Here the role of mediation as a moderator of access to information can be seen (McCreadie & Rice 1999a, p. 52). Parents passively receiving the kit never became aware of the theoretical availability of community transport or if aware, never perceived its relevance to their own circumstances. There were many other examples of this.

Parent resource collections often held exceptionally valuable resources, covering a wide array of subject matter from specific services in local areas, to copies of a range of government policies and sector documents such as Standards in Action, to more theoretical works on different therapeutic approaches. These resources were by and large rarely used. They were never used at all by the receptive, passive and avoidant parents, none of whom could recall having been “introduced” to the collection. This is consistent with Dewdney and Harris’ (1992) findings. Notwithstanding their potential utility, research among a broad population in relation to perceptions of resources available to battered women in the community failed to identify traditional information repositories such as libraries and information centres, as sources of information and referral at all (Dewdney & Harris 1992, p. 24). Nicholas and Marden (1998, pp. 45f) also found very few parents used public libraries for parenting information, as libraries are “not open when [information is] needed” and they tend to be viewed as passive “resources for printed information and not as providers of advice”. In this sense advice can be seen as the application of information held within the information repository.

Generic kits or standardised information packs, as noted above, were frequently though not systematically delivered to parents entering services, making contact with support groups or attending assessment centres, for example. Yet few parents, apart from the hypervigilant, vigilant and active, thoroughly familiarised themselves with the contents, in the sense of actually reading what was there! This is quite extraordinary as there seemed to be a common misconception among service providers that passive delivery of a generic kit or package equated with the actual delivery of information. This was evidently not so and parent acquisition of the information content of such kits was low.

Again parent perceptions of relevance, as well as inaccurate self-assessment of knowledge (see 3.3.6), had the capacity for a considerable impact on the efficacy of passive delivery of bulk information that was neither applied to the individual nor revisited to ensure uptake had occurred.
When an issue arises you go asking for answers. You go looking for answers. But until that issue arises, you don’t know that that’s where you’re going to need help. In amongst that original package that I was given in hospital... was also a folder of information as well. Some leaflets, out of date leaflets mostly, but a whole host of different things. I actually jotted down some of the organisations and so on... I came across that piece of paper a year later, and some of those organisations would actually be useful, or things that I’d later come across, but I hadn’t remembered that I’d got it on the original list. So, it wasn’t at all relevant to me at the time. So that’s why you need to revisit it... it’s okay being handed that package of information at the beginning, but until its relevant, you don’t [apply it]

This parent had an active information style and was able to acquire the information rendered inaccessible by a memory failure, through other modes. Indeed, generally speaking, only hypervigilant, vigilant and to a lesser degree active parents usually took such a package and either absorbed its contents at the time by active reading, or recalled it later when a situation arose and applied its contents at that time. Yet as noted most providers delivered some type of information kit or package upon application or entry to a service, without ever applying or revisiting the information within.

Bodies of information passively delivered or made available to clients also occurred as disparate or connected series of information in the form of ephemera displayed, for example on noticeboards and in leaflet racks, or grouped into directories or folders. Pain’s (1999, pp. 304, 307) research among families of children with disabilities gives various examples of sources of information which are a form of passive information delivery, such as newsletters, local service provider booklets and leaflet racks. Nicholas and Marden’s (1998) research among parents in the community generally did find that magazines were useful for their currency. Chatman (1986, p. 384) also identified the imperative of currency in the design of an information delivery system among the poor, noting that “freshness of the information was a critical factor in acceptance”. Interestingly, Chatman (1996, pp. 202,204) was studying groups of “outsiders” who were “undergoing emotional, social and psychological adjustments for which their familiar world had not prepared them”, and who did not appear to benefit from “potentially helpful sources of information ... because [among other things] a source even when perceived as useful, often required too much effort”. That is to say, the individual was required to be instrumental in the acquisition of information to a degree that was beyond their capacity.
Even in the case where parents are able to approach and acquire "general printed information" as described by Pain (1999 p. 301), of the generic one-size-fits-all type, it was limited in utility as it generally failed to address individual parent concerns in regard to the individual child and the family circumstances. Certainly Chatman (1996, p.202) argued that "the concept of relevance provides insight as to why potentially helpful sources might be ignored". Dewdney and Harris (1992, p. 18) found the utility of static or passive resources, such as directories, is limited for women in crisis, as information acquisition is contingent on, for example, knowing the correct headings to check. They observed that the utility of such resources could be increased by improving their delivery through their internal organisation (Dewdney & Harris 1992, p. 28), a point also argued by Mitchell and Sloper (2000). Pain (1999, p. 303) considered that this type of information delivery has its role as a "backup" to what is said, rather than a primary source.

Passive information delivery would therefore appear to be most dangerous where parents are also less vigilant. Certainly the more passive parents described "glancing at" and "flicking through" bulk packs of information in case something may have been relevant. As already observed, such parents, in not actively information grounding and building a knowledge base were also in a lesser position to make accurate judgments of relevance of information passively delivered. Inaccurate judgments may well have resulted in failure to approach or receive the information in the sense of being interested to uptake.

Furthermore, the lack of awareness of information itself may have led parents incorrectly to appraise their situation as not being amenable to change. As discussed in Chapter 2, emotion-focused coping is more likely to be used in situations appraised as being out of the individual’s control, “not amenable to change” (Folkman 1984, p. 844). If one applies an information perspective to this contention an interesting possibility emerges. What may appear to be an unchangeable situation leading to an appraisal by the individual of having no control, and thus employing emotion focused coping, may indeed be a situation that is amenable to change, were the individual only aware of relevant information. (See analysis following 2.1.2.1.) This problem seemed to be far more likely to occur where the parent was neither actively seeking information nor information grounding. In the passive information delivery environment they would
have no inherent means of becoming aware of information which may lead to changing their original appraisal of a situation as not being amenable to change.

In fact it may well be that many providers employ the passive/generic mode of information delivery as a de facto adjunct to responsive delivery or a default position where responsive delivery is either not embraced or not considered feasible on an ongoing basis. Organisations may well do so not realising the impact in terms of parental acquisition of information, for all the reasons given above. Unfortunately, as standards and best practice models fail to detail the provider’s instrumental role in, and means of, achieving the desired outcome of “informing parents” all professionals and providers are virtually free to define their own mode of delivery, irrespective of whether that issues in information acquisition by parents.

As observed in Chapter 3, passive information delivery may have efficacy among active, constructivist users who have clearly identifiable and succinctly articulated problem areas, and who have the information skills necessary to approach a sometimes amorphous and disparate body of information, perceive relevance accurately and uptake and apply information as necessary. The reality is, however, that only those parents at the vigilant end of the information style spectrum appear to function in this way, leaving the majority of parents, who are located toward the passive end of the spectrum, unlikely to derive benefit from this mode of information delivery.

6.1.3 Serendipity

McCreadie and Rice (1999a, p. 69) observed that “in many instances, access to information comes about serendipitously, through unplanned encounters or conversations with others”. Certainly parental information acquisition also occurred where there were no intentional, purposeful seeking or delivery efforts by individual parents or other persons. Consistent with Dewdney and Harris’ (1992 p. 6) report on Beal (1979) and Dervin (1976) “most people are uninformed about public and private resources for solving everyday problems and that contact with sources of information appropriate to their needs occurs largely by chance”. Hence this was termed serendipity, as the individual events were wholly random and unpredictable, although they occurred in a predictable array of subsets. Erdelez’ (1996, p. 412) earlier work on information encountering is useful here as it is defined as the “accidental discovery of useful or
interesting information”. Information acquisition through serendipity was clearly distinguishable from information acquisition through information grounding activities (where parents literally “bumped into” information of which they had previously been unaware) and location on information grounds as envisaged by Pettigrew (1999). Such acquisition did not occur in the context of other information activity, as envisaged in Erdelez’ (2004) OAI. Indeed, the serendipitous events did not flow from any intentional information-related activity, such as is seen in grounding, and hence there was no expectation of information acquisition. Thus while on the surface the activity may have looked the same, for example talking to other parents, there was no sense of expectation by the parent acquiring the information that information acquisition was a likely result of the activity they were undertaking. Furthermore, the parents had not, by virtue of their own instrumental (seeking) actions, increased the probability of becoming aware of information, the need for it and OAI.

It was also the case that were it not for the serendipitous event the parent in all probability may not have otherwise acquired the information, through the functioning of his/her normal information seeking and delivery modes.

Williamson’s (1998, p. 31) research on incidental information acquisition among the elderly noted that “there were many examples of respondents acquiring information unexpectedly – where they were totally unaware of an information gap”. It was the acquisition of information that alerted individuals to their information need. “Incidental information acquisition” is clearly analogous to “serendipity”. Interestingly, incidental acquisition of information not recognised as needed until acquired, is actually evidence of latent information need. The need existed before the individual’s capacity to recognise, construct and articulate it. The triggering event to the awareness of both the information and the unrecognised need was the acquisition of information itself. Although Wilson’s (1997, p. 562) “passive attention” refers in part to the serendipitous nature of an information discovery, it is too limited in scope to describe adequately what was observed to occur among parents acquiring information serendipitously. Some serendipitous events did involve the media, as described by Wilson (1997), but many more involved direct contact with other people including complete strangers and acquisition as an unintended consequence of another action/event. One of the most striking examples of serendipitous acquisition occurring as an unintended consequence
of another action involved the late diagnosis of a baby with Down syndrome in the context of attending a routine appointment with an older child with a disability.

Sometimes the unintended consequence was a matter of the aggregation of intangible information such that the parent apparently “all of a sudden” realised or knew or became aware of something. This had all the hallmarks of being serendipitous while occurring more as a process rather than an identifiable event. Acquisition by serendipity also occurred where parents acquired information for another purpose and suddenly/unexpectedly realised its application to their child with a disability. The final mode of acquisition by serendipity was essentially all information otherwise “stumbled across” – information which was not otherwise systematically delivered. A parent described a significant example of this in relation to respite. She recognised in retrospect that because she had been unaware of the different types of respite available she had chosen not to use it because she did not think it appropriate to her son. Her knowledge base had been inadequate to make an accurate judgment about the relevance of respite. The parent described a person as possibly “hinting” at the information and it seems feasible that someone may have made a statement from which the parent was able to extrapolate that something such as occasional respite was an option.

The concept of information as data in the environment has particular utility in approaching this mode of acquisition, as a useful filter for identifying communication of information that occurs by virtue of events, activities and other phenomena, rather than intentional information exchange. McReadie and Rice (1999a, p. 47) see it an informing process that occurs “by perceptions of things that are communicated unintentionally”. Overheard conversations, tangential information utility in information delivered for other purposes, and observation of information and services received by others, are examples. Pettigrew’s (1999, p. 812) chiropody clinic patients acquired information in the context of receiving chiropody services in a community clinic: “information about local resources [was] shared serendipitously without anyone expressing (or necessarily having) a need for that information”. There are a number of good examples of unrecognised information need resolved by serendipity, embedded within Williamson’s (1998, p. 31) report.

One particular piece of information – regarding the availability of the Seniors Card and its entitlements – had been acquired incidentally by a number of
respondents. This card entitles older Victorians to a range of concessions and appears not to have been frequently mentioned in the mass media.

The latter finding is certainly consistent with what could be observed among parents of children with disabilities. Where information was acquired from the media it was usually serendipitous in the sense that the parent was not utilising the media in a way such that it functioned as an information grounding mode. Furthermore, the media were not proactively delivering information of use to parents. Nicholas and Marden (1998, p. 44) found that one of the reasons media was not preferred as a source among parents was that the timing of media exposure needed to coincide fortuitously with information need. Solomon (1997, p. 1107) has upheld that “information has a time value” and that “treatment of time ... [is] an input to understanding why systems sometimes are used and sometimes are not”. Certainly Nicholas and Marden (1998, p. 45) found “media does not appear when [parents] need it”. This emphasises the inherent unreliability of serendipity and its potential to increase stress when it occurs. In the case of Williamson’s (1998) research, the recipients were unaware of specific information for which, it would appear, there was no systematic program of information delivery. Each information event was serendipitous in nature. Yet clearly the information was needed by the recipients, as evidenced by their uptake and application. It was information of which they had previously been unaware and only its acquisition enabled identification of need.

The serendipitous nature of the information acquisition certainly created a number of problems for parents. There were often deep concerns regarding why nobody had apprised them of the information and recognition that were it not for serendipity they may never have “found out”. There was also a considerable impact on feelings of safety and assurance. Parental anxiety increased regarding other information that may have been “out there” of which they were not only unaware, but also unaware of how to become aware of its existence, other than a vague sense of needing to “do more”. Sloper and Turner (1992, p. 278) also argued that failure to acquire, or acquiring fortuitously, meant parents were less able to take an active role in their coping strategy and in turn acquired less help.

If this basic information is not available to parents from the time of diagnosis onwards, they are reliant on what is offered professionally, sometimes only finding out about other services fortuitously from informal sources, and less able to take an active role.
Hence the significance of information acquisition by serendipity must not be underestimated.

6.2 ISSUES AFFECTING INFORMATION ACCESS AND ACQUISITION

6.2.1 Causative Factors

Four causative factors could be identified exerting a direct influence on parental capacity to acquire information, both in terms of theoretical access and specific acquisition activity. They were parent information style; the awareness heuristic; and the miscalibration of professional/provider information delivery practices and policies, and, parent information needs/behaviours, expectations and assumptions regarding delivery. In addition, the involvement of a proactive professional with the family demonstrated a positive causal link with information acquisition, overcoming the negative impact of more passive information styles, the awareness heuristic and miscalibration. Each factor is presented below.

6.2.1.1 Parent Information Style

McCreadie and Rice (1999a, p. 54) observed that some individuals develop a communication competence, honed by effective access to and participation in communication processes that increases levels of participation, “increasing opportunities and skills for access in the future.” Importantly, they identified that the converse is also true, where “the impact of such deficiencies tends to compound over time” (McCreadie and Rice 1999a, p. 54). Taking into account conceptualisations of information as communication process and access to information as access to communication, described in McCreadie and Rice (1999a, pp. 48, 53), the significance of personal communication competence in the acquisition of information becomes apparent.

Miller’s (1990) work on cognitive information styles is particularly relevant in this context. She identified patterns of information-related activity that suggest basic differences in cognitive information styles in threat situations that are dispositionally
oriented and “fit” different situations more effectively. In essence individuals are either moving toward information (monitoring) or moving away from information (blunting). “How well an individual copes is determined, in part, by the fit of his or her characteristic [cognitive information] style to the individual situation” (Miller 1990, p. 113). For example, in a situation where a parent needs to acquire services in order to help a child, a monitoring stance would fit most appropriately and yield the best outcomes. This is consistent with the problem-focussed coping encouraged in the stress and coping literature (see 2.1.2.1). However this approach, and the body of literature that supports it, does not take into account the potentially dispositional basis of the differences in characteristic information activities undertaken by parents.

The analytical framework for modes of information acquisition developed for this thesis yielded a rich tool for understanding parent information styles from the perspective of their characteristic information activities. It became evident in the course of interviews that parents exhibited quite distinctive information styles.

Erdelez’ (1997, p. 417) analysis of the information-encountering experiences of students and employees in an academic environment, focussing on actual information activity rather than cognitive information style, found not the “binary classification” Wilson (1999, p. 845) reports, but four discrete subsets of individuals. Each group reported discernible variations in information activities. The “superencounterer” appeared to seek out opportunities for information encountering, such as that envisaged in the information grounding mode (see 6.1.1.2), the “encounterer” often experienced acquisition but did not perceive how these related to their own information activities, the “occasional encouters” simply experienced encountering as serendipity (see 6.1.3), and the “nonencounterers” reported seldom experiencing information encounters (Erdelez 1997, p. 417). The latter group included the non-participants whom one would expect to equate with the “blunters” who tend to be information avoidant (Miller 1987, 1990) and those identified in the stress and coping literature as adopting an emotion-focussed rather than a problem-focussed coping style (Folkman 1984).

All this is suggestive of a continuum-type array of information styles, ranging from the active to the passive. This research identified six parent information styles, on the basis of information activity and the stance taken in information acquisition efforts, however passive. That is to say, the specific activities undertaken (or not undertaken) to acquire
information through either seeking or receiving what was delivered, and the response to resistance or failure to acquire, predicted and evidenced information style. Kuhlthau's (1993) "mood corollary" is also worth considering in this context. "Mood corollary" is a term Kuhlthau employs to describe "the stance or attitude that the user assumes which opens or closes the range of possibilities in a search" (Kuhlthau 1993, p. 350). Interestingly the individual chooses whether to take an invitational stance, which opens up a wide array of possibilities, or an indicative stance, which limits the possibilities to those issuing in a conclusive result (Kuhlthau 1993, p. 350). Stance may tend to be dispositional in nature, which may in turn tend to confirm an individual's "typical" information activities and the approach to information acquisition difficulties and lack of success. Furthermore, there was a clear correlation between certain styles and information acquisition results. There were also quite specific reasons for the correlation, deriving from the behaviours themselves, as seen below.

At one end of the information style continuum were those individuals similar to Erdelez' (1997) superencounterers, who were actively engaged in moving toward and seeking information both in response to identified needs and anomalies and as part of a non-directional pattern of activity. Termed by the author of this thesis "hypervigilant", "vigilant" and "active" information styles, these parents were all active, problem-solving information seekers as envisaged in both classic information need and seeking theory (such as Belkin 1980, 1986, 2000; Dervin 1983, Dervin & Nilan 1986; Ellis 1989; Kuhlthau 1991, 1993), and stress, adaptation and coping theory (Folkman 1984; Folkman & Lazarus 1988). These parents comprised 47% (n=23) of the total parent sample (n=49).

Where a specific information need or knowledge anomaly was identified, hypervigilant, vigilant and active parents would actively seek its resolution using all the resources at hand. These parents were also engaged, significantly, in constant information grounding efforts, where there was no specific information need or knowledge anomaly necessarily in view. Such efforts immediately distinguished these parents from all others. They utilised the broad array of information grounding mode subsets, actively reading all resources acquired, attending appointments and routine sessions armed with questions, browsing the Internet, reading noticeboards, brochures, newsletters, attending expos and conferences, networking and becoming involved in management committees.
The effect of constant grounding efforts was the acquisition of information previously unrecognised as needed and/or of which the parent was not aware. It was also the case that the more vigilant parent was building his or her knowledge base generally and being alerted to anomalies in that knowledge base. That is to say, among these parents constant grounding frequently had the effect of overcoming the problem of the awareness heuristic (see 6.2.1.2), triggering identification of latent information needs and increasing the accuracy of relevance judgments.

For the hypervigilants and vigilants only, if one mode of acquisition proved unsuccessful others would be utilised until satisfaction was achieved. If this required constant visits to different professionals or “making 50 phone calls”, the hypervigilants and vigilants maintained a “whatever it takes” stance. In contrast the active parent’s failure to acquire information using one mode of acquisition would not always prompt more active efforts using another mode. The author described this as “pulling back with resistance”, and was a common phenomenon among the “receptive” and “passive” parents, described further below. Certainly research among parents utilising advocacy-type organisations in an attempt to get their needs met found they also faced resistance from professionals and great difficulty acquiring information and services but they did not cease seeking efforts (Case 2000, 2001).

Furthermore, while the hypervigilant, vigilant and active information style parents all utilised the widest array of modes in information acquisition there were specific points at which the active parents diverged from the more vigilant. One point was in the actual activities employed in each mode and the purpose for which they were undertaken. While the hypervigilants and vigilants were always alert to the information potential of any situation, identical to Erdelez’ (1997) superencounterers, the active parents were often seeking to satisfy only recognised needs, rather than seeking actively and consciously to become aware of all that they might need to know. Hence, active parents did not necessarily adopt what has been defined as an information grounding activity, for the purpose of acquiring information and similar to Erdelez’ (1997) encounterers would not necessarily relate information acquisition to their own information activities. For example, some active parents were members of committees however this was more with the intention of serving/helping the organisation than deliberately seeking to undertake activities with information potential and when information was acquired it was felt to be opportunistic, as per Erdelez’ (2004) OAI. Attending conferences and
information and skills sessions was also less a part of a conscious rationale to become aware of broad ranging information than specific purpose oriented. For example, active parents would attend information sessions regarding schooling options specifically to find out about the schooling possibilities for their individual child. Hypervigilants and vigilants would seize those same opportunities to meet local Department of Education and Training representatives and others to find out about departmental policies and initiatives, structures and useful contacts, among other things.

The second point of divergence was in the stance taken in information activities. The stance of hypervigilants and vigilants tended to remain constant. That is to say, in the face of resistance or failure to acquire they exhibited perseverance, while active parents tended to pull back with resistance and would often stop efforts when a failure to acquire occurred. Pulling back when facing resistance, or even the absence of support from the professional in articulating around a problem area, was more marked when the parent was experiencing something like Belkin’s anomalous state of knowledge (ASK) (Belkin 1980, 1986, Belkin, Oddy & Brooks 1982) rather than having a specific and recognised information need. This was almost certainly the case because the parent was less certain of his/her position and therefore less inclined to be dogmatic.

Indeed it emerged that the fear of being perceived in a negative light by professionals and providers was a significant concern to most parents. While it did not ultimately influence the information activities of hypervigilant and vigilant parents, it exerted a considerable influence over all other parents namely the active, receptive, passive and avoidant information style parents (n=39, approximately 80%) and the stance taken in all information acquisition activities. This proved highly significant in understanding differential information acquisition among parents. Stallard and Lenton’s (1992) reasoning regarding the use of data collectors who were independent of service providers to avoid response bias, lest the research be plagued by distortions “borne of the need to please or fear of adversely affecting future treatment” (Stallard and Lenton 1992, p. 203), is worthy of note in this regard.

It was certainly the case that participants in four of Mitchell and Sloper’s (2001, p. 244) seven focus groups considering characteristics of services that were helpful and unhelpful, did not wish to be tape recorded due to language difficulties and “parental unease”. The notion of parental unease suggested a concern not to be recorded voicing
criticism of their service providers. Yet the freedom of parents to express their views and wishes is a cornerstone of family-centred service delivery. Indeed the collaborative partnership between parents and professionals underlying the family-centred approach (Epps & Jackson 2000, p. 90) must be unachievable where parents are concerned about affecting future service to their child, and this is certainly the testimony of parents at interview within this research.

Again, while the more vigilant parents were concerned about being perceived in a negative light, as were other parents, this did not exert a negative influence on their information activities. Indeed these parents tended to face professional resistance with an “I’m going to do whatever it takes to get information/help” attitude. Folkman and Lazarus (1988, p. 313) seem to speak to just this approach describing it as “confrontive coping”, which tended to elicit “primarily information rather than emotional support”. Parents at the vigilant end of the spectrum were certainly more assertive than many professionals felt comfortable with. Yet this clearly yielded not only increasing levels of information access and acquisition, but quite evidently benefits, services and resources. Hypervigilants and vigilants seemed less concerned to acquire emotional support if information acquisition was at stake. The reduced emotional support experienced by more vigilant parents tends to validate parental concerns regarding not wishing to take information action or adopt a stance that may result in being viewed in a negative light. It also seems feasible that these hypervigilants and vigilants as superencounterers identified by Erdelez (1997) may equate with the parents perceived by some professional service providers as seeking excessive information (Pain 1999, p. 305). It is interesting to note Nicholas and Marden (1998, p. 43) found that where most parents utilised four sources on average one parent used more than twice as many as others, and two parents utilised fewer than a quarter used by others.

In contrast to the hypervigilants, vigilants and actives, a group of parents could be readily identified exhibiting more passive information styles. These information-passive individuals may in fact be identical to the primarily emotion-focused copers Folkman (1984) identified, disinclined or unable to adopt problem-focused strategies such as information seeking or even being dispositionally information avoidant (Miller 1987, 1990). The array of information activity undertaken by these people was far narrower and the employment of specific activities was more limited. The stance exhibited in information activity could also be described as more passive.
The identification of the problem-focussed coping style in childhood disability sector theory and research (for example, Folkman 1984; Folkman & Lazarus 1988) and efforts to encourage parents to adopt more active styles (Sloper & Turner 1992), necessarily evidences the fact that there are parents who do not characteristically display active coping strategies. Indeed it has been this author’s contention that one of the deep flaws in both stress, adaptation and coping theory, and, information need and seeking theory, is the failure to explicate “what is not” as much as “what is”. As asked in Chapter 1 Introduction, what happens when parents are not characteristically “active information seekers”, and, when they are not aware of the availability of potentially relevant information to seek?

The information experiences and behaviours of parents who could be clearly identified as receptive, passive and avoidant in information style speak eloquently to these questions.

Firstly it is important to note that the receptive parents (n=21) far and away comprised the largest single group within the interview sample1. Hence it would be fair to argue that the group also yielded the most data evidencing a more passive style. It would also be true to say that these parents did acquire information, but at nothing approaching the rate, quantity and quality of the more vigilant parents and this had a direct and measurable effect on both their awareness of services and resources and their capacity to acquire them.

The receptive parents were characterised by their “receptiveness” to information. That is to say, unlike the passives and avoidant who were either disinterested or moving away from information such as seen in the classic “blunting” identified by Miller (1987, 1990), these parents were often keen to receive information. However, they used significantly lower rates of active information seeking and grounding efforts than the more vigilant parents. As noted, while they were generally willing to receive information they usually required a significant trigger for active information seeking. Unfortunately they often either lacked the necessary information skills to know where and how to seek and even what was available to be sought, or, the capacity to apply those skills in the disability sector. This arose in part because of their limited knowledge

1 Hypervigilant n=8; Vigilant n=2; Active n=13; Receptive n=21; Passive n=4; Avoidant n=1
base due to the lack of information grounding efforts. Grounding activities were usually limited to occasional specific purpose conferences and information sessions. In an analogy of Pettigrew's (1999) chiropody clinic, these parents' attendance at information grounds, such as routine therapeutic sessions, did not yield the same information acquisition as for the more vigilant parents. Membership of support organisations often yielded only sporadic involvement or contact for specific problems and newsletters were either unread or scanned for relevance, in contrast to the exhaustive reading of newsletters often exhibited by hypervigilants, vigilants and usually active information style parents. The scanning was problematic in that in order to be effective the knowledge base needed to be adequate to make a realistic determination of relevance. Often this was not the case.

Consumer research on knowledge calibration and the accuracy of self-perception of knowledge has particular salience here. It must be understood within the context of family-centred care which promotes the “expertise” of parents of children with disabilities. Lichtenstein and Fischhoff (1977, p. 178) found that among those who actually knew nothing, in relation to a matter, the “situation typically led to vast over-confidence, terrible calibration and no resolution”. Furthermore, Radecki and Jaccard (1995, p. 133) found that “higher effort in knowledge acquisition may inflate estimates of the amount of knowledge gained” and evidence that inflated perceptions of knowledge actually interfered with information seeking. This is consistent with Alba and Hutchinson's (2000, 3. Implications for Consumer research section, para. 4) contention that “overconfidence will tend to inhibit search and under-confidence will increase search”. This is of particular concern as Radecki and Jaccard's (1995) research on the effects of educational interventions found that where, for example, such interventions are utilised to increase the individual's perception of the relevance or importance of certain information to their own life, there was a commensurate danger that “the interventions ultimately may lead to overestimations of one's knowledge level, thereby interfering with effective search strategies” (Radecki & Jaccard 1995, p. 133). Thus for example, parents may have concluded that information about respite was not relevant because of a limited understanding of the types of respite available and their potential eligibility, as a consequence they would tend to scan past and disregard information referring to respite, while genuinely believing that their decision not to use respite was “informed”. The family-centred approach, in confirming the centrality of
parental “expertise”, would have accepted that the parent made an informed choice not to utilise respite.

If the more passive information style parent was located in primarily responsive and passive information delivery environments, which required the parent to identify and articulate need for information, there was a high probability of failure to acquire. The parents were not systematically seeking and the professionals/providers were not proactively delivering.

Furthermore, the lack of awareness of information and comparatively inadequate knowledge base problems experienced by these parents were compounded by their stance when undertaking information activities. Along with active parents, receptives were very concerned not to “rock the boat” or to be viewed in a negative light and always pulled back with resistance or when facing difficulty or lack of support from professionals. Receptives often had a fear of retribution however vague or ill-formed (especially in terms of services to their child) and found it very difficult at a personal level to engage in “a fight” to get information and services for their child.

I don’t really know that, whether I should say that ['this service doesn’t meet my needs, you don’t seem to be interested in what my family needs'] or not because I’m afraid that if I say it, then you know, he will treat me different, or you know it’s not me, I feel like it’s not fair for [my son] if something happens, if [the service provider] takes it personally. (19/1867-1870)

It was also the case that anomalous states of knowledge among receptive parents were always characterised by difficulties in clarification and articulation of the “right question” that would open the door. While all parents struggled with this to some degree, the receptive parents would often not continue in their efforts to achieve satisfactory clarification. In the case of diagnosis, it appeared that their children may be at risk of later diagnosis (especially of diagnoses such as autism and global developmental delay) unless other factors intervened. These parents had high levels of expectation that professionals would proactively deliver information that was important. Hence if for example the parent expressed concerns about the child’s lack of language development or difficult or strange behaviours to a professional and was “fobbed off”, he/she would pull back for a period of time, assuming the professional’s expertise and/or capacity to deliver appropriate information. These parents were far less likely to
seek a second opinion or to challenge any professional’s comments and were always shocked to discover information of which they had not been apprised.

It is not surprising therefore that the receptive parents had very low rates of awareness of benefits, services and entitlements (evidencing information acquisition), with correlates in lower use. They faced significant difficulty overcoming the awareness heuristic because of their limited use of information grounding activity and higher expectation of professional information delivery. As a result they had a considerable array of latent information needs, as evidenced by receptiveness to information delivered at interview. As their knowledge bases were far less well developed than the more vigilant parents their judgments of relevance of information, used when scanning, were often inaccurate. It may well be that they experienced much greater knowledge miscalibration (Alba & Hutchinson 2000) than more vigilant parents, although this was not tested. The family-centred model’s attribution of expertise to the parent may have contributed to any miscalibration. It certainly seemed to be the case that the positive correlation between information activity and stance, and, information acquisition also held true with these parents.

Furthermore, it is the contention of this author that there must be a question of whether the information passivity observed derived, at least in part, from awareness. McReadie and Rice (1999a, p. 64) observe that “to gain access to information, a user must be aware that the means of addressing the situation are available”. Parents with receptive and passive information styles may well have been incorrectly appraising situations as not amenable to change simply because they are not aware of information, resulting in a failure to utilise active problem solving through information seeking. As these parents did not employ active information grounding activities, they were in turn less likely to become aware that situations in which they found themselves were actually amenable to change. They therefore had a far higher incidence of incorrectly appraising situations as unamenable to change, and therefore remaining passive. Sloper and Turner (1992, p. 276) certainly found the highest areas of unmet need were in the “provision of information” where, among other things, parents were either unaware of information or had attempted and failed to acquire. van Zuuren and Wolfs’ (1991) study supports the link between appraisal of a situation as being amenable/not amenable and information behaviour.
It should be noted that information styles were spread randomly across centres and there appeared to be no discernible pattern of attribution. There did not appear to be any association between information style and either parent educational level or the nature of the child’s disability. Information style did however exhibit a strong impact on awareness of benefits, services and entitlements. All parents with higher levels of awareness of ancillary benefits, services and entitlements were either hypervigilant or vigilant in information style, or, had a community worker or proactive professional. In stark contrast parents with neither a hypervigilant nor vigilant information style, and with no community worker or proactive professional, had markedly lower rates of awareness of ancillary benefits, services and entitlements.

As a final point, it is important to note that the information activities of individuals had not necessarily always been hypervigilant, vigilant and active. Nor indeed were these styles uniformly the case whenever the awareness heuristic came into play, especially as individual families entered a crisis or transition phase and their extant knowledge base was inadequate (see 6.2.1.2 Parent Knowledge Base and Effects of the Awareness Heuristic). In the “early days”, as parents entered the unknown domain for the first time, most information activities would have been similar to those of the receptives. However failure to acquire soon triggered information grounding efforts as a function of which these parents frequently acquired information of which they had been unaware. This in turn built knowledge bases and alerted parents both to anomalies in those knowledge bases and latent information needs. Over time these parents lowered their reliance on professionals to deliver. Action and resolve began to characterise their modus operandi.

Information style was thus clearly a causative factor in information acquisition/non-acquisition. All parents with the highest levels of awareness of ancillary benefits, services and entitlements (evidencing information acquisition) were either hypervigilant or vigilant in information style, or, enjoyed the services of a community worker or proactive professional. In stark contrast parents with neither a hypervigilant nor vigilant information style, and with no community worker or proactive professional, had commensurately lower rates of awareness of ancillary benefits, services and entitlements, based on limited information activity and a recessive stance to resistance.
6.2.1.2 Parent Knowledge Base and Effects of the Awareness Heuristic

The single most significant factor in parental acquisition of information next to parent information style, evident at interview, was awareness. Indeed McCreadie and Rice's (1999a) “awareness” facet of access to information is particularly relevant in attaining an understanding of parental difficulty in the acquisition of information. Those aspects identified are awareness of the availability of information, one’s right to information, one’s need for access to use of information, and how to proceed (McCreadie & Rice 1999a, pp. 56, 59, 64, 70). Also, knowledge or experience of a domain is recognised as affecting one’s capacity to access information (McCreadie & Rice 1999a, pp. 56, 59, 64, 70).

Yet the domain of the childhood disability sector was unknown to virtually all parents entering it, they had no extant knowledge base from which to make the kind of “connections” envisaged by Kuhlthau (1991, p. 362). They therefore had no inherent means of identifying what information “would be” available, their information needs and their knowledge anomalies, and no capacity to make accurate relevance judgments. They were literally unaware that they were unaware of a vast array of information potentially addressing their circumstances (consider McCreadie & Rice 1999a pp. 56, 59, 64, 70). They were therefore also unaware of need in relation to that information and could not actively engage in information seeking in relation to it. At the same time, the prevailing models of information delivery were responsive and passive because the family-centred model of service delivery holds that the parent is the expert on the child and family and therefore best placed to identify and articulate needs. This approach has unintentionally accorded a degree of importance to the instrumental role of parents in achieving awareness of information and recognition of need. Therefore providers frequently waited for parents to articulate needs for information and service at the very times they were least able to do so. It was only as parents’ knowledge bases grew, deliberately or otherwise, that they began to become aware of knowledge anomalies, latent information need and the relevance of information acquired.

Hence, the author conceptualised the problem of “the awareness heuristic” to explain predictable failure to acquire information that was extant, theoretically available for delivery and directly relevant to the circumstances in which the individual found him or herself. The effect of the awareness heuristic is such that the individual must be aware...
that he or she is unaware if they are to take action to resolve a knowledge anomaly. The awareness heuristic can only be overcome by the individual's information grounding activities, proactive information delivery or serendipity.

Awareness pertains to awareness of (threat relevant) information, awareness of (threat relevant) information need and awareness of an anomalous state of knowledge. The characteristics and effects of the awareness heuristic are as follows:

- Upon entering an unknown domain an individual will always experience effects of the awareness heuristic, namely lack of awareness of extant information and lack of awareness of information need. Furthermore, the individual will be unaware that he or she is unaware.

- The individual cannot, ipso facto, identify any gap or anomalous state of knowledge occurring nor formulate a specific question to overcome such a gap or anomalous state. Unless other factors intervene this will result in negative sequelae such as latent information need, information in-action, and failure to acquire information.

- Under conditions of heightened uncertainty or recognition in principle of the need for information in an unknown domain, an individual may undertake an array of information grounding activities. This may have the effect of alerting him or her both to a gap or anomalous state of knowledge and his or her pre-existing lack of awareness in relation to it and the extant information of relevance. This will have the effect of overcoming the negative sequelae to the awareness heuristic.

- The negative sequelae may only be otherwise overcome by either proactive mediation of information by a third party objectively identifying the individual's latent information need state, or, serendipity.

There is also a possibility that the awareness heuristic becomes a mediator of coping style, inasmuch as individuals may incorrectly appraise situations as being out of their control because of an awareness failure and hence adopt a more passive, emotion-focused approach. This has significant ramifications for stress and coping theory.

It should be noted that at times the sudden awareness of a gap or anomaly in knowledge structure, as envisaged by Belkin (1986, 2000), Dervin (1983) and Cole (1997), did
occur among parents, usually triggered by a significant and traumatic event, such as a child losing the capacity to walk or speak. The fact remains, however, that this does not and cannot explain why a gap in knowledge structure so enormous that it changes one’s entire life, (namely, having a child with disability), does not appear to automatically trigger an information seeking response among all parents. It would seem to this author that the issue then is not so much one of recognition of a sufficiently sized gap capable breaching awareness as Cole (1997) posits. Rather, it is the size and content of the extant knowledge base/structure as events occur and/or information is acquired that triggers awareness of the gap, influencing whether indeed the connections Kuhlthau (1991, p. 362) envisaged can be made. Hence matters of perceived relevance and so on act as filters.

Seligman and Darling’s (1997, p. 42, 43, 49) application of the sociological theory of anomie is highly relevant at this point, as there is a sense in which the known world abruptly ceases, leaving the parents not knowing how to “be” – in this case the parents of a child with a disability. “The taken for granted world abruptly ceases to exist” (Cohen 1993, pp. 82f.). Clearly a fissure has opened in the knowledge structure.

One of the hardest things for me...as much as my husband’s supportive it’s a new area, and he’s not coped very well at all with it. So, because it’s like he doesn’t know what to do, ‘How do I do this sort of thing?’ (3/1894-1898)

This would seem to be particularly the case in relation to information not known to exist, either as a general or a specific lack of awareness of information – a significant problem of the unknown domain as described above. For the gap itself (no matter how large) does not bring the individual any closer to knowing what he/she does not know, or even to being able to identify and articulate that he or she is not knowing, and what information is needed to fill the gap.

There were numerous examples of significant disjunctures in relation to which parents could not seek information, or not seek effectively, because of awareness heuristic problems. In one interview a parent described in detail the trauma of witnessing his child suffer and his failed attempts to resolve his knowledge anomaly around what he could do to help both her and his family end the suffering. His attempt to resolve the anomaly was expressed as a request to bring his daughter’s cardiac surgery forward so that if she was going to die it would be before the family had time to bond with her. It
was not until some time later that a family member stepped in and advised the family of their right to request a ‘do not resuscitate’ (DNR) order, by which time the child had already died and been resuscitated on several occasions causing extreme anguish to both parents and child.

It may well be that the smaller, qualitatively and quantitatively, the parent knowledge base, the greater the trigger required to breach the awareness threshold of a gap, as envisaged by Cole (1997). In this case “greater” would pertain to specificity and applied relevance. This would certainly seem to be consistent with the behaviours evident among parents at the more vigilant end of the spectrum. Their constant information grounding efforts had the effect of building their knowledge bases, frequently triggering recognition of both specific need and ASKs, further triggering specific seeking.

In contrast, parents undertaking far fewer grounding activities required a much greater and very specific trigger, often including some kind of relevance application made by another person, to recognise a gap and the need to seek information actively. Their knowledge bases were clearly lesser, qualitatively and quantitatively, than the more vigilant parents. The work of Chiesi, Spilich and Voss (1979) on variations in the acquisition of domain-related knowledge as correlations of the existing knowledge base is relevant here. It may well be that just as it is easier to graft new information onto an existing knowledge base (Chiesi, Spilich & Voss 1979, p. 270), so it may be easier to perceive a gap, to perceive that there is something one is not knowing, when there is an existing knowledge base. That is to say, either the gap in the knowledge structure can more readily be identified when there is an existing knowledge base, or, what is required to breach the threshold of awareness is lesser qualitatively and/or quantitatively where there is an existing knowledge base. This would certainly seem to be consistent with Chiesi, Spilich and Voss’ (1979, p. 263) finding that a “high knowledge” group required less information to recognise whether information was old or new (previously unknown). Hence what was required by the high knowledge group to breach the threshold of recognition was lesser than for the low knowledge group.

Thus in the case of the parents, where they had an existing knowledge base, what was required to breach their threshold of awareness may have also been lesser qualitatively and/or quantitatively. If this is so, it would explain the great significance of the information grounding activities, the wide array of which were utilised by parents at the
more vigilant end of the spectrum. They were in turn more readily able to identify specific needs and knowledge anomalies, and unequivocally acquired more information and services than other parents.

Furthermore, when information was delivered to parents it often required revisiting several times before uptake. This was especially the case where the information had no anchor points in the family’s existing knowledge base, that is, no prior knowledge or Kuhlthau’s (1991) “connections”. There may have been an inability either to uptake the information on first delivery, perceive its relevance or to apply it effectively. One parent whose children were having some issues with their sibling with autism was asked if she was aware of sibling support groups

I need that. You see somebody should have drummed that one into me. They probably did tell me. (5/2008)

The parent suspected she may have been told but the information delivery was not successful in the sense of uptake. When the parent expressed the need for having the information “drummed in”, the application of that information to the family’s unique circumstances in a way that made the information meaningful was almost certainly in view. Indeed the parent’s early intervention provider did have an active sibling support group, information regarding which was available in various introductory letters, brochures and other documents received by the parent. However as is apparent from the parent commentary something more than passive information delivery was required for the parent to acquire the information in a real sense. The information needed to be revisited and made meaningful to her, as her knowledge base at the time was inadequate to make the necessary connections and judgments of relevance.

The problem of inaccurate knowledge calibration may also evidence the significance of parent knowledge base and in particular personal perceptions of knowledge, as they appear to have a direct influence on what is called “information search behaviour” as noted earlier.

...perceived knowledge influences information search and the vigor with which individuals will seek out information in order to make decisions and form preferences. Individuals who overestimate their knowledge levels are at higher risk for making decisions based on inadequate information...overinflated perceptions of knowledge...lead to decreased vigilance in searching out new information and knowledge... (Radecki & Jaccard 1995, pp. 130, 132)
The awareness heuristic seems to exacerbate the problem, as Alba and Hutchinson (2000, Empirical Findings section, para. 6) observe of Radecki and Jaccard's (1995) findings, "These consumers do not know that they do not know and therefore are unaware of the need to search for more information or take other corrective actions." In the case of families of children with disabilities this search behaviour would include among other things the articulation of requests for information to professionals and providers, who could then exercise responsive delivery

One particularly significant possible source of inaccurate self-assessment of knowledge base, among families of children with disabilities, appears to be "the perceived importance of the topic...to an individual":

the more important a topic to an individual, the more likely it is that he or she will view him or herself as knowledgeable about that topic area...the result may derive from ... Higher effort in knowledge acquisition [which] may inflate estimates of the amount of knowledge gained. (Radecki & Jaccard 1995, pp.133)

When this is seen in the context of family-centred practice, which holds that the parent is expert and therefore best placed to identify and articulate needs, a number of significant problems become apparent. Given the extreme importance attaching to the whole issue of disability for the family of a child with a disability the propensity to miscalibrate knowledge must be intense, if Radecki and Jaccard's (1995) analysis is accepted. There is no question but that many parents engage in lengthy searches for information, meeting both the higher effort and higher importance criteria. Furthermore, it becomes apparent that parents' already potentially biased judgments of their own knowledge may in fact be affirmed by family-centred provider assertions that they are "the expert". This occurs when the reality is they are often unaware of critical information and they simply do not have the knowledge they would require to formulate an understanding of real need as premised on the panoply of possibilities.

The role of perception of one's knowledge base and the significance of miscalibration do require further investigation in the domain of parents of children with disabilities. However it remains that where parents were not actively information grounding, for reasons of miscalibration or otherwise, triggers to awareness of information needs and knowledge anomalies were either less likely or later to occur. For example, irrespective of how desperate the need of a family for therapeutic or other services, the need itself
could not trigger awareness of the knowledge anomaly in relation to services potentially available.

The awareness heuristic also had a direct influence on information acquisition around the whole problem area of diagnosis. Parents not recognising the inappropriateness, developmentally or otherwise, of their child's behaviours or symptoms, either would not seek diagnostic information, or, the efficacy of any seeking efforts was significantly reduced. It was not the case that these parents had no information need, but rather no recognition of their need because they were unaware of the significance of the child's behaviours. Some were also simply unaware that they were in an information-applicable domain. That is to say, that there was information available that spoke directly to experiences they were having. There were many examples of this.

I never even knew there was such a thing as autism [and] no one actually asked me “What's he like with socialisation?”...I thought he was shy and timid but that was all I knew... (2/299-328)

Indeed many serious problems arose apropos of the awareness heuristic. Even the more vigilant of parents were affected when lack of awareness of information itself caused the parent to appraise a situation incorrectly as not amenable to change and therefore ceased, or did not initiate, information seeking activity. Folkman (1984) observed, when 1300 stressful episodes were analysed, that problem focussed coping (as evidenced by activities such as information search) increased where situations were appraised by the individual as amenable to change. In contrast, emotion-focussed coping increased where situations were appraised as not amenable to change.

The significance of this in terms of information behaviour is enormous, especially when understood in the light of McReadie and Rice's (1999a, p. 64) observation that “to gain access to information, a user must be aware that the means of addressing the situation are available”. Where situations are incorrectly appraised as not amenable to change simply because the individual is not aware of information, this may well result in a failure to utilise active problem solving through information seeking. This may occur not only because of a parent characteristic, namely information style, but because of an information access variable, namely the awareness heuristic.
It is of some concern to this author whether in fact awareness of information itself may be partly responsible for triggering active information and help seeking, or act as a mediator of coping style as observed earlier. There is a possibility that more passive families at times actually chose a passive strategy because of the incorrect appraisal of the situation as being out of their control because of a lack of awareness of information. This would tend to be more consistent with parents complaining about a "lack of information", identifying unmet needs for information and yet apparently taking no action to seek information themselves. This is also consistent with Sloper and Turner’s (1992, p. 276) research where parents’ capacity to have needs met was affected “where parents were unaware of where help could be obtained or had attempted and failed to obtain appropriate help” [emphasis added]. This raises the question of what happened when information was delivered effectively to families, who may or may not have a passive coping strategy? (See 6.2.1.4 The Proactive Professional.)

It was clear in any event that awareness acted as either a trigger to a range of information behaviours or, a considerable barrier to acquisition of information. Where awareness of information triggered information seeking, it may have been either of an active or of a grounding, more exploratory nature. The converse was also true; lack of awareness of information not only meant that information seeking behaviour was not triggered, but specifically gave rise to the phenomenon of latent information need. In short, latent information need is the need for information unrecognised by the individual but identifiable either to others at the time through precedent and experience, or by the individual in retrospect. It can be distinguished from the unrecognised information need inherent in Erdelez (1997, 1999, 2004) and Williamson’s (1998) work through the potential role of a mediator to identify the likelihood of the phenomenon occurring in another, and, that it is identifiable by the individual in retrospect.

Even the most active seekers of information, hypervigilant parents who utilised multi-modal seeking and grounding, struggled at least in the very early days with awareness issues, particularly regarding anomalous states of knowledge. These usually concerned diagnostic and service information. It is interesting that one of the early issues pertained to being aware that other parents were also struggling to acquire information and services. Sometimes this awareness dawned slowly over time, sometimes awareness came with a sudden serendipitous event.
Problems of awareness did not end with the assessment, basic diagnosis and help seeking of the early days, as noted, parents consistently reported the need for, and absence of, information on their child’s diagnosis etc and information on services. Yet the information required was not only that which empowered the families to adapt to and live with the sequelae arising from their child’s disability (in health, educational and social terms) but empowered families to engage with professionals at an equal level. The notion of family “empowerment” is fundamental to family-centred practice (Epps & Jackson 2000; Porter & McKenzie 2000; Seligman & Darling 1997) however the information practices required to make it workable do not seem to be understood within the sector.

An effective family-focused service system needs to address the individualised needs of families at various levels of the family system with increased access to information ... one is left wondering whether the structure of the service system will ever allow this to happen, since some of the concerns pointed out by families have been the focus of professional attention for many years now. (Fyffe, Gavidia-Payne and McCubbery 1995, p. 39)

Most families interviewed were unaware for example of how to change policies, how to overcome waiting lists, how not to accept “no” for an answer. This was empowering information, for which parents were unlikely to articulate a request, because they were unaware that they were in an information applicable domain (when they were on the waiting list for example). The Map of the Information Milieu reflects the phasing nature of awareness of empowering information (see Chart 5.1).

Awareness also affected information acquisition less directly yet with equally significant results. A considerable mismatch between parent assumptions and expectations of professional information delivery, and, the reality of professional policies and practices in information delivery, was evident at interview. Parents frequently assumed proactive delivery on the part of the many professionals with whom they were dealing especially in the early days, quite unaware that professionals were not operating by the same set of information delivery assumptions. This is described below.

6.2.1.3 Miscalibration of Professional/Provider Information Delivery Practices and Parent Information Behaviour, Assumptions, Expectations

Of particular concern was evidence of a strong mismatch between parental expectations of professional information delivery and professional practices and policies. This was
evident in both information seeking and information delivery modes. That is to say, whether parents focussed on their own efforts in information acquisition or the professional’s, most parents had an expectation of delivery that was not matched by professional practice. This is consistent with Dewdney and Harris’ (1992) findings on the match between information need and information delivery in relation to domestic violence. They observed that “clearly there is a serious mismatch between the community’s expectations about the kinds of help available from physicians for abused women and the types of help they are likely to obtain” (Dewdney & Harris 1992, p. 17). Furthermore, this seemed to be part of a broader problem of miscalibration in the information environment, between the expectations of individuals and the reality of information practices by professionals and social service agencies, “in some instances the types of help that might be expected from an agency are not those which it provides” (Dewdney & Harris 1992, p. 23).

The work of Perrin, Lewkowicz and Young (2000) evidences the same miscalibration, revealing a lack of concordance between professionals and parents in key areas concerning information needs, which may go some way to explaining failures in information delivery by medical practitioners from the parent perspective. “Physicians noted significantly fewer needs with regard to both information and specific help than did either mothers or fathers...” (Perrin, Lewkowicz & Young 2000, V. Concordance Between Parents and Physicians section, para 4). That is to say, medical practitioners did not recognise many of the information needs their clients had and hence did not deliver information in relation to them.

If there is miscalibration, and this research along with that quoted above suggests there is, the question is why it occurs and what it is in the proactive professional’s role that addresses the problem. It is the contention of this author that two quite specific problems arising from sectoral policy are indicated as causative factors. Firstly, much current policy is premised upon family-centred practice as the model of service delivery, as addressed in Chapter I and noted repeatedly above. Indeed the Local Support Coordinator role funded in a growing number of areas by DADHC, as discussed earlier, is specifically premised on the understanding that individuals/families are best placed to identify their own needs. (DADHC c. 2001.)

Family-centred practice...is based upon a collaborative partnership between parents and professionals based on a mutual recognition and valuing of their
respective expertise, building on family strengths, and responding to family priorities. [emphasis added] (Moore 2003, p. 11)

However subtle, the instrumentality for family acquisition of information and services being vested in parents is seen here in the "responsive" stance taken by professionals. Hence, parents must necessarily become initiators. The effect then of policies emphasising family-centred service delivery, however unintended, has been to accord an importance to the capacity of parents to identify and articulate need for information and service. Yet the family-centred model may well be assuming a degree of awareness, a knowledge base, that this thesis demonstrates is simply not present. As Moore has stated (2003, p. 12)

Despite family-centred practice being accepted as best practice in early childhood intervention service for a decade or more, there is often a considerable gap between the rhetoric of what professionals and services think and say they are doing and the reality of what they are actually providing.

This may have resulted in part from the failure of professionals to understand fully the nature of information delivery required to support such practice and render it workable. Indeed it may well be that the changing models of service delivery have also subtly shifted the responsibility for parental information acquisition, and hence awareness, from information delivery by providers to information seeking by parents. This would certainly appear to be consistent with the changing research focus from stressors toward stress, adaptation and coping with the aim of fostering factors related to more effective coping. In particular, problem focused coping strategies such as information seeking are seen as important to develop. (See Chapter 2.)

Hence the information behaviours required of both professionals and parents to render the model workable may be neither properly recognised nor practiced, leading to miscalibration, where the parent assumes professional information delivery and the professional assumes parental information seeking in response to recognised need.

The danger lay not just in the philosophy of parent as expert articulating need, but in parents' absence of awareness that that was how providers are operating.

It also seems feasible, secondly, that part of the reason for miscalibration lies in the failure of sectoral policy to specify what exactly is meant by "information delivery" and "informing parents". As noted earlier, even DADHC's (2004a) most recent set of
standards “Children’s Standards in Action: a resource for service providers working with children and young people with a disability” fails both to conceptualise information delivery and to explain the instrumental means of its achievement. For an element that is clearly so significant to achieving the aims of the standards it is extraordinary that the extent of specification of what information delivery means is found in ambiguous statements such as “families should be provided with detailed information”, “providing timely and user-friendly information” and “information should be provided on a range of issues such as ...”. Patently, it falls to the individual professional/provider to define what is meant and thus to define their own practices.

Delivery of information by professionals was therefore not only affected by such policy, but was also subject to miscalibration with parent expectations because of consequent practices adopted and other factors beyond the parents’ actual needs for information. Hasnat and Graves’ (2000a, b) parallel studies of paediatricians’ disclosure of disability practices, and parents’ experiences of disclosure of disability, suggest some other factors. While parents, irrespective of educational level, were more likely to be satisfied with greater information (Hasnat and Graves 2000b, Determinants of Satisfaction with Disclosure section) paediatricians delivery practices were influenced by perception of parent characteristics such as intelligence and educational level (Hasnat & Graves 2000a, Reported Influences and Constraints on Disclosure Practices section). It seems reasonable to assume that the paediatrician arrived at a perception of parental intelligence during an initial informing process and that as parents were able to articulate more complex requests for information so the paediatrician responded with greater complexity and necessarily volume. This echoes Baxter’s (1989) much earlier work, which found the greatest discrepancy between three social status categories lay in “parents receiving information about their child ...The higher the occupational status the more likely were parents to have gained access to information” (Baxter 1989, pp. 19f).

An extremely important information acquisition issue arises from these findings. Were information acquisition failures related (at least in part) to parental ability/inability to seek information from professionals, or, to the inability of professionals to impart information effectively to parents with a range of intellectual and information seeking abilities? It is worthy of note that parents report information acquisition failures in terms of professional delivery failure (rather than their own seeking failure) and professionals
defend information non-delivery from the perspective of parent characteristics (rather than their own delivery preferences and abilities).

The answer would appear to be in the notion of miscalibration. Neither approach, parental expectation or professional practice, is inherently wrong; it is the fact of the miscalibration itself that creates the problems; the fact that both parties to the "information transaction" have incompatible perceptions of what is actually happening. It is simply true that some parents do not wish to receive information at times of deep crisis (in which case professional variations in delivery practice is appropriate), and, parents are subject to the problem of the awareness heuristic (as a result of which proactive delivery is logical to assume as necessary.) However, if parents knew professionals would not deliver information unless they were asked specific questions that demonstrated insight and understanding, because of professional concern that they may be unable to absorb all the information, parents may seek to find a way of expressing interest in acquiring information. Parents may even increase their level of information activity were they to recognise that they were not located on "safe information ground", where proactive delivery necessarily occurred. If professionals knew and accepted that all parents were subject to the awareness heuristic and had differential capacities to seek information in no way related to their actual information need, they may seek to understand the individual parent information style and recognise the need for proactive delivery.

Clearly the effects of the miscalibration were serious, lying in the impact of those assumptions or expectations on parent information activity and consequent information acquisition failure. Where parents assumed a level of proactive information delivery, they perceived less need to seek actively. Yet very few professionals in reality practised proactive delivery in any consistent way. Professional practices were largely responsive or passive. There were many examples parents reported at interview of professional failure to deliver critical information, however, when asked by the interviewer if they had ever sought either the information specifically or to find out as much as they could about the issue area, the answer among more passive parents was frequently "No." These parents simply assumed not only proactive information delivery but often continued passivity believing it should be so. The passivity among the more passive information style parents did in fact appear to continue even when miscalibration was revealed. It seemed that the concern not to be perceived in a negative light may have
meant that these parents preferred to continue assuming important information would be proactively delivered rather than "rocking the boat" by demanding more information and/or better service, or going elsewhere.

One would have expected to find least evidence of this type of miscalibration among parents' employing active information seeking on a regular basis, however their criticisms of professional information delivery failures were often the most strident. It is feasible that the heightened awareness of parents employing active seeking and grounding to the "panoply of possibilities" also issued in heightened awareness of any professional failure to deliver such information.

Two other factors may also exacerbate the problem of miscalibration. One is the insider/outsider dichotomy described by Chatman (1996). It suggests that insiders, who in this case would be parents, may shield themselves from needed resources where they perceive the professional/provider inhabits a different world. Hence although parents may expect proactive information delivery from professionals, they may also hold the belief, consistent with Chatman's (1996, p. 194) statement that only "insiders can truly understand the social and information worlds of other insiders". Certainly there was abundant evidence among parents interviewed along the lines that "professionals don't really understand". This may have had a direct impact on the degree to which information was actively sought from professionals and the stance taken in seeking. This contention is supported in part by the overwhelming preference for "other parents" (of children with disabilities) as sources of information both in the childhood disability sector literature (see for example Families First Inner West 2002a; Mitchell & Sloper 2001; OCYP 2001a, b) and within this research.

The miscalibration may also be effected by Kuhlthau's (1993, p. 351) "prediction corollary" which suggests that the search process is "a series of choices based on predictions of what will happen if a particular action is taken": "predictions are based on expectations derived from constructs built on past experiences". Where parents have learned that medical practitioners provide information in relation to health matters, according to the prediction corollary it would be reasonable for them to expect that doctors will provide information on disability issues. The parent's under-developed knowledge base of the childhood disability sector would not inform them at this point of the complex structure of the service sector and the differing roles played by actors
within it. And this is the point at which the application of Kuhlthau’s (1993) prediction
corollary falls down because the parents would have had no basis on which to formulate
predictions, having not been exposed previously to the disability sector and thus having
no capacity for the constructing activity based on previous experience.

It is interesting then that Williamson (1998, pp. 30, 35) has observed:

The notion of people “being informed” rather than “seeking information” often
seems to be appropriate … The majority of respondents indicated a strong desire
to “be informed” about a wide range of information topics for everyday life.

The significance of this is considerable. The desire to be informed implicitly recognises
that there are things the individual will/may wish to know about, but in not knowing all
that is available to be known (the panoply of possibilities), cannot identify and articulate
a need there for. Furthermore, the desire reveals an expectation of passive acquisition of
information, based on need-responsive information delivery, notwithstanding that that
need has not been articulated. This clearly would require proactive mediation of
information by objective outsiders able to identify information needs that the individual
is not recognising. This is entirely consistent with the stance taken by many parents of
children with disabilities.

Additionally, it is important to recognise that professional and service provider’s
information activities were also affected by the awareness heuristic. This goes not only
to the information need state of the client but also the information addressing the need.
The awareness heuristic as experienced by professionals had a significant impact on
professional capacity to identify and respond to parent information needs. A parent may
have been seeking to resolve a knowledge anomaly around the question “what is wrong
with my child?”, but the professional also had a knowledge anomaly in relation to the
child. The assessment process for example, was always fraught with difficulty and high
emotion, where the professional was effectively taking a snapshot of the child’s
behaviour to make an assessment while the parent often felt the image achieved of the
child was not realistic. This contributed to miscalibration as professionals were unable
to deliver information they did not recognise to be necessary or appropriate.

The professional literature has never sought to apply an information science perspective
to the information problems so frequently reported. This is strongly suggestive of an
inflated sense of expertise in relation to information. Yet miscalibration was a causative
factor in parental failure to acquire information for a number of reasons. If parents believed themselves to be on “safe information ground”, operating with the underlying assumption of proactive delivery, they frequently did not seek to acquire information. At the same time many professionals appeared to operate on the assumption that if a matter was important to parents they would talk about it and seek information. Professionals/service providers did not appear to recognise the problem of the awareness heuristic and its impact on the individual’s capacity to seek information. It also seemed that some professionals may tailor information delivery efforts not to information need but to frequently incorrect attributions of ability to receive information. All these issues were clearly exacerbated by problems of conceptual ambiguity around information and its delivery, together with family-centred policy and practice, contributing significant causation in the failure to acquire information.

6.2.1.4 The Proactive Professional

Parents’ information acquisition experiences of professionals and providers were not uniformly poor. There was a direct causal link between parental acquisition of information and the involvement of a proactive professional. A small number of parents within the sample (n=14) enjoyed the services of what the author has termed a “proactive professional”. This may have been a very effective DADHC community worker, or a medical or therapeutic professional. There was an effective relationship between the parents and the proactive professional; in each case the professional understood the family’s unique circumstances and information that was appropriate as to form and content was delivered proactively in appropriate ways. Appropriateness was achieved by the application of any generic information to the family’s unique circumstances and/or needs. Information previously delivered was revisited at times to ensure uptake and/or accurate judgments of relevance by the parents. Delivery was both proactive and responsive. Professionals were regularly apprising parents of information of which they were not aware, and, responding actively to parent requests for information – assisting with clarification of knowledge anomalies, identification of latent information needs and going to some lengths to locate and apply information.

A range of childhood disability research affirms the significance of such a role, described variously as a “key worker”, “link worker”, “information adviser”, “facilitator” (Fyffe, Gavidia-Payne & McCubbery 1995; Mitchell & Sloper 2000, 2001,
factor in parental failure to acquire information for a number of reasons. If parents believed themselves to be on "safe information ground", operating with the underlying assumption of proactive delivery, they frequently did not seek to acquire information. At the same time many professionals appeared to operate on the assumption that if a matter was important to parents they would talk about it and seek information. Professionals/service providers did not appear to recognise the problem of the awareness heuristic and its impact on the individual's capacity to seek information. It also seemed that some professionals may tailor information delivery efforts not to information need but to frequently incorrect attributions of ability to receive information. All these issues were clearly exacerbated by problems of conceptual ambiguity around information and its delivery, together with family-centred policy and practice, contributing significant causation in the failure to acquire information.

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Yet there is also a largely unrecognised requirement for proactive practice underlying much sectoral research (Case 2001, Quine & Pahl 1985). The role is assumed to be both proactive in delivery and importantly involving the application of information to the unique circumstances of the individual family. Furthermore, revisiting of information previously delivered is central to the role, along with on-going delivery in a type of targeted, selective dissemination of information (SDI) service. In moving away from a generic one-size-fits-all approach to information delivery, toward applied information, information must be targeted not just at the ages/stages of the child, but must be appropriate to the individual family’s situation and perception of needs. It is not possible to accomplish this apart from an effective information delivery process that sees the information provider in some sort of relationship with the family, and thus able to identify the specific needs of the family and how information may be appropriately applied.

The findings of this thesis validate the significance of the role of the proactive professional or link/key worker, from both theoretical and evidentiary perspectives. The key worker or proactive professional as an expert in the panoply of possibilities has a significant role to play in assisting parents to overcome the problem of the awareness heuristic, as conceptualised by the author, in the context of relationship with parents. The role addresses the access to information issues identified by McCreadie and Rice (1999a, b) including awareness: of the availability of information and ones right to it; of one’s need for access to/use of information; and of how to proceed.

From an evidentiary perspective, those parents enjoying the services of a community worker or other proactive professional unequivocally enjoyed the highest rates of awareness of benefits, services and entitlements. That is to say there was clear evidence that these parents had acquired information directly due to the intervention of a proactive professional, particularly in the case of the ten parents who did not have a hypervigilant or vigilant information style. It would appear then that the role of the proactive professional was such that the parent was able to acquire information and raise awareness levels irrespective of whether they had the information skills and knowledge base that was otherwise necessary to do so.

Only those parents with a hypervigilant or vigilant information style achieved the same levels of awareness and this was no doubt due to their constant information grounding
efforts. The fact that 4 of the 10 hypervigilants and vigilants also had a proactive professional does raise the interesting possibility that the “information savviness” of these parents extended to recognising the informing potential of certain professionals and others and actively “sought” them for that purpose. Whilst these parents did not articulate it thus at interview it was clear that they enjoyed more encounters with proactive people than other parents and seemed more able to maximise those opportunities.

It should be noted that while parents expressed the need for a person to guide them “through the maze” and advise them of benefits, services etc, they were not usually able to make explicit the connection between their own knowledge base and awareness of information, and the proactively informing role that was be played by a proactive professional or key worker. The literature also fails to do so. Indeed none of Mitchell and Sloper’s (2000, 2001, 2002) key research makes explicit the connection either, partly because the information acquisition implications of awareness of information are not given due consideration. The evidence, however, of this thesis is abundantly clear. Parents enjoying the services of a proactive professional, irrespective of their information style, had the highest rates of awareness of benefits, services and entitlements, demonstrating a significant information acquisition correlation with the services of a proactive professional.

As an aside, it is important to note that the “Local Support Coordinator” role provided by DADHC in a number of rural and regional communities would specifically not meet the requirements of the proactive professional for a number of reasons.

- Local Support coordinators are only intended to provide “basic information regarding the services and supports available” (DADHC 2004b, p. 7).
- No proactive role is envisaged as the Local Support Coordinator responds to the request for assistance by assisting families “to identify, build and maintain informal support networks” (DADHC 2004b, p. 7).
- Furthermore, “Families assisted through Local Support Coordination would not normally be accessing significant levels of specialist disability services” (DADHC 2004b, p. 7). Whereas need for proactive involvement actually increases with the array of services the child requires because of the
complexity of the service sector and very lack of coordination which characterises information and service delivery in the sector.

6.2.2 Associated Factors

Associated factors tended to exacerbate problems of information access and acquisition, sometimes to a profound degree, but were not causative per se. That is to say, these factors were identified as having an impact on parents' capacity to acquire information, for example making the process more difficult, without necessarily precluding access by virtue of their inherent characteristics.

6.2.2.1 Contextual Factors - Complexity of the Service Sector

A classic example of associated factors exacerbating problems of information access and acquisition was the complexity of the service sector. This has been remarked frequently in Australia, within the literature, among parent participants in this research, and within government/non-government publications alike. As would be apparent from 1.1.2 Major Developments, Underpinning Legislation and Government Policy, the disability service sector is enormously complex, both as to funding and actual service delivery. Indeed, the complexity of the service sector and the sheer number of different professionals and organisations with which any one parent needed to interact to acquire help for their child was unmitigated. There were medical, therapeutic, educational and ancillary supports to acquire, in government, non-government, charitable and diverse other settings.

These problems are well recognised in the early childhood intervention sector in Australia (ACD 2001a; Baxter 1989; NSW CCYP 2003), as overseas (Gravelle 1997; McConachie 1997; Spiker et al 2000). "Disability Direction: tomorrow's blueprint" (1994, p. 9) described the system in NSW as "a mosaic of disparate services", while the NSW Commission for Children and Young People (2003, Navigating 'the system' section, para. 6) reported "Kids and adults told us of their confusion and alienation while seeking help from the complex assortment of State, Federal and local government and non-government organisations and professionals". As one parent reported:
As parents of a child with a disability, you don't always know the structure, and where to go from point a to b to c, to end up at z. There's all these services out there, no one has any idea where they are, and how they interact with each other, if they interact at all...(6/801-804)

Complexity is not a causative factor in the failure to acquire information by, for example, prohibiting access. One only needs to consider the degree of complexity of knowledge organised in many special and technical libraries to appreciate that complexity alone is not a problem for information access and acquisition. However, the knowledge in special and technical libraries is subject to sound, systematic and consistent information management through the informed application of a set of commonly understood rules. Roberts (1996, p. 30) has described this as “the body of systematic principles governing the information environment and [the] perceptive understanding of their capability in use”. The childhood disability sector, in stark contrast, enjoys no systematic and consistent information management. The fragmentation of services is mirrored in fragmentation of information management.

The effect of the complexity of the sector when coupled with the total absence of systematic, coordinated information management has a devastating impact on the potential for information access and acquisition. This is detailed further below.

6.2.2.2 Contextual Factors - The Absence of Systematic, Coordinated Information Management Including Delivery and the Problem of Conceptual Ambiguity

The single most salient and apparent feature of information access and acquisition in the sector was the profoundly disorganised state of information management, including delivery, at every level regarding all subject matter; from health and medical matters through educational and therapeutic to ancillary benefits, services and resources. Whether structured settings, such as those within early intervention services, or the unstructured among private medical and therapeutic practitioners, whether government departments, services or charitable non-government organisations were in view, the management of information resources was in a parlous state. It would be fair to say that there was a total absence of any systematic information management including delivery. There was no central repository, no one-stop-shop, no coordination.
In particular there were significant and irreconcilable variations in information management practices between different professionals/providers across subject and geographic domains; within or by one professional/provider at different times and stages; within or by one professional/provider between different families; and, professional/provider strengths in one subject area were not necessarily available in others.

There was considerable parent testimony to the need to "navigate" the disability sector "maze", both in this research and within the literature. Information was an essential navigational aid, yet it was as much a part of the maze as the rest of the sector.

As most parents had not parented a child with a disability before the experience of trying to navigate the sector while coming to terms with their child's disability, a time of extreme anguish and grief in itself, was almost unbearable. At interview, as parents reflected on the experiences they had endured, virtually all believed the process of trying to navigate the complex service structure was untenable and required urgent attention. This clearly arose by virtue of the absence of systematic and coordinated information management in the sector.

I can't believe that it is so hard to have got an answer. It shouldn't be such a struggle you're going through enough emotional problems without all of this hard, difficult drama. It's just like you're against a brick wall to get an answer and it shouldn't be that hard. (29/1958)

Staff changes within therapeutic service providers and government organisations were constant and added to the stress. Even when parents managed to navigate the sector, it would appear to change before their eyes just as they mastered it. Not only was there complexity, it was constantly shifting, without any central information point of coordination or referral.

I think also it keeps changing, you know, is it a community service or is it - you know? You're changing departments too, and then you have some of the things coming from one, some of the things coming from others, so they're not connected. (7/1359)
The title of a Victorian childhood disability sector publication informing parents and carers of benefits and services available and approaches to take to acquire them, “Through the Maze” (ACD 2001a) eloquently reflected the status quo:

The mix of services and organisations varies from region to region, so the types of services available ... will depend on where [a family lives]. In some regions ... some services may be in short supply, or not available at all. It may not be fair but the fact is that often, to get the best services ... [a family will have] to fight very hard. (ACD 2001a, para 2)

Finding out about the services ... can be difficult. Different services have different eligibility criteria... (ACD 2001a, Difficulties You may Encounter section, para 1)  

Indeed it is of no small significance to this research that within Australia there is no central reference point within the multiplicity of services, universal and targeted, to which families, service providers, policy makers and funding bodies can turn for comprehensive, sector-wide access to information. There is no one-stop-shop, no central point of coordination to which families can turn for guidance in finding the right direction if not specific information. Of the three service examples given below, very few parents, if even aware of the service notionally, were aware of its relevance to their particular needs and even fewer had ever used their services.

Individual offices of Commonwealth Carelink, which may have served the function of one-stop-shop in part, do not cross geographic boundaries to advise on services, support, statistics and meta structure issues. Furthermore, while the Commonwealth Carelink Service Charter specifies that centres have a responsibility to “inform you of your rights ... [and to] inform you about service availability and alternatives” it does not make explicit how this is achieved (Commonwealth Carelink Centres n.d., Commonwealth Carelink Centre responsibilities — In providing Services, Commonwealth Carelink Centres Have a Responsibility to section, paras. 4, 5). It can almost certainly be assumed that the centres would be deemed to meet their responsibilities if they responded to inquiries. This is particularly significant if the individual is unaware of services/service types about which inquiries can be made. There is no suggestion of any proactive role in information delivery. It would appear

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2 While the Victorian version is in its 5th edition, the first ACD NSW is still attempting to secure funding for publication of the NSW version “Through the Maze”.
3 Although these comments were made by the Victorian ACD they apply equally to NSW as is evident in the soon to be published NSW version.
therefore that while government recognises generally the complexity and difficulties attending access to information in the sector, it has not recognised that these arise not only for structural reasons (i.e. lack of access points to information) but also for reasons pertaining to the individual needing information. These will include individual information styles, lack of awareness/recognition of need and information, inability to apply information to personal circumstances affecting ability to articulate an inquiry and so on.

Thus while the implementation of a network of Commonwealth Carelink Centres may go some way to addressing the structural problems of access to information in the sector, by providing regionalised databases of services, the question is whether this constitutes coherent and systematic management of the sector’s information resources. And furthermore, the serious problems of awareness, application and uptake of information by individuals are simply not addressed. The same criticisms could be levelled at all information services operating in the sector, all of which respond, at best, to inquiry.

The Commonwealth Carer Resource Centre specifically distinguishes itself from Carelink. The Carer Resource Centre only serves carers, through information and referral and offering emotional support, recognising “carers need to be able to discuss their situation with … people who understand their concerns and issues and who won’t make judgments” (Carers NSW 2005, para. 5), and, in being able to provide information about services out of region. It would be interesting to ascertain whether in the context of “emotional support” a degree of proactive mediation of information occurs, which may be part of a process which from a non-information science perspective might be described as “having one’s concerns understood”.

The Early Childhood Intervention Infoline has comprehensive listings of early intervention and some other services and is funded by the State government to deliver information to the early childhood disability sector, but it does not function as a central repository or disseminator of sector-wide information and it too responds to the queries of only those who are sufficiently informed to know of the service. Its usage statistics suggest an on-going bias toward information delivery to professionals.
The State Library of New South Wales Disability Information Service has abundant potential to offer the sector but plays no role in either managing or advising on the sector's information resources and its services were virtually unknown to parent participants within this research.

In short, there was no process by which parents were able, systematically to become informed. Those information services, which ought properly to be playing a central role in the management of the information resources of the sector, were largely unknown to most parents. They also have no meta functions in terms of sector-wide information management issues, therefore the problems of access and acquisition are continually reified.

It's all been, none of it's been systematic, at no time have I been presented with options that are available. I feel stumbling across the right person, happening to meet the right person, who happens to tell me about the right services. There are quite possibly tons of services out there that could be great for [my daughter], that I don't know about. I wish there was a central data bank somewhere, maybe there is. (15/980-986)

Elliot and Apte (Families First Inner West 2002a, p. 42) found in research among Inner West parents that:

Once children were diagnosed parents often reported confusion about service availability and identified a preference for a comprehensive resource with information about service provision.

Government itself has recognised that much service provision has grown out of ad hoc responses to crises rather than as a planned approach to the delivery of services. Attempts to address these problems have emerged in recent years. As observed in Chapter 1, the Early Intervention Coordination Project was commenced to assess and improve early childhood intervention service planning and delivery (ADD 1999, p. 9). Of particular note more recently is the New South Wales' Families First strategy wherein the coordination of service planning is emphasised again and again (Families First 2002a, b). How this can be achieved without centrally coordinated and systematic information management is unclear, and no government policy or model of best practice has adequately addressed the issue.

The absence of a national, systematic approach to information delivery premised on the systematic, coordinated management of the disability sector's information resources is
not unique to Australia. There is abundant evidence across the literature of parents reporting the need for a central point of collection and delivery of information, such as a "one-stop-shop" (Dean 1975, Fyffe, Gavidia-Payne & McCubbery 1995, Mitchell & Sloper 2001, Mittler 1995, Stallard & Lenton 1992, Sloper 1999).

There were also many information acquisition failures at the "local level" of individual professionals and providers. Problems were particularly evident in the "grey area" of private practice, which seems in some respects elevated beyond accountability to government policy and standards, except to a degree where the professional is practicing in public settings (e.g. public hospitals and government funded service providers). For example, one paediatrician may deliver to parents at diagnosis of disability only basic diagnostic information and thereafter adopt a responsive approach to information delivery. Yet another paediatrician may provide diagnostic information at varying levels of complexity according parent articulated preferences, on-going management information and ancillary benefits, services and supports information, checking regularly that each area of need is being addressed. (See 6.2.1.3 Miscalibration of Professional/Provider Information Delivery Practices and Parent Information Behaviour/Assumptions/Expectations.)

The problem of conceptual ambiguity around all information terminology must also be taken into account when considering the lack of sound information management in the sector. The recently produced DADHC (2004a) standards governing the delivery of services in the childhood disability sector provide a case in point. The standards reveal a comprehensive failure to grasp the centrality of "information" to all family processes covered by the standards, the instrumental means of information acquisition and the importance of defining not only information delivery practices but also the information management underpinning these practices. These problems are seen most graphically in the two examples below.

Standard 1 Service Access holds that "Each service user seeking a service has access to that service on the basis of relative need and the available resources." One of the strategies described for promoting this standard is:

Making available current information about appropriate services and supports (mainstream and specialist disability services) including therapy, early childhood
services, local council services, education, recreation and sports, youth activities and services, employment and training. (DADHC 2004a, p. 9)

Firstly, a parent can only seek information or service that they know to exist. The standard and the strategy both assume parents have an innate capacity to find out about services in the first instance, how else can the individual attain to “access”? Clearly parents are unlikely to do so without the instrumental intervention of proactive information delivery. Yet there is no evidence that service providers are being called to get out into their communities and proactively alert families to the potential availability of service.

Secondly, access to services derives not just from acquisition of information about those services per se, but information that enables the parent to make evaluative judgments in terms of their own family circumstances. Such information would include quality criteria, information about what services other families in similar circumstances get both locally and in other areas, how waiting lists are being managed, criteria used for evaluating “relative need” etc.

Thirdly, “making available current information” is a clear example of conceptual ambiguity. Theoretically, this standard could be achieved simply by putting a wad of brochures in a rack. Indeed it seems likely that passive information delivery really is in view given the failure to specify otherwise.

The second example is in some ways more serious. The third standard pertains to Decision Making and Choice and states:

Each person with a disability has the opportunity to participate as fully as possible in making decisions about the events and activities of his/her daily life in relation to the services he/she receives. (DADHC 2004a, p. 12)

The document goes on to say:

Children and young people with a disability and their families should be involved in making decisions and choices about things that affect them...this may involve providing information to the child or young person and their family about how they can participate...[emphasis added] (DADHC 2004a, p. 12)

The information required to support family involvement in decision making and choice is immensely greater than that envisaged in this standard, requiring in fact detailed explanation to safeguard its effective delivery. The treatment of information concepts in
the standards generally strongly suggest that there is no real understanding of the fundamental role of information to the achievement of the standards and the need for proactive delivery to maximise the probability of acquisition occurring.

Indeed it seems feasible that the very conceptual ambiguity itself, evident in the research literature, sectoral policy and other documents alike, may be if not responsible for the on-going information acquisition problems, a contributing factor to their longevity. If the standards and best practice documents do not call for systematic information management and do not specify what information delivery is and how to achieve it, home-grown solutions will develop at the level of each local provider. This will inevitably yield information mismanagement, lack of coordination and a miasma of different delivery modes and practices, fraught with inequities and inconsistencies, which is exactly what has occurred.

6.2.2.3 Contextual Factors – Inadequacy of Resources, Geographic Inequities and Unmet Need

At first glance the relationship between inadequacy of resources, geographic inequities in distribution and unmet need, and, parent information access and acquisition may appear causal in reverse. That is to say, failure to acquire information leads to geographic inequities in distribution and unmet need. Certainly the research behind this thesis found significant information and service inequities between the six centres investigated, unmet need and a direct relation with the failure of individuals and groups of parents to acquire information. Parents were largely unaware of information and services received by parents in other centres and it has been remarked elsewhere that under these conditions parents do not know what is reasonable to request. “If I hadn’t been introduced to the mum of another disabled child I would never have known what was really available and what it was fair to ask for” (Fyffe, Gavidia-Payne & McCubbery 1995, p. 36).

Yet this is a consequence of failure to acquire information. Under consideration in this section are the factors associated with failure to acquire; why failure to acquire occurs.

Parents interviewed were aware of their unmet needs for services, benefits and resources, to the degree that they were aware that such services, benefits and resources
existed for which they would be theoretically eligible. Yet it seemed to the author of this thesis, that where a particular resource was inadequate in one geographic region (such as Home Care Service or case management), parents had a commensurate lack of awareness of those resources. It seems feasible, although it would require further investigation, that information was more likely to be delivered to parents only when there was capacity within the service provider to deliver service or resource. The problem with this of course was that parents could only express a need for a service, benefit or resource they both knew to exist and for which they would theoretically be eligible. Service providers in turn would only put in submissions for funding based on expressed needs. Hence it can be seen that the very inadequacy of the resources may itself lead to a failure to deliver and hence acquire information in relation to those resources, further fuelling unmet need and geographic inequity.

There is a massive variation in Australia in the distribution and range (as to format and content) of disability support services for children in the early childhood intervention period (0-6 years), across geographic regions (ACD 2001a, b, c; Baxter 1989, p. 15). Rural areas of New South Wales face additional significant problems: “There are many gaps in servicing children and their families in rural regions. Staff shortages, equipment, resources and isolation are but a few of the areas of need” (ADD 1999, p. 30).

It is thus apparent that parents acquire or fail to acquire information in the context of a service system that is not only complex and difficult to navigate, but inequitably distributed, quantitatively and qualitatively. This is a function of the legislative, funding, policy and service provision factors described in Chapter 1, together with the fact that the service population is neither clearly delineated, as to raw numbers and needs, nor systematically informed of its “rights”, “entitlements” and eligibilities. The inadequacy of resources, geographic inequities and unmet need can then be seen to function as associated factors in failure to acquire information, as they reduce the probability of access. They seemed to cause a filtering effect on delivery of information, as providers were very reluctant to provide information about services that they were unable to deliver or that parents were unlikely to acquire.
6.2.2.4 Personal Factors - Parental Skills and Attributes – Perseverance

Many parents clearly identified the need “to fight”, persevering and not giving up in efforts to acquire information and services as a necessary skill. Some parents adapted to this role more comfortably than others and these parents usually acquired more information and services than their peers. Such parents were largely the hypervigilants and vigilants.

Basically I called 3 or 4 times a week for about 4 weeks and kept getting “I’m so sorry this person will call you back.” And then I said “Just give me their [mobile] numbers and I will call them.” [But] they were reluctant to do it at first. I got it though, I got it through the people [who run one of the groups] they were hearing my frustration every week and feeling very apologetic. And one of them [offered to ring for me]. I said “No just give me the numbers and I’ll call them myself.” And as a result we’ve now got home visits, we have people come to see us and all that kind of stuff. But it’s not the way it should have been. (18476-484)

One parent’s acquisition of an oxygen tank, for use when his child stopped breathing during a seizure, demonstrated the importance of parental perseverance in the face of professional resistance. The family had clearly identified needs and were seeking to satisfy them, they persevered in seeking until achieving the desired outcome. The father reported that other parents were surprised to learn they had acquired an oxygen tank as they had sought one unsuccessfully, unaware of the information that would have opened the door, namely the threat of litigation.

It is likely that there is an association between the perseverance observed among the more vigilant information style parents and the active problem solving approach of stress and coping literature. Furthermore, that this may dovetail with Dervin’s sense making approach to information need from information science, where the focus is upon what the individual did, what questions he/she asked to move from gap to reconstructed sense (Dervin 1983 Core Conceptual Premises section, paras. 6, 7). This seems to accord with the more vigilant parents who face information and other blockages or gaps with perseverance, devising means of overcoming them through heightened information seeking efforts and more adversarial behaviours.

As noted in Chapter 3, Savolainen (1993, p. 26) makes a remarkable observation in this regard:

386
In Dervin's theory, the basic values of American culture are interestingly reflected: the central position of the individual actor, the importance of making things happen and moving forward, in spite of barriers faced, and relying on individual capacities in problem solving.

Indeed an American participant in the research of this thesis specifically addressed this notion in describing what was in effect his own perseverance.

If something’s important, you’re not going to sidetrack me. Well, there’s never been anything more important in my life than this, so. Other than that, I think a lot of it is more, there’s less, there’s less paternalism in the [American] Government. So if you’re not willing to do it for yourself, it’s not going to get done. And that’s also, like the Midwest philosophy. That is the Midwest philosophy. If you’re not willing to do it yourself, you don’t deserve to have it done. (7/2256-2264)

It is of great concern to the author of this thesis that cultural factors may have intervened in both information science theories, such as those of Dervin and Kuhlthau which see the individual as necessarily instrumental in his/her own information acquisition, and, family-centred practices within the childhood disability sector, that have effectively precluded each from adequately addressing profoundly important information access and acquisition issues. This is certainly problematic, as this thesis unequivocally found that in over half of the sample, both the distinctive information styles evident among parents, and the awareness heuristic, precluded the type of perseverance and active, problem-focused coping such theories and practices require. Both necessarily require a standard of information behaviour that may not be equally accessible to all individuals, for dispositional, information literacy, awareness and/or cultural reasons. Furthermore, inasmuch as they were to be dispositional or cultural in nature, the notion of helping individuals to become more active and in particular problem solving (see for example Sloper & Turner 1992), may well be entirely inappropriate and/or doomed to failure. This requires further investigation.

Perseverance, on the part of the individual parent, is clearly associated with information acquisition yet is also clearly not equally available to all parents. Professional and provider practices that respond more readily to perseverance, to the parent who has the fortitude to make 16 repeat phone calls for example, appear to exacerbate the problems of information access and acquisition, particularly among those parents with more passive information styles.
There were other parent factors that appeared to be associated with information acquisition, described below.

The practice of secrecy and deception was remarked by a number of parents at interview and as such the interviewer checked it as a theme in the course of all subsequent interviews.

The private ‘speechy’ I’ve been seeing, has told me not to tell people at [the early intervention service] that I’m using her, she said you may find that some of it’s taken away from you, or not offered...I don’t like [it], I was quite shocked that she said it to me, and because certainly up until that point, I had always been very open with everyone, about all the support we were getting. And then it made me think, maybe there’s been other situations where I shouldn’t have said something. (11/2784-2815)

As noted earlier in this chapter, exchange of information was traded off where access to services was potentially in jeopardy for a number of parents. It was certainly the case that some parents had not been aware of the consequences of not sharing information, nor indeed the benefits accruing from doing so. Shortages of resources and vast unmet need meant that some parents simply felt the need to practice secrecy and deception. Although parents did not like having to do so, they sometimes felt it was the only way to get the help their child needed.

... it’s this lying all the time, it’s this lying, I hate this dishonesty. It’s just not me, but I need to be able to keep these services that I need for my child, and I don’t like lying! I just, it’s just ruining my soul, it’s making me feel sick. Every time I say something I’ve got to watch what I say because I can’t say that ... but I think ‘But I really need that service! And I really need this service ... Then I’m not able to give the best to my child because then I’m so concentrating on not saying [things].’ (4/1419+)

The practice of secrecy and deception was particularly problematic where responsive and passive information delivery was practiced as there was little probability of information exchange occurring and revealing needs for coordination of effort etc. Just as Chatman (1996, p. 194) observed, the practice of secrecy and deception had the effect of establishing an “information barrier”, which had the effect in turn of shielding insiders “from needed resources”.

388
Indeed, secrecy and deception created a number of distinct problems in terms of information acquisition. Firstly, the professional working with the family did not know the "whole picture" and therefore could not identify what was known and not known and where (were it practised) proactive delivery may have been required. Secondly, free flow of information and consistency across all professionals working with a child and family is often crucial but was unattainable where there was secrecy. Thirdly, the whole relational context of information acquisition became fraught with tension. The capacity to build relationship was far less achievable where one of the parties was practising secrecy and deception, with all the attendant loss of information exchange opportunities which may have resulted in knowledge anomalies being identified and so on. In turn, the capacity to achieve family-centred support was greatly reduced.

It was also the case that families interviewed who were under surveillance by DoCS Child Protection Service at the time of interview were extremely guarded and fearful about being seen as needing information in case that could be construed as failing to be a responsible parent. This was also entirely consistent with Chatman's (1996) findings.

Respondents were not engaging in information-seeking or sharing behaviours because they wanted to give an appearance of normalcy...The end result was that many residents were desperately in need of information but pretended they were successfully coping without it. (Chatman 1996, p. 201)

It is interesting in this regard that all parents under DoCS surveillance demonstrated a passive information style. One person caring for a child removed from his mother by DoCS spoke clearly about the dilemma of needing information and help without appearing to be needy and therefore unable to care for the child.

Maybe I should be talking to DoCS, but then they feel as though 'well, you can't handle [the situation] maybe we should find somewhere else for baby.' That has been their attitude in the past....Talking about grandparents, or foster parents, they're actually looking after that child because the parent hasn't been any good and they're [grandparent/carer] struggling, they're looking for help as well, because the child's had emotional problems, and DoCS has come along and taken the child away, feeling like they're [grandparent/carer] not capable of looking after them just because they're crying for help. (21/742-852)

The threat of removal of children from parents seemed to be more a cause for some concern among parents interviewed in the rural region. The concerns were not without substance. In the case of one parent interviewed who had been actively seeking information about the side effects of potent drugs her child was being given to control a
medical condition, she not only encountered difficulty acquiring the information but also an overt threat from a medical practitioner. The medical practitioner specifically stated to the parent that if she did not comply with the regimen she would be reported to DoCS. The medical practitioner may have been concerned that the mother’s active seeking of information in relation to side effects may have resulted in non-compliance with the drug administration regimen. The mother’s concerns in relation to her child escalated as her child developed autistic tendencies, however the shortage of medical practitioners and privacy problems associated with a small town meant she was unable to achieve satisfaction in relation to her concerns.

The “coping conundrum” was also observable among a small number of parents. The author of this thesis coined the expression to describe the information acquisition problem faced by certain parents, apropos of their coping efforts.

Firstly, there were a small number of parents for whom “appearing” to be coping effectively was actually a part of a coping strategy. The only way these parents felt able to “keep it all together” was by “looking good”, looking as if everything was OK. Kraft and Kraft (1998, Chronic Sorrow, Grief and Pathologic Grief section, para. 3) have described this as spurious coping which may in fact be “more the result of a need to function because of the demands”. Yet parents were more likely to be proactively delivered information and support where they appeared not to be coping effectively. In other words, in order to acquire information and support the parents needed to behave in a way injurious to their own coping strategy.

By way of example, some parents were embarrassed to talk about their financial difficulties with any of the professionals with whom they interacted; many felt unable to ask to medical practitioners to bulk-bill. It is worthy of note that these parents were among those who had not received Carers Allowance in a timely fashion. Those parents still not in receipt of Carers Allowance at the time of interview were shocked to discover they may have been eligible, which for some would have had significant implications because of the adjunct Health Care Card.

Furthermore some parents often felt that they most needed help and information when they were least able to ask for it. A number of parents observed sentiments similar to these, “if you appear to be doing well nobody helps you, you have to fall apart, almost
lose everything before anyone offers to help”. “Help” here refers to proactive information delivery and assistance in acquiring miscellaneous therapeutic and ancillary supports, benefits and services, such as respite, home care, mobility parking, Carers Allowance. Certainly, Kramer and Houston’s (1998, Parental Interviews section, para. 5) research among families adopting children with special needs found evidence of the coping conundrum, (although that term was not used).

...the interviews also revealed that there are some situations in which a parent’s drive and determination may paradoxically prevent them from getting the assistance they need....

It is interesting that one hypervigilant parent was constantly threatened with loss of respite by a service provider because her house was neat and tidy and her child was clean and cared for.

The community nurse would come home and she’d say, “Your house is neat, you look clean, your son is neat and clean, so obviously you’re coping really well. So I think I’ll be able to stop this respite now...” So then every time she was coming to visit I’d feel sick, I’d be really stressed out, I’d be wondering whether I should be sitting around in my nightie...So one day I actually told her... “If you stop by unexpectedly you’d probably catch me in my nightie, with [my son] dirty and me a mess and my son looking dreadful. But when you’ve booked an appointment weeks in advance and you’re visiting on an appointment basis, there’s no way I could sit around looking messy and dirty.”...She didn’t realise how stressed I was before she came or how much later I went to bed the night before because I was tidying the lounge for the visit the next day... (9/notes9)

Such parents also belonged to a second, small group of more vigilant information style parents, who experienced failure to acquire information, sometimes proactively delivered to more passive parents. Professionals/providers appeared to have concluded that because these parents were so articulate, “in touch”, active in their approach, they did not need information/help/support. Yet as one parent observed, “…being articulate and having a certain level of intelligence doesn’t mean you have the knowledge” (31/1131-1132).

As a result when these parents subsequently acquired such information indirectly through information grounding efforts, such as networking, they were left feeling “let down”, wondering why they had missed out and sometimes experiencing a sense of betrayal. There may indeed be a connection here with Folkman and Lazarus’ contention (1988, p. 313) regarding confrontive coping, where these parents sometimes saw the
more passive style parents elicit information, emotional support and tangible assistance without apparent effort, in contrast to their own constant efforts and wondered why.

The problem of the coping conundrum to information acquisition was usually less problematic for the more vigilant parents though because of their very propensity for information grounding which increased the incidence of acquisition for all the reasons before described. However, for those parents who coped by “looking OK” the coping conundrum presented a serious problem for information acquisition, as they were largely unable, ipso facto, to reveal their needs in a way that would have elicited information and support from professionals/providers.

The fear of being perceived in a negative light was also clearly associated with information acquisition, inasmuch as the fear precluded certain parents at certain times from expressing needs and concerns, and affected their stance in information activities. This is presented in more detail under 6.2.1.1 Parent Information Styles. While not a causal factor alone in information acquisition, this fear seemed to be a part of a more general, passive “modus vivendi” (way of living, coping) and as such had a significant impact on parental capacity to access and acquire information in the context of information activities flowing from parental information style. The major concern, apart from the emotionally damaging burden parents are living with, is that this fear actually precludes many parents from freely and openly expressing their information and services needs, (such as they recognise them), which is a cornerstone of family-centred practice, as before-observed.

The problem of anomie was also significant to information access and acquisition. Seligman and Darling (1997) hold that the anomie experienced by parents concerns meaningless and powerlessness, which are addressed over time by “seeking” behaviours aimed at restoring sense or meaning. It is the contention of this author that when parents either give birth to a child with a disability, or, have a child diagnosed or indeed undiagnosed with a disability, they enter an anomie state, characterised by normlessness, high attendant stress and chronicity of crisis. This finds expression in, among other things, their information behaviour. Where a parent may have demonstrated strong information literacy skills in their work and everyday life environments, generally speaking they bring no knowledge base to the problem area with all the attendant lack of awareness of information problems. This situation can be
described as information anomic. All the norms and ways of being with which they have operated in the past no longer apply. Inasmuch as the individual may have had competent information literacy skills, they have been diminished. The specific impact of anomic on information literacy skills and the nexus with the awareness heuristic requires further investigation. Certainly Krafft and Krafft’s (1998) work on chronic sorrow, relating to the chronic nature of crises experienced by parents of children with disabilities, would suggest that great difficulty attaches to overcoming anomic. As new crises constantly arise, the whole process of adaptation to what is not known must begin again and thus families live in a perpetual state of uncertainty and unrecognised need.

6.2.2.6 Family Circumstances

It was clear that parents within the sample came from a wide variety of backgrounds with a wide variety of family circumstances. These individual circumstances also had a significant impact on information access and acquisition, without being causative in success and failure per se.

Poverty, single parenting, DoCS involvement, sibling issues, housing, transport, employment and isolation were all family circumstances identified at interview that yielded an impact on the parent’s capacity to acquire information, either by active seeking or delivery. Although some of the associations were more abstract, their influence over the capacity of individuals to seek or even to receive information appeared considerable.

...at first I was, I really threw my energy in and I found out about so much, so much that I wasn’t getting off anyone else. And I was telling people, I was telling the therapists etc. And now I’m too busy and tired to keep on top of things. I just can’t do it any more...It’s exhausting all this travelling around when you’ve got to try and do everything, fit everything in, get different services from different avenues. It’s just...I know I’m not up-to-date now...I feel like I’ve failed her, I’m slipping in my duty as a mother caring for her because of that sort of thing...And to me, there should be someone like a doctor saying ‘yes, she should be having the thyroid [test] every six months or every twelve months’, and there’s not. (22/1Bmark2)

6.2.2.7 Parents from a Non-English Speaking Background (NESB)

It was not the purpose of this research to investigate NESB issues as this is a specific subset of the childhood disability sector and the broad sector was under consideration.
Also, NESB issues were quite specifically canvassed in the OCYP (2001a, pp. 15-23) review of “Research on Immigrant Communities” giving an exhaustive listing of research on people from NESB, much of which pertained specifically to families’ and parents’ needs and views. However, the commentary of one parent from a non-English speaking background is quoted below as it gave eloquent testimony to the desperate plight of parents from a non-English speaking background exacerbating all the attendant information access and acquisition problems experienced by other parents to a tremendous degree.

... one thing that I notice is that, those mothers who have the same experience with me, also a lot of them are from non-English speaking backgrounds. They don’t know ... they didn’t get enough information, and because they don’t know English, they don’t know much enough English to ask, so they’ve been missing out a lot. I know a mother that in [my son’s] Pre School, she only speak Chinese, she doesn’t even know the Early Intervention programme, the Early Intervention Centre and she doesn’t even know about the Carers Allowance...No, so I mean, it’s really, I feel sad that for these people. I mean, if they don’t know English or they only speaking very little English, and they don’t know where to ask. And also plus, they can’t go to a Playgroup because they also fear, because they don’t speak English, they can’t communicate, you know? I feel sad about that. I been advising them a lot, my friends call me, so I’ve been kind of like a keeper to them, telling them all this kind of things as well...Yes, because one of the mother, I really feel sad for her, I ask her about her daughter. Her daughter had a similar problem like [my son], she’s a little bit older than [my son], and I think she’s more severe than [my son], like she’s more delayed. And I ask her does she know about this Early Intervention programme and she’s like, she doesn’t know...I said, “Why hasn’t your daughter been diagnosed?” I feel like she’s also in a way, she feel hopeless, because she say to me, “She’s not smart, her brain is abnormal.” That’s what she say to me, and I feel like you can’t [give up], you know? (19/2610-2670)

Evert (1996, pp. 25f) found in research among ethnic families of children with disabilities eleven years ago:

In terms of access and equity, and the social justice policy...these findings illustrate that NESB families who have a child with a disability have not been aware of the choices available to them. As a consequence they are unable to make an informed choice about which services they may or may not need.

Clearly this has continued to be the case.
CHAPTER 7 - SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

7.0 INTRODUCTION

This research has investigated how parents of children with disabilities acquire information and the issues that have an impact upon access and acquisition, along with possible areas for improvement. This chapter summarises the findings of the research, identifying possible areas for improvement and recommendations for action.

7.1 SUMMARY AND CONCLUSIONS

The literatures of child development and special education, psychology and social science, nursing and medicine, uniformly agree on both the importance of information to families of children with disabilities and the on-going parental dissatisfaction and unmet need in relation to its acquisition. Parents frequently appear to be critically uninformed during many phases of the “becoming a parent of a child with a disability” process and each of the crisis and transition phases beyond. What could be loosely described as “information problems” have indeed beset the childhood disability sector for more than 25 years. Those years have witnessed significant changes in professional policies and practices of government and providers, models of service delivery and research approaches aimed at addressing sectoral issues. It is arguable whether the longevity of the problems has occurred at least in part because of the considerable conceptual ambiguity surrounding the use of information-related terminology across the sector. It is also true (and the conceptual ambiguity may be a derivative factor), that no information science perspective has ever been brought to bear on those information problems.

The history of research in the sector has seen significant changes. It shows a shift in emphasis from family stressors arising from childhood disability, toward adaptation and coping, in an effort to identify and foster those factors related to improved outcomes for families. Models of service delivery have also shifted in emphasis from expert through consumer to family-centred practice (Case 2000). This has seen a shift in the role of parents from passive receptors of professional expertise to “experts about their child and
family” (ADD 1997, p. 2). Yet none of these developments has resulted in any change or approach, philosophical, structural or otherwise, capable of demonstrating an appreciable and lasting influence on access to and acquisition of information. Indeed, specific negative information sequelae appear to be flowing from those very models and research approaches otherwise intended to build family resilience and support the whole family such that it can provide an optimal environment for the child’s development.

Hence, not only are there significant and continuing information access and acquisition problems in the sector, but the current research approaches, models of service delivery and even government policy may well have both exacerbated some of the information problems and precluded their effective investigation.

Recent, influential information research in the sector has tended to take the view that the time for analysis of the problems is over and the time for action in the form of best practice solutions is nigh (Sloper 1999; Mitchell & Sloper 2000, 2001, 2002). There is considerable danger attaching to this approach. While many of the issue areas have indeed been reiterated over the years, they have often arisen tangentially and have not been investigated and understood from an information science perspective, nor have their underlying causes. The danger of this approach is in best practices either reifying existing problems or simply not addressing them. Conversely, where a best practice may be effective there is no rational basis from which to explain why this is so.

This research has sought therefore to move beyond existing paradigms and research approaches to investigate parental information access and acquisition. The research mapped the information theoretically “knowable” to the group and also sought to understand, in the context of that and individual family circumstances, information access and acquisition as it occurred and did not occur, pinpointing causative and associated factors in access and acquisition: that is to say, where success and failure occurred and why.

It was necessary then to build a framework for understanding how parents do acquire information in daily lived experience, the points at which they fail to acquire information and why this occurs. Did the parent acquire information by seeking? What did that seeking look like? Were there other modes of information acquisition? What did they look like? Was it the same for all parents? What were the differences in
parental information acquisition and why did they occur? Were there situational, contextual and/or personal factors that influenced outcomes? Discovering the answers to these questions has been the essence of this research.

7.1.1 Modes of Information Acquisition

Parental information acquisition occurred in three distinct modes each with subsets, as summarised below. It is important to note that each of the modes and their subsets was not equally accessible to individual parent participants for reasons related to the causal and associated factors in failure to acquire, summarised at 7.1.2.

- **Information seeking**
  Occurred in active, grounding and passive modes. Active seeking fell within the ambit of classic information need and seeking theories, such as those of Taylor, Dervin, Kuhlthau, Ellis and Belkin. These theories assume action on the part of the individual in response to a recognised need, gap or knowledge anomaly. Information grounding, premised on Pettigrew’s information grounds, had similarities with the optimal foraging of scholars (Sandstrom 1999) and environmental scanning (Choo 1999). Information activities were undertaken that were not prompted by specific need but had the effect of increasing the probability of the individual becoming aware of information and knowledge anomalies related thereto; at the same time the individual’s knowledge base was being built. Passive seeking was the action of response to what was available or offered, rather than the active initiation of an information seeking process.

- **Information delivery**
  Refers to professionals, other service providers and persons in the sector making information available to parents. Delivery ranged from the passive (e.g. a poster on a wall or a generic one-size-fits-all information kit), to the responsive (responding to articulated requests for information), through to proactive and targetted information delivery, where the individual client is proactively apprised of information of which he or she may not have been aware. The array has similarities with Kuhlthau’s (1994) zones of intervention. Proactive mediation of information in the context of relationship is consistent
with the link worker role recommended in Mitchell and Sloper’s (2000, 2001, 2002) research. It was the favoured mode of information acquisition among parents, yet was also that least available to them.

- **Serendipity**
  Information acquisition in this mode occurred through no intentional, purposeful seeking or delivery efforts by individual parents or other persons. The individual events were wholly random and unpredictable and were therefore not analogous to Erdelez’ (2004) OAI concept, although they occurred in a predictable array of subsets, including contact with strangers and acquisition as an unintended consequence of another action/event.

### 7.1.2 Issues Affecting Information Access and Acquisition

The issues affecting parental information access and acquisition could be broadly classified as causative or associated factors. The four *causative factors* identified exerted a direct influence on parental capacity to acquire information, both in terms of theoretical access and specific acquisition activity.

- **Parent information styles**
  The specific activities *undertaken* (or not *undertaken*) by individual parents to acquire information through either seeking or receiving what was delivered, and the *response to resistance or failure to acquire*, predicted and evidenced information style. Hypervigilant, vigilant and active parents were all active, problem-solving information seekers, as envisaged in stress and coping theory and around whom classic information need and seeking theory has developed. Significantly these parents were engaged in constant information grounding efforts, which immediately distinguished them from all others. Furthermore, in the face of resistance or failure to acquire, hypervigilants and vigilants exhibited extreme perseverance and tenacity. (Active parents, in contrast, tended to pull back with resistance.) There was a direct positive correlation between information activity and stance, and actual information acquisition. Hypervigilant, vigilant and active parents were unequivocally more aware of benefits, services and entitlements than the receptive, passive and avoidant parents. The array of information activity undertaken by more passive parents
was far narrower and the employment of specific activities was more limited. The stance exhibited in information activity could also be described as more passive. The receptive parents, the single largest group within the interview sample, were characterised by their receptiveness to information being delivered, however they used significantly lower rates of active seeking and grounding than the more active parents, with commensurately very low rates of awareness of benefits, services and entitlements. Along with active parents, receptives were very concerned not to "rock the boat" or to be viewed in a negative light, and always pulled back with resistance or when facing difficulty or lack of support from professionals. Passive and avoidant parents frequently did not acquire information without the intervention of a proactive professional or other parent. The shift in models of service delivery to family-centred practice, in unwittingly transferring responsibility for information acquisition onto the instrumental action of the parent, has put these parents in grave danger of comprehensive failure to acquire.

- **the awareness heuristic.**

  The awareness heuristic postulates that the individual must be aware that he or she is unaware in order to take action to resolve a knowledge anomaly. The concept predicts failure to acquire information that is extant, theoretically available for acquisition and directly relevant to the circumstances in which the individual finds him or herself. The phenomenon is particularly noticeable when an individual enters an unknown domain and has no inherent means of identifying what is potentially knowable. Individuals with more vigilant information styles are will tend to ameliorate the effects of the phenomenon over time by constant information grounding efforts. The problem is only overcome otherwise by proactive information delivery or serendipity.

In the childhood disability sector the problem was potent because the domain was unknown to virtually all parents entering it. They had no extant knowledge base from which to make the kind of "connections" envisaged by Kuhithan (1991, p. 362), no inherent means of identifying what information "would be" available, their information needs, or their knowledge anomalies and hence no capacity to engage in information seeking. At the same time, the prevailing models of information delivery were responsive and passive, with providers
waiting for parents to articulate needs for information and service because family-centred practice deems the parent to be expert.

- **miscalibration of professional/provider information delivery practices and parent information behaviour/assumptions/expectations.**
  Miscalibration between parents and professionals arose because both parties to the “information transaction” had incompatible perceptions of what was actually happening. Whether parents focussed on their own efforts in information acquisition or the professional’s, most had an expectation of delivery that was not matched by professional practice. Many parents assumed a level of proactive information delivery and hence perceived less need to seek actively. Yet very few professionals in reality practised proactive delivery in any consistent way. Professional practices were largely responsive or passive.

- **the proactive professional**
  This factor yielded positive outcomes for information access and acquisition. These professionals were regularly apprising parents of information of which they were not aware, and responding actively to parent requests for information – assisting with clarification of knowledge anomalies, identifying latent information needs and going to some lengths to locate and apply information. There was clear evidence that the relatively few parents who enjoyed the services of a community worker or other proactive professional also enjoyed the highest rates of awareness of benefits, services and entitlements, matched only by the hypervigilants and vigilants.

The reason this role is so significant to parental information access and acquisition has both a theoretical and an evidentiary base within this research. Firstly, the proactive professional has a powerful role to play in overcoming the problem of the awareness heuristic for the individual parent, through proactive information delivery. Secondly, the evidence of this research is that the proactive professional was able to overcome the problems of the more passive information styles to the acquisition of information.

There was also an array of associated factors that exacerbated information access and acquisition problems, including:
- the complexity of the service sector
- the absence of systematic, coordinated information management
- inadequacy of resources, significant unmet need, and geographic inequities
- parental factors, including extreme perseverance and tenacity, the practice of secrecy and deception, the coping conundrum, fear of being perceived in a negative light, chronicity of crisis, anomie and family circumstances. Parents from non-English speaking backgrounds faced all the same issues with the added difficulties of language and cultural barriers.

The longevity of many of these issues suggests that they will not be overcome with either great speed or economy. However, having established a framework for understanding how parents do acquire information in daily lived experience, having identified the points at which they fail to acquire and having explained why this occurs, it is feasible to address these issues through the recommendations below with confidence in their theoretical and evidentiary foundation.

7.2 POTENTIAL AREAS FOR IMPROVEMENT IN INFORMATION ACCESS AND ACQUISITION

In developing a comprehensive understanding of the sector and the information issues as reported in both the research literature and parent interviews for this research, it became possible to identify certain areas yielding significant potential for improving parental information access and acquisition.

7.2.1 The Need for Achievable Outcomes

The importance of identifying achievable targets for improvement in information access and acquisition cannot be overstated. This is especially so when the effect of current research and practice developments has been to accord an importance to the instrumental role of parents in the acquisition of information (see 1.4.3.0 and 3.1).

Yet if there are dispositional aspects to cognitive information style, as suggested by Miller’s (1987, 1990) work, it may well be that the parent information styles evidenced
in information behaviours, as conceptualised in this research, cannot be comprehensively changed. This is significant. Research based on stress and coping theory that aims to identify ways of helping parents to adopt more active, problem-focussed coping strategies, in their information behaviour for example, may be doomed to failure if information style is indeed dispositional. Interventions that seek to encourage parents to adopt behaviours that are not consistent with their own style may indeed have very low efficacy rates over time.

Improvements must be designed based on the reality of parents' information behaviour. This research has gone some way to analysing the behaviour of one sample of parents and developing an original conceptual framework for analysing the information acquisition behaviour of any given parent/group of parents. Using this framework it is possible to determine information style on the basis of actual information activities undertaken and response to resistance or failure to acquire.

The problem of the awareness heuristic must also be addressed, in the first instance by educating both parents and providers as to its presence and functioning. Yet at the level of specific measures, full regard must be given to the differential capacities of parents to address the problem themselves. For example, within any group of parents this research suggests that more than half will not, in all likelihood, undertake the comprehensive information grounding efforts that would tend to overcome the awareness heuristic naturally.

Hence it would be true to say that sparse resources may well be better spent on achievable delivery activities rather than attempting to educate parents who are not characteristically active seekers and grounders into becoming so. Having said this, it may also be possible to effect changes at the margins, as it were, of information acquisition behaviour, without seeking to change fundamental information styles, as described further below. A number of areas for improvement, which do not focus on changing parents per se, are first described.
7.2.2 Development and Cross-Sector Implementation of Standard Working Definitions of Information and Associated Concepts

There can be no doubt that the conceptual ambiguity surrounding information-related terminology has contributed in no small degree to the longevity of information problems within the sector. Research, general literature, policy and practice documentation all exhibit significant conceptual ambiguity, in particular around the notions of “information seeking” and “information delivery”. A starting point in tackling the enormous problems of information access and acquisition in the sector must be the development of working definitions of information, information seeking, information delivery and related terms, similar to those definitions presented in this thesis, and achieving rapid diffusion of these to all stakeholders in the sector. The structures are already theoretically in place to do so as they exist for the purpose of making and delivering policy or delivering service.

The diffusion process could also be harnessed to tackle the awareness heuristic, latent information need and miscalibration problems. In the first instance, what is required is to alert both parents and professionals to the problems, their presence and functioning. To avoid reifying conceptual ambiguities it is important that any information presented include “scenarios” giving daily lived examples of the issues in question. This will enable parents and professionals to make connections with their existing knowledge bases, thereby increasing perceptions of relevance and likely uptake.

The diffusion process would itself need to be multi-faceted, in recognition of the findings of this research. Parents clearly acquire information in a wide range of modes, and the probability of the widest scope of target parents acquiring the information to be diffused will increase with the increasing number of modes harnessed.

7.2.3 Development of Sectoral Information Management Standards

There are currently no standards governing the management of the sector’s information resources. Information policy, such as it is, tends to be embedded in more general sectoral policies (see 1.1.4.2). The ECICP Procedures Manual insightfully observes, “Effective strategies need to be put in place to ensure [information exchange] occurs. It doesn’t just happen” (ADD 1999, p. 11). Yet the structural and procedural strategies
implemented appear to have had very little impact on either the management of information resources or parent information access and acquisition. This clearly derives at least in part from the conceptual ambiguity that has plagued much research and sectoral documentation over many years, as observed above.

Therefore, a set of Information Management Standards should also be developed, premised upon the working definitions of information concepts, providing a "body of systematic principles governing the information environment" (Roberts 1996, p. 30). This is far more than a set of cataloguing rules. It is a whole approach to information, from the basic precepts of information and each of the elements of information as a process, through to the concrete and more abstract aspects of "parents being informed" and how in reality it is achieved in the context of the information resources of the sector.

While this would address collection, organisation, analysis, retrieval and dissemination of information, at both meta and local levels, it must also necessarily address what may appear to be the vaguer or more amorphous aspects of access to information and its acquisition. All the ways in which parents become informed of matters affecting their children, and the functioning of their children and family within the childhood disability sector, and beyond as necessary, must be subject, to the greatest degree possible, to these principles. At the same time, all those professionals and providers operating in the sector must develop practices informed by the reality of differential parent information behaviour and the constraints imposed by the awareness heuristic. These practices must seek to overcome the problems of miscalibration and be subject to the systematic principles governing the information environment. For it is only in these ways that the sector can begin to approach the notion of parents "being informed" and making informed choices.

7.2.4 One-Stop-Shop

It is logical that the most likely developer of such a set of standards would be a central, coordinating body, also functioning as a central repository and model information manager for sectoral information. Yet the Australian disability sector enjoys no comprehensive information one-stop-shop, as to the make-up of disability in Australia and the services, resources and supports theoretically available. There has effectively 404
been a transformation in the sector, resulting from the process of deinstitutionalisation, which has not been mapped as “there has been no central repository for such information” (AIHW 2001, p. 96). There is an urgent need for such a central repository of information. There is abundant evidence in the childhood disability sector literature, and from this research, of parents reporting the need for a central point of collection and delivery of information.

Yet difficulties in acquiring information are not experienced by parents alone. Service providers themselves have identified the need for the equivalent of an information one-stop-shop, which is reported as “a single contact point listing available brochures and their source [which] could at least cut down the time spent researching options.” (Families First Inner West 2002a, p. 64) In fact the need is far greater – it is for an external, umbrella body that, as observed above, also sets standards for information delivery and possibly evaluation of performance against the standards. At the same time it would act as a central and compulsory repository of sectoral information. That body could be the same point of contact for parents.

7.2.5 Mapping the Information Milieu - Navigational Aids

The organisation taking on the one-stop-shop role could also develop navigational aids for parents and professionals, as a series of pathfinders through the sector. The content would vary by subject matter, geographic region, statistical orientation and so on. The information would be presented in a diverse array of formats, and be proactively delivered to the sector, using the same diffusion patterns noted above.

As a starting point, the information milieu mapping exercise conducted for this research (see 4.2.1) needs to be completed in detail and applied to all regions of NSW. It is interesting in this regard that the Local Area Committees, of the ECICP, are responsible, among other things,

- To clarify and record what services are available, eligibility criteria and referral processes
- To provide and promote accurate information about services available
Each representative of the committee has a responsibility to disseminate all relevant information to individual services, networks and the community. (ADD 1999, pp. 20f)

Hence there is an existing structure with some functional responsibility for information collection and dissemination which, given proper direction and guidelines, could be utilised for the purpose of accurately mapping the information milieu of each region (covered by an ECIPC Local Area Committee).

The development of "visualization schemes for domain novices" (Leide et al 2003) may also have some exciting potential for the childhood disability sector. Leide et al (2003, p. 923) have described one such scheme thus:

The navigation classification scheme uses the metaphor of a ship and a ship’s navigator traveling through charted (but unknown to the user) waters, guided by a series of lighthouses. The lighthouses contain mediation interfaces linking the user to the information store through agents created for each.

Although this scheme has been developed specifically in relation to the IR system environment, and in particular information spaces on the internet, its applications to the childhood disability sector are clear. Firstly, parents are domain novices travelling through waters unknown to them. However, the waters are not uncharted per se; they only appear to be so to the individual parent in the “early days” of diagnosis and transition phases. What they require is access to the navigational tools developed by others who have successfully (ultimately) navigated the waters. Documents such as the Association for Children with Disabilities’ (2001a) guidebook “Through the Maze” are such navigational tools. Further multi-modal tools need to be developed to alleviate the burden parents face as they each attempt, individually, to navigate the apparently uncharted waters for the first time. It is therefore also important that as the navigation tools are developed they be widely disseminated, ensuring they are available for assisting parents moving through the sector’s “information space”.

As the central findings of this research have reflected the individuality of families and the need to address the reality of their unique circumstances, information needs and behaviours, it would seem essential that a model “Family Information Profile” be developed and applied. Services in close proximity to families would use the profile to
map the information and service needs of individual families, including information style and information preferences. The profile would encompass:

- Services and resources the family is currently utilising
- Services and resources the family wants and/or needs but are inaccessible and why
- Information the family routinely receives (e.g. from doctor, early intervention service)
- Information acquisition activities, using the Framework for Information Acquisition
- Information style, information preferences, including modes, formats etc.
- Biographical information – to aid in understanding the family and its unique circumstances
- Particular issues affecting the family.

Ideally this profile would be developed and used by a proactive professional, for the purpose of proactive information delivery including services such as Selective Dissemination of Information and Current Awareness Services. The proactive professional would use the profile to become aware of the family's information awareness status, charting phased information delivery and information revisiting, recording delivery efforts and outcomes in terms of service access etc. Analysis of a sample of such profiles would yield evidence of the efficacy of proactive mediation of information and personalised delivery.

7.2.6 The Proactive Professional - Link Worker, Case Manager

The importance of a link worker, case manager or support person role has been identified in the research literature for some time (see Chapter 2). The role of such a person, as envisaged by the author of this thesis, is to mediate information proactively to the family in the context of relationship. The proactive professional seeks to understand the individual family and its circumstances, seeking and applying information to the families' unique needs. In this way the family is exposed to the “panoply of possibilities”, and with the growing knowledge base is enabled to make informed choices, based on accurate judgements of relevance. What the research
literature has failed to demonstrate is why the role is pivotal in parental acquisition of information, among other things. This "why" ought properly to be theoretical and evidentiary in nature.

Current approaches to professional service delivery, and the requirements of funding and regulatory bodies, demand an evidence base to best practice. While it is clear that parents’ perceptions of what would constitute "good information provision" are immensely important, those perceptions do not constitute evidence as such. Parents may express the need for a person to guide them through the maze and advise them of benefits, services etc. They are not usually able, however, to make explicit the connection between their own knowledge base and awareness of information, for example, and the proactively informing role that can be played by a proactive professional or key worker.

In research such as Mitchell and Sloper (2000), parents are defining what they would like rather than providing evidence of positive outcomes from information delivery models they have actually experienced. This cannot form an adequate justification for the model adopted. It is not possible to support a design as best practice simply by stating "that’s what parents want". Quite apart from the absence of evidence, there is no theoretical framework that may explain or support parents’ preferences. Hence, in pragmatic terms, where parents’ preferences may be expensive or difficult to support, funding bodies may far more readily set them aside. On the other hand, theoretical and/or evidentiary justification in support of arguments that, for example, x, y or z is essential for effective information delivery, is very much more difficult to dismiss.

There are very sound reasons parents have difficulty with access to information generally and the consequent failure to acquire information specifically, as detailed at 7.1.2 above. These reasons validate the role of the proactive professional, but as observed they are not explored in the research literature. In fact, the findings of this research validate the significance of the role of the proactive professional, from both theoretical and evidentiary perspectives.

As to evidence, it was unequivocal that parents who did not have a hypervigilant or vigilant information style, but who enjoyed the services of a community worker or other proactive professional, enjoyed similar levels of information acquisition to the
hypervigilant and vigilant parents with clear service access correlates. This is enormously significant. The theoretical underpinning is just as significant, as it has both explicative and predictive capacity. The conceptualisations in this thesis, when placed in the context of current information need and seeking theory, have the capacity to explain and predict what happens in information terms as the individual enters the unknown domain, with no extant knowledge base. The awareness heuristic operates and the individual experiences latent information need. The only ways of overcoming the problem of the awareness heuristic, and its corollary in latent information need, are information grounding, proactive information delivery and serendipity. If the information style of the parent does not encompass active information grounding it is unlikely that the problem of the awareness heuristic will be overcome in this way. Serendipity, on the other hand, is too inherently unreliable for ensuring access to information. Therefore the role of proactive information delivery can be seen as of paramount importance in the overcoming of awareness heuristic problems, especially where the parent has a more passive information style. This research suggests that this is likely to be in the order of more than 50% of any group of parents.

It is important to recognise that roles such as the DADHC-funded “Local Support Coordinator”, while theoretically intended to help families acquire information, support and services, cannot fulfill this role. They must comprehensively fail at three significant points. Firstly, the role is based on the premise that the family is expert and best placed to identify and articulate needs. This research, and the conceptualisation of the awareness heuristic and its corollary in latent information need, eloquently demonstrate why this is not achievable where there is no proactive delivery of information occurring. Secondly, the practices of this role, and all similar information service provider roles, are, at best, of a responsive delivery nature. They require as a starting point the family to make contact and begin to articulate needs. This research demonstrates that families are most vulnerable to lack of information acquisition, and are indeed experiencing failure to acquire information, at the very times they are expected to identify and articulate their needs. Only proactive information delivery can enable a family to start becoming the “expert” in any workable sense and from there begin to have the capacity to identify and articulate need. Thirdly, the role is also based on the premise that families can be supported to identify their own supports and be assisted to make use of them. The differential capacities of parents would strongly suggest that this is not feasible for parents at the more passive end of the information style spectrum.
Indeed, the role has been more recently re-defined, in relation to information, as to “provide basic information regarding the services and supports available in the communities in which they operate” [emphasis added] (DADHC 2004c, p.7). The pull-back to basic information is wholly inconsistent with the needs of “domain novices” in an extremely complex, difficult-to-navigate service sector.

It must be observed that there is a problem in the capacity of the proactive professional role to achieve its purposes equitably in the absence of a national, systematic approach to information delivery and the systematic, coordinated management of the sector’s information resources. This may indeed be possible only through a centralised information collection and dissemination system, as described at 7.2.4.

7.2.7 Use of Naturally Occurring Phenomena

7.2.7.1 Reference Groups - Proximation Synchronicity

While it is probably not possible to change an individual’s core information style, it may be feasible to “tinker around the edges” to a sufficient degree to improve information acquisition substantially. This may occur naturally where more passive parents are in regular, close proximity with at least one hypervigilant parent. It may also occur in professional settings.

The capacity of “reference groups” to overcome certain negative information acquisition sequelae arising from parental information styles, at least at certain information points, was observed by the researcher (see 5.2.3.1). It seemed feasible that the power of these groups could be harnessed in some way to enable less vigilant parents to benefit from the domain expertise and knowledge bases (effectively navigation aids) of the more vigilant parents.

Reference groups tended to be those forming around therapeutic/early intervention group sessions for the child. Thus in any one group there was often a mix of demographics and information styles. It seemed that information acquisition sometimes accrued from sufficiently close proximity to hypervigilants. Receptives, passives and
even avoidants acquired information and services when within their reference group was at least one hypervigilant. This may have been a social expression of proximation synchronicity, analogous to the group dynamic whereby an individual will act out of character, emulating the group behaviour. This requires further investigation to ascertain whether information is flowing from the information activity of the hypervigilant to all the reference group members, or whether the information activities themselves are being emulated by other parents uncharacteristically engaging in information activities on their own behalf. Nevertheless there is powerful potential to harness, especially given that “other parents” are so frequently identified as a major source of information.

It could well be, as one parent participant remarked, that parents who are further along the journey need to be employed to mentor others newly started. Certainly parents at the more vigilant end of the spectrum were better equipped to advise parents than many of the professionals from whom parents sought information.

7.2.7.2 *Value Added Information Exchange*

Virtually all parents attend both medical appointments and routine therapeutic sessions on a regular basis. If efforts were made by the professional to increase the incidence and value of information exchanges, it may be possible over time, as the parent knowledge base grows, to move parents incrementally along from passivity toward a more active approach. The professional could adopt a type of value-added information exchange, where each appointment/session is seen as an opportunity to seek/deliver information beyond the immediate matter at hand. Indeed if professionals took each appointment/session as an opportunity to take information exchange even one step beyond what parents know into what they do not know but may need, the face of information delivery could change, as the effects of each of the value-added information exchanges cumulate.

A classic example of where this could take place on a regular basis is the IFSP. Specific efforts could be made to expose parents to the panoply of possibilities. Forms are routinely given to parents to fill in prior to the IFSP meeting. These forms could incorporate both “valued examples” of information/service possibilities (Mitchell & Sloper 2001) and scenarios with which parents could identify, thereby increasing their capacity to identify and articulate need.
7.3 RECOMMENDATIONS

The following recommendations arise as natural corollaries of the findings of this research. They are intended to provide a reform agenda for the childhood disability sector.

7.3.1 The development and cross-sector implementation of standard working definitions of information and associated concepts, particularly “information delivery”, could profitably be initiated as a matter of urgency, using professionals with information science expertise. The NSW State Library’s Disability Information Service is one organisation that is well-placed to carry out this recommendation.

7.3.2 Existing policy, procedural and best practice documentation in the sector could be reviewed to ascertain changes required to reflect the growing understanding of “information delivery” and the additional detail required to explicate the means of achieving it. Again, the NSW State Library’s Disability Information Service is one organisation that has the relevant expertise to carry this out.

7.3.3 A process for developing information management standards within the sector should be initiated. The NSW State Library’s Disability Information Service is well-placed to undertake this role with its information science expertise, and in particular, its access to expertise in the management of diverse, community-based information resources. It could also play a lead role in the implementation of such standards.

7.3.4 Sectoral documentation described in 1.1.4 should be re-worked in line with the standard working definitions and information management standards developed as indicated in 7.2.1, 7.2.2, 7.2.3, giving due regard to the problem of the awareness heuristic and differential capacities in information seeking. This would most properly occur with advice and assistance from the NSW State Library’s Disability Information Service.

7.3.5 State and federal governments need to be encouraged to review the CSTDA to incorporate provision for a national information strategy, to operate
functionally at the State level through a service such as the Disability Information Service of each State Library or its equivalent. Each State Library Disability Information Service, or its equivalent, could have compulsory deposit of all materials developed in the sector and operate as a working model for information management of the sector’s resources.

7.3.6 A project to map the NSW childhood disability sector information milieu should be undertaken, with both State-wide mapping and DADHC-region-based mapping as appropriate. Organisations such as the ECICP Local Area Committees would be well placed to undertake this project at local levels and the NSW State Library’s Disability Information Service would have the expertise necessary to coordinate the project.

7.3.7 Conduct a series of further pieces of research, testing the findings of this research and ascertaining its wider applications.

7.3.7.1 Using the Commonwealth Centrelink carers database for recipients of Carers Allowance, undertake a large-scale piece of quantitative research testing the conceptual framework for information acquisition developed for this research. Particular emphasis should be placed upon the relative utility of different modes of acquisition to ascertain the efficacy of differing information practices in information diffusion programs.

This will yield rich data not only for predicting the relative efficacy of information diffusion programs, such as the Internet, but also validate individual variations in information activity. This will enable the development of more appropriate multi-modal information diffusion programs, targeting both modes and content information to particular client groups.

7.3.7.2 Investigate the application of the conceptual framework for information acquisition developed for this research in analogous “unknown domains”, especially those with high attendant stress and chronicity of crisis dimensions: for example, among those newly
diagnosed with life-threatening health conditions such as cancer, multiple sclerosis and lung/heart disease, and related domains within unemployment, substance abuse and domestic violence. Refinements specific to the subject matter will be required.

7.3.7.3 Investigate the application of the conceptual framework for information acquisition developed for this research in non-analogous “unknown domains”.

7.3.7.4 Conduct multi-disciplinary research, incorporating both psychology and information science, to investigate the nexus between Miller’s cognitive information styles and the information styles evidenced in information behaviour, as identified by this researcher (see 5.2.3.2.2).

7.3.7.5 Conduct multi-disciplinary research, incorporating both psychology and information science, to investigate the efficacy of a proactive-style information intervention compared with current practice.

7.3.8 Implement a two-part Proactive Professionals Program, based on the findings of the “information intervention” research.

7.3.8.1 Implement a link worker/key worker/community worker program fully, such that parents beginning to have concerns about their child get help from a key worker immediately, with increasing layers of involvement as concerns become more serious.

7.3.8.2 Develop and use as a model, a mobile information program to reach out to NSW community groups with information available in the sector, assisting groups to access information. The NSW State Library Disability Information Service could usefully model such a service.

7.3.9 Use the Commonwealth Centrelink database for Carers Allowance, with individual carer approval, to develop an effective Selective Dissemination of
Information (SDI) service for parents/carers of children with disabilities. This could operate through the Disability Information Service of each State Library or its equivalent.

7.3.10 An urgent review of the efficacy of the “Blue Book” for effecting action in the case of children not meeting developmental milestones is required. General practitioners, paediatricians, paediatric specialists along with the frontline early childhood centre nurses, community nurses and other health visitors, must significantly improve their capacity for early detection of disorders and disabilities and referral of parents for early intervention and other support before formal diagnosis to prevent family breakdown. This may require a NSW Health-auspiced “roundtable” and would benefit from an active interface with the Families First initiative.

7.3.11 Core responsibility for the proactive delivery of information to parents must be established. Using, for example, resources developed by the State Library of NSW Disability Information Service, parents/carers of children with disabilities and those seeking diagnoses must be apprised of:

7.3.11.1 a sectoral overview, including structure, functions, responsibilities

7.3.11.2 allowances and benefits, including those paid direct to parents such as Carers Allowance, and those paid to other organisations for provision of services to the child, such as respite, SNSS etc.

7.3.11.3 services, including therapeutic, educational and ancillary service providers, including government, non-government, charitable and any other organisations

7.3.11.4 scenarios that demonstrate “pathways” different parents have followed, showing the widest possible array of services, service delivery models and parent roles.

7.3.12 An urgent review of the delivery of information to families of children with disabilities by all DADHC-funded service providers is undertaken, along with
the creation of appropriate performance indicators and an incentive scheme for improved performance. As a starting point standard information practice documentation along with a verbal explanation ought to be given to parents at the commencement of any on-going service. (The current ‘Integrated Monitoring Framework’, DADHC 2005, is inadequate to the task for the reasons described in 6.1.2 (p. 276) and 7.1.1 (p. 335) as applied to the ‘Children’s Standards in Action’, DADHC 2004a).

7.3.13 An urgent review of the delivery of information to families of children with disabilities by general practitioners, paediatricians, paediatric specialists along with the frontline early childhood centre nurses, community nurses and other health visitors is also required. Appropriate performance indicators must be developed along with an incentive scheme for improved performance. As a starting point standard information practice documentation along with a verbal explanation must be given to parents at the commencement of any on-going service.
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APPENDIX 1: Parent Carer Interview Schedule

PART 1

1.2 Baby/child
1.2.1 Initials
1.2.2 Age
1.2.3 Gender
1.2.4 Hospital (specify public/private patient)
1.2.5 When was a delay/issue/problem diagnosed/suspected
1.2.6 Impairment/syndrome

1.3 Information Acquisition
When your child was first diagnosed (try to maintain chronological perspective)
1.3.1 Were you automatically given any information? What? By whom? Was it useful/appropriate?

1.3.2 What did you do?
1.3.2.1 Immediate reaction – did you want/not want information, to talk to people?

1.3.2.2 And then later? (e.g. wanted to find out as much as possible)

As time went on
1.3.3 Were you automatically given further information? What? By whom? Did it relate to specific crises (please describe), or was there general, on-going provision of information? What? By whom?

1.3.4 What sort of people did you go on to speak to (e.g. medical, therapists, other parents, friends, family ...) Did you initiate contact? Did you get information, support, advice? Can you describe it?

1.3.5 Did you join groups? (e.g. Lifestart) Did they give you information, support, advice, service? Can you describe it?
1.3.6
Was information ever revisited by people who had initially given it to you? Can you describe whether this was effective? (Or, hearing the same information from more than one source?)

1.3.7
Apart from those already mentioned, where else have you found things out, what other information sources do you have (e.g. noticeboards, chance discoveries, brochures, libraries, books, videos, Internet). How did/do you find them? How do you use them?

1.3.8
Have you had any chance discoveries of information that had a significant impact on you? Could you describe the chance discovery and its impact. Has this affected how you feel about access to information in this sector/how you find things out/strategies to use.

1.3.9
Currently, where do you get most of your information, advice, support

1.3.10
Of all the people, places, means (e.g. therapists, DSA, DoCS, technical info from the Internet), from whom/by which you have acquired information, can you talk about what has been the most helpful and the least helpful? Can you explain why. (i.e. what would you continue to use/never use again/use only if desperate)

1.3.11
Have you ever been asked by anyone to identify what information, advice and support you would find helpful/useful? Who were they?

1.3.12
Have you had any specific problem areas? (e.g. obtaining services? information? Getting good advice? Co-ordination of services? Health? Isolation?) Do these problems arise, in part, or full, from problems in just finding things out (i.e. access to information)? Can you explain how?

1.3.13
What have been your need areas for information since your child was diagnosed, including the present? What is the most effective/useful way for you personally to obtain this information?
PART 2

2.1 Biographical

2.1.1 Age

2.1.2 Are you

2.1.3 Do you have other children

2.1.4 Education

2.1.5 Education

2.1.6 Are you in the paid workforce

2.1.7 Are you a student?

2.1.8 Do you use child care for this child?

2.2 Information Access (utilise location specific information items, in addition, where appropriate)

2.2.1 Have you ever heard of

2.2.2 Have you ever used any of their services?
2.2.2.1 If yes, how often
Early Intervention Infoline
State Library Disability Information Service
IDEAS
Disability Information Network Australia (DINA)
NSW Council on Intellectual Disability
etc (more to be specified)
(F) Frequent (O) Occasional (R) Rare

2.2.3 Have you ever heard of the following Internet based resources

www.e-ibility.com
www.disabilityinfo.org.au
www.ideas.org.au
etc (more specified as appropriate)

2.2.3.1 If yes, how often do you use them? F/O/R/Never

www.e-ibility.com
www.disabilityinfo.org.au
www.ideas.org.au
etc (more specified as appropriate)

3 Benefits/Services/Entitlements

3.1 Are you aware of your entitlement to:

RTA Mobility Parking Scheme  yes/no
Respite care  yes/no
SNSS or equiv (for your child’s centre)  yes/no
A nominated person/case manager  yes/no
Carers Allowance  yes/no
etc (more specified as appropriate)

3.2 If yes, do you:
Have a mobility parking scheme sticker  yes/no
Use respite care  yes/no
Access SNSS funds or equiv  yes/no
Have a nominated person/case manager  yes/no
Receive Carers Allowance  yes/no
etc (more specified as appropriate)

3.3 Are there any other comments you would like to make?
APPENDIX 2: Information Statement for Research Participants

My name is Merryl Uebel-Yan and I am the mother of Matthew, James, Jonathan and Talitha. Talitha is 3 years old and has Down syndrome. We currently attend Noah’s Ark, an early intervention service in Nowra. Before moving to Nowra at the end of 2000, we attended the Early Education Clinic at North Sydney and the Lifestart Playgroups at Marrickville and Clovelly.

I am currently undertaking a Master of Applied Science (by thesis), in Information Studies, through Charles Sturt University. The subject of my research is access to information in the “disability sector” by parents of children with disabilities, 0-6 years. I am hoping to learn how parents “find things out” when they discover their child has additional needs, considering for example, what information they are automatically given and by whom, what they need to find themselves and how successful they feel their attempts have been. I am also investigating the role information services and service organisations/facilities/government departments are filling within the parents/carers “information network”. The research aims to identify potential areas for improving access to information.

Parents and Carers from two services are being asked to participate, voluntarily, in interviews. If you agree to participate, you will be asked to attend one two-part interview, at a time and location of your choice. The first part of the interview is a series of open ended questions aimed at allowing you to talk freely of your experiences in obtaining information, including identifying what have been information issues of significance to you. The second part of the interview is a brief, formal questionnaire-type component, looking at your family’s demographic details, and knowledge and use of certain services and entitlements. This will assist in identifying whether current information delivery methods are actually getting essential information to parents. Each interview is expected to last from twenty minutes, onwards, depending on the length of time a parent wishes to speak.

The National Health and Medical Research Council provides ethical guidelines under which research involving human participants must be conducted. Ethics Approval requires that I explain any potential risks to you. The potential risks I have identified are:

• You may experience some emotional pain as you are asked to relive aspects of what were probably for you, traumatic events. Issues arising at the time of diagnosis, during crises, and through each developmental stage, relating to obtaining information, advice and support, will be discussed. You may find the recollection causes discomfort and possibly pain. If you feel anxious at the prospect of facing this situation, you may wish to choose not to participate.

• You may also experience emotional pain from the discovery of information previously unknown, which had you known, may have influenced some decision making or action, or your quality of life. For example, in a study in the UK a parent was advised that her son would have been eligible for community transport to a special school. It would have had a marked impact on her quality of life as they had needed to use public transport for some years. Unfortunately, the study was conducted at the end of her son’s education, and so was of little use to the family at that time. The information the study provided thus caused some discomfort.

At the completion of each interview, you will be invited to ask the researcher any questions concerning access to information, services etc. Every effort will be made to ensure you are given, or directed to, any relevant information resources.

During your interview, data will be recorded on standard forms, by the researcher taking notes. In addition, the interview will be tape recorded, if you feel comfortable. Tapes will be transcribed as soon as practical, and re-used. Data recorded will be examined for common themes and issues, which will then be coded and recorded in a database. You and your
comments will not be identifiable. Your name will not be recorded anywhere on the interview notes, nor on the tape recording. Each interview will be uniquely classified by your child’s initials and months of age. Once interviewing is completed your child’s initials will be stripped from the data ensuring complete anonymity. This process cannot take place until interviews are completed as I need a way of cross-matching the interview list of participants with completed interviews/data collection forms, so I will know who has been interviewed and who is still outstanding. If your child has a rare disorder, which would automatically render you identifiable, this detail will be coded generically to avoid identification. your specific permission would be sought to do otherwise.

Any publications arising from the research, including the Thesis itself, will not uniquely identify any parent/carer participant and their comments unless specific written permission is obtained.

During the course of the study, all papers, documents, tape recordings and other data related to the study, will be retained in a locked filing cabinet, accessible only to the researcher. The computer used by the researcher will be password encoded, and used only by the researcher. It will be housed in a lockable office. At no time will comments attributed to any individual participant be discussed with another person, including other parents/carers, therapist, educators, service providers, academic Supervisors and so on. This is a stringent ethical requirement. Naturally, important issues arising, will be discussed over time, with service providers and others, but always with the proviso that any individual’s identity must not be disclosed by the researcher.

You must be aware that your participation is voluntary. If you do choose to participate, you can still withdraw at any time, and any data already recorded will either be handed to you, or destroyed.

Bearing in mind all these things, would you agree to participate in this research?

Note: Charles Sturt University’s Ethics in Human Research Committee has approved this Project. If you have any complaints or reservations about the ethical conduct of this project, you may contact the Committee through the Executive Officer:

The Executive Officer
Ethics in Human Research Committee
The Grange
Charles Sturt University
Bathurst NSW 2795

Tel: (02) 6338 4628
Fax: (02) 6338 4194

Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.
APPENDIX 3: Information Needs of Parents of Children with Disabilities - a comprehensive listing by subject area

1. Medical

- Pre-diagnosis information - including symptoms, significances, possible courses of action, interim supports and activities
- Diagnostic information as it pertains to the specific child - specific, detailed, targeted information
- The condition, syndrome, diagnosis - broad based general information
- The condition - causes, prevalence, course of the condition, life expectancy
- Detailed information on developmental, behavioural, physical, emotional corollaries that (may) flow from the diagnosis, to include symptoms, manifestations, progression of illness/disability, prognosis, lifelong sequenc, the future, eventual outcomes, anticipated progress or lack of progress, development
- Detailed information on all potential treatments including medications and surgical interventions together with their uses/purposes and their advantages and disadvantages, side effects, plus comparisons and best practice in other countries
- Implications of child's diagnosis for the future - medical, therapeutic and educational interventions
- Medical assistance/care available from health professionals and the context of the caregiving (e.g. private, public, institutional)
- The use/purpose of all visits, assessments, tests, appointments reports etc
- Practical tips specific to the child, their condition and their condition as it uniquely affects them e.g. techniques for coping with behavioural problems
- Actual help in dealing with behavioural and emotional problems
- Information of a type and quality that enables parents to have a meaningful input into treatment
- Explanation of service providers roles and responsibilities, including definitions and acronyms
  - Health and related individual professionals
  - Agencies, organisations etc
- Skill sharing
- "Flexible information" - some information is hard to predetermine as it depends on the individual needs and circumstances of the child and family

2. Therapeutic

- Early intervention including every therapeutic professional option - who, what, when, where, why
- Including uses/purpose of all therapeutic interventions - speech therapy, physiotherapy, occupational therapy, special education, behaviour therapy/psychologist, dietician etc
- Service options and services available - this is a very important distinction - options reveal services that could be offered and that other children/families are or may be receiving, possibly elsewhere, but may or may not be available to this child/family. The advantages and disadvantages of what is available compared with other options is needed. If services are not available full reasons for this and courses of action the family can take are needed.
- [It is important to note some conceptual ambiguity attaches to the use of terms "service options" and "services available" in the field, which frequently results in parents only being aware of what they are being offered personally as opposed to options that may be available]
- Other and alternative service and therapeutic approaches
- How to access/acquire services
- Explanation of service providers roles and responsibilities
- Individual therapeutic professionals
- Agencies, organisations etc
• The actual program the child is following, the role and function of all professionals working with the child, other programs in use elsewhere

• Skill sharing

• Information of a type and quality that enables parents to have a meaningful input into treatment/intervention/therapy

• Information enabling parents to acquire items, toys etc needed to support therapeutic outcomes e.g. where to buy/borrow items/toys used for therapy, advice about toy libraries

• Practical tips specific to the child and their condition

• Suggestions on how to transfer skills developed in one specialist setting to another and to home

3. Ancillary Supports, Benefits and Services

• Social support and services available

• Service options and services available – this is a very important distinction – options reveal services that could be offered and that other children/families are receiving, possibly elsewhere, but may or may not be available to this child/family. The advantages and disadvantages of what is available compared with other options is needed. If services are not available full reasons for this and courses of action the family can take are needed.

• How to access/acquire services

• Explanation of service providers roles and responsibilities

• individuals

• Agencies, organisations etc

• Voluntary and community agencies that can provide support and the nature of the support that could be offered

• Financial and other resources

• Government benefits, subsidies, entitlements

• Allowances, payments, one-off assistance

• Housing

• Home modification, car modification

• Travel

• Mobility parking

• Other sources of funding – NGO, charitable, one-off submission

• Subsidies to acquire services and supports

• Equipment, what is needed, how and where to acquire and pay for it, including

• Personal aids, calipers, wheelchairs, frames

• Hoists, lifts

• Nappies

• Parent support groups

• Home help

• Community transport

• Respite, including advice re value, importance

4. Educational

• Uses/purpose of (special) education

• Educational service options and services available - this is a very important distinction – options reveal services that could be offered and that other children/families are receiving, possibly elsewhere, but may or may not be available to this child/family. The advantages and disadvantages of what is available compared with other options is needed. If services are not available full reasons for this and courses of action the family can take are needed.

• Curriculum/program child is following

• Explanation of service providers roles and responsibilities

• individual professionals
• Agencies, organisations etc
• Skill sharing
• Suggestions on how to transfer skills developed in one specialist setting to another and to home
• Practical tips specific to the child and their condition
• Information of a type and quality that enables parents to have a meaningful input into education/schooling options
• Community education to change perceptions of disability

5. **Caring** (this overlaps and interacts with other categories)

• The diagnosis as it specifically affects the individual child and what it actually means for the family
• How to “care” for the child
• Medical – checklists, reviews, assessments, tests, further diagnoses
• Therapeutic
• Educational
• Being a family
• How to acquire/develop social support
• Special needs at home – lifting, bathing, stimulating etc
• Use and maintenance of equipment
• Practical advice on how to parent a child with “x”
• Support systems, what they are how to access or develop them
• Practical hints, suggestions, resources for coping with the affects of the disability and coping generally
• Information to provide to others explaining the child’s disability and the child and family’s support needs
• Longer term prospects

6. **Empowering Information**

• “how to change laws, rules and regulations” (Dean 1975, p.527)
• how to acquire information
• developments in education and social welfare systems
• rights and entitlements
• “how to be heard as parents” (Gravelle 1997, Seeking Information section, para. 1)
• assistance in identifying needed services, resources, supports
• negotiating to acquire needed services, resources, supports

7. **Information Needs – information characteristics**

• Information must be provided early, with appropriate timing
• Information/teaching regarding coping strategies should occur before problems arise
• Information must be accurate, up-to-date and honest
• There must be full and complete disclosure, in accessible, readily understood language
• Information needs change and develop according to the individual child/family – information is a process, not a one-off event.

(Ideas from each of the following authors and pieces of research assisted in the compilation of the above list: Case 2001; Dean 1975; Fisher 2001; Fyffe et al 1995; Gallagher, Beckman & Cross 1983; Gravelle 1997; Joseph Rowntree Foundation 1999; Kerr & McIntosh 2000; Krafft & Krafft 1998; Laybourn & Hill 1994; Mittler 1995; Quine & Pahl 1985; Rosenbaum, King &
APPENDIX 4: Modes of Information Acquisition – Overview

1. Information Seeking

1.1 Active Information Seeking
1.1.1 information seeking in response to specific recognised need
1.1.2 aware of gap/anomalous state (actual/potential) seeking to clarify/satisfy

1.2 Information Grounding
1.2.1. medical/therapeutic professional contact, appointments (parent initiated)
1.2.2 active reading noticeboards, brochures, information packs, newsletters (general and specific)
1.2.3 browsing parent libraries, info service, books
1.2.4 browsing internet-extensive use of hyperlinks, webrings, gateways
1.2.5 networking - parents, support groups-including DSA parent contact, listservs
1.2.6 committee membership
1.2.7 conferences, expo’s, seminars, workshops

1.3 Passive Information Seeking
1.3.1 responding to what is visible/available/known to be (e.g. brochures)
1.3.2 responding to what is offered (e.g. “what do you need?”)

2. Information Delivery

2.1 Proactive Information Mediation
2.1.1 friends, fellow parents, family
2.1.2 professionals in the field - including medical, therapeutic and other support people, DADHC Community Workers

2.2 Responsive Information Delivery
2.2.1 provider initiates information exchange and responds to requests for information e.g. IFSP, Local Support Coordinator
2.2.2 provider responds to request initiated by parent/family e.g. DSA, Infoline (often one-off)

2.3 Passive/Generic Information Delivery
2.3.1 one size fits all – information pack, showbag, folder, booklet (e.g. DSA kit, DADHC showbag)
2.3.2 parent library, resource centre or room
2.3.3 noticeboard, brochures
2.3.4 newsletters
2.3.5 appointments, tests, assessments, reports, discussions, routine therapeutic and other sessions (not used purposively to deliver or acquire information other than information pertaining specifically to the matter at hand)

3. Serendipity (tends to be one-off, information acquisition may not otherwise have occurred)

3.1 Direct contact (e.g. in conversation with another parent who mentions 'X', not active networking)
3.2 Unintended consequence (e.g. overheard conversation, intangible info)
3.3 Media
3.4 Information obtained for other purpose (e.g. another child)
3.5 Stranger
3.6 Information otherwise “stumbled across” (i.e. not purposefully given)
APPENDIX 4.1: Modes of Information Acquisition

1. INFORMATION SEEKING

1.1 Active Information Seeking

1.1.1 Information seeking in response to specific, recognised need

Defining Characteristics
1. awareness of information need
2. awareness of information required to satisfy need
3. awareness of means to acquire information
4. capacity to integrate new information with existing knowledge base to resolve need
5. understanding of relevance of information to specific, personal circumstances and need
6. may include political action to acquire information and services not otherwise available

Sample Activities
1. contact professional/s with questions, including conferences, expo’s etc where specific information need is in view
2. contact support group/organisation with question/s
3. contact network with question/s
4. information resource search - review information previously acquired - brochures, directories, books, information packs
5. information resource search - Internet, parent libraries, bookshops

Frequency of Use
Low-medium

Use Determinants/Barriers
1. awareness heuristic
2. knowledge base
3. parent information style
4. personal coping style
5. information literacy
6. family circumstances
7. match between parent expectations and professional practices
8. professional resistance

Utility
Mixed

Sample Failure Points
1. parent unaware of information need
2. parent unaware of information relevant to circumstances or the range of potential sources
3. parent knowledge base precludes or restricts recognition of need, information potentially available, modes of information acquisition, capacity to apply information, perseverance
4. parent does not have information acquisition skills
5. parent does not have ability to use available information to resolve information need
6. parent does not have capacity to apply information to personal circumstances
7. parent assuming professional proactive delivery therefore not actively seeking
8. parent “backs off” with professional resistance or failure to acquire using one mode or source
9. professional information delivery failure
10. information does not exist, or is unavailable
11. parent in survival mode
APPENDIX 4.2: Modes of Information Acquisition

1. INFORMATION SEEKING

1.1 Active Information Seeking

1.1.2 Aware of gap in or anomalous state of knowledge (actual or potential) and information seeking is aimed at satisfying or clarifying

Defining Characteristics
1. awareness of general ASK\(^1\), gap, something “missing”, the need to know “something”, therefore seeking to clarify what it is
2. sometimes accompanied by sense of inability to articulate the “right” question
3. may be unaware of info required to resolve knowledge anomaly
4. may be unaware of means to acquire information resolving the anomaly
5. some capacity to utilise information to build knowledge base and resolve anomaly
6. some understanding of relevance of information to anomaly

Sample Activities
1. contact professional/s with questions
2. contact support group/organisation with question/s
3. contact network with question/s
4. information resource search - review information previously acquired - brochures, directories, books, information packs
5. information resource search - Internet, parent libraries

Frequency of Use
Low-medium

Use Determinants/Barriers
1. awareness heuristic
2. parent information style
3. personal coping style
4. information literacy
5. perseverance in seeking answers, formulating the “right question”
6. family circumstances

Utility
Low-medium

Sample Failure Points
1. parent unaware of ASK
2. parent unaware of information relevant to sense of “gap”
3. parent does not have information acquisition skills
4. parent does not have ability to use available information to resolve knowledge anomaly
5. parent does not have capacity to apply information to personal circumstances
6. parent “backs off” with resistance
7. professional information delivery failure
8. information does not exist, or is unavailable
9. parent in survival mode

\(^1\) ASK = anomalous state of knowledge as defined by Belkin
APPENDIX 4.3: Modes of Information Acquisition

1. INFORMATION SEEKING

1.2 Information Grounding

1.2.1 Professional contact - medical, therapeutic, educational, appointments (parent initiated)

Defining Characteristics
1. parent initiated
2. information exchange (where there is awareness)
3. receptivity to information delivered, good uptake (where there is awareness)
4. use of contact to build knowledge base generally
5. no specific information need in view
6. may trigger recognition of specific information need and active information seeking
7. determination to acquire information and “get answers”

Sample Activities
1. appointments, regular checks, tests, reviews (medical, therapeutic, educational, ancillary supports)
2. attendance at early intervention
3. all attempts to secure support, including both direct service contact and political and advocacy action

Frequency of Use
Medium-high

Use Determinants/Barriers
1. relative ease of access/use
2. access/use facilitated by a professional/other person
3. parent knowledge base
   • affirms value
   • enables information exchange
4. awareness heuristic
5. information literacy
6. perseverance in seeking answers, formulating the “right question”
7. family circumstances
8. reference group activity
9. match between parent expectations & professional practices
10. professional knowledge base
11. professional relational capacity
12. professional resistance

Utility
Mixed

Sample Failure Points
1. negative or ineffective past experience
2. parent awareness heuristic issues (see 1.1.1 sample failure points) e.g.
   • Unaware of information needed
3. parent information literacy issues (see 1.1.1 sample failure points) e.g.
   • Unable to articulate “right question”
4. professional information delivery failures
   • Context (manner) and content failures
   • false assumptions about parents’ knowledge base/capacity to receive information
   • responsive delivery when proactive is required
• Incompetence
5. Parent assuming professional proactive delivery therefore not actively seeking
6. Parent “backs off” with resistance, accepts “expert” opinion
APPENDIX 4.4: Modes of Information Acquisition

1. INFORMATION SEEKING

1.2 Information Grounding

1.2.2 Networking

**Defining Characteristics**

1. attempts to make connections with “like” people/parents, people with similar experiences, children, issues
2. attempts to use connections to build knowledge base
3. social activity beyond essential/immediate contact
4. crossover contacts built up over time
5. recognition of information value of networking
6. *intentional and unintentional* information acquisition
7. no specific information need in view
8. may trigger recognition of specific information need and active information seeking

**Sample Activities**

1. joining support organisation/s, attending functions
2. making and maintaining contact with support group/s
3. making and maintaining contact with individual parents, this may be achieved in person or via the Internet
4. social activities – fundraising
5. social activities – non-fundraising

**Frequency of Use**

Medium

**Use Determinants/Barriers**

1. availability of appropriate groups – locale and focus
2. personal coping style
3. awareness heuristic
4. sense of “connectedness” with group members, relational strength, cohesion among network members
5. information delivery occurs irrespective of parent awareness, information literacy, information style and coping style
6. network has active information seeker/s
7. family circumstances
8. group resources limited

**Utility**

Very high

**Sample Failure Points**

1. parent has not adapted to disability
2. parent discomfort in disability-support settings
3. group related issue areas e.g. exclusivity
4. parent awareness heuristic issues (see 1.1.1 sample failure points) e.g.
   - Unaware of information potentially acquired in this way
5. parent in survival mode
6. parent hostile to proactive information delivery
7. parent shame regarding family circumstances
8. Support group assumed by professionals to address all information needs, therefore not reviewing parents’ needs
APPENDIX 4.5: Modes of Information Acquisition

1. INFORMATION SEEKING

1.2 Information Grounding

1.2.3 Seeking out and actively using existing information resources – active reading of information packs, newsletters, brochures, books, noticeboards

Defining Characteristics
1. information resources are available passively in the parent environment
2. if information resources are not delivered or readily apparent they may be sought out
3. no specific information need is in view
4. active reading and uptake of information
5. capacity to apply information
6. claiming effects may alert parent to unrecognised need and prompt active seeking

Sample Activities
1. information resource review, read information previously acquired - brochures, directories, books, information packs
2. seek out and read all promo’s, posters, notes etc. on noticeboards, including perusal of those that may not appear relevant
3. read regularly received newsletters
4. look through brochure racks and read brochures

Frequency of Use
Low

Use Determinants/Barriers
1. perception of relevance
2. knowledge base affirms value
3. access/use facilitated by a professional/other person
4. awareness heuristic
5. information literacy
6. reference group activity
7. parent information style
8. family circumstances

Utility
Mixed

Sample Failure Points
1. limited knowledge base, resources assumed irrelevant or not considered
2. parent awareness heuristic issues (see 1.1.1 sample failure points) e.g.
   - Unaware of information needed
   - Unaware of potential applications
3. parent information literacy issues (see 1.1.1 sample failure points) e.g.
   - Unable to use resources effectively to acquire information
   - Unable to apply information to personal circumstances
4. parent assuming professional proactive delivery therefore not actively reading
APPENDIX 4.6: Modes of Information Acquisition

1. INFORMATION SEEKING

1.2 Information Grounding

1.2.4 Browsing parent libraries, resource centres, information services

Defining Characteristics
1. resources are available passively in the parent environment
2. may not be sought out if unaware of resource and/or its contents
3. no specific information need is in view
4. browsing, perusal of information
5. chaining effects may alert parent to unrecognised need and prompt active seeking

Sample Activities
1. browse local el service or other parent library, perusing books, reports, newsletters, ephemera
2. browse DADHC-funded resources, including communication rooms/centres etc
3. browse information services, including Carelink, local information services e.g. DIRC

Frequency of Use
Low

Use Determinants/Barriers
1. perception of relevance
2. knowledge base affirms value
3. relative case of access/use/application
4. access/use facilitated by a professional/other person
5. awareness heuristic
6. information literacy
7. reference group activity
8. parent information style

Utility
Mixed

Sample Failure Points
1. parent awareness heuristic issues (see 1.1.1 sample failure points) e.g.
   • unaware of resource itself
   • unaware of information potentially acquired in this way
2. library, information service, resource centre not advertised appropriately by host organisation
3. parent information literacy skills may not be adequate to achieve information acquisition from browsing efforts e.g.
   • unable to apply information to personal circumstances
   • unable to integrate new information with existing knowledge base to identify specific need
APPENDIX 4.7: Modes of Information Acquisition

1. INFORMATION SEEKING

1.2 Information Grounding

1.2.5 Browsing the Internet

Defining Characteristics

1. quite distinct from the use of the Internet for specific, recognised need
2. no specific information need is in view
3. browsing, perusal of information
4. looking to build knowledge base generally
5. looking to be alerted to information of which previously unaware
6. intentional and unintentional information acquisition
7. chaining effects may alert parent to unrecognised need and prompt active seeking

Sample Activities

1. browsing, perusal of favourite websites
2. use of webrings
3. following hyperlinks and webrings for chaining effect
4. general and specific searches using multiple search engines
5. joining special interest chatrooms
6. joining special interest listservs

Frequency of Use

Low

Use Determinants/Barriers

1. access to the Internet within the home, or,
2. relative ease of access/use within ei setting
3. nature of the Internet – indiscriminate dumping of vast quantities of information of differing quality requires high level retrieval and evaluation skill
4. nature of the Internet – limited interaction/information exchange
5. access/use facilitated by a professional/other person
6. awareness heuristic
7. information literacy skills
8. reference group activity
9. parent information style
10. time required to acquire relevant information

Utility

Mixed

Sample Failure Points

1. ei service does not provide supported Internet access
2. parent awareness heuristic issues (see 1.1.1 sample failure points) e.g.
   • Unaware of information needed
3. parent information literacy issues (see 1.1.1 sample failure points) e.g.
   • parent has attempted & failed to acquire specific information previously, browsing not attempted
   • search strategy inappropriate or inadequate
4. difficulty devising search strategy without interaction/information exchange
5. extensive browsing fails to yield relevant information
APPENDIX 4.8: Modes of Information Acquisition

1. INFORMATION SEEKING

1.2 Information Grounding

1.2.6 Attending information and skills development events or functions

Defining Characteristics
1. distinct from use of events for specific, recognised need
2. no specific information need is in view
3. browsing, perusal, cherry picking of information
4. looking to build knowledge base generally
5. looking to be alerted to information of which previously unaware
6. intentional and unintentional information acquisition
7. issues raised and networking effects may alert parent to unrecognised need and prompt active seeking

Sample Activities
1. conferences - disability specific & general e.g. DSA conference, Early Intervention conference, Learning Disability conference
2. expo's - disability specific and general e.g. Disability Expo Inner West
3. seminars and information sessions e.g. Department Education and Training – Transition to School, DSA seminar on Wills and the Public Guardian
4. workshops - skill specific and disability general e.g. Family Advocacy “Shaping the Future”

Frequency of Use
Very low

Use Determinants/Barriers
1. availability of appropriate events/functions – locale & subject matter
2. personal coping style
3. awareness heuristic
4. sense of “connectedness” with group members or subject matter
5. family circumstances
6. reference group activity
7. professional attitudes

Utility
Very high

Sample Failure Points
1. event/function not available locally
2. event/function not advertised effectively
3. no childcare and other family support for non-disabled family members
4. inadequate financial assistance enabling parent to attend
5. event/function related issue areas e.g. exclusivity, professional attitudes to parents
6. parent discomfort in disability-support settings
7. parent awareness heuristic issues (see 1.1.1.1 sample failure points) e.g.
   a. Unaware of information potentially acquired in this way
   b. Perceived relevance problem
8. parent in survival mode
APPENDIX 4.9: Modes of Information Acquisition

1. INFORMATION SEEKING

1.2 Information Grounding

1.2.7 Membership of committees, review teams, forums, panels, parent representative functions on peak bodies, research participant etc

Defining Characteristics
1. aim is presence where decisions affecting service delivery to child are made
2. no specific information need is in view, rather, potential for information exchange
3. looking to build knowledge base generally
4. looking to be alerted to information of which previously unaware
5. intentional and unintentional information acquisition
6. issues raised & networking effects may alert parent to unrecognised need and prompt active seeking

Sample Activities
1. membership of parent management committees of EI and other services
2. membership of management committees of disability support orgs
3. parent representative on miscellaneous review panels, regional committees, forums, peak bodies, DADHC fact finding sessions, etc.
4. invited research participant

Frequency of Use
Very low

Use Determinants/Barriers
1. availability of appropriate rep opportunities
2. ease of entry and demands of membership
3. awareness heuristic
4. personal coping style
5. information literacy skill
6. sense of “connectedness” with organisation group members or subject matter
7. sense of empowerment
8. family circumstances
9. reference group activity
10. professional attitudes

Utility
Very high

Sample Failure Points
1. appropriate representative opportunities not available locally
2. representative opportunities not advertised or not advertised effectively
3. difficulties gaining entrée
4. inadequate support enabling parent to attend
5. group related issue areas e.g. exclusivity, professional attitudes to parents
6. parent discomfort in disability-support settings
7. parent awareness heuristic issues (see 1.1.1 sample failure points) e.g.
   - Unaware of information potentially acquired in this way
   - Perceived relevance problem
8. parent in survival mode
APPENDIX 4.10: Modes of Information Acquisition

1. INFORMATION SEEKING

1.3 Passive Information Seeking

1.3.1 Responding positively to visible/available/known information

Defining Characteristics
1. no specific information need is in view
2. browsing, perusal, ‘flicking through’ of information often follows prompts to view specific resources
3. parent able to use opportunity presented to acquire information
4. key is responsive behaviour rather than initiating action
5. unintentional information acquisition
6. looking to be alerted to information of which previously unaware
7. information discovered may alert parent to unrecognised need and prompt request for assistance with active information seeking

Sample Activities
1. another parent may say “have you heard/thought about ...?” and direct parent to resources in the immediate environment, which are then perused
2. media report, professional advice etc. may trigger recollection of resources seen and prompt perusal

Frequency of Use
Medium

Use Determinants/Barriers
1. relative ease of access/use
2. perception of relevance influenced by ‘flicking through’ rather than active reading
3. awareness heuristic - knowledge base affects capacity to perceive relevance
4. information literacy skills
5. parent information style
6. reference group activity
7. the quality of the information available and its display
8. family circumstances/need context at the time

Utility
Low

Sample Failure Points
1. absence of systematic coordinated information delivery
   - inadequate, inappropriate access mechanisms
   - gaps in information displayed, presented, made available
2. parent awareness heuristic issues (see 1.1.1 sample failure points) e.g.
   - parent requires sufficient knowledge base to perceive relevance
   - unaware of information needed
   - parent assumes information displayed, available or known is all there is
3. parent information literacy issues (see 1.1.1 sample failure points) e.g.
   - unable to apply information to personal circumstances
4. provider assumes parent able to perceive relevance and apply information to personal circumstances
5. no information exchange opportunities to reveal knowledge anomalies
6. quality of information available
APPENDIX 4.11: Modes of Information Acquisition

1. INFORMATION SEEKING

1.3 Passive Information Seeking

1.3.2 Responding positively to what is offered without initiating the initial action

*Defining Characteristics*
1. no specific information need is in view
2. receptive to information delivery
3. able to use opportunity presented to acquire information
4. key is responsive behaviour rather than initiating action
5. may be keen to acquire information but not have necessary information skills to seek actively or successfully
6. may have information skills to seek actively but other factors preclude use, such as awareness, family circumstances, other contextual factors

*Sample Activities*
1. professional may ask “What do you need?”
2. professional may suggest information resources to peruse
3. another parent may say “Look at this/Read this”

*Frequency of Use*
Medium-high

*Use Determinants/Barriers*
1. relational attributes – parent-provider
2. information exchange between parent and professional/provider
3. match between parent expectations and professional practices in information delivery
4. awareness heuristic
   * knowledge base affects capacity to perceive relevance
5. parent information style
6. coping style

*Utility*
Low

*Sample Failure Points*
1. parent awareness heuristic issues (see 1.1.1 sample failure points) e.g.
   * unaware of information needed
   * unaware of panoply of possibilities
   * parent assumes provider has delivered needed information
   * parent assumes awareness of information, possibilities
2. provider fails to inform parent of needed information, panoply of possibilities
3. provider assumes parent sufficiently informed to identify and articulate needs
4. information not re-visited
APPENDIX 4.12: Modes of Information Acquisition

2. INFORMATION DELIVERY

2.1 Proactive Information Delivery

2.1.1 Fellow parent, friends, family mediate information to family

Defining Characteristics
1. context is usually relationship between parent and person delivering information
2. effective information exchange
3. other person knows “whole story” and family circumstances
4. information mediation is usually on-going but sometimes issue specific
5. information is applied to the individual family
6. does not require parent request to trigger delivery

Sample Activities
1. fellow parents regularly update network members on information discoveries
2. family, friends may discover information and apply it to the family, this may be one-off or regular

Frequency of Use
Low-medium

Use Determinants/Barriers
1. parent has at least one contact able to acquire and disseminate information proactively
2. contact's awareness heuristic
   • aware of information needs of parent
   • capacity to mediate information effectively to individual parent
3. contact's information literacy skills
   • access to information resources
   • able to apply information to individual family’s circumstances
4. relational strength, cohesion between parent and contact
   • information delivery occurs irrespective of parent awareness, information literacy, information style and coping style
   • information delivered is appropriate
   • delivery not deterred by parent information avoidance or failure to seek, trigger
5. parent information style

Utility
High

Sample Failure Points
1. parent contact/s has/have same information deficiencies as parent
2. connections between parent and contact/s loose
   • unaware of parent’s needs
   • information is not mediated effectively
3. reference group does not contain active information seekers
4. contact/s may assume active information delivery will be received by information avoidant parents
5. parent hostile to proactive information delivery
APPENDIX 4.13: Modes of Information Acquisition

2. INFORMATION DELIVERY

2.1 Proactive Information Delivery

2.1.2 Professionals in the field, including medical, therapeutic and other support people, DADHC Community Workers, proactively deliver information

Defining Characteristics
1. context is usually relationship between parent and professional
2. effective information exchange
3. professional knows “whole story” and family circumstances
4. information mediation may be on-going or issue specific
5. information is applied to individual family
6. information is revisited
7. uptake may be tested
8. may be functioning as a SDI or current awareness service
9. does not require parent request to trigger delivery
10. preferred mode for most parents

Sample Activities
1. DADHC community worker maintaining regular contact with client, advising upcoming events, services available etc.
2. therapist or other professional playing case manager role and alerting family to additional services and benefits they may be able to access
3. ci service professional alerting family to in-house services other families are receiving, or services families receive elsewhere as comparison, of which parent had been unaware and therefore unable to request

Frequency of Use
Low

Use Determinants/Barriers
1. professional information skill – acquisition, evaluation, exchange, dissemination, mediation, application
2. professional knowledge base
   • parent information needs
   • broad subject expertise
   • lateral awareness – panoply of possibilities
3. professional relational skill
4. relational attributes – parent-provider
5. information exchange opportunities
6. parent/s receptivity

Utility
High

Sample Failure Points
1. professional has same information deficiencies as parent
2. connections between parent and professional loose
   • unaware of parent’s needs
   • unaware of family’s “story”
   • information not mediated effectively
3. professional mediates what is readily available but is not an active information seeker
4. professional information strengths in one area not available in other areas
5. Organisational changes affect information dynamics, no longer conducive to proactive delivery
6. Professional may assume active information delivery will be received by information avoidant parents
7. Parent hostile to proactive information delivery
APPENDIX 4.14: Modes of Information Acquisition

2. INFORMATION DELIVERY

2.2 Responsive Information Delivery

2.2.1 Provider initiates information exchange event and responds to requests for information

*Defining Characteristics*
1. provider initiation of information exchange opportunity
2. relationship between parent and provider, plus information exchange opportunities may/may not be superficial and formulaic
3. provider response to parent queries
4. parents may not have necessary knowledge base to identify information need and therefore may not be able to utilise the mode subset effectively for information acquisition
5. where mode subset is accompanied by opportunities for exposure to “panoply of possibilities” information acquisition may still occur
6. level of parent activity relates specifically to knowledge base
7. practice is said to be family-centred but emphasis is often on professional expertise to identify problem areas and suggest solutions
8. requires parent request to trigger information delivery

*Sample Activities*
1. professional may ask “What do you need?"
2. professional may ask what family’s/child’s need or problem areas are
3. IFSP
4. planning and other meetings
5. DADHC information gathering forums
6. special projects e.g. Carers NSW Connections

*Frequency of Use*
Medium

*Use Determinants/Barriers*
1. information exchange opportunity is appropriate to parent skills and knowledge base
2. provider knowledge base
   - parent information needs
   - subject expertise
   - lateral awareness – panoply of possibilities
3. professional relational skill
4. relational attributes – provider-parent
5. parent awareness heuristic
6. information literacy skills
7. parent information style
8. reference group activity
9. degree of match between professional/provider practices and parent expectations

*Utility*
Mixed

*Sample Failure Points*
1. provider conducts IFSP meeting and asks parents what they want or need
   - without informing parents of panoply of possibilities
   - insufficient resources available to meet needs
2. parent awareness heuristic issues (see 1.1.1 sample failure points) e.g.
   - Unaware of information needed
• Unaware of panoply of possibilities
• therefore cannot id and articulate need
3. parent information literacy issues (see 1.1.1 sample failure points) e.g.
  • parent has attempted and failed to acquire information in information exchange setting
    unsuccessfully previously so just “goes through the motions”
  • parent cannot articulate need for information and provider is not aware of family “story”
    from which to build information need profile
4. parent information exchange circumscribed by
  • limited knowledge base
  • incorrect perception of likely outcomes
APPENDIX 4.15: Modes of Information Acquisition

2. INFORMATION DELIVERY

2.1 Responsive Information Delivery

2.1.2 Provider responds to parent request/s for information

Defining Characteristics
1. professional willingness to provide information upon request, without specifically initiating or maintaining contact or information exchange opportunities
2. provider response to parent queries
3. irregular or one-off queries (otherwise see 2.1.1 or 2.1.2)
4. is not usually a part of the regular cache of information acquisition tools
5. may be no/little relationship between provider and parent
6. requires parent request to trigger delivery

Sample Activities
1. most medical and therapeutic providers operate in this mode
2. Infotline
3. local information and referral services and Carelink
4. Local Support Coordinator role
5. disability-specific support groups e.g. DSA (where contact is infrequent unless parent initiates)
6. general disability groups e.g. Carers NSW (where contact is infrequent unless parent initiates)
7. service provider responds to parent initiated request for information session e.g. respite provider presents talk on respite to parent group at ei service

Frequency of Use
Medium

Use Determinants/Barriers
1. provider knowledge base
   • family circumstances, history
   • information needs
   • subject expertise
   • lateral awareness – panoply of possibilities
2. professional relational skill
3. relational attributes – provider-parent
4. degree of match between professional/provider practices and parent expectations
5. parent awareness heuristic
   • parent awareness of child issues
   • parent awareness of panoply of possibilities
6. information literacy skills
7. parent information style
8. reference group activity

Utility
Mixed

Sample Failure Points
1. provider awareness heuristic issues
   • unaware of family “story” and actual need
   • unaware of limitations in parent knowledge base
2. provider only responds to what parent requests rather than what they may actually need but of which parent is unaware
3. parent awareness heuristic issues (see 1.1.1 sample failure points) e.g.
   - unaware of child’s issues, significance of symptoms etc.
   - unaware of information needed
4. parent information literacy issues (see 1.1.1 sample failure points) e.g.
   - parent request for information does not satisfy actual need because of awareness heuristic
   and information literacy issues.
APPENDIX 4.16: Modes of Information Acquisition

2. INFORMATION DELIVERY

2.3 Passive/Generic Information Delivery

2.3.1 Passive delivery of generic information resources – one-size-fits-all package, information pack, showbag, folder, booklet

**Defining Characteristics**
1. pre-existing information kit or package is delivered to parent, often in a service application or orientation to service or support group stage.
2. information kit or package content is standard irrespective of individual needs, circumstances, issues of parent/child
3. scope of contents and depth of coverage within information kits and packages vary completely by individual organisation and geographical area.
4. strengths in one subject area often not matched in others, within one kit and across kits. Thus, acquiring all kits (if feasible) may not necessarily yield information required.
5. to acquire additional information, or information pertaining more appropriately to family needs, parent must specifically request additional information, or describe circumstances in a way that triggers provider awareness that additional information is required.
6. rarely targeting or application of information delivered in this way to the individual family’s circumstances.
7. rarely revisiting of information delivered in this way with parents

**Sample Activities**
1. DADHC showbag or equivalent, given to some parents when their child becomes a client – includes information booklets, brochures, forms, lists etc. usually regarding services, benefits etc. but contents vary significantly by geographic region
2. disability support group information kit e.g. DSA Kit handed to parents in hospital, entailing delivery protocol
3. information package reed by parents upon entry to, or application to enter, an early intervention service, special education unit or equivalent
4. information sheets or other information generically provided to all parents whose child is attending an assessment centre for an assessment for the first time
4. Carers Kit NSW, by geographical area

**Frequency of Use**

Medium

**Use Determinants/Barriers**
1. acquisition requires application/entry into a service provider or support group
2. relative ease of acquisition
3. use facilitated by a professional/other person
4. parent awareness heuristic
   • knowledge base affects capacity to perceive relevance
5. parent information literacy skills
   • capacity to apply information to personal circumstances to resolve problem
6. parent information style
7. parent coping style
8. qualitative aspects of information content

**Utility**
Low-medium

**Sample Failure Points**
1. parent needs to be a member or applicant to receive package
2. information within the kit/package is delivered indiscriminately
3. information content is generic, one-size-fits-all and not applied to the individual family's needs
4. information is not re-visited apropos of changing circumstances
5. information content is inaccurate, not updated
6. parent awareness heuristic issues (see 1.1.1 sample failure points) e.g.
   • unaware of information needed
   • unaware of application of information to personal circumstances
7. avoidant parent may
   • not join support group and therefore not receive package
   • "receive" package but fail to read, uptake, apply
APPENDIX 4.17: Modes of Information Acquisition

2. INFORMATION DELIVERY

2.3 Passive/Generic Information Delivery

2.3.2 Passive delivery of information resources locally - parent library, resource centre, room

Defining Characteristics
1. totally passive delivery
2. parents may be "directed" to library but its resources are rarely mediated.
3. client parents are frequently unaware of the resource per se, or its capacity to yield information useful to them
4. no specific parent information need is in view, although sometimes compilations of information addressing specific problems areas experienced by a parent previously and filed in the library may serve this purpose
5. as reports and journal articles are read they are filed
6. there is rarely SDI or current awareness type service among parents (unless parent initiated through a newsletter)

Sample Activities
1. a compilation of local service and other information in a folder
2. ephemera collections
3. full scale parent library with books, reports, journal articles, policy documents, information compilations for specific problems etc
4. acquisition of books and articles to cover array of disabilities, conditions of children within the service

Frequency of Use
Low

Use Determinants/Barriers
1. parent awareness heuristic issues,
   - knowledge base affects capacity to perceive relevance both of library as information resource and information resources per se
2. provider staff awareness heuristic issues
   - awareness of client information needs
   - awareness of application of library information resources to those needs
3. relative ease of access (if library co-located with service delivery)
4. parent information literacy skills
   - capacity to apply information to personal circumstances to resolve problem
5. parent information style
6. coping style

Utility
Low

Sample Failure Points
1. parents unaware of
   - library
   - its resources
   - the utility of its resources for their own circumstances
2. provider staff unaware
   - library's resources
   - the utility of the resources for their clients' needs
3. value of library as information resource neither promoted nor recognised widely across service
APPENDIX 4.18: Modes of Information Acquisition

2. INFORMATION DELIVERY

2.3 Passive/Generic Information Delivery

2.3.3 Passive delivery of information resources locally – brochures, noticeboards

Defining Characteristics
1. may either be the sole element of a minimalist approach to information delivery, or, part of a cache of passive modes used by the provider
2. the mode is usually passive both in its acquisition of information for delivery and in the delivery of information acquired
3. provider may believe delivering information in this way is effective because of assumptions made about client knowledge base and client capacity to apply information independently
3. provider may be unaware that many clients may not independently acquire information delivered in this way but would expect to be referred to the information "if it was important to them"
4. parents may be directed to peruse noticeboards, brochure racks, etc, without specific guidance regarding the contents and their needs
5. rarely application of information delivered in this way to the individual family's circumstances.
6. information contained is often out of date, as to actual service delivery and contact details, and depleted stocks are often neglected and replacements or other useful resources not actively pursued.

Sample Activities
1. service provider brochure stands, noticeboards etc – Paediatrician, GP, local early intervention service, hospital, community health centres
2. a provider will often receive bulk brochures for dissemination, which are filed in a rack
3. any seeking of information for passive delivery would usually be by the parent group, or staff responding to parent-identified need

Frequency of Use
Low-medium

Use Determinants/Barriers
1. relative ease of access
2. use facilitated by a professional/other person
3. provider staff information skills – awareness/discrimination of information needs, information acquisition, evaluation, dissemination
4. parent awareness heuristic
   • knowledge base affects capacity to perceive relevance
5. parent information literacy skills
   • capacity to apply information to personal circumstances to resolve problem
6. parent information style
7. parent coping style
8. reference group activity
9. quality aspects of information content

Utility
Low-medium

Sample Failure Points
1. requires parent to take initiative to look at noticeboard, read brochure etc
2. information is displayed, delivered indiscriminately
3. information contents are generic, one-size-fits-all and rarely applied to individual family's needs by provider staff
4. contents frequently out-of-date unless culled regularly
5. contents may reflect information delivered to provider rather than needs of clients
6. parent awareness heuristic issues (see 1.1.1 sample failure points) e.g.
   • unaware of information needed
   • unaware of application of information to personal circumstances
7. avoidant parent will not move toward information without a very strong trigger
8. standards, practices, procedures described in brochure not followed
APPENDIX 4.19: Modes of Information Acquisition

2. INFORMATION DELIVERY

2.3 Passive/Generic Information Delivery

2.3.4 Passive delivery of information resources locally – newsletters

Defining Characteristics
1. while newsletter may be aimed at a specific client group (e.g. child service parents) it is one newsletter for all, irrespective of family background, child and family needs etc.
2. may address specific information needs, but requires parents to recognise, uptake and apply information independently
3. may have proactive informing elements (e.g. alerting parents to issues) but generic delivery means it is hit/miss whether it reaches target audience. Whether there is information uptake is also unknown.
4. parents with more active information style may often be responsible for compiling newsletter and may seek to have information specific to their needs addressed
5. quality and quantity of information varies significantly between newsletters even those with similar purposes
6. some newsletter are received when an organisation is joined and annual subscription paid others flow from attendance at events etc and require no payment
7. may fulfil SDI, current awareness function if
   • All incoming information is vetted for application to client body and targeted in newsletter
   • Information is sought to cover issue areas
   • Parents have capacity to recognise relevance, uptake and apply information independently

Sample Activities
1. disability support groups’ newsletters e.g. DSA monthly sheet and quarterly glossy mag
2. generic disability newsletters e.g. Carers NSW
3. local service providers newsletters e.g. DADHC, child service providers, respite providers etc
4. local HACC groups newsletters
5. broad based newsletters e.g. Australian Government newsletters to recipients of Carers Allowance or Pension

Frequency of Use
Low-medium

Use Determinants/Barriers
1. parent must either be recipient of newsletter or aware of and able to acquire it
2. parent awareness heuristic issues,
   • knowledge base affects capacity to perceive relevance both of newsletter generally and specific contents
3. editorial staff information skills – acquisition, evaluation, application, dissemination
4. parent information literacy skills
   • capacity to apply information to personal circumstances to resolve problem
5. parent information style
6. parent coping style

Utility
Medium

Sample Failure Points
1. parents unaware of newsletter or unable to acquire it
2. parent unaware of application of article information to individual circumstances
3. articles targeted at needs of active information seeker group
4. articles targeted at client needs perceived by professionals
5. editorial bias – provider produces newsletter about provider and limits information delivered to clients
   - does not canvass difficult, contentious issue
   - does not advise rights and recourse information
   - does not report information potentially "offensive" to funding organisation
6. parents assume information delivered from a neutral or supportive position
APPENDIX 4.20: Modes of Information Acquisition

2. INFORMATION DELIVERY

2.3 Passive/Generic Information Delivery

2.3.5 Passive delivery of information resources – during appointments, tests, assessments, routine sessions (not used purposively to deliver or acquire information other than information pertaining to the specific matter at hand), discussions

Defining Characteristics
1. quite distinct from use of appointments, tests, assessments and other conversations with professionals, by parents, to acquire information actively or to build the knowledge base
2. information need beyond the specific matter at hand is either not effectively addressed or not addressed at all e.g. focus may be prescription of medication and careful adherence to delivery regimen, with no ref to behavioural sequence to be aware of, and the likely impact on the family
3. little information exchange that would yield the possibility of raising awareness of unrecognised need and trigger active seeking/delivery
4. pursuing options and information dead-ends are the parent's responsibility
5. parent efforts to be “heard”, especially efforts to articulate what is not known, are rarely supported
6. facilitation of parent-identified need rarely occurs

Sample Activities
1. often seen in delivery of medical diagnoses (as distinct from developmental assessments) – “Here is the diagnosis”, “Here is the report, if you have any questions let me know.”
2. developmental assessments may often be accompanied by broader based information delivery but parents may be expected to uptake and apply information, and to pursue options independently
3. routine attendance at therapeutic sessions, early intervention etc
4. routine attendance at early childhood centres for regular “blue book” checks

Frequency of Use
Medium-high

Use Determinants/Barriers
1. frequently a naturally occurring event
2. professional knowledge base
   • parent information needs
   • family circumstances
   • subject expertise
   • lateral awareness – panoply of possibilities
3. professional relational skill
4. parent awareness heuristic issues - knowledge base affects capacity to recognise information need beyond the matter at hand
5. parent information literacy skills
   • capacity to recognise ASK and seek to resolve
6. parent information style
7. coping style

Utility
Low

Sample Failure Points
1. limitations of parent knowledge base affect quality and scope of information exchange
2. limitations of professional knowledge base affect quality and scope of information exchange
2. parent awareness heuristic issues (see 1.1.1 sample failure points) e.g.
   - Unaware of information needed
3. parent information literacy issues (see 1.1.1 sample failure points) e.g.
   - parent has attempted and failed to acquire information previously, grounding not attempted
   - inability to present pertinent information to trigger professional awareness of need
4. parent “pulls back” with resistance
5. professional incompetence
APPENDIX 4.21: Modes of Information Acquisition

3. SERENDIPITY

3.1 Serendipitous event occurs in direct contact with another person

Defining Characteristics
1. parent frequently has no awareness either of information need or relevance of information prior to acquisition and/or application
2. discovery is wholly unexpected and fortuitous
3. event may be one-off or repeated
4. information acquisition may not otherwise have occurred
5. distinct from information grounding because contact was not part of a networking strategy/style/approach

Sample Activities
1. conversation with another parent who may be describing a therapeutic service or benefit s/he is receiving, of which other parent was unaware
2. conversation with another parent who specifically informs of, or asks other parent if they are aware of, certain information
3. conversation with professional revealing knowledge anomaly

Frequency of Occurrence
Medium

Determinants/Barriers
1. by virtue of its defining characteristics is unpredictable and therefore inherently unreliable
2. some parents experience serendipitous occurrences as a catalyst triggering information grounding activities
3. parent must as a minimum be receptive to forthcoming information

Utility
Mixed

Sample Impact Points
1. raises parental anxiety
2. decreases satisfaction with and trust in professionals perceived to have failed to deliver
3. increases anger and relational difficulties with service providers, with potential information sequelae
4. raises parental understanding of awareness heuristic and its impact on information and service acquisition
5. parent may become highly motivated active information seeker and grounder
6. networked parents may quickly diffuse information acquired throughout their network
3. SERENDIPITY

3.2 Serendipitous event occurs as an unintended consequence of another action or event

Defining Characteristics
1. parent acquires information not intended for, nor delivered to, her/him
2. parent had previously been either unaware of information or unaware of its relevance or application to her/his family
3. parent recognises salience of information either immediately or later on reflection
4. the “penny drops”, or awareness and/or acquisition is suddenly achieved
5. discovery is wholly unexpected and fortuitous
6. event may be one-off or repeated
7. information acquisition may not otherwise have occurred

Sample Activities
1. overheard discussion between other parents, or other parent and professional
2. parent observes, or otherwise learns about, other parent/s receiving information, services, benefits, of which possibility they had been unaware
3. reading another child or family’s report
4. the cumulation of intangible and tangential information building a parent’s knowledge base
5. parent attends a professional appt or acquires information for another child

Frequency of Occurrence
Medium

Determinants/Barriers
1. by virtue of its defining characteristics is unpredictable and therefore inherently unreliable
2. some parents experience serendipitous occurrences as a catalyst triggering information grounding activities
3. parent must as a minimum be receptive to forthcoming information

Utility
mixed

Sample Impact Points
1. raises parental anxiety
2. decreases satisfaction with and trust in professionals perceived to have failed to deliver
3. increases anger and relational difficulties with service providers, with potential information sequelae
4. raises parental understanding of awareness heuristic and its impact on information and service acquisition
5. parent may become highly motivated active information seeker and grounder
6. networked parents may quickly diffuse information acquired throughout their network
APPENDIX 4.23: Modes of Information Acquisition

3. SERENDIPITY

3.3 Serendipitous event occurs through exposure to the formal media

Defining Characteristics
1. media exposure may be parent’s or another person’s who then alerts parent to the information
2. parent had previously been either unaware of information or unaware of its relevance or application to her/his family
3. distinct from information grounding as discovery is wholly unintentional and fortuitous
4. does not occur as part of a systematic strategy or approach to information acquisition
5. parent recognises salience of information either immediately or later on reflection
6. event may be one-off or repeated
7. information acquisition may not otherwise have occurred

Sample Activities
1. ad hoc, random reports, ad’s, commentaries etc on radio, TV – free and cable – newspapers

Frequency of Occurrence
Medium

Determinants/Barriers
1. by virtue of its defining characteristics is unpredictable and therefore inherently unreliable.
2. some parents experience serendipitous occurrences as a catalyst triggering information grounding activities
3. parent must as a minimum be receptive to forthcoming information

Utility
Mixed

Sample Impact Points
1. raises parental anxiety
2. decreases satisfaction with and trust in professionals perceived to have failed to deliver
3. increases anger and relational difficulties with service providers, with potential information sequelae
4. raises parental understanding of awareness heuristic and its impact on information and service acquisition
5. parent may become highly motivated active information seeker and grounder
6. networked parents may quickly diffuse information acquired throughout their network
APPENDIX 4.24: Modes of Information Acquisition

3. SERENDIPITY

3.4 Information acquired for another purpose

**Defining Characteristics**
1. sudden recognition that information acquired for another purpose has utility for an issue pertaining to child with disability
2. parent had not previously been aware of application of information (e.g. to family or child with disability)
3. application information may not otherwise have been acquired
4. acquisition of information alerts parents to other information of which they had been unaware
5. information achieves a tangential informing purpose unintentionally

**Sample Activities**
1. parent acquires information for another of their children, or another family, and suddenly recognises application of information to their own child and/or circumstances

**Frequency of Occurrence**
Medium

**Determinants/Barriers**
1. by virtue of its defining characteristics is unpredictable and therefore inherently unreliable
2. some parents experience serendipitous occurrences as a catalyst triggering information grounding activities
3. parent must as a minimum be receptive to forthcoming information

**Utility**
Mixed

**Sample Impact Points**
1. raises parental anxiety
2. decreases satisfaction with and trust in professionals perceived to have failed to deliver
3. increases anger and relational difficulties with service providers, with potential information sequelae
4. raises parental understanding of awareness heuristic and its impact on information and service acquisition
5. parent may become highly motivated active information seeker and grounder
6. networked parents may quickly diffuse information acquired throughout their network
APPENDIX 4.25: Modes of Information Acquisition

3. SERENDIPITY

3.5 Stranger delivers information

Defining Characteristics
1. totally random, unexpected and unpredictable event
2. ad hoc conversations commenced in random locations leading parent to the discovery of previously unknown information
3. parent may have no previous awareness of information need, or information pertaining to a recognised need, or application of known information to their need
4. event would usually be one-off
5. information acquisition may not otherwise have occurred

Sample Activities
1. an acquaintance, as a parent of a child with a disability, may start up a conversation with the parent and deliver information
2. a stranger may stop parent in a shopping centre or other location and start conversation about the child with a disability which may result in information exchange and delivery
3. stranger contacts parent through mutual acquaintance and offers information, help

Frequency of Occurrence
Medium

Determinants/Barriers
1. by virtue of its defining characteristics is unpredictable and therefore inherently unreliable.
2. some parents experience serendipitous occurrences as a catalyst triggering information grounding activities
3. parent must as a minimum be receptive to forthcoming information

Utility
Mixed

Sample Impact Points
1. raises parental anxiety
2. decreases satisfaction with and trust in professionals perceived to have failed to deliver
3. increases anger and relational difficulties with service providers, with potential information sequelae
4. raises parental understanding of awareness heuristic and its impact on information and service acquisition
5. parent may become highly motivated active information seeker and grounder
6. networked parents may quickly diffuse information acquired throughout their network
APPENDIX 4.26: Modes of Information Acquisition

3. SERENDIPITY

3.6 Information otherwise “stumbled across”

Defining Characteristics
1. any random events that do not otherwise constitute part of a systematic approach to information acquisition or delivery
2. information not purposively sought or delivered
3. information may be extrapolated from information delivered

Sample Activities
1. written information – brochures, news sheets etc. – not purposively acquired or read
2. somewhat vague, amorphous delivery, resulting in information acquisition, though exactly how may be unclear

Frequency of Occurrence
Medium

Determinants/Barriers
1. by virtue of its defining characteristics is unpredictable and therefore inherently unreliable.
2. some parents experience serendipitous occurrences as a catalyst triggering information grounding activities
3. parent must as a minimum be receptive to forthcoming information

Utility
Mixed

Sample Impact Points
1. raises parental anxiety
2. decreases satisfaction with and trust in professionals perceived to have failed to deliver
3. increases anger and relational difficulties with service providers, with potential information sequelae
4. raises parental understanding of awareness heuristic and its impact on information and service acquisition
5. parent may become highly motivated active information seeker and grounder
6. networked parents may quickly diffuse information acquired throughout their network