CHILDREN WITH DISABILITIES AND THEIR FAMILIES: TEAM WORKING AND THE ROLE OF THE KEY WORKER

JULIA GRAHAM

A thesis submitted in partial fulfilment of the requirements of the University of Brighton for the degree of Professional Doctorate in Physiotherapy

June 2012
Abstract

Children with Disabilities and their Families: Team Working and the Role of the Key Worker

The unique nature of the needs of children with disabilities and the varied dynamics of family life mean that service provision cannot be boxed neatly into the individual arenas of health, education or social care. These children and their families’ present service providers with complex challenges that often test the system. The co-ordination of, and communication between, members of the team around the child often falls to the parent.

The concept of ‘key working’ has been suggested as a way of co-ordinating service provision for children with a disability and their families. However, it has been reported that there are less than one-third of these families who have such a support mechanism in place (Department of Health 2004a). The policy and legislative framework exists for the introduction of the ‘key worker’ system to health, education and social care practice (Department of Health 2004a). Therefore, it is difficult to discern why the key worker role is not more prevalent. However a contributing factor may be that there is no universally recognised definition for the role and no consensus on the specific tasks that should be undertaken by a key worker.

Using grounded theory methodology, this qualitative study investigated and explored the dynamics of team working for children with disabilities and the process of co-ordination of services with specific reference to the role of the key worker. Using interviews and focus groups data were generated from professional members of the team, as well as parents of children with disabilities. Analysis of the data identified issues in current practice that present barriers to effective team working and the application of the key worker role. A model of supportive practice was developed to promote improved collaborative team working and utilise the key worker role to provide a more positive experience of service provision for children with disabilities and their families.
Contents

Abstract 2

Contents 3

List of Figures 16

List of Tables 18

Acknowledgements 19

Declaration 20

List of Appendices 21

Chapter 1: Introduction 24
1.1 Study Context within Statutory Provision 24
1.2 Literature Context 25
1.3 Origin of the Topic 26
1.3.1 Origin of the Topic: National Picture 26
1.3.2 Origin of the Topic: Practice Experience 27
1.3.3 Origin of the Topic: Professional Training 27
1.3.4 Origin of the Topic: Professional Contact 28
1.4 The Gap in Current Knowledge 28
1.5 The Aim of the Study 29
1.5.1 The Objectives of the Study 29
1.6 Philosophical Basis and Methodological Rationale of the Study 30
1.7 Support for the Study
1.8 Summary of Thesis Structure

Chapter 2: Background to Key Working

2.1 Definition of Disability
2.2 Team Around the Child
2.3 Key Working: Historical Context
   2.3.1 The Court Report
   2.3.2 The Warnock Committee Report
   2.3.3 The Children Act 1989
   2.3.4 The Laming Inquiry
   2.3.5 Every Child Matters
   2.3.6 The National Service Framework For Children, Young People and Maternity Services
   2.3.7 Aiming High for Disabled Children
   2.3.8 Recent Policy
2.4 Defining a Key Worker
   2.4.1 Key Worker: Partnership Role
   2.4.2 Key Worker: First Point of Contact
   2.4.3 Key Worker: Role Descriptors
   2.4.4 Elements of Key Working
   2.4.5 Key Worker Role: Parents Perspective
2.5 Key Working and Teams
   2.5.1 Key Working and Teams: Team Working
   2.5.2 Key Working and Teams: Parental Views
   2.5.3 Key Working and Teams: Aims and Management
   2.5.4 Key Working and Teams: Care Management Approach
   2.5.5 Key Working and Teams: Developing a
Collaborative Culture 59

2.5.6 Key Working and Teams: Influences on Effectiveness 61

2.5.7 Key Working and Teams: Summary 64

2.6 Key Working: Models of Care Delivery 64

2.6.1 Medical and Social Models of Care 64

2.7 Models of Key Working 67

2.7.1 Mukherjee Model of Key Working 67

2.7.2 May/Gupta Model of Key Working 70

2.7.3 Enhanced Key Worker Liaison Model 72

2.7.4 Care Co-ordination Key Worker Model 73

2.8 Key Working: Professional Influence on the Role 73

2.8.1 Key Working: Therapists as Key Workers 74

2.8.2 Key Working: Professional Knowledge and Skills 74

2.8.3 Key Working: Professionals in a Position without Power 75

2.8.4 Key Working: Professional Culture 76

2.8.5 Key Working: Working with other Professional Cultures 76

2.8.6 Key Working: Designated and Non-designated Key Workers 77

2.9 Training and Education of Key Workers 77

2.9.1 Separatist Education of Professionals 78

2.9.2 Inter-Professional Learning 79

2.10 The Family and the Key Worker 80

2.10.1 Key Working: Parent Partnership 81

2.10.2 Key Working: A Family-Centred Approach 81

2.10.3 Key Working: Family Support 82

2.10.4 Key Working by Family Members 83
3.2.1 The Historical Background of Grounded Theory Methodology

3.2.2 Evolution of Current Day Grounded Theory Methodology

3.2.3 The Role of the Researcher in Grounded Theory

3.2.4 The Researching Practitioner

3.2.5 A Disturbance in Practice

3.3 The Role of Reflexivity in Grounded Theory

3.4 Sampling in Qualitative Research

3.4.1 Purposeful Sampling

3.4.2 Theoretical Sampling

3.4.3 Sample Size

3.5 Data Generation Methods

3.5.1 Selection of Method: Focus Groups

3.5.2 Selection of Method: Semi-Structured Interviews

3.5.3 Impact of the use of Different Tools in Data Generation

3.5.4 Selection of Method: Field Notes

3.6 Data Analysis

3.6.1 Constant Comparative Analysis

3.6.2 Terminology used in Analysis of Grounded Theory Research Data

3.6.3 The Analysis Process

3.7 Trustworthiness, Validity and Rigour in Qualitative Research

3.7.1. The Issue of Quality

3.7.2 Interpretation of the Data

3.7.3 Generalisability of Research

3.7.4 Auditability of Research
3.8 Philosophical Standpoint

3.8.1. Epistemology
3.8.2 Constructionism
3.8.3 Mutual Recognition between Researcher and Participant
3.8.4 The Researcher as a Research Tool

3.9 Summary

Chapter 4: Method

4.1 Research Governance

4.2 The Pilot Study

4.2.1 Aim of Pilot Study
4.2.2 Pilot Study Participants
4.2.3 Outcomes of the Pilot Study

4.3 Identification and Recruitment of Participants

4.3.1 Sampling Methods Used in the Main Study
4.3.2 Eligibility Criteria
4.3.3 Access and Recruitment of Professional Participants
4.3.4 Access and Recruitment of Parent Participants

4.4 Methods of Data Generation

4.4.1 Focus Groups
4.4.2 Individual Interviews

4.5 Data Management and Analysis

4.5.1 Transcription
4.5.2 Analysis

4.6 Rigour

4.7 Validity or Truthfulness

4.8 Field Notes

4.9 Reflective Diary
4.10 Summary

Chapter 5: Findings

5.1 Characteristics of Study Participants

5.1.1 Parent Participants

5.1.2 Health Staff Participants

5.1.3 Children's Services – Education Staff Participants

5.1.4 Children's Services - Social Services Staff Participants

5.2 Emergent Sub-Categories and Categories

5.3 Category One: Human Factors

5.3.1 Complexities of Family Life with a Disabled Child

5.3.1.1 Emotional Impact on Parents

5.3.1.2 Strain on Parents

5.3.1.3 Impact on Family Life

5.3.1.4 Impact on Parental Relationships

5.3.2 Child and Family Needs

5.3.2.1 Uniqueness of Need

5.3.2.2 Immediacy of Support

5.3.2.3 Availability of Support

5.3.2.4 Type of Need

5.3.2.5 Sibling Support

5.3.2.6 Key Worker Support Role

5.3.3 The Influence of Personalities

5.3.3.1 Influence of Individual

5.3.3.2 Influence of Previous Experience

5.4 Category Two: Service Organisation and Delivery

5.4.1 Time & Caseload Constraints

5.4.1.1 Lack of Time
5.4.1.2 Size of Caseloads 168

5.4.2 Access to Resource 169
  5.4.2.1 Lack of Pooled Budgets 169
  5.4.2.2 Influence of Access Criteria 170

5.4.3 Influences on Services 170
  5.4.3.1 External Influences 170
  5.4.3.2 Legislative Constraints 171
  5.4.3.3 Public Accountability 172
  5.4.3.4 Service Re-organisation 172

5.4.4 Influence of Location 174
  5.4.4.1 Geographical Borders 174
  5.4.4.2 Co-Location 175

5.4.5 The Key Worker Role 176
  5.4.5.1 Informal Key Worker Role 176
  5.4.5.2 Parents as Key Workers 177
  5.4.5.3 Cross-Agency Involvement in Key Worker Role 177
  5.4.5.4 Context of Key Worker Role 179
  5.4.5.5 Perception of Key Worker Role 179

5.4.6 Key Worker Skills 180
  5.4.6.1 Role Definition 180
  5.4.6.2 Key Worker Skills 181

5.4.7 Training Needs 182
  5.4.7.1 Core Training Needs 182
  5.4.7.2 Parental Involvement in Training 183

5.5 Category Three: Working Together 186

5.5.1 Professional Role 186
  5.5.1.1 Understanding Professional Roles 186
  5.5.1.2 Professional Identity 187
  5.5.1.3 Professional Respect 188
  5.5.1.4 Professional Protectionism 188
5.5.2 Collaborative Working
5.5.2.1 Lack of Collaborative Working

5.5.3 Child & Family Focused Working
5.5.3.1 Lack of Child and Family Focus
5.5.3.2 Impact of Policy and Procedure
5.5.3.3 Holistic Working

5.5.4 Parent-Professional Interaction
5.5.4.1 Honesty Based Relationships
5.5.4.2 Impact of Acceptance of Disability
5.5.4.3 Continuity of Care
5.5.4.4 Relationship Boundaries
5.5.4.5 Parent Partnership
5.5.4.6 Parental Capability
5.5.4.7 Parental Engagement
5.5.4.8 Relationship Power Imbalance
5.5.4.9 Advocacy
5.5.4.10 Dependency
5.5.4.11 Key Worker Relationship

5.6 Category Four: Communication
5.6.1 Communicating the Diagnosis

5.6.2 Communication Across The Team
5.6.2.1 Numbers in the Team
5.6.2.2 Contact Difficulties
5.6.2.3 One Point of Contact
5.6.2.4 Key Worker and Communication
5.6.2.5 Proactive Communication
5.6.2.6 Team Communication

5.6.3 Inter-Agency Communication
5.6.3.1 Lack of Common Language
5.6.3.2 Cross Agency Communication

5.6.4 Face to Face Contact
5.6.5 Information Sharing

5.6.5.1 Information Sources 212
5.6.5.2 Impact of Lack of Information 214
5.6.5.3 Information Sharing 215
5.6.5.4 Incompatible Information Technology Systems 216
5.6.5.5 Lack of Joint Documentation 216

5.7 Summary 219

Chapter 6: Discussion 220

6.1 Criticisms of Current Service Provision 223

6.1.1 Human Factors: Individual Personalities 223
6.1.2 Human Factors: Professional Ideology 224
6.1.3 Service Organisation and Delivery: Agency Silos 224
6.1.4 Service Organisation and Delivery: Professional Language 225
6.1.5 Service Organisation and Delivery: Bureaucracy 226
6.1.6 Service Organisation and Delivery: Organisational Drivers 228
6.1.7 Service Organisation and Delivery: Funding 228
6.1.8 Service Organisation and Delivery: Location 230
6.1.9 Working Together: Team Organisation & Membership 232
6.1.10 Working Together: Understanding Roles 232
6.1.11 Working Together: The Key Worker Role 233
6.1.12 Working Together: Relationships 235
6.1.13 Working Together: Parent Partnerships 236
6.1.14 Working Together: The Core Team 239
6.1.15 Working Together: Specific Roles 241
6.1.16 Communication: Team Communication 241
6.1.17 Communication: The Key worker – One Point of Contact 243
6.1.18 Communication: Information Technology 245
6.1.19 Communication: Regularity of Contact 245
6.1.20 Communication: Documentation 246
6.1.21 Communication: Shared Experiences and Information Sources 247

6.2 Child, Parent and Family Needs 248

6.3 Conceptualisation of Findings 253
  6.3.1 Impact of Impairment 253
  6.3.2 Impact of Individual Culture 254
  6.3.3 Impact of Societal Views 255

6.4 Recommendations for Service Development 256
  6.4.1 Definition of a Key Worker 256
  6.4.2 Model of Practice 257

6.5 Recent Literature 264
  6.5.1 Children’s Trusts 264
  6.5.2 NHS Next Stage Review 268
  6.5.3 Government White Paper 268
  6.5.4 Department of Education Green Paper 270

6.6 Factors Mitigating against Change and Development 271
  6.6.1 Professional Culture 272
  6.6.2 Time Pressures 272
  6.6.3 Financial Constraints 272
  6.6.4 Resistance to Change 273

6.7 Summary and Conclusion 273

Chapter 7: Conclusions 276
7.1 The Aim of the Study
7.2 Significance of Study
7.3 Key Findings: Novel Contribution to Knowledge Relating to Practice within the Clinical Field
7.3.1 The Voice of Parents of Children with Disabilities
7.3.2 A Flexible Approach to Key Working
7.3.3 Model of Practice
7.4 Limitations of the Study
7.4.1 Participants
7.4.2 Study Context
7.4.3 Research Design: Methodology
7.4.4 Generalisability
7.5 Implications for Practice
7.6 Dissemination and Implementation
7.6.1 Celebrating Success
7.7 Recommendations for Future Research
7.8 Conclusion

Chapter 8: Reflections of a Research Journey
8.1 The Study
8.2 Consent to Participate
8.2.1 Influences on Participation
8.3 Role of the Researcher Practitioner
8.3.1 Preconceptions and Pre-understandings
8.3.2 Therapeutic Relationships
8.4 Methodology
8.4.1 Pilot Study Experience
8.4.2 Clarification of Meaning
8.5 Support Mechanisms for the Researcher
8.5.1 Emotional Challenges of the Research
<table>
<thead>
<tr>
<th>Figure Number</th>
<th>Figure Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>The Team Around the Child: The Family Unit</td>
<td>40</td>
</tr>
<tr>
<td>2</td>
<td>Model of Key Working (Mukherjee et al 1999)</td>
<td>69</td>
</tr>
<tr>
<td>3</td>
<td>Schematisation of the Key Worker Role by Gupta (1995)</td>
<td>71</td>
</tr>
<tr>
<td></td>
<td>Adapted by May (1996a)</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Analytic Development Category One: Human Factors</td>
<td>166</td>
</tr>
<tr>
<td>5</td>
<td>Analytic Development Category Two: Service Organisation and Delivery</td>
<td>185</td>
</tr>
<tr>
<td>6</td>
<td>Analytic Development Category Three: Working Together</td>
<td>201</td>
</tr>
<tr>
<td>7</td>
<td>Analytic Development Category Four: Communication</td>
<td>218</td>
</tr>
<tr>
<td>8</td>
<td>Discussion Route</td>
<td>222</td>
</tr>
</tbody>
</table>
List of Figures Continued

<table>
<thead>
<tr>
<th>Figure Number</th>
<th>Figure Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>Key Worker Co-ordinated Service Model</td>
<td>261</td>
</tr>
</tbody>
</table>
## List of Tables

<table>
<thead>
<tr>
<th>Table Number</th>
<th>Table Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>The Team Around the Child: Health Services</td>
<td>36</td>
</tr>
<tr>
<td>Two</td>
<td>The Team Around the Child: Education Services</td>
<td>37</td>
</tr>
<tr>
<td>Three</td>
<td>The Team Around the Child: Social Services</td>
<td>38</td>
</tr>
<tr>
<td>Four</td>
<td>The Team Around the Child: Voluntary Organisations</td>
<td>39</td>
</tr>
<tr>
<td>Five</td>
<td>Background of Participants in Study</td>
<td>150</td>
</tr>
</tbody>
</table>
Acknowledgements

I would like to thank my supervisors Dr Virginia Jenkins and Dr Christine Davey for their support and encouragement. Thanks go also to my sponsors NHS Education South Central, Basingstoke and North Hampshire Foundation NHS Trust and The Chartered Society of Physiotherapy whose support of my studies was much appreciated. To my work colleagues in the therapy team – thank you for your patience. Heartfelt thanks to all my family in particular my husband Derek who has been there every step of the way. And finally sincere thanks to all those who participated in the study, who by sharing their thoughts and experiences made it all possible.
Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed:

Julia Graham

Dated:
<table>
<thead>
<tr>
<th>Appendix Number</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>Brighton University Research Governance Approval</td>
<td>329</td>
</tr>
<tr>
<td>Two</td>
<td>Ethical Approval Confirmation</td>
<td>331</td>
</tr>
<tr>
<td>Three</td>
<td>Letter of R&amp;D Approval</td>
<td>335</td>
</tr>
<tr>
<td>Four</td>
<td>Professional Participant Information Sheet</td>
<td>337</td>
</tr>
<tr>
<td>Five</td>
<td>Parent Participant Information Sheet</td>
<td>341</td>
</tr>
<tr>
<td>Six</td>
<td>Focus Group Protocol</td>
<td>345</td>
</tr>
<tr>
<td>Seven</td>
<td>Letter to Education Gatekeeper</td>
<td>347</td>
</tr>
<tr>
<td></td>
<td>Response from Education Gatekeeper</td>
<td></td>
</tr>
<tr>
<td>Eight</td>
<td>Letter to Health Gatekeeper</td>
<td>351</td>
</tr>
<tr>
<td></td>
<td>Response from Health Gatekeeper</td>
<td></td>
</tr>
<tr>
<td>Nine</td>
<td>Letters to Social Services Gatekeeper</td>
<td>354</td>
</tr>
<tr>
<td></td>
<td>Response from Social Services Gatekeeper</td>
<td></td>
</tr>
<tr>
<td>Appendix Number</td>
<td>Title</td>
<td>Page</td>
</tr>
<tr>
<td>-----------------</td>
<td>------------------------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Ten</td>
<td>Reply Slip for Participants</td>
<td>360</td>
</tr>
<tr>
<td>Eleven</td>
<td>Letter to Professionals willing to Participate in Study</td>
<td>362</td>
</tr>
<tr>
<td>Twelve</td>
<td>Letter of Invitation to Parents to Participate in Study</td>
<td>364</td>
</tr>
<tr>
<td>Thirteen</td>
<td>Participant Consent Form</td>
<td>366</td>
</tr>
<tr>
<td>Fourteen</td>
<td>Question Schedule for Focus Group</td>
<td>368</td>
</tr>
<tr>
<td>Fifteen</td>
<td>Question Schedule for Parent Interviews</td>
<td>371</td>
</tr>
<tr>
<td>Sixteen</td>
<td>Development of Interview Topics during Data Collection</td>
<td>373</td>
</tr>
<tr>
<td>Seventeen</td>
<td>Participant Background: Interviewees</td>
<td>380</td>
</tr>
<tr>
<td>Eighteen</td>
<td>Participant Background: Focus Groups</td>
<td>382</td>
</tr>
</tbody>
</table>
List of Appendices Continued

<table>
<thead>
<tr>
<th>Appendix Number</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nineteen</td>
<td>Example of Transcript</td>
<td>385</td>
</tr>
<tr>
<td>Twenty</td>
<td>Example of Thematic Analysis: Initial Coding</td>
<td>409</td>
</tr>
<tr>
<td></td>
<td>(Showing Researcher’s Coding Notes)</td>
<td></td>
</tr>
<tr>
<td>Twenty One</td>
<td>Example of Thematic Analysis: Initial Coding and Development of Categories</td>
<td>412</td>
</tr>
<tr>
<td>Twenty Two</td>
<td>List of Thesis Dissemination to Date</td>
<td>424</td>
</tr>
</tbody>
</table>
Chapter 1.0: Introduction

The first section of this introduction will locate the study context of children with disabilities within the overall services provided by the statutory agencies of health, education and social care. The next section will outline a brief description of the current state of knowledge at the outset of the study. This will be expanded upon in chapter 2. The introduction will then move on to the origin of the problem for the researcher and how this became the study focus. Justification for the need for this study will follow identifying the gap within current knowledge. Focus will then move to identifying the aims and objectives of the study. Exploration of the philosophical basis and methodological rationale will follow. The chapter will conclude with identification of the support given to the study and a summary of the structure of how the thesis is presented.

New data which has been published since the outset of the study and which played no part in the original study design will be discussed at the end of the thesis.

1.1 Study Context within Statutory Provision

Children with disabilities often have many needs which span the boundaries of the statutory providers of health, education and social care services. Children with disabilities are in fact a minority group when compared to other service users and yet place high demands on providers from a wide variety of professional groups and organisations. The intricate and individual needs of the children often fall outside the core activities of the services and can present complex challenges to providers. Families of children with disabilities often experience fragmentation, duplication or lack of service provision due to poor co-ordination of the team around the child (The Dartington Hall Trust 2004).
1.2 Literature Context

Consistent themes emerge from literature, legislation and Government policy regarding the care of disabled children. Services should be integrated to improve co-ordination across agencies (Department of Health 1991, Department of Health 2004a, Department for Education and Skills 2004). Effective, inter-professional teamwork and collaborative partnerships should be encouraged (Sloper et al 1999, Tait et al 2002, Vetere 2007). There should be multi-agency joint funding wherever possible (Department of Health and Department for Children Schools and Families 2008). Information should be shared across agencies as appropriate and necessary and at all times a family perspective should be included in planning and implementing change (Department for Education and Skills 2003). However, the evidence that supports the apparent simple concept of a trans-disciplinary, integrated model of care is contrasted by the complexity of implementing this approach within current organisations.

The ‘key worker’ has been suggested as a way of co-ordinating provision and offering support for these children and their families, aiming to provide a seamless service. In the literature there is evidence to support the role of the key worker in the team around the child (Contact a Family 2003, Barton & Clarke 2005) but little evidence which explores the perceptions and understandings of the team members, of that role. Theoretical studies on the models of key working indicate benefits for the child and family as well as the professionals within the team (Mukherjee et al 1999, Emmanuel et al 2002); however, there appears to be no consensus on the basic profile of the tasks that should be undertaken by a key worker and no shared opinion about the definition of the role.
1.3 Origin of the Topic

The implementation of the key worker role in paediatrics is set against a backdrop of policies and legislation for disabled children and children in general, affecting the working practice of the professionals involved. However, the inconsistency of the key worker roles described reflects the unique nature of the needs of children with disabilities and their families and the complexity of this area of practice.

1.3.1 Origin of the Topic: National Picture
The National Service Framework (NSF) for Children, Young People and Maternity Services states that:

‘The parents of severely disabled children or those with high levels of need require a single point of contact with services and an effective, trusted and informed named person (a key worker or care manager) to help them obtain the services they require’

(Department of Health 2004b, p28)

The NSF goes on to state that currently less than one third of families who have a child with a disability have a named key worker. This finding suggests that there is a significant problem with the current way of working that is limiting the creation and implementation of the key worker role but offers no clarification why the role is not more common. This evident lack of established key workers within this field of practice presented something of an enigma for the researcher.

The prevalence of documentation about the need for key workers in literature, policy and legislation across health and social care services and the notable inconsistencies when identifying the role
within this arena, stimulated an interest in the subject for the researcher.

1.3.2 Origin of the Topic: Practice Experience
The interest in this topic also arose from the researcher's personal experiences of working as a paediatric physiotherapist with children with disabilities and their families. This experience has included observation of situations which have led to parental and professional frustration due to the complex nature of the current system of statutory provision within this context.

The following vignette gives an example of such a practice experience:

In one particular clinical situation a mother of a young boy with complex cerebral palsy who also had a very active three and a half year old daughter broke down during a home visit. Once calmed she described how difficult it was to meet the ongoing demands of all the different visiting professionals. She described how much time she spent working with professionals who visited her home for individual appointments and how this impacted on normal family life. Due to the fact that her husband, who was in the army, was deployed abroad much of the time it was her responsibility to co-ordinate all her sons’ appointments and hospital visits. In addition she had to cater for the needs of her daughter. Her frustration at the lack of co-ordination across the various professionals involved in the care of her disabled child was palpable.

1.3.3 Origin of the Topic: Professional Training
In addition to the concerns raised in day to day clinical practice around the subject of the key worker, prior to embarking on the study the researcher attended three separate conferences on the subject of team working and the Team Around the Child. At each
of these conferences, which were run by separate organisations, there were presentations given on the theme of the key worker. The researcher’s experience was that each presentation gave a different perspective on the role and audience comments reinforced the belief that there was a lack of consensus as to what the role required and how it should be defined.

1.3.4 Origin of the Topic: Professional Contact
At one of the conferences the researcher made contact with a Health Visitor. The Health Visitor worked in an adjoining geographical area as a key worker in a team around the child. It was helpful to discuss her perspective on the role of the key worker and to hear some of the issues she faced in her day to day work. Some of these related to the understanding of the role itself and others to the way in which different members of the team worked together. Once again this indicated to the researcher that there was justification in investigating team working and the role of the key worker for children with disabilities and their family.

1.4 The Gap in Current Knowledge

Current understanding would suggest that although there are many interpretations of the role of the key worker there is little consistency in its application. This may lead to inequity of provision for some children and their families and ongoing frustration across the team around the child. Existing studies have failed to address the detailed reasons behind the problems of team working across agencies and the reasons for the evident lack of implementation of the key worker role. The evidence presented suggests there is sufficient justification for a study to investigate in more depth these
reasons through exploration of the perception of the key worker role by those who are involved within this study context.

1.5 The Aim of the Study

The aim of this qualitative research study was to explore the experiences and understanding of the team around the child with a disability (including professionals and parents), of multi-agency, multi-professional team work with particular reference to the role of the key worker.

1.5.1 The Objectives of the Study

The objectives of the study were to:

- Review current and relevant literature relating to the study context and subject
- Investigate views of the professional team on the role of the key worker for children with disabilities and their families.
- Investigate the views of the parents, of children with disabilities, on the role of the key worker.
- Explore the experiences of parents, of children with disabilities, working with the professionals who care for their child.
- Examine the wider needs of parents of children with disabilities in relation to the role of the key worker.
- Develop guidance for key workers in current and future service provision

The anticipated outcome of the study was to create knowledge which would better inform and underpin professional practice; the study outcomes providing evidence which could support change in clinical practice and systems.
1.6 Philosophical Basis and Methodological Rationale of the Study

Crotty (2003) described how individuals construct knowledge and meaning through their engagement with the realities of their world.

‘All knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context’

(Crotty 2003, p42)

Meaning of that world is constructed by the person engaging in that world. Therefore different people construct meaning in different ways – even around the same phenomenon. Qualitative research is based on social inquiry focussing on the way people interpret and make sense of their experiences and the world in which they live. This study is based within a qualitative paradigm using grounded theory methodology. Qualitative research using grounded theory methodology is an investigative process whereby sense is gradually made by generating, analysing, comparing and interpreting data produced during interaction between participants - an inductive process. The world, which in this study is the world of the team working with the child with a disability, is therefore a different place for each of the different professionals and the family interacting within it. The aim of this study was to gain a better understanding of the social construct of key working within the context of multi-agency and multi-professional team working. In addition the study aimed to present an interpretation of the meaning of the phenomenon of the key worker from the data generated by multiple participants of the study from their world viewpoint. The participants were professionals working in a team around the child with a disability and parents of children with
disabilities. The study was therefore co-constructed jointly with the study participants.

The chosen methods of data generation for the study were focus groups and semi-structured interviews using open-ended questions. Data collection methods were piloted prior to the main study.

1.7 Support for the Study

Support for the study was given by NHS Education South Central, Basingstoke and North Hampshire Foundation NHS Trust and The Chartered Society of Physiotherapy.

1.8 Summary of Thesis Structure

The thesis is presented in chronological order initially by developing the background and context of the subject using literature evidence to present current thinking around the phenomenon of the team around the child with disabilities and the role of the key worker. The philosophical basis of research design is then discussed in light of the researcher’s own epistemological and ontological stand point. The methods by which data generation took place are then given, together with an explanation of the process of simultaneous analysis by which the researcher developed initial codes, categories and concepts. An audit trail is provided to ensure the accurate portrayal of participant experiences. These findings are then discussed using current literature to develop the arguments for interpretation. A model for future practice is offered. The conclusions plus practical and academic limitations of the study are given prior to a personal reflective account of the complete research journey undertaken. Reference is given
throughout the text to numerous supporting documents which are presented in the appendices.
Chapter 2.0: Background to Key Working

Differing perspectives within current literature are examined here to demonstrate the complexity of context of this area of practice which cannot be underestimated. The parameters of the study with regard to the definition of disability and the features of the team around the child are established. An historical background to the emergence of the concept of the key worker in policy and legislation, relating to children and young people in general, and then focussing more specifically on disabled children is presented. The difficulties of defining the role of the key worker in theory and practice are identified. The literature around the phenomenon of the key worker and team working is explored. Examples of the various models of practice application of the key worker role are then given. The impact of professional role and professional culture on key working are examined. Following this there is an exploration of the family and the role of the key worker, looking at family dynamics and needs with regard to support from the team around the child. The next section gives a brief insight into specialist roles similar to that of the key worker and similar roles in private healthcare, leisure, industry and commerce. Prior to summarising the current context of key working there is a final section which explores briefly the literature on the process of change management. Change to practice is one of the aims of the Professional Doctorate programme and this section gives suggestions of how change may be achieved. The chapter concludes with suggestions of the possible challenges to the implementation of the key working role in practice.
2.1 Definition of Disability

The definition of disability taken from the Disability Discrimination Act 1995 (HM Government 1995) was used to define in general the impairments of the children, of the parents involved in this study.

“A person has a disability if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities.”

Disability Discrimination Act 1995 (Part 1:1 p2)

The definition was used as it was representative of the diversity within the population. It is the only definition that all agencies and service providers are legally obliged to recognise and apply and is also the definition that the Government is likely to use in future policy and guidance. It is noteworthy that this definition is constructed and focuses on the central reason for co-ordinated service provision – the adverse impact of long term impairment or health needs on a person’s ability to carry out normal day to day activities. Perhaps all service interventions should be more obviously rooted in enabling a person to interact positively with their environment and achieve their full potential in life in this way.

2.2 The Team Around the Child

The ‘team around the child’ is a concept defined by Limbrick (2001, 2007) as the group of professionals who work closely with the child and family. The team provide practical input and intervention in education, health and social care. The team meet on a regular basis to share observations, agree a co-ordinated service plan and review progress. An effective team may be seen as being a group
of people working collaboratively towards a shared goal (Hinojosa et al 2001). The philosophy behind the team is that everyone, including parents and carers of the child, are equal members. Beattie (1999) carried out a study to identify the potential members of a team who may be involved in the care or management of a child with a disability. Since that time new roles have been developed within this practice context and the tables shown in the pages that follow are adapted from Beattie’s work. These tables identify some of the professionals and non-trained staff from the agencies of Health (Table One), Education (Table Two), Social Services (Table Three) and Voluntary Organisations (Table Four) that may now be involved in the treatment, management or care of a child with a disability. It can be seen that there may be upwards of twenty health professionals, eighteen education professionals, eleven professionals in social care and six or eight voluntary sector workers involved with the child and family at any one time. Not only are there high numbers of professionals involved with the child and family but the family unit itself may present complicated dynamics for team working in this context. Figure 1 demonstrates the complexity of the family unit often seen today.

One can see that any one child and family may have regular contact with a vast number and wide variety of people. This large number of people involved in the child’s care and welfare clearly need to know what others are doing for the child. Members of the team around the child need to share aims in order for the objectives of the management of the child to be transparent. The key worker role has been suggested as a way forward for clarity and co-ordination in this area of practice.
<table>
<thead>
<tr>
<th>The Team Around the Child: Health Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>• General Practitioner</td>
</tr>
<tr>
<td>• Health Visitor</td>
</tr>
<tr>
<td>• Community Paediatrician</td>
</tr>
<tr>
<td>• Hospital Doctors: Paediatrician; Urologist; Neurologist; Geneticist; Orthopaedic Consultant; Rheumatologist; ENT Specialist</td>
</tr>
<tr>
<td>• Hospital Based Nurse</td>
</tr>
<tr>
<td>• School Health Nurse</td>
</tr>
<tr>
<td>• Community Children’s Nurse</td>
</tr>
<tr>
<td>• Specialist Nurses – continence, diabetes</td>
</tr>
<tr>
<td>• Physiotherapist</td>
</tr>
<tr>
<td>• Occupational Therapist</td>
</tr>
<tr>
<td>• Speech and Language Therapist</td>
</tr>
<tr>
<td>• Respite Care Staff</td>
</tr>
<tr>
<td>• Dentist</td>
</tr>
<tr>
<td>• Optometrist</td>
</tr>
<tr>
<td>• Psychiatric Service: Clinical Psychologist, Mental Health Nurses</td>
</tr>
<tr>
<td>• Orthotist</td>
</tr>
<tr>
<td>• Play Therapist</td>
</tr>
<tr>
<td>• Hospital Play Specialist</td>
</tr>
<tr>
<td>• Music/Art Therapist</td>
</tr>
</tbody>
</table>

Adapted from Beattie 1999

**Table One: The Team Around the Child: Health Services**
<table>
<thead>
<tr>
<th>The Team Around the Child: Education Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Principal Special Needs Officer</td>
</tr>
<tr>
<td>• Specialist Teacher Advisory Service</td>
</tr>
<tr>
<td>Hearing Impairment</td>
</tr>
<tr>
<td>Visual Impairment</td>
</tr>
<tr>
<td>Physical Disability</td>
</tr>
<tr>
<td>• Portage Home Visitor</td>
</tr>
<tr>
<td>• Risk Assessors</td>
</tr>
<tr>
<td>• Educational Psychology Services</td>
</tr>
<tr>
<td>• Special Educational Needs Co-ordinator (SENCo)</td>
</tr>
<tr>
<td>• Preschool Inclusion Co-ordinator (INCo)</td>
</tr>
<tr>
<td>• Early Years Co-ordinator</td>
</tr>
<tr>
<td>• Specialist or Mainstream Nursery Staff</td>
</tr>
<tr>
<td>• Specialist or Mainstream School Staff</td>
</tr>
<tr>
<td>• Teacher/Learning Support Assistant/Head Teacher</td>
</tr>
<tr>
<td>• Educational Welfare Officer</td>
</tr>
<tr>
<td>• Home Tutor (Education Other Than At School)</td>
</tr>
<tr>
<td>• Travel Escorts</td>
</tr>
<tr>
<td>• Taxi/Mini Bus Drivers</td>
</tr>
<tr>
<td>• Lunch Time Supervisors</td>
</tr>
</tbody>
</table>

Adapted from Beattie 1999

**Table Two: The Team Around the Child: Education Services**
### The Team Around the Child: Social Services

- Social Worker – Hospital Based or from Locality Children’s Disability Teams
- Family Centre Worker
- Home Care Support Workers
- Child Minders
- Occupational Therapist - Equipment
- Occupational Therapist - Housing
- Occupational Therapist - Moving and Handling
- Foster Carers
- Respite Care Workers
- Agency Carers
- Surveyor/ Planning Department

Adapted from Beattie 1999

---

**Table Three: The Team Around the Child: Social Services**
The Team Around the Child: Voluntary Organisations

- Respite Care Facility
- Hospice Facility
- Face to Face Support Workers
- HomeStart
- Specialist Disability Groups e.g. MENCAP, Scope, Muscular Dystrophy Society, Contact a Family
- Play Group/Mother and Toddler
- Activity Groups – Church, Brownies/Guides/Scouts etc.
- Summer Holiday Play Schemes

Adapted from Beattie 1999

Table Four: The Team Around the Child: Voluntary Organisations
Figure 1: The Team Around the Child: The Family Unit

[Original in Colour]
2.3 Key Working: Historical Context

Since the mid nineteen seventies the concept of ‘key working’ has been recommended in policy and practice documentation relating to the provision of support to families of vulnerable children, and children with disabilities in particular.

2.3.1 The Court Report

1976 saw the publication of the Court Report (Department of Health and Social Security, Department of Education and Science & Welsh Office 1976). This was the first review of its kind in the UK and recognised that:

- Childhood is a period of human existence in its own right.
- Children have different needs from adults.
- A healthy childhood is critically important to ensuring optimum health in adulthood.

The report followed a three year review by Professor Court of the health services for children up to and through school life.

In summary the Court Report recommended:

- An integrated service and a named person, to facilitate the abilities of parents to care for their children.
- Better liaison between primary and secondary care services.
- Specialised training in paediatrics for GPs and health visitors.
- Community paediatricians who were specialists in the care of children outside the hospital.
- A full range of psychiatric services in child health.
• Development of effective working relationships between health services, education and social services departments – particularly for children with disabilities.
• Establishment of multi disciplinary teams responsible for the assessment and continuing care of children with disabilities.

2.3.2 The Warnock Committee Report
Two years later in 1978, The Warnock Committee (Department of Education and Science & Welsh Office 1978) reported on special educational needs and again the emphasis was on close effective working relationships between the local agencies for health, education and social services – multi-agency working. The Warnock Committee strongly re-iterated the recommendation of previous work that there should be a named person who would provide a single and continuing point of contact for parents, who would be able to see that their anxieties were followed up and would be able to put them in touch with members of the different supporting services (National Children’s Bureau 1987).

2.3.3 The Children Act 1989
The theme of the need for co-ordinated services for all children and young people, not just those with a disability, continued throughout policy in the following decade and just a few years later the publication of The Children Act 1989 (Department of Health 1989) provided a legal framework for better co-operation and co-ordination of information and services for children. The Children Act 1989 had two major roles:

1. Support and protection of a child in need.
2. Support and protection of a child with a disability.
This was the first time children with disabilities had been recognised and included in legislation as a defined group (Department of Health 1991). The Act imposed a key duty for professionals working with children and young people, to seek the views of children, parents and other significant people in the child’s life; thus moving away from an authoritarian model of professionals as experts, to one focussed on partnership, consultation and involvement (Hinojosa et al 2001). However, there is little evidence to show that anything had changed over the ensuing years (Braye 2001, Greco and Sloper 2004). Suzy Braye (2001) a reader in social work at Staffordshire University believed that key workers could improve the co-ordination of services for children with disabilities and their families. However, she stated that to do so the model of disability that underpins the key worker service must locate medical and health needs in a broader social model of practice and that those using the service were actively involved, their participation being sought from the beginning. There is however, a paucity of proof that in practice, professionals routinely seek the views of children during clinical intervention or service development and evidence to support this fact this was provided by Greco and Sloper (2004) in their survey of 35 care co-ordination schemes across the country. They suggested that the involvement of children and young people involved in setting up such schemes was scarce. These views were provided following analysis of data from postal questionnaires. It should be noted that only 70% of services that were surveyed replied. Although a good response rate, it is not an exhaustive picture of all services and information from some which may be more inclusive of service users may remain untapped.
2.3.4 The Laming Inquiry
Evidence for the lack of co-ordinated service provision and multi-agency working is supported by the outcome of the inquiry by Lord Laming (Department of Health and Home Office 2003), prompted by the death of Victoria Climbié. Victoria’s case was known to social services, health care and education professionals, but services were not co-ordinated and none of the string of professionals involved spoke directly to her to ascertain her wishes and feelings. Lord Laming reported little communication between agencies and even between professionals within agencies (Department of Health and Home Office 2003). No-one appeared to have responsibility to co-ordinate the case or act as a ‘key worker’ - a factor which may well have contributed to the child’s death. Victoria’s case once again demonstrated the need for co-ordinated services and adherence to the legislation with regard to children and young people.

Children with disabilities are equally and in some cases more vulnerable than those like Victoria Climbié (Westcott and Cross 1996). Therefore the need for co-ordinated services is greater in provision of their care. The Laming Report has been a major influence and key driver behind recent changes in legislation and policy for children’s services.

2.3.5 Every Child Matters
In response to the Laming Inquiry following the death of Victoria Climbié The Department for Education and Skills Green Paper: Every Child Matters (Department for Education and Skills 2003), proposed legislation – The Children Act 2004 (Department for Education and Skills 2004) - which again advocated the introduction of a lead professional or key worker where children are known to more than
one agency - Health, Social Services, Education and voluntary sector services.

2.3.6 The National Service Framework for Children, Young People and Maternity Services.

The National Service Framework (NSF) for Children, Young People and Maternity Services (Department of Health 2004a) was a ten year programme intended to stimulate long-term and sustained improvement in children’s health. Following the Laming and Kennedy inquiries it aimed to tackle child poverty and improve the lives of children. It aimed to develop services designed and delivered around the needs of the child – child centered and holistic. The plan was to address the issues of inequality, difficulty of access to services and, joint working across Health, Social Services and Education stating that all staff from all sectors should work together. The framework also strongly supported the involvement of service users:

“Children, young people and pregnant women need to be listened to and be involved in all decisions about their care”

Department of Health (2004a, p3)

Also the role of the key worker for children with disabilities was emphasised within the NSF and supporting documents:

“Parents of severely disabled children or those with high levels of need require a single point of contact with services and an effective, trusted and informed named person (‘a key worker’ or care manager) to help them obtain the services they require.”

Department of Health (2004b, p28)
2.3.7 Aiming High for Disabled Children

The publication of Aiming High for Disabled Children: better support for families, (HM Treasury et al 2007) provided a set of proposals aimed at improving the opportunities of disabled children and their families, giving families the support they need to live ordinary family lives as a matter of course (Department of Health et al 2008). Aiming High for Disabled Children was established following the culmination of the Disabled Children’s Review. Part of the review included consultation events with professionals, parents, members of the voluntary sector, disabled children and young people. There were also Government department seminars, Local Authority visits, engagement with Children’s Trusts, Primary Care Trusts and voluntary sector organisations. There were also three parliamentary hearings and written submissions to the review group. The Aiming High for Disabled Children programme was launched in May of 2007 and was described as being the transformation programme for disabled children’s services. Once again it emphasised the importance of co-ordinated planning, commissioning and deliverance of services across agencies.

2.3.8 Recent Policy

The need for key workers and effective team working in this practice context has continued to be at the forefront of policy, literature and political drive in more recent years (NHS Confederation 2008, Department of Health et al 2008, Franklin 2009, and NHS South Central 2009). It is a need which from all perspectives is described almost without question as essential in the care and management of a child with a disability (Vetere 2007, Dempsey and Keen 2008, Cameron 2009, Koshti-Richman 2009). However, over thirty years after the publication of the Court Report and ensuing literature, it is reported that in practice there are still
less than one third of the families with a disabled child, who have a key worker (Sloper 2004, Department of Health 2004b). There appears to be little understanding in the literature as to why this should be therefore identifying a gap in knowledge that this study aims to fill.

2.4 Defining a Key Worker

An anomaly noted during the exploration of the literature on the subject of key working is that there is no recognised definitive definition of the role. It is evident from many studies that the same or similar role is given a different title depending on the context in which it occurs and the background of the professional undertaking the role e.g. care co-ordinator (Appleton et al 1997), case manager (Meeks 2001), named nurse (Leaver et al 1996), named person (Sloper 2004), care manager (Carey 2003), service co-ordinator (Beattie 1999), health facilitator (Department of Health 2001), professional lead (Riddell-Heaney 2003) and link worker (Sloper 2004). This lack of consistent definition may be influencing the recognition, perception and understanding of the key worker role and there may in fact be more activities and practices established across the country which are just not identified by this particular term. Discussion of the elements included in the role and suggestion of a definition of the key worker are given later in this text.

In order to explore the extent and nature of multi-agency working for children with complex health care needs Townsley et al (2004b) carried out a three year empirical study of six multi-agency services. In the course of the study they interviewed 115 professionals and spent time with 25 families and 18 children and young people with
disabilities. As an outcome of the study they reinforced the importance of providing a key worker in the multi-agency team. However they qualified their statement with the proviso that attention should be paid to clarification of the nature of the role having identified discrepancies and confusion across the team members as to what the role involved and how it was perceived. This perhaps again highlights the need for a definitive nationally recognised definition.

2.4.1 Key Worker: Partnership Role

In a recent study by Gurr (2006) to review the usefulness of the key worker system in one particular area of practice – an inpatient brain injury rehabilitation service - the key worker role was described as being:

“…designed to optimise information provision and communication with the patients and their relatives"

Gurr (2006, p134)

Gurr goes on to state that the aim of the key worker system is to improve the ‘partnership’ between patients, their relatives or carers and the staff within the rehabilitation team. The role also included co-ordination and integration of patient management – key features that once again reflect the recommendations of the Court Report (Department of Health et al 1976) of over thirty years ago. The outcome of the study which surveyed patients, relatives and staff was that the key worker system provided in this unit was positive and did achieve its objectives. However, it should be noted that this system was provided for an adult service, within a small inpatient unit and once the patients were discharged very few were followed up by a key worker in the community setting. It is
therefore difficult to equate this to the context of children with disabilities where there may be many more stakeholders involved in the child’s care from many more agencies where the ever changing needs of the child and family span boundaries of services.

2.4.2 Key Worker: First Point of Contact
Townsley et al (2004a and 2004b) described the key worker as a named worker who acts as a family’s primary contact and first port of call for help and support in accessing services and professionals. This description is succinct and includes what is documented in much of the literature as the pivotal role of the key worker (Kirk and Glendinning 2004; Department of Health 2004a). For the purposes of consistency the term ‘key worker’ based on Townsley et al’s (2004a and 2004b) description will be used within this thesis as an all encompassing term, although allusion may be made to the terminology used within papers referenced and discussed.

2.4.3 Key Worker: Role Descriptors
Although not universally agreed upon, the role of the key worker has been described in many studies and there are key features of the role which repeatedly appear. Prominent features of the key worker role include the key worker as:

- The initial ‘named’ contact for the child and family. (May 1996a, Townsley et al 2004a and 2004b).
2.4.4 Elements of Key Working

Six elements of key working were identified by Mukherjee et al (1999) as those that the parents involved in the study valued and found distinctive compared to the other forms of support they received from the statutory agencies. The six elements were:

- Regular, pro-active contact.
- A supportive open relationship.
- A family centred approach.
- Working across agencies.
- Working with families’ strengths and ways of coping.
- Working for the family rather than the agency.

These core elements of the key worker role were reflected with only slight variation, in the more recent study by Barton and Clarke (2005). Barton and Clarke (2005) listed regular pro-active contact with families, offering support, giving information and advice, co-ordinating effective and timely service delivery and acting as an advocate as identified core elements of the role and function of the key worker. To be effective the key worker needs to be flexible and individualistic, responding to the specific needs and requests of the family. Some disabled children are acutely ill whilst others have physical or learning disabilities but remain medically well (Beattie 1999; Kirk and Glendinning 2004)) however, all have very different and varied needs with regard to support and service provision.
2.4.5 Key Worker Role: Parents Perspective

Mukherjee et al (1999) identified certain aspects of the key worker role that were important to positive outcomes for the family. These were that the key worker was pro-active in making and maintaining contact with the family and that the key worker had a holistic approach to the whole family and not just a child centred approach. These views were supported by Carpenter (2000) and Townsley et al (2004a and 2004b); however, it was evident that there were considerable differences in need between families depending on their strengths and weaknesses and their own coping strategies and mechanisms. In a recent study by Lundman et al (2010) inner strength was described as a resource that actually promoted well-being. They described the qualities of resilience, sense of coherence, hardiness, purpose in life and self-transcendence as inner resources important for recovery after adversities e.g. having a child with a disability. Levels of resilience within a family with a disabled child may affect their level of need of support from service providers and a key worker. This once again emphasises the need for the key worker role to be flexible and adaptive.

In summarising the outcomes of the literature families described support needed in a range of areas (Chamba et al 1999, Limbrick-Spencer 2000, MENCAP 2003 and Contact a Family 2003). The benefit of such support appears to reflect in the overall quality of life within the family in the following areas:

- Daily family life.
- Physical environment.
- Financial well being.
- Social well being.
- Emotional well being.
- Skills and learning.
- Contact with services and professionals.

However, many studies show support for families to be lacking identifying a gap in service provision, particularly in the areas of social and emotional support (Guinea 2001; Mitchell and Sloper 2002; Kirk and Glendinning 2004).

### 2.5 Key Working and Teams

The concept of ‘key working’ within a multi-agency team has been the subject of several studies. Some of these examine what is involved in the role (Braye 2001; Care Co-ordination Network UK 2004; Emmanuel et al 2002); others take a multi-faceted approach – from the perspective of the child, the family and the professionals (Townsley et al 2004a and 2004b). Some studies look at one particular aspect of key working – for example the perception of the role in a community learning disability team (Boarder 2002), some look at aspects of team training (May 1996a; May 1996b) while others look at the process of establishing the key worker system within a team (Greco and Sloper 2004; Hinojosa et al 2001). According to Mukherjee et al (1999); Beattie (1999); Braye (2001); Limbrick (2001); Sloper (2004); Abbott et al (2005); and Limbrick (2007), key working should take place within a co-ordinated, multi-agency system and within a multi-agency team.

Although the identified studies above will be discussed at different points within this thesis it is important to note at this point the recognition of the key worker as a significant member of a team.
2.5.1 Key Working and Teams: Team Working

McConachie et al (1999b) carried out a postal survey of 330 child development teams across the country. The aim of the study was to identify the variety in organisation of child development teams and to provide information for future study and was in that respect limited in it’s identification of the effectiveness of team working. Basic questions were asked regarding team composition, management and processes to create a sampling frame for further study. McConachie et al (1999b) studied the data supplied by the 242 child development teams who responded and acknowledged that less than half were able to identify a key worker service or co-ordinator for the child and family. The picture presented was one of considerable diversity in composition of the team and working practice with less than half carrying out joint assessments on initial contact with the child and family. Although not stated in the study text this may have indicated that the teams although established were not actually working collaboratively and further details about the effectiveness of working practices of the teams may have been informative. Much of the detail regarding the teams who did have key workers such as team training, understanding of the key worker role, and strategic support for the role and general funding was not gathered. There was also no scope for comparison of team working between those teams who did employ key workers with those who did not. Similarly there was no scope to measure the outcome for the child and family. All of these areas could provide useful research study focus in the future.

Mukherjee et al (1999) studied two diverse geographical areas in the UK, as they developed and implemented pilot key worker services within multi-agency teams. One area was a mixed urban and rural site with pockets of deprivation and the other a deprived
urban site. Both areas were varied in their approach to multi-agency working at the onset of the study. One had established multi-agency working in place; the other, although the staff group were willing, did not. Interestingly these factors appeared to play a part in the success of the key worker service and the managers of the two sites noted the impact of the contextual factors on implementation. The manager of the site where joint working was not well established stating that this had a negative impact on key worker service implementation. However the causal factors of this negativity were not explored.

Initially the two sites used different approaches to recruit staff as key workers - one asking individuals directly to undertake the role and the other asking for volunteers. The professional background and working context (i.e. social care – respite, health or education) of the participants agreeing to become key workers varied between the two sites. The way key workers were recruited to the study; differences in their professional background and the setting in which the key working was taking place may have influenced the outcome of the key worker service development. These factors were not explored in any great depth and it is unclear from the study if this was the case.

The site asking for volunteers to be key workers gave an ‘information’ day to recruit professionals to the project. It is unclear what was included in the information day about the role and it is possible that only people interested in the concept would have attended. Little is known about the views of others in the team around the child who did not attend the information day. It is impossible to discern the teams’ understanding of the key worker role or if staff had any interest in the concept of key working or of
developing and supporting such a role which could have influenced the outcome of the success of the project. As the key worker has to work within the context of a multi-disciplinary team it would seem essential that the whole team received a certain level of education about the nature of the role and the project itself but this does not seem to have been the case.

Similarly the second pilot site gave a one day training event but this was also only given to those that had been asked to undertake the role and not the whole team. Also the issue of training for the families involved in the study could have been explored further in light of the fact that at least two families – one on each site, were not aware that they had a key worker assigned even after being involved in discussions about the project. This lack of awareness of having a key worker was potentially reinforced by the professionals who were working as the key worker and their reluctance to introduce themselves using that title. The authors did not clarify why this was so and the reasons may have provided informative valuable data.

One of the differences between the two pilot sites that was not explored was the geographical spread of the services across urban and rural areas. These differences may have influenced the success of the project outcome but there was no evaluation of this.

The co-ordinators in each pilot area felt that it would be unethical to include families of newly diagnosed children in the study however, this is the context in which key workers have to practice on a day to day basis and including families who already had services in place may have been somewhat unrealistic, producing different data. If new families had been included in the study this
may have reflected the specific issues faced by key workers trying to establish services for the child and family and draw together the team around the child - possibly resulting in very different data and outcomes.

2.5.2 Key Working and Teams: Parental Views
One of the key findings identified by parents interviewed during the Mukherjee et al (1999) study supported the view of the need for good multi-agency working. The parents stated the importance of the key worker role in health, education and social services and the key worker being able to ‘work across agencies’ - providing them with a more seamless service for their child. This concept was supported in later work by Braye (2001) who believed that good relationships between professionals in a locality were often what made a service network tolerable for families.

Mukherjee et al (1999) concluded that there was more to a key worker service than just the professionals working with the families. It involved commitment and recognition of the role across agencies and formal structures at a strategic level to support professionals within the role. For example an understanding by managers of the objectives of the key worker role and time released from day to day work for staff members who undertake the role in a non-designated capacity, including organising and attending case meetings and being proactive in contacting and supporting families.

2.5.3 Key Working and Teams: Aims and Management
McConachie (1997) in her editorial comment on the organisation of child disability services identified not only the lack of aims for teams of professionals working within multi-agency services being
common, but also two fundamental structural problems within teams – how services were funded and how they were managed. Although not expanded upon in the editorial these factors could well be contributory factors to the difference between effective and ineffective team working and are worthy of further investigation.

Abbott et al (2005) when studying the impact of multi-agency working on professionals identified six teams who demonstrated three key components of multi-agency working which were:

- A defined structure setting out how the multi-agency team would operate.
- A degree of resource sharing in terms of staff, time and money to provide services.
- Multi-agency steering or management groups.

Abbott et al (2005) presented these six services as being the most developed, organised and structured services from their original sample of 26. Abbott et al (2005) went on to qualify that each of these teams had slightly different characteristics implying that there was no uniformity or common guidance on how multi-agency teams should work – a finding which echoes the earlier work of Townsley et al (2004a, 2004b). It is also interesting to note that of the six teams in the study, described as well established and defined as multi-agency teams only four had key worker roles. The areas which had key workers in the teams were all rural only one having an additional urban area. There was no discussion as to whether geographical factors were in any way influential on the establishment of a key worker role within the multi-agency team.
and why the predominantly ‘urban’ teams did not have key workers.

2.5.4 Key Working and Teams: Care Management Approach

According to Sloper (2004) the most effective model of multi-agency working within teams was the case or care management/programme approach (Department of Health 1990, Greenwood et al 2000). This approach is where an identified individual (a key worker) has responsibility for ensuring a coordinated service for children and families. The case or care management approach is often used in the social care arena (Meeks 2001). However, when reviewing the available literature on multi-agency working gathered to inform the National Service Framework for Children, Young People and Maternity Services (Department of Health 2004a), Sloper (2004) who carried out literature review on co-ordination of services found it was the least common approach used in practice for children’s service provision. When viewing this approach from the child and family perspective it may be seen as an authoritarian approach in that they are described as a ‘case’ and in need of management. Using the descriptor - care co-ordination - may be viewed more favourably being more suggestive of a supportive partnership arrangement for services.

Sloper’s (2004) review covered all services both adult and paediatric and in all fields of practice not only children’s disability service provision. Only three of the reviews included studied identified specific models of practice. The model that was least used was the only one which aimed at ensuring services were coordinated at the point of delivery for children and families. The majority of the other models described were focused more on the
organisation of the professional groups and were not child or family focused.

Of all the reviews undertaken there was little evidence to demonstrate positive outcomes for children and families. Sloper’s work has been useful in identifying the processes involved in multi-agency, multi-professional working and has identified the need to seek data which identifies the relationship of process to outcomes for the service users.

2.5.5 Key Working and Teams: Developing a Collaborative Culture
In their qualitative study of an early intervention team based in the USA, Hinojosa et al (2001) gathered data through intensive interviews and direct observation of one family with a child with a disability and the team members who provided a range of services to that child, over a period of six months. Initially the team around the child were found to be protective of their own thoughts and professional culture; however prolonged engagement provided the team members’ time to build relationships reflect on their roles and engage more positively with each other. They identified the challenge of creating a collaborative culture and described a five step process to the development and creation of a ‘team’ based on work by Dukewits and Gowin (1996). Hinojosa et al (2001) found that the critical element that was glaringly missing in their studied team was that of time to develop a common understanding and language to begin collaboration, also seen by Dukewits and Gowin (1996). Hinojosa et al (2001) found that a group of people asked to come together and magically function as a team were likely to experience frustration and increased stress levels. Their findings demonstrated that professionals often address their own interpretation of the child’s needs with regard to treatment and
management and although included in the team meetings the family goals were often ignored - thus identifying a lack of true parent partnership in the team around the child. The authors at no point refer to introducing a key worker within this team to overcome such issues. Although only studying one small team, because of the rich nature of the data gathered and the context of that data, Hinojosa et al (2001) were able to demonstrate a lack of collaborative working and expose the gap between theory and practice. This view was supported in the study mentioned earlier by Abbott et al (2005) who agreed that it should not be assumed that by putting structures in place to develop multi-agency working it will automatically lead to effective partnership and collaboration between professionals.

Dukewits and Gowin (1996) established a programme in Missouri, USA, called the Accelerated Schools Project. Over a period of eight years (1988 to 1996), the project involved staff from 150 individual schools in team development training, spending a week in the first summer, one day per month in the first year and then three workshops per year in the second and third years of their involvement in the project. As a result of their experiences of the project Dukewits and Gowin (1996) described teams that were able to work collaboratively and productively as having five key components in common. These included:

1. Trust.  
2. Common beliefs and attitudes.  
3. Team members who are empowered.  
4. Effective team meeting management.  
5. Shared feedback about team functioning and performance.
The outcome of Dukewits and Gowin’s study highlighted the need for long term sustained investment in team building activities to develop truly collaborative teams. It should be noted however, that the project was focussed on team development within each single school (although several schools were involved). Therefore it does not capture the problems and issues that may be faced when working with a team which includes people employed by and working for different agencies such as in the team around the child and therefore may be too simplistic to employ within the context of the health, education and social care settings. Here it would be important to establish the need for strategic sign up and long term commitment across all agencies to this type of team development.

2.5.6 Key Working and Teams: Influences on Effectiveness

Robinson and Cottrell (2005) carried out a qualitative study using mixed methods of five multi-agency teams working with children in different contexts. The study used observation, interview and focus group methods to generate rich data to analyse team working in this context. Participants included a range of professionals with a broad scope of experience to give variability to the data. However, the study omitted to gather the views of the service users – either the parents or children who should be seen to be part of this team. In the study Robinson and Cottrell (2005) identified complex dilemmas experienced by the members of those teams which impacted on the effectiveness of team working. In their study, some of the professionals interviewed, observed and participating in focus groups identified the following factors as being influential in the effectiveness of team functioning:

- lack of understanding of other agencies’ procedures,
- lack of knowledge of available resources,
misunderstanding of other professionals’ expertise,
issues around distribution of status and power,
issues around sharing of information,
interpretation of confidentiality,
clash of work priorities and
differences in inclusion criteria.

Robinson and Cottrell (2005) concluded that often professionals have simply been exhorted to initiate multi-agency working with little training or guidance (or lack of time to interact and learn together) in addition to a lack of strategic support from managers as has been previously described. The teams involved in their study were found to have overcome the barriers and strengthened team cohesion by employing their own strategies e.g. respect of specialist expertise in combination with a willingness to explore and celebrate professional diversity regardless of status, but there were major disturbances in the way the team worked when individual roles were not clarified and objectives for the team were not clearly established. They emphasised the importance of setting aside time for team building and development of team protocols, effective communication systems and shared training opportunities.

These issues were also identified in the earlier work of Cameron and Lart (2003) who reported on 32 studies of models of joint working. Although their systematic review only reported on health and social care interfacing, Cameron and Lart (2003) identified factors which hindered joint working and grouped them into three themes of organisational issues, cultural and professional issues and contextual issues. Although paediatric services were not the specific focus of the review it would be helpful in the context of working with children to include the education interface. In addition, for both
adults and children inclusion of the interface with the voluntary sector organisations within the review may have highlighted additional factors influencing joint working such as the way services are commissioned. Similar themes have since been re-iterated in the work of Doyle (2008) who has more recently reviewed literature exploring the barriers and facilitators of multi-disciplinary working. The review of only 8 articles focused on multi-agency working within (disabled) children's community services. Doyle (2008) rather simplistically claims that many of the barriers to multi-agency working she has identified may be overcome purely through effective multi-disciplinary working itself – i.e. just by doing it, it will improve. Similarly in their work Robinson and Cottrell (2005) described the differences of team members potentially ‘colliding’ as boundaries, specialisms, professional roles and language were broken down as teams were developing (a process of learning as they interact), with an inevitable outcome of conflict as tasks were redefined. Robinson and Cottrell (2005) utilise the theories of Wenger (1998) – “communities of practice” and Engestrom (1999) – “activity”, to investigate and interpret the issues faced within these teams when establishing a team identity.

Communities of practice refer to the collective learning in a shared domain – groups of people who share an interest in an area who learn as they interact. That is we learn by participating in daily life in a particular context and from our experiences in doing so. The basic concept of ‘activity theory’ is that learning is a human activity that is socially situated and artefact mediated. At its centre is the idea that internal activities such as thinking, emerge out of practical external activity which has a cultural specificity and must therefore include the individual and their culturally defined context.
2.5.7 Key Working and Teams: Summary
The scope of the literature gives some indication of the complex nature of the phenomenon of the team and its functioning within the practice arena. The rhetoric of team working, joined up thinking and seamless services (Warin 2007), may not be all it seems in reality and may therefore be a potential influence on the establishment and performance of the key worker role.

2.6 Key Working: Models of Care Delivery

There appear to be different models of key working in practice and these may be dependent on, and influenced by, not only the context in which they operate but on the professional background of the person involved in the role.

2.6.1 Medical and Social Models of Care
The concept of specific models of delivery of care is supported by Hinojosa et al (2001) who identified that the different professionals from different agencies, working with a child and family, held differing and diverse philosophies towards the intervention they provided for that child. Hinojosa et al (2001) studied a single clinical team over a period of six months working with one child therefore the results of the study may not be seen to be generalisable to other teams however, similarities of practice may exist in other contexts. Instead of working collaboratively as a team they were actually working in parallel on two entirely different programmes. The therapists worked on a hospital–governed, therapy treatment programme, following a ‘medical model’ of disability and care delivery, whereas the education staff followed a ‘social and cognitive model’ of care delivery. In addition, following observation of the team in practice, Hinojosa et al (2001) felt that both the
education and therapy staff programmes were dominated by the
teams’ interpretations of the child’s individual needs, thus
demonstrating a lack of acceptance of the family goals which
were identified in the team meetings and a lack of true parent
partnership. They stressed the importance of accepting the family
as equal members of the team and acknowledging and valuing
the insight, input and expertise of the parents and other family
members, moving more into a partnership model of working rather
than an authoritarian model of working. The study demonstrated
the influence of professional and employing agency, background
and culture on the management of the child with a disability. This
view was supported in a later study by Goodley and Tregaskis
(2006). When exploring the experiences of parents of disabled
children they described the care that the parents received in the
ante and post natal periods as being:

“…a phenomenon that is socially constructed through a variety of
cultural, professional, service, and institutional practices, which
begin in pre- and postnatal care and carry on throughout the
various stages of an infant and child’s development.”

Goodley and Tregaskis (2006, p631)

Goodley and Tregaskis (2006) used retrospective narrative
accounts of five parents of their experiences of services,
professionals and health and social care interventions during the
ante and post natal periods of their disabled child’s life when
found that far from being passive recipients of care parents were
actively seeking information that would help them in their parenting
role. They wanted parent-professional relationships based on
equality and respect. Although only based on a very small number
of parents the outcome of the study appears to reflect what many other parents request and supports much of the literature on parent partnership approaches to teamwork, moving away from the authoritarian mode of the medical model of disability.

Meeks (2001) described the role of the case manager in the context of the social care setting i.e. social model of disability, as carried out by social workers. The description of the case manager’s role closely reflected that of the key worker role that other authors had identified and it is possible because of their background social workers may feel that they already fulfil this role within their routine professional practice.

The role of the key worker does not fit exclusively into a medical model of disability - it steps outside the boundaries (Boarder 2002). However, neither does it fit purely into a social model of disability because of the range of medical needs often experienced by children with disabilities (Kirk and Glendinning 2004). Somehow the way in which the team around the child work together has to marry these two approaches and cover aspects of both depending on the needs of the child and family.

The model of disability that underpins a key worker service needs to locate medical and health needs within a broader social model of care delivery. The focus should be on removing barriers to the participation of children with disabilities in society and meeting all the individual needs of that child and family (Braye 2001, Connors and Stalker 2007).
2.7 Models of Key Working

There are several models of key working presented in the literature. The lack of standardised approach to key working may indicate once again the difference in the role when applied in distinct contexts and the diverse understanding of the nature of the role by professionals and parents.

2.7.1 Mukherjee Model of Key Working

Mukherjee et al (1999) as a conclusion to their study of two key worker services presented a model of key working which embedded six elements of the key worker role in the foundations of a supportive organisational context (see Figure 2).

In this model the child and family were central to the whole process. The key workers who were successful in the study were supported by a system of initial and on-going training and supervision whilst carrying out the role. The multi-agency context in which the key working took place straddled boundaries between agencies and was supported at a strategic level across inter-agency structure.

However, the model appears somewhat idealistic in its assumptions and the reality of practice may be that organisations and their integral functioning are far more complex than the model would suggest and accommodate. The complexities of just one element of the model, for example ‘a family centred approach’ in the context of family dynamics in the 21st century and in particular in families with children who have disabilities (MENCAP 2003, Contact a Family 2003), presents the team around the child with a myriad of situations which may not be easy to address or resolve e.g. when a
child’s parents are separated and the child spends time at both parents homes at different times during the week the team may have to organise duplicate specialist equipment so that the child’s needs may be met in both places.

Mukherjee et al (1999) only studied two geographical areas and a team around the child within different localities across the country may demonstrate quite different local variations in the way they work together and function. There was no evidence in the study that the model proposed had been tried and tested as the sites under study were only just establishing their key worker services. It may have been helpful to return to the two sites after a period of time had elapsed and repeat the study to see if the model had been successful in its application.
Figure 2: Model of Key Working. (Mukherjee et al 1999)

[Original in Colour]
2.7.2 May/Gupta Model of Key Working

An alternative model was described by May (1996a) who identified the principal components of the key worker role which was earlier schematised by Gupta (1995). This schematisation is shown in Figure 3.

The extent and complexity of the key worker role can be seen in the two example models of practice given, and similarities to these roles are also reflected across other studies e.g. Townsley et al 2004a and 2004b; and Emmanuel et al 2002.
Figure 3: Schematisation of the Key Worker Role by Gupta (1995) 
Adapted by May (1996a).

[Original in Colour]
2.7.3 Enhanced Key Worker Liaison Model

Emmanuel et al (2002) carried out a feasibility study of the use of a model of enhanced key worker liaison in mental health services, over a period of ten months, in two London districts. Key workers were asked to undertake a pro-active role in liaison with primary care services about patients in their care. The outcome of their study demonstrated only limited success for the patients and that the model was difficult to achieve without extra resources. Some of the reasons they noted for this lack of success they attributed to significant levels of staff turnover, insufficient time perceived by the staff involved, and the inclusion of key workers from a range of disciplines who had widely different attitudes and competencies towards the task requested of them. The study indicated once again the lack of uniformity and common agreement on the profile of the key worker and key components of the role in addition to the influence of the professional background of those in the role. The lack of time expressed by those undertaking the role may have been due to the fact that they were all non-designated key workers (i.e. they also had other professional roles in the team) and there may have been a lack of strategic sign up by managers allowing the team members more time to complete the key working tasks. This was not identified within the study. The high turnover of staff affecting the outcomes of key working suggests the importance of continuity of the person in the role of key worker. In children’s services this may be difficult to achieve or may result in one particular group of staff being more regularly identified to undertake the role. The needs of children change over time and certain professionals are only involved at certain stages in the child’s life e.g. health visitors only see children up to the age of five. Therefore these professionals would not be available as key workers for children over five. Thus it may be impossible to achieve
continuity for extended periods of time and this may affect the satisfaction experienced by the child and family of the role.

2.7.4 Care Co-ordination Key Worker Model
Since the year 2000 Care Co-ordination Network UK (2000) has provided a resource pack which demonstrates how to develop a key worker service for families with disabled children. The pack is based on work carried out at the Social Policy Research Unit at the University of York. Researchers were involved in the late 1990s in facilitating and evaluating the development of key worker services for families of disabled children in two areas in England (Mukherjee et al 1999, Sloper et al 1999). Within the pack the authors not only identify the work needed to plan, initiate and implement a key worker service but they also identify operational realities that need to be addressed in order to avoid some of the pitfalls that, from experience, they have identified as barriers to the success of the key worker service model. An indication also recognised by Drennan et al (2005), that one of the limitations of key working is that the simplicity of the idea stands in stark contrast to the complexity of implementation. This may reflect the complex nature of the needs of the children with disabilities and their families and is possibly an explanation for the fact that the effectiveness of key working is not well documented and the role not commonly adopted.

2.8 Key Working: Professional Influence on the Role

The question of who should undertake the key worker role arises throughout the literature. The professional identity of the team member has been shown to influence the level of success when assuming the key worker role (Hinojosa et al 2001). Statutory
agencies have different cultures and inherently different philosophies, priorities and perspectives. The key worker may therefore have agency loyalties and may or may not be aware of the impact of these in practice (Mukherjee et al 1999). Key workers may be employed and accountable to different organisations and services may differ according to the context, needs and priorities of those individual organisations.

2.8.1 Key Working: Therapists as Key Workers
There appears to be little mention of physiotherapists or occupational therapists related to key working, which may be surprising to some considering the involvement these professions often have with children with disabilities. Studies examine the key worker role carried out by nurses (Leaver et al 1996; Boarder 2002) and social workers (Carey 2003) and others (Kirk and Glendinning 2004) but rarely include therapists. Therapists tend to carry out focused goal-orientated, time limited interventions particularly in acute settings – a very different approach to the protracted role often needed by the key worker. However, therapists working in disability services usually have a close working relationship with the child and family over a prolonged period of time, often from diagnosis to transition to adult services - presenting an ideal opportunity for key working.

2.8.2 Key Working: Professional Knowledge and Skills
Some of the current literature identifies the knowledge, skills and attitude required by a successful key worker (Mukherjee et al 1999; Boarder 2002; Care Co-ordination Network UK 2004). Whatever their professional background, the key worker requires a range of knowledge in such areas as medical information, child development, service availability, access criteria and funding
The key worker should have the necessary skills to act as a negotiator, interviewer, listener, enabler, consultant and controller. In addition the key worker needs to be flexible, resourceful, an advocate, a mediator, a cost accountant, a facilitator and have a positive, proactive attitude.

2.8.3 Key Working: Professionals in a Position without Power
Professionals may assume the key worker role but may not be empowered to make decisions and may not have the financial responsibility needed to purchase equipment or services for the family – a position found to cause frustration in practice for professionals (May 1996a). Professionals may have access to different budgets but these may construct restrictive parameters for service provision. Carey (2003) described the budget as being ‘an important component of team culture which impinges on everyday practice’. In his study, care managers in local authority social work teams were described as providing a ‘budget led’ service - a situation which has been the cause of low morale for staff in post that realise there is likely to be only a limited chance of a client accessing services available whatever the ‘need’ that is assessed.

Difficulties can also arise for professionals in a key worker role across agencies resulting from different eligibility criteria of children and families for service provision. For example the provision of 24 hour postural management equipment (e.g. sleep systems, standing frames and mobility equipment) for children in one area may be provided through statutory agencies but in another may have to be sought from charitable organisations (BDF Newlife 2007). Any professional undertaking the key worker role would need to have knowledge of eligibility criteria for all services other than their own.
2.8.4 Key Working: Professional Culture

Professional groups are trained in different ways and therefore have different values and belief structures, knowledge bases and ultimately, differing aims for the child with whom they work. This theme is supported by Holloway (1997) who also comments on the fact that certain cultures do not just consist of the environment in which they exist but that they also have particular ideologies, values, beliefs and ways of thinking. Professionals often have a language exclusive to their group and they may be housed in separate locations where working practices are very unique to that agency or organisation. This issue is identified in the literature as having a major influence on the effectiveness of the work of the key worker (May 1996a and 1996b; Appleton et al 1997; Mukherjee et al 1999).

2.8.5 Key Working: Working with other Professional Cultures

A key worker may have to ask, and co-ordinate, staff from another agency or profession to carry out a task for the child and family. This also raises issues about how much respect the key worker will have in the spirit of co-operation across agencies, to carry out their role over other professionals who are not within their employing structure. This is an aspect of the phenomenon worthy of deeper exploration, as it has been identified and documented by other authors (Beresford and Trevillion 1995; Sloper 2004) that different professionals undertaking the role of the ‘key worker’ have entirely different philosophical approaches due to their knowledge base, professional training and employing agency. So much so that Beresford and Trevillion (1995) refer to professionals needing to undergo a major culture revolution in order to produce effective multi-disciplinary team working - an essential element in an effective key worker model. This view is supported by Sloper (2004)
who described a lack of trust and negative stereotyping of other professionals as well as different professional ideologies and agency cultures in her literature review which included barriers for co-ordinated multi-agency services. The key worker role because of lack of understanding and cross agency support can result in confusion, isolation, stress and burnout for professionals (May 1996b; Beattie 1999). Many authors stress the need for a clear role descriptor to facilitate the success of the role (Beattie 1999, Limbrick 2001, Limbrick-Spencer 2001).

2.8.6 Key Working: Designated and Non-designated Key Workers

Some key workers are not trained in a specific profession but are employed, usually by one of the lead agencies, as care workers and carry a caseload for which they act solely as the key worker – they are often referred to as the designated key worker (The Dartington Hall Trust 2004). Other professionals may take on the role in a more informal way but in addition to their normal workload and professional role. They are often referred to as non-designated key workers (Greco and Sloper 2004). There are very few studies which compare the efficacy of the two systems of key working although some studies mentioned previously identify the perceived lack of time for key working duties experienced by staff in non-designated key worker positions. This may be an area for future investigation.

2.9 Training and Education of Key Workers

There may be a case for a qualification and profession of key worker in its own right in the United Kingdom. In the United States of America there are service co-ordination agencies and the service co-ordinators role is:
“...to ensure that comprehensive care, including emotional, physical, spiritual, and developmental aspects have been provided’ and ‘to act in an advocate capacity and provide emotional support for parents and siblings”

Jackson et al. (1992 p 227)

The care co-ordination model as described by Jackson et al (1992) is designed through a care co-ordinator, to provide family-centred services based on the child and family’s individual needs in a way that maximises their capacity to access services independently i.e. to work with their strengths. The key functions described in the care co-ordinator’s role responsibilities closely map those described in the literature in the UK about key working services. Jackson et al (1992) described the process of the care co-ordination project a three year demonstration project the goal of which was to provide a co-ordinated approach to bridge the boundaries of health, education and social care for medically fragile infants and toddlers. The Jackson et al (1992) study was primarily located within an acute hospital setting for children with complex needs where it may be assumed team co-ordination and access to resources was easier than in the community. The challenge would be to transition this model across the acute care to community setting boundary to ensure continuity of care for the child and support for the family. Jackson et al (1992) do identify the fact that beyond their own study there is little research evidence which describes the efficacy of care co-ordinator’s interventions or outcomes of service provision using this approach.

2.9.1 Separatist Education of Professionals

Separate education of professionals training in health, education or social care, may hinder future collaboration (May 1996a). May
(1996a; 1996b) reported on a two day training programme for mental health workers on the role of the key worker. Participants of the programme reported through course evaluation, that the course highlighted the differences between agencies – Health, Social Services and Education, their management structure, policy and procedural structures. Some of these could significantly facilitate or inhibit joint working practice. It was also evident from the participants that there was a lack of understanding of the role of professionals from different agencies thus highlighting some of the possible barriers to effective key working in a multi-professional, multi-agency team.

This is a view supported by Appleton et al (1997) following a study carried out to introduce a care co-ordination model of service for a cohort of children with disabilities entering nursery education. Here continued training and support was found to be needed to ensure a client centred approach as opposed to a profession specific or multi-disciplinary team specific role.

Hinojosa et al (2001) emphasised the fact that:

“Professional education has not necessarily trained clinicians to work with others on the provision of care”

Hinojosa et al (2001, p210)

2.9.2 Inter-Professional Learning
The ethos of inter-professional learning was given added impetus following the Bristol inquiry (Kennedy 2001), in which Sir Ian Kennedy reported that future healthcare professionals should work in multi-disciplinary teams, and recommended that shared learning begin as soon as possible. In clinical practice this is now beginning to be
addressed with the introduction into pre-registration health and social care programmes in England, of Common Learning.

“The need is to provide services in which divisions and demarcations between professions are set aside, to be able to work differently and collaboratively in the interests of the patient or client, and to prepare future practitioners for that future reality.”

University of Southampton (2003, p3)

During this programme students on Health (medical, nursing and therapies) and Social Care courses will come together at various stages of their undergraduate training to work together both in the educational establishment and on placement in a variety of health care and social care settings. They will be tasked to work as a team and will be peer and facilitator assessed on their contribution to the team working, a theme which is repeated throughout the literature on key working.

It remains to be seen in the long term whether this approach will affect the effectiveness of multi-disciplinary working in practice but hopefully it is a step towards addressing some of the fundamental issues professionals of different cultures have when working together. The interface and joint working between statutory agencies and the private, voluntary and charitable sector may also become more important as more and more services are being provided by such organisations.

2.10 The Family and the Key Worker

Professional boundaries and status may have to be eroded before effective team collaboration can occur (Beresford and Trevillion
1995). This would no less apply to the perception of the child and family as team members and a respect for the perspective of the parents and carers (Contact a Family 2003, Contact a Family 2005, Ware and Raval 2007).

2.10.1 Key Working: Parent Partnership
McConachie (1999a) reported on a group of parents of children with disabilities who felt they received differing advice from professionals, felt their concerns were not fully understood and did not feel involved in the decisions made about their child - an overt example of lack of partnership working. McConachie’s observations also indicated a lack of collaborative working not only with the family but across the professional team. Vetere (2007) reported that plans by professionals to make any health-related changes would only work if the family was ready to adapt and support the changes suggested, indicating the importance and need of collaborative or partnership working with the family when setting goals and objectives of intervention.

2.10.2 Key Working: A Family-Centred Approach
The key worker has a role to identify, through discussion with the family members, the needs of that family as a whole unit – not just the child with the disability. This approach is akin to the family systems theory as described by Rosenbaum et al (1998) and family centred care (McConachie 1999a, Pickering and Busse 2010). The family systems theory:

“...emphasises the interactions of various members of the family and the impact of each member upon all others”
Family systems theory provides the basis for what Rosenbaum et al (1998) described as family centred services which were based on the recognition that the family is the constant in a child’s life and that professional service providers should work in collaborative partnership with parents. Family centred care (McConachie 1999a, Pickering and Busse 2010) similarly aims to employ an individual family service plan, going beyond simply an individual plan for the child. However, different members of the family may have different perspectives and do not always agree on needs and priorities (Braye 2001); thus demonstrating the range of skills and attributes needed by the key worker to help resolve complex family issues.

2.10.3 Key Working: Family Support
When given the diagnosis that their child has a disability, parents often react with shock, despair and disbelief (Yerbury 1997, Ware and Raval 2007). In a recent paper by Stevenson (2009) the impact of dealing with the emotions of family members which are often projected onto those working closely with them, as well as the professionals’ own emotions, were explored. Stevenson (2009) identified the heightened emotional turmoil of the family members and the consequent need for training in counselling skills and ongoing support for the professionals working in this context. A professional who undertakes the role of the key worker in this situation therefore, not only has to function within the context of the multi-agency organisational structure but in the family context which may be highly charged with emotions and fraught with difficulty (Ketelaar et al 2008).

Quinton (2004) examined the meaning of support and implied that it is an action that makes a difference. However, Quinton (2004) suggested that support involved a giver and a receiver and
pointed out that the views of the giver and receiver, on what is needed, may not be the same. It is about a balance of family life – somewhere between the neglect of family problems and intrusion into family life, plus the differences in individual and cultural ideas of satisfactory parenting. This is a balance the key worker co-ordinating the team and intervention for the child and family may have to judge. It may be difficult for some parents to accept a high level of intervention if they are not ready to accept the child’s needs and disability; thus presenting them with a potential emotional conflict.

2.10.4 Key Working by Family Members
Family members often assume the role of the key worker by necessity rather than by choice. In the qualitative study carried out by Kirk and Glendinning (2004) the experiences of a small number of families caring for technology dependent children at home and the issues around service co-ordination were explored. When interviewed about their experiences of caring for their child, the parents were found to perform multiple roles many of which have been identified in the role of the key worker earlier in this text. In the absence of any formal key worker in the team around their child the parents carried out tasks which included managing their child’s condition, organising services, advocating for their child as well as day to day parenting.

2.10.5 Key Working: Addressing the Information Needs of Families
Mitchell and Sloper (2002) interviewed a small number of parents with regard to the provision of information about their child from the professional team. Information was often found to be lacking, given at an inappropriate time or given in quantities that were overwhelming for the parents. One factor that was felt to be
essential was personal contact given by a member of the team who was able to explore the family’s individual information needs at different points in time and adjust these accordingly, helping the parents to become more active decision makers and more empowered when caring for their child.

If the child and family have a key worker this is often a role expected of them. The key worker may need to provide information in a relevant and accessible form about facilities, opportunities, benefits and entitlements with respect to both voluntary and statutory agencies.

The key worker will need to be flexible in what they provide as each child and family may have varying and unique needs with regard to information. This may be due not only to the individuality of their condition and circumstances but with regard to where they are on their emotional and psychological ‘journey’ and their acceptance of their child’s disability.

2.10.6 Key Working: Negotiating the Service Maze

The family’s experiences of service provision are often frustrated by the lack of communication between and within services. Health, Education and Social Care for children with disabilities is a complex maze for professionals let alone parents, carers and families. The literature shows that parents call for a ‘named person’ – a single person through whom the service maze is accessed and negotiated (Care Co-ordination Network UK 2004; Kirk and Glendinning 2004). Beattie (1999) using literature available demonstrated the sheer numbers of professionals from different agencies that may be involved in the care and management of a child with a disability. Following this she carried out semi-structured interviews with seven professionals of various backgrounds. Using
the outcomes of her study she questioned the feasibility of how all of the professionals working with the child and family could realistically function as members of a cohesive team. The task of liaison with and co-ordination of the services provided by such a team, with which many parents are currently struggling, may not be in practice any easier for a lone key worker and may introduce yet another layer of bureaucracy for the family. One limitation of the study was that Beattie (1999) did not interview parents and it may have been helpful to have their view on the service co-ordinators role.

2.10.7 Key Working: Education Needs of Families
Townsley et al (2004a and 2004b) reported on a study in which they explored the experience of multi-agency working for children with disabilities, their families and the professionals who supported them. Within the study over half the families interviewed reported that they had a key worker although some reported that there was lack of clarity regarding the role of that person. If the family did not understand the purpose of the role this suggests that it was not clearly explained to them. It is feasible that the professionals undertaking the role did not truly understand it enough to offer an explanation to parents. The study highlighted a lack of education for the family of the key worker role and identifies an information and training need. However, 24% of the families in the study felt that the key worker did co-ordinate services and 66% felt the key worker had a beneficial effect on their perception of overall quality of family life. Interestingly within the same study there was a paucity of evidence of a good working relationship between the child and the key worker. Some children, who did have a key worker, could not name them.
2.11 Key Working: Specialist Roles

There are several roles described in the literature as specialist roles which could be seen to reflect the role of the key worker as has been described in this text but in very specific contexts. Two examples of such roles are the co-ordinator role in Safeguarding Children (Bajaj et al 2006) and the Multiple Sclerosis Specialist Nurse (North West MS Nurse Group 2007).

2.11.1 Safeguarding Children Co-ordinator Role

Bajaj et al (2006) described and reviewed the outcomes of the role of a safeguarding co-ordinator for children across a hospital and community context. The co-ordinator had only one job focus - safeguarding, and did not carry out any other professional role (akin to a designated key worker role). The co-ordinator could be called to support families in any department where there were safeguarding concerns. The co-ordinator liaised with other relevant agencies and attended case conferences. They were visible and contactable within the Trust during working hours and had a 24 hour response message service out of hours. To provide a holistic picture of the child’s situation the co-ordinator had the role of information gathering from the team around the child. Bajaj et al (2006) reviewed the post after one year of practice and although could not state that child abuse had reduced within their area identified that concerns were followed up better by the co-ordinator, documentation had improved and general awareness of safeguarding had been raised across staff teams. It was felt that this had only been possible due to the fact that there was a dedicated person to carry out the necessary work – liaison, communication and documentation and this may be a helpful
indicator for the usefulness of such a person in the team around the child with a disability.

2.11.2 Multiple Sclerosis Specialist Nurses
Multiple Sclerosis (MS) specialist nurses provide flexible and timely care for patients who have the neurological condition of MS which affects the central nervous system resulting over time in cumulative or progressive disability. They act as the first point of contact for patients with MS similar to the key worker in the team around the child. They work in partnership with the patients and their families to develop a responsive service according to their need (North West MS Nurse Group 2007). They also provide a seamless service through communication between different providers within the health, social and voluntary care sectors. All these activities are matched to those of the key worker role as described above. Although they may not interface with education staff there may be many other stakeholders involved in the MS patients’ care and well being e.g. those in the voluntary sector, and the patient is likely to have changing needs over time as does a child with a disability. The roles could be seen as very similar and there may be lessons to be learnt from this practice which could be transposed to the paediatric field.

2.12 Key Working in Private Healthcare, Leisure, Industry and Commerce

The role of the key worker is not the exclusive property of the statutory agencies of health, education and social care. In the domain of private healthcare, leisure, industry and commerce there are roles which although may not be called a key worker have features which can be aligned to that of the key worker as
has been described in this text. For example Specialist Macmillan nurses, a Wedding or Party Planner, a Brownie Pack leader, youth worker, a Project Co-ordinator or Retail Manager. All these roles involve co-ordination, liaison and communication with a range of stakeholders, acting as a point of contact, managing, planning, negotiating, financial responsibility and advocating for clients. All need to be flexible to meet the changing needs and demands of their clients or service users and keep abreast of changing profile of the wider world (e.g. social, economic, political etc). Many may undertake these roles as full time designated employment but some such as a brownie pack leader or youth worker may also have full or part time jobs in addition akin to the non-designated key worker described in health, education and social care contexts. One of the differences of these roles to that of the key worker in the team around the child is that some, but not all, are time limited – they are employed for a specific project which on completion ends the need for the role. When working with children with disabilities and their families the role is much more protracted and has the potential to span up to nineteen years. However, it may be possible to learn from these external roles in these different contexts and apply some of the knowledge and experience gained to the health, education and social care setting.

2.12.1 Macmillan Nurses
For people affected by cancer Macmillan nurses – often employed by the NHS but funded by the charitable organisation Macmillan Cancer Support – can provide a trusted, valued source of support and advice (Macmillan Cancer Support 2011). The nurses have specialist knowledge having worked in nursing for at least five years, two of which have been spent in the speciality fields of oncology or palliative care. The nurses do not carry out basic
nursing tasks but provide specialist care with regard to chemotherapy and the side effects of treatment. They also provide practical and emotional support. Their services ensure that the patients can be treated in their own homes for as long as possible. Theses nurses are often seen by the patients and their families as the key worker during their illness and a strong relationship often develops.

2.12.2 Project Management
Lalonde et al (2010) described the role of the Project Manager in industry and commerce as a professional discipline comparing it to those in health such as nursing, and education such as teaching. Many of the skills and qualities they identify as needed to be a project manager reflects those needed by a key worker in a team around a child with a disability. Interestingly as with key working the authors describe different models of practice of project management comparing and contrasting the positive and negative aspects of each. Project management usually involves setting the scope of the project and a time frame. The team involved need to be co-ordinated and therefore a project co-ordinator (akin to the key worker) is identified. Information technology and information systems are established to manage and make accessible key information about the project and its progress to all key participants – similar to information sharing across the team around the child. Lalonde et al (2010) described a process of collaboration with other providers as crucial to the role and that this may have to be negotiated as the progress of the project may be dependent upon them meeting targets and timescales. This reflects the dependency of the members of a team around the child on each other to provide services and produce successful outcomes at an agreed time in order to meet service
targets. Project management involves analysis and review at different stages to evaluate the project progress – a process that mirrors case conferences and team meetings for the team around the child.

It is interesting to note that there is no fixed project management ‘recipe’ to fit all situations and these need to be flexible to meet the individual needs of the scope of the project concerned a factor similar to the individual needs of the child and family.

According to Dietrich et al (2010) who carried out a literature review projects do not always run smoothly particularly where project managers are dependent on collaboration between specialist providers of materials and equipment as is often the case between members of the team around the child who provide specialist skills in the care and management of that child. This interdependency of stakeholders has the potential to affect the outcome of the whole project in terms of failure - if one party fails to meet it’s stated targets - or success and could lead to costly over runs. Dietrich et al (2010) proposed five elements of collaboration and describe these as:

- Communication
  - [Where there was sufficient, open and efficient information exchange between partners]
- Co-ordination
  - [Where there was a shared understanding of goals between partners and actions needed]
- Mutual support
  - [Where there was a willingness of collaborating partners to help each other to achieve the common
agreed goals and flexibility to address unforeseen incidents and changes]

• Aligned efforts
  o [Where there was an expectation of contribution and commonly agreed upon priorities]

• Cohesion
  o [Where there was an existence of the collaborative spirit between partners]

These elements could equally be applied to collaboration in the context of health, education and social care when working as a multi-agency team around the child in a key worker service.

2.13 Change Management

The overall aim of the Professional Doctorate programme is to develop a practitioner who can use research to address problems of professional practice (University of Brighton 2009). On completion of a Doctoral study the recommendations may be applied in practice through a process of change management.

Change management is a process which moves through several developmental stages which according to Handy (1985) are recognised as forming, storming, norming and performing. However, professional culture and beliefs can affect acceptance of, and resistance to, change and this has proved to be problematic in service for children.

2.13.1 Cultural Values, Norms and Beliefs: Impact on Change
Culture is often viewed as ‘the way we do things around here’ (Schein 2004). Culture could be said to consist of the norms, values,
behaviours, beliefs and attitudes of those that work within an organisation or team (Karp and Helgø 2008). As has been seen in this review of the literature professional and organisational culture has a strong influence on the working practice of the professionals in the team around the child. Often these cultures are not compatible when brought together. Culture is often represented diagrammatically as a picture of a tree or iceberg with elements of both being ‘under the surface’ therefore not immediately apparent to the onlooker (Schein 2004, Iles 2005). In this situation when a group of people are brought together and expected to work as a team the elements of cultural beliefs which are ‘under the surface’ and not explicit may lead to difficulties in the way the team can work together until they can be resolved. The resolution of cultural differences may take an investment of time which tends not to be addressed in current service provision.

The behaviour of professionals is what staff actually do – what is apparent to the service users accessing the organisation, what they can see happening. Cultural values are those which an organisation says they should do i.e. their mission statement. Norms are ‘what is usually done here’ and may have been done that way for years. These are often the taken for granted elements of a culture. Finally the beliefs are what underpin the whole system – what individuals think and feel is right in their particular context. Spurgeon and Barwell (1991) refer to what has usually been the norm in practice as institutional inertia. It is difficult to anticipate how staff will react to any proposed change and professionalism may strongly dominate the change process.
2.13.2 Change Processes

In some instances staff and teams involved in change are thought to go through processes akin to the seven stages of bereavement as described by Kubler-Ross (1969). These include shock – is this happening; denial – that it is happening; frustration – often expressed in anger or rage; depression – as anger turns inwards; experimentation – exploring the issues of a new reality; decision-making – choices between the options of the new reality and finally, integration – when change is internalised and made sense of which may ultimately lead to acceptance of the new situation (Edmund 1999).

Not all staff will pass through this sequential process during change. Some may miss out stages, some may go through the process at a different pace and others may never get to the acceptance stage or take much longer and need on going support to get there. Because of this the team leader through the change process will face many challenges and will need to utilise many skills to support the needs of the team.

Cole (1997) presented a useful but fairly simplistic three stage model of change management with particular reference to behaviour change.

1. The need to unfreeze existing behaviours and gain acceptance of the change.
2. Change the behaviour and adopt the new way of looking at the service.
3. Refreeze behaviours to reinforce the benefits of the new way of delivering the service.
This model is fairly unsophisticated and may be difficult to apply within the study context due to the complexity of the children and their family situations and the influence of individual personalities and organisations involved in addition to the ever changing external influences on service providers. Cole's model clearly identifies what needs to be achieved, but the reality of this in practice may prove to be much more convoluted.

These models and an understanding of the change management process may be useful in developing the recommendations of this research study in the future. Application in practice however may prove problematic in that the models may be too simplistic for the complex nature of the study context.

2.14 Summary: Key Working - Rhetoric or Reality?

The evidence from the literature suggests that multi-agency working practice over the past decades has not been in line with policy development and this is needed to improve current service delivery and key working. Examples from other areas of healthcare practice, organisations and activities outside of the public sector could be applied to the key worker for services for children.

2.14.1 Establishing a Key Working Service: The Challenges

Reflecting on professional practice and experiences one may wonder if professional boundaries as highlighted within the literature translate to professional barriers in current practice. Putting disparate people together in a group does not lead to spontaneous team working. However, the overall recommendation emerging from the literature is that key working should be
employed within a multi-agency team, in the context of working with children with disabilities, and their families.

There is some evidence to suggest that to establish a key working process is by no means an easy task (Townsley et al 2004a and 2004b). It is possible that current working practice and processes may present significant challenges to a person who undertakes such a role. Theoretically the advice is that support for the process has to be provided from staff at all levels, both strategic and management, as well as professional providers of care. This may mean that joint working procedures and protocols have to be agreed across professional groups and more importantly joint funding proposals for resources between the major agencies (Mukherjee et al 1999).

Commitment has to be given and sustained and ongoing support should be provided for the key workers (Greco and Sloper 2004). Education on a multi-agency basis is essential for all concerned and this should include parents and carers too (May 1996a and May 1996b). Pitfalls and complications of the process of setting up key working have been identified in a variety of teams and settings with a variety of patients (Hinojosa et al 2001; Meeks 2001; Kirk and Glendinning 2004). The evidence suggests that breakdown of traditional professional boundaries along with professional cultures and beliefs should take place in association with inter-agency team building and cross professional collaboration (Appleton et al 1997). Professionals should recognise the pivotal importance of the partnership of parents, carers and child as members of the team (Pickering and Busse 2010). The literature often focuses around certain professional disciplines and patient diagnoses (Boarder 2002, Greenwood et al 2000). There are well structured standards
established for the role of the key worker and a resource pack is readily available from the Care Co-ordination Network UK - an umbrella organisation promoting key working for disabled children and their families throughout the UK (Care Co-ordination Network UK 2000).

The National Service Framework for Children, Young People and Maternity Services (Department of Health 2004a) states that:

“Studies of key workers consistently report positive effects on (parents) relationships with services, fewer unmet needs and greater family well-being”.

Department of Health (2004a, p28)

However, it is reported within the same document that there are still less than one third of families receiving this support mechanism (Department of Health 2004a). There do not appear to be any plans to support the implementation of further key worker schemes by the government and many pilot areas have stated that the key worker system requires ongoing funding investment.

There is limited evidence that the key worker system actually does benefit the child and family. Townsley et al (2004b) found that although two thirds of the families in their study reported beneficial effects on access to services and improved quality of life with a key worker, the key worker, no matter how well they work with the family, or how effective they are in their role, can not change the fact that resources are scarce in many areas of service provision e.g. sitting services, respite care, funding for home adaptation, and short break support.
2.14.2 Key Working in a Landscape of Change
Changes in children’s services are currently taking place which can be attributed to a series of influences:

- An increase in focus on the Rights of the Child.
- An increase in the number of children with disabilities due to the survival of increasingly premature babies (Sainsbury 1998, The Dartington Hall Trust 2004).
- A move to family-centred care.
- The growth of Disability and Human Rights Movements.

The guiding principles of the Court Report (Department of Health and Social Security, Department of Education and Science & Welsh Office 1976) still remain pertinent to children’s services today and practitioners working in the field need to be active participants in improving child services and the outcomes for the child and family.

2.14.3 Key Working: The Focus of this Study
Due to the complex nature of the phenomenon and concept of key working, and the themes which were presented in the literature, there are many issues that evolved from preliminary investigation. By recruiting the team around the child with a disability, including the parent or carer, to this study, the perceptions of the role of the key worker were investigated and the reality of multi-professional, multi-agency working for those concerned explored. Using a qualitative approach, this study
aimed to address the gap in the available literature as to what, in current practice, could inhibit team working and the implementation of the role of the key worker, including what it is that parents and professionals expect and want from such a role. The methodology provided the flexibility to delve into areas that were exposed by the participants themselves that were not an original research priority.

Current government policy and legislative framework provide a timely backdrop on which to base this study. Although there is a wealth of literature available, the scope of the phenomenon of key working is so vast and the contexts and settings in which the role can be employed are so variable that it may be difficult to find one approach that will suit all situations and needs. The team around the child may face challenges in their day to day work with regard to team working. The researcher aimed to establish if practice within the study context reflected the established policy guidance and if the guidance itself reflected what was identified as needed by the families of the children with disabilities.

In the chapter that follows the author demonstrates the philosophical context and chosen methodology for the study.
Chapter 3.0: Research Design

The focus of this chapter will be to address the question of methodological approach and provide a theoretical framework for the study i.e. method selection, data analysis, validity and rigour. A brief exploration of available methodologies will be made and the chosen methodology will then be discussed in more detail. Finally the methodology will be related to the researcher’s own epistemological stand point reflecting back on the established aims given in chapter one.

3.1 Methodological Approaches

In discussing the contrasts between quantitative and qualitative research Rolfe (2006) explored the views of the proponents of the epistemological distinction of ‘realists – who posit a material world that exists independent of any observers’; and, ‘idealists – who argue the world, in one way or another, exists only or fundamentally in our minds’ (p306). He stated that they often refer to the quantitative and qualitative research paradigms as Positivism and Interpretivism, thus reflecting the differing aims of research – one to perceive and measure the world, the other to offer a more or less subjective interpretation of it. French sociologist Pierre Bourdieu in the early 1980’s identified that individuals engage with others in their social worlds and in doing so make sense of and respond to different situations in a dynamic way. Experience is therefore not just about what happens to a person as an individual, but about perception and understanding.
3.1.1 Interpretive Approach
Carter and Little (2007) described social research as that in which the researcher relies on text data as opposed to numerical data, aiming to understand the meaning of human action, asking open questions about a phenomenon under study as it occurs in context. Qualitative research is often described as holistic, naturalistic, contextualised, and focused on human experience with a high level of researcher involvement (Munhall 2001). It aims to understand the social reality of individuals, groups or cultures – the basis being in the interpretive approach to a social reality. This is as opposed to the positivist approach. Darlaston-Jones (2007) claimed that those adopting the positivist belief that a single universal reality exists for all and that this reality can be discovered via systematically controlled investigation, fail to recognise the ability of the human individual to interpret and make sense of his or her world. This view is presented in the earlier work of Blaikie (1993) who stated that:

‘Interpretivism entails an ontology in which social reality is regarded as the product of processes by which social actors together negotiate the meanings for actions and situations; it is a complex of socially constructed meanings’

(Blaikie 1993 p96)

3.1.2 Making Sense of Reality
Qualitative research is a way of enabling us to make sense of reality. Although researchers who are strongly positioned within a quantative based, positivist philosophical paradigm may disagree. For researchers who approach from a qualitative, interpretive standpoint, qualitative research provides a description and explanation of the social world in which we live and enables
development of explanatory models and theories (Morse and Field 1995). Researchers within this paradigm play an integral and active part in the research studies they undertake, for example in the collection of data through a variety of methods by observing phenomena in day-to-day life. Interaction between the researcher and participants generates a wealth of rich data of the observed phenomena from which the researchers, following systematic analysis, go on to develop or construct themes, concepts and theories as an outcome of their research. Quantitative researchers on the other hand work deductively, testing hypotheses by experimental design. They are more likely to remain removed from the research process and objective towards it, whilst testing or developing theory.

3.1.3 The Research Question
The choice of which approach to use – qualitative or quantitative, is often dependent on the research question to be asked, the phenomenon to be studied, the aims of the study and to a certain extent the researchers own epistemological standpoint. Quantitative researchers tend to study phenomena that are measurable whereas qualitative researchers explore issues where little is known (Stanley 2006). Qualitative research aims to explore a phenomenon from an ‘emic’ perspective – i.e. an insider’s viewpoint. What is the experience like for those who are ‘native to that view’ (Morse and Field 1995)? Quantitative research however, tends to approach inquiry from an ‘etic’ or world perspective i.e. the findings are based on the researcher’s interpretations of the experimental results and not on those of the participant. The researcher in this instance looks for links between variables to explain cause and effect. A quantitative approach could have been used in this study. For example, a quantitative study surveying
a population of multi-professional teams managing children with disabilities would be feasible but much of this work has been done before (Department of Health 2004a). On the basis that in quantitative research the researcher has a ‘theory’ to be tested or that there are very specific questions to be answered, it was not chosen to be the approach for this particular study. For this study richer, thicker data of a qualitative nature was needed in order to inform and influence practice, as Holloway (1997) stated:

‘Qualitative research is based on social inquiry focussing on the way people interpret and make sense of their experiences and the world in which they live...’

Holloway (1997 p1)

In addition, a qualitative approach was chosen for this study due to the nature of the phenomenon under study – the role of the key worker in the multi-professional team around the child with a disability, and the desire to investigate the nature of this role from the viewpoint and experiences of the different participants involved.

3.1.4 Alternative Methodologies
Within the qualitative research arena there have been a number of approaches or methodologies, referred to by some authors as strategies of inquiry (Denzin and Lincoln 2005) or traditions of inquiry (Cresswell 1998), developed over the decades. These include phenomenology, ethnography, and grounded theory.

3.1.4.1 Phenomenology
Phenomenology describes the lived experience of individuals within their life world. This approach originated in the work of Husserl,
Heidegger, Sartre and Merleau Ponty (Denzil and Lincoln 2005). Phenomenology aims not to generate theory, but to describe accurately the experience of the phenomenon under study and does so often by using in-depth conversations in which the researcher and subject are co-participants. Phenomenological research, however, does not tend to further our understanding of why such experiences take place and why therefore there may be differences between individual phenomenological representations. That is, phenomenological research describes and documents the personal lived experience of participants but it could be argued that this limits understanding of phenomena. If the aim is to move beyond sharing an experience with participants and understand their experiences well enough to explain them, there needs to be an awareness of the conditions that gave rise to these experiences in the first place. Such conditions may lie far beyond the moment and location of the experience itself. They may be found in the past events, histories or social and material structures within which lives are lived. In this study the researcher wanted to investigate the broader experiences of the whole team around the child and the key worker role. Although they were all involved in service provision for a disabled child and their family, not all of the proposed participants would have had the personal ‘lived experience’ (as advocated in a phenomenological approach) of having a disabled child, or being a key worker. Therefore phenomenology was not felt to be the most appropriate methodology.

3.1.4.2 Ethnography
An Ethnographic approach was also considered. Ethnography has been used to study cultures for many years and has its origins in anthropology i.e. the study of man as an individual, the study of groups or cultures in the broadest sense e.g. members of a tribe.
Ethnography from the Greek language means writing about people. Notable work includes that of Malinowski Bronislaw who wrote about Pueblo Indians in the United States of America on his travels in the late 1920s. Ethnographers are expected to ‘live’ within a society for an extended period in order to gain an insight into the native’s own viewpoint about reality (Morse and Richards 2002). An ethnographic approach could have been utilised to address this inquiry in part, investigating the culture of disability from the child and family’s standpoint or from an alternative perspective, the culture of multi-agency teams. In each example, the study would not have addressed the broader perspective of the whole team including professionals and the family with particular relevance to the key worker role. As the researcher was interested in a broad perspective, this was not felt to be the right approach for this study.

3.2 Grounded Theory Methodological Approach

After due consideration the chosen methodology was grounded theory as this approach seemed to offer a ‘best fit’ solution to the research.

3.2.1 The Historical Background of Grounded Theory Methodology

The Grounded Theory approach arose originally from the symbolic interactionism tradition. Glaser and Strauss (1967) described grounded theory as the discovery of theory from data, which has been systematically obtained and analysed, in social research. Constant comparison of the data during the analysis process provides categories, themes and conceptualisation for describing and explaining the phenomenon under study (Finlay & Ballinger 2006). The emphasis being on the conceptualisation and explaining, which by interpretation goes beyond pure description...
and according to Glaser (2002) is what makes grounded theory unique amongst other qualitative methodologies. Denzin and Lincoln (2005) described ‘grounded theory’ as referring to both the method of inquiry as well as the product of inquiry. Both theory and data analysis involve a process of interpretation but in this methodology, the interpretation is based on systematic inquiry. The concept of constant comparison in grounded theory allows the researcher to simultaneously collect and analyse data – each process going on to inform the next. It provides flexibility throughout the research process to build inductively on concepts and themes, which emerge from the data that can be used to inform further data generation and collection as the study progresses. Strauss and Corbin (1998) stated that grounded theories, because they are drawn from data, are likely to ‘offer insight, enhance understanding and provide a meaningful guide to action’ (p12). These properties reflect the aims of the study specified in chapter one of this thesis.

3.2.2 Evolution of Current Day Grounded Theory Methodology
Initially developed by Glaser and Strauss in the 1960s the approach of grounded theory at that time demonstrated a strong foundation in what is now referred to as mid twentieth century post-positivism. As stated earlier, Glaser and Strauss advocated developing theories from research grounded in data rather than deducing testable hypotheses from existing research (Charmaz 2006). As time has passed grounded theory authors have developed more of a social constructionist perspective and grounded theory methodology can now be seen as emerging into the interpretivist paradigm no longer subscribing to the objectivist, positivist assumptions it once had (Anells 1996, Charmaz 2005, Cutcliffe 2005). This evolution allowed for a broader range and more
flexibility of method of data collection for researchers e.g. use of picture or form boards, poetry and mime, as well as the more traditional interviews and focus groups.

3.2.3 The Role of the Researcher in Grounded Theory
The researcher in grounded theory methodology was described by Carter and Little (2007) as being an ‘active creator of the research’. Darlaston-Jones (2007) described the interest and value base of the researcher, and how this might interact with the research process, as being what drives or motivates that interest as well as which methods of inquiry best meet the objectives of the study. For example a researching practitioner who undertakes such a study has a vested interest in the phenomenon and field of practice. The outcome of the study may go on to influence the clinical practice of the practitioner and those in the field around them and be a strong motivating factor during the research process (Dearnley 2005). As previously mentioned, in qualitative research the researchers involvement with the research process is in direct contrast to that of the researcher in positivist methodologies whereby the researcher is objective to, and separate from the research process – an original standpoint of Glaser and Strauss (1967). This is a view which has changed in the work of the more recent emergent-grounded theorists who now believe the researcher to be interactive – bringing current interests and past interactions into the research role. The researcher is no longer a passive tool in the process. The researcher now takes a reflexive stance on knowing and representing the studied phenomenon – the conceptual categories and themes arising through the researcher’s interpretations of the data, rather than ‘emanating’ from them.
3.2.4 The Researching Practitioner

During grounded theory research, the recording of data can lead to the researcher pursuing leads and avenues that they may otherwise have ignored or failed to realize had any relevance or importance. Daly et al (2007) described this as one of the strengths of qualitative research - the flexibility and capacity to adapt. This may result in a shift of direction for the inquiry and can often be the case when the researcher is close to the field in which they are carrying out the research – as with a practitioner researcher.

Grounded theory today is looking for variation and difference, rather than looking for abstract realities, which is where it has its roots. Familiarity with the research arena can lead to an oversight of what is the norm in day-to-day practice but which may have significance in the field of the research phenomenon - hence the importance of reflexivity, on the part of the researcher, and the need for systematic data analysis. The researcher also needs to be aware that the participants may not think to say what is routine to them about their setting due to an expectation that the researching practitioner would know due to personal involvement or familiarity. Charmaz (2003) believes that this critical analysis attends to the contradictions between myths and realities, rhetoric and practice, what people say and what they do, what theory is, what policy is and what reality is.

3.2.5 A Disturbance in Practice

The phenomenon of the key worker under study is a role that has been described within policy and practice documents for decades now. However, it remains a disturbance in practice for the researcher, as the reality of the role being widely used, appears to be otherwise (Department of Health 2004a). By using grounded theory methodology, the researcher believes that the reality of the
world of the team around the child with a disability can be investigated and the life meaning of the participants explored to explain the gap between rhetoric and reality.

For the parents and professionals working in this situation, having to work with others – professional and non-professional - the reality is dealing with the multitude of people caring for the child with a disability, on a day-to-day basis. Each member of the team will have their own realities embedded in their own historical, cultural, situational, economic, political, locational and philosophical context (Corbin and Strauss 2008). The role of the researcher will be to generate data that will provide rich material to interpret and analyse how each of these participants makes sense of their situations and acts upon them. As analysis develops, this will allow the examination of the relationships between emergent categories and themes with the view to the development of concepts and theories or models, that could be utilised to influence and change work within this field of practice. Theories, according to Reeves et al (2008), provide complex and comprehensive conceptual understandings of things that cannot be pinned down. They give researchers different ‘lenses’ through which to look at complicated problems and social issues.

3.4 The Role of Reflexivity in Grounded Theory

Nightingale and Cromby (1999) referred to reflexivity as being an awareness of the researcher’s contribution to the construction of meanings throughout the research process and an acknowledgement of the impossibility of remaining ‘outside of’ one’s subject matter when conducting research. Reflexivity urges
us to explore how the researcher’s involvement influences and acts upon and informs the research undertaken.

Willig (2001) identifies two types of reflexivity:

- Personal reflexivity
- Epistemological reflexivity

Personal reflexivity involves a process of reflection on the ways the researcher’s own values, experiences, interests, beliefs, culture, political commitments, wider aims in life, and social identities may have shaped the research. It also involves reflection on how the research process and outcomes may have changed the researcher as a person and as a researcher.

Epistemological reflexivity requires an engagement with certain questions about the research. For example:

- How has the research question defined and limited what can be found?
- How have the design of the study and the method of analysis ‘constructed’ the data and the findings?
- How could the research question have been investigated differently and to what extent would this have produced a different understanding of the phenomenon in question?

According to Willig (2001) epistemological reflexivity allows researchers to reflect on the assumptions (about the world and about knowledge) that they have made during the course of their research journey. Thus it helps the researcher to think about the implications of such assumptions for the research itself and its findings.
During this particular research journey the author has kept a reflexive diary and the personal issues of reflexivity will be addressed later in this text.

3.4 Sampling in Qualitative Research

In qualitative research the researcher deliberately seeks valid representation in the research sample (participants) of the phenomenon under study rather than representativeness or randomness.

3.4.1 Purposeful Sampling

The researcher uses a strategy known as purposeful sampling – selecting information rich cases for in depth study (Patton 2002). Examples of purposeful sampling include opportunistic sampling, convenience sampling, criterion sampling, maximum variation sampling, sampling by case type – typical case, extreme or deviant case, and network sampling also known as snowball or chain sampling. In this study purposeful sampling was used to select ‘information–rich’ participants with knowledge of the phenomenon under study. Although all participants had a common interest – the child with a disability - their individual beliefs, culture, professional background and origins from different agencies, were varied. They were a group from whom to generate data and obtain maximum differences of perception about key working in the team around the child - a purposeful sampling technique described as maximum variation sampling.

Maykut and Morehouse (2000) stated that:
A maximum variation sample is a purposefully selected sample of persons or settings that represent a wide range of experience related to the phenomenon of interest. With a maximum variation sample, the goal is not to build a random generalisable sample, but rather to represent a range of experiences related to what one is studying. Maximum variation sampling is an emergent or sequential approach – what one learns from initial participants can inform subsequent direction of the study.

Maykut and Morehouse (2000 p57)

3.4.2 Theoretical Sampling

Often as a study progresses the sampling methods move from purposeful to theoretical. Theoretical sampling according to Mason (1996) is a method of:

‘...constructing a sample which is meaningful theoretically because it builds in certain characteristics or criteria which help develop and test theory and explanation’.

Mason (1996 p94)

A theoretical sample method may also allow the researcher to explore themes, concepts and ideas that have arisen in earlier data generation. Glaser and Strauss (1967) identify theoretical sampling as a process of data collection for generating theory whereby the researcher collects, codes, and analyzes the data and decides what data to collect next and from where in order to develop the theory as it emerges. Therefore the data collection is controlled by the emerging theory. Initial decisions for theoretical collection of data are based only on a general sociological perspective and on a general subject or problem area not on a preconceived theoretical framework. Theoretical sampling pertains
only to conceptual and theoretical development. It is not about representing a population or increasing the statistical generalizability of the results. Jane Hood in Charmaz (2006) describes theoretical sampling as purposeful sampling but its purposeful sampling according to categories that one develops from one’s analyses and these categories are not based upon quotas they’re based on theoretical concerns. One can then make logical inference that offers a theoretical interpretation of the relationships between cases.

3.4.3 Sample Size
Sample size in purposeful sampling may be smaller than is common in quantitative research. There are no fixed rules in qualitative research which dictate sample size. This is dependent on the question being asked, what would be helpful, what would be credible and what can indeed be accomplished with the time and resources available. The validity, meaning and insights generated from the qualitative inquiry have more to do with the richness of the information of the data generated with the participants and the interpretations of the researcher than the sample size.

3.5 Data Generation Methods

In qualitative inquiry, the methods by which the researcher gathers or generates data are tools and these are selected in order to help answer the research question and address the scope of the inquiry. Methods may include for example structured, semi-structured or open interviews; focus groups; field observation and field notes. For this study the chosen methods of data collection were focus groups and interviews.
3.5.1 Selection of Method: Focus Groups

The purpose of focus group discussion is to explore and understand how people think or feel about an issue – in this case ‘key working in the context of the multi-professional, multi-agency team around the child with a disability’.

The focus group allows the researcher to obtain information (generate data) about attitudes and behaviours which are sparked through interaction between the members of the group (Morgan and Krueger 1998, Seale and Barnard 1998, Carpenter and Suto 2008). The setting for the focus group should be comfortable and the environment conducive towards participation (Bowling 1999).

This method respects the view that there is no one ‘specific truth’ but value in multiple perspectives (Carpenter and Suto 2008). Focus group methods have been widely used in the past to explore participants’ experiences of services, both as service users (Murray et al 1994) and as service providers (Denning et al 1993 and Morgan 1998a and 1998b) and would therefore seem an appropriate method to use within this study.

Kitzinger (1995) described the focus group as:

‘...a form of group interview that capitalises on communication between research participants in order to generate data. Although group interviews are often used simply as a quick and convenient way to collect data from several people simultaneously, focus groups explicitly use group interaction as part of the method.’

Kitzinger (1995 p299)
Focus groups are purposive in their approach – the researcher is seeking out information from participants regarding a specific issue. The participants themselves are purposive in that they have been selected because they know something about the issue in question.

The advantages of using this method can be summarised as follows:

- The focus group provides a forum to explore how knowledge and ideas develop and operate within a cultural context (Morgan and Krueger 1998).

- This method can reduce the influence of the researcher as the power shifts to the group – the researcher is outnumbered by the participants (Polgar and Thomas 2001).

- The focus group can encourage participation of those who would rather not be interviewed alone, as well as those who may feel they have little contribution to make (Carpenter and Suto 2008).

- The focus group does not discriminate against those who are unable to read or write (Seale and Barnard 1998).

- It enables group discussion to explore the experiences, opinions, attitudes and concerns of participants (Carpenter and Suto 2008).

- It generates a great deal of data within a short space of time (Bury and Mead 1998).
The focus group however, is not used to gain a consensus and it is important to value the contribution of all members – the value is in the debate amongst the participants.

Kitzinger (1995) purported that the focus group situation exposes the researcher to other forms of interpersonal communication used by people in their day-to-day interaction e.g. teasing, anecdotes, and arguing, which provides a useful insight into knowledge and attitudes, which are not purely encapsulated in reasoned responses to direct questions. The focus group is believed to be a particularly sensitive method by which cultural variables i.e. professional or work place cultures can be explored (Bowling 1999).

According to Morgan (1997), group interaction generates data and this is the principle source of data for the researcher to analyse. The aim is to produce a deep, rich, data that may not have been produced had the researcher interviewed each of the participants on an individual basis or used a survey method. Issues raised within the group can be followed up at the time by the researcher facilitating the group, asking probing questions to stimulate further group discussion and interaction, thus exploring the issue and generating yet more depth to the data. Comments made by one member of the focus group may trigger thought processes of others within the group and produce ideas that they may not have otherwise disclosed had they not been prompted. The group is also likely to contain members who do not necessarily agree on certain issues discussed. The group will undoubtedly include members who have very different experiences, backgrounds and cultures so will provide a rich variation of data of the phenomenon in question - the key worker.
The benefit of using a focus group method within this study is that it facilitates and enables the development of inductive theory - part of an iterative process appropriate to grounded theory methodology. The developing theory can then be discussed in the groups that follow.

The aim of the Professional Doctorate student is to investigate a disturbance in practice with the view to becoming a change agent in the future. The use of focus groups as a method whereby the facilitation of critical expression and exploration of different types of solution is encouraged by participants, who are themselves clinicians, is invaluable if the outcome or aim of the research is to improve services and facilitate change in policy and practice (Denzil and Lincoln 2005).

There are however, limitations with this method in that if one member disagrees with the others within the group as a lone voice they may feel inhibited to speak out. The very nature of the group compromises the confidentiality of all that is discussed within the group and clear guidelines with regard to confidentiality need to be established at the outset of the session.

3.5.2 Selection of Method: Semi-Structured Interviews

The value of the semi-structured interview is to gather information of depth and quality on the phenomenon in question. Unplanned probes may be used to supplement open-ended questions, depending on the participant’s answers. The participants’ accounts of their experiences are the primary source of data (Dearnley 2005). An interview schedule can be used to frame the discussion in advance and to include prompts for questioning but by using a grounded theory approach; the researcher has the
flexibility to explore themes and ideas raised by participants that may not have originally been included within this framework of questions planned for these sessions. The open-ended nature of the questions allows the participants to elaborate on the subject area from their perspective and encourages more depth to the interaction. Participants are encouraged to talk about their experiences and the future ordering of the questions can be dependent on their responses.

Using a constant comparative analysis on the interview transcripts, the researcher is able to use the themes and topics that emerge from previous interviews and focus groups to inform future interaction with participants – theoretical sampling.

Rennie (2000) stated that if interviews were used as a mode of inquiry the researcher already has a sense of the text even before it is transcribed. The very act of transcription deepens that understanding further, therefore a hermeneutic circle is entered and the understanding of the whole text influences understanding of each part and vice versa. This results in a progressive, iterative understanding process and interpretation of the data.

3.5.3 Impact of the use of Different Tools in Data Generation

The use of different tools within a study has the potential to generate different data. The quality of the data produced in a semi-structured interview on a one to one basis between the researcher and the participant depends very much on the individual dynamics and interaction between the two people involved. The focus group is used to gain knowledge of a range of experiences and opinions across a group of people not specific individuals (Morgan 1998a). The amount of data generated which
is related to specific individuals is limited in the focus group setting whereas the volume of data in the one to one interview from individuals tends to be greater. The focus group is about wide ranging exploration of thoughts and experiences within the study context through a process of guided or facilitated group discussion. The group dynamics and individual personalities all influence the data generated and the process is about balanced discussion whereby the facilitator ensures the group is not dominated by one or two individuals. Hearing how participants react to each other gives an in-depth view of the range of their experiences and opinions. Participants begin to find out about each other and often two similar people can have very different experiences of the same phenomenon. This is generally not so in a one to one interview situation and can therefore provide the researcher with interpretative insights. The focus group participants when sharing and comparing begin to investigate issues in both context and depth and will actually generate their own interpretations of topics. From this the researcher can also begin to interpret why people think and act the way they do.

It was helpful to consider these two methods for this study as in one respect the researcher is seeking to explore the individual experiences of the parents of children with disabilities as these will be unique to them. In addition, using the focus group approach for the professional team potentially sacrificed the details about individuals in favour of engaging participants in active comparisons of their opinions and experiences regarding the study subject matter. In many ways this reflected the reality of team work in that the professionals, not withstanding respect for their own individuality, have to work as a team in practice and therefore their
collective representation through categories and themes would be a useful way of presenting the analysis of the findings of the study.

3.5.4 Selection of Method: Field Notes
Field notes taken by the researcher immediately after each focus group or interview act as a form of memo and express the personal reflections of the researcher on the interaction that occurred in the interviews and groups. Field notes also capture any initial thoughts and insights into the data generated – the beginnings of the data analysis process (Patton 2002).

3.6 Data Analysis

Grounded theory is not just about what is in the data but the interpretative strategies the researcher uses in their interaction with that data. Grounded theory according to Bryant and Charmaz (2007) is designed to ‘encourage researchers’ persistent interaction with their data, while remaining constantly involved with their emerging analyses’ (p1). Throughout the process the researcher is involved in thinking about the data and the world from which it evolves. Grounded theory is therefore an inductive approach.

There are no rigid frameworks to the approach but according to Charmaz (2003), grounded theory methodology presents the researcher with a set of flexible analytical guidelines, which enables the researcher to focus on data analysis and not techniques of data collection.

3.6.1 Constant Comparative Analysis
The comparative methods used in grounded theory methodology are unusual in advocating simultaneous data collection and
analysis, each informing and focusing the other. The researcher is then able to build inductive theories through successive levels of data analysis and conceptual development, the construct of which reduces the qualitative ‘chaos’ and ambiguity often assumed with qualitative research. The categories and themes, which emerge from the data, can then be used to inform further data generation and collection as the study progresses. In practice what this means to the researcher is that after each participant contact the researcher analyses the data that is generated – this may be from an interview transcript. This analysis is then used to inform the next phase of data generation – an interview or focus group for example.

Results of ongoing analysis may lead the researcher down paths that were not thought of at a project’s inception. Archbold (1985) considered this a particular strength of qualitative research, a view supported by Morse and Richards (2002) in their comment that the qualitative researcher develops and modifies the focus of the research throughout the project.

Morgan (1998a and 1998b) reported that it may be necessary to review the data in the form of tapes or transcripts several times, comparing different groups and the comments of different participants within the groups, until the central themes emerge. Thus through systematic repetition the researcher can ensure the analysis generated is more than just superficial and impressionistic. Allen and Skinner (2002) warned that it will be easy to recognise links that fit with the researcher’s own conceptualisation and theorising but more difficult not to gloss over the events that run counter to that thinking - which is when reflexivity on the part of the researcher is important.
3.6.2 Terminology used in Analysis of Grounded Theory Research

Data

When carrying out research using Grounded Theory methodology the terminology used in the data analysis reporting may differ from one researcher to another e.g. codes, in-vivo codes, open coding, descriptive coding, focused coding, selective coding, topical coding, analytical coding sub categories, categories, sub-themes, themes, axial coding, theoretical coding, and concepts to identify but a few (Glaser and Strauss 1967, Glaser 1978, Corbin and Strauss 1998, Cresswell 1998, Richards 2005). Many authors use these terms interchangeably which can be confusing for the reader. It is interesting to note that even the originators of the methodology once they were no longer collaborating did not agree on the terms to be used. Which ever terms are utilised may be purely down to semantics however, the process of analysis must be clear and transparent and the analysis pathway auditable. Until such time as Grounded Theory researchers come to an agreement on standardised terminology what is used may be down to individual researcher preference.

3.6.3 The Analysis Process

Analysis begins with initial coding that is word by word and line by line coding examining the fit and relevance of the data to construct codes. These codes are developed into subcategories and categories (or sub-themes and themes) that ‘crystallize’ the participant’s experiences. The analysis process presents the researchers interpretation of the research data and identifies relationships. The analysis develops relevance when there is an analytical framework offered that interprets what is happening and makes visible the relationships between implicit processes and structures.
Careful coding in this manner can prevent the researcher inputting their personal issues into the collected data. The process can help see the familiar in a new light.

Giving in-vivo codes can preserve participant’s special terms and terminology and as a consequence preserve meaning and capture experience. This can lead to a deeper understanding of what is happening and a greater grasp on what is crucial and significant to the participants.

As coding becomes more focused it begins to synthesise and explain larger sections of data once strong analytical direction has been established. The process helps to sift through large amounts of data to determine the adequacy of the codes. The researcher is active throughout the process and through this action new threads may become apparent and lead to the process of theoretical sampling to explore new avenues – an emergent process.

Axial Coding (Strauss 1987, Strauss and Corbin 1990, 1998) was presented as a means of relating subcategories (sub-themes) and categories (themes). Charmaz (2006) describes axial coding as a strategy to bring the data back together again in a coherent whole. It helps to answer the questions of when, why, who, where, how, what consequences; therefore describing at a conceptual level the studied experience more fully. Analyzing the data means converting the text into concepts (by a process of axial coding). This enables the researcher to specify the dimensions of categories establishing links with subcategories and identifying relationships between them.
In Grounded Theory axial coding presents a framework – like other aspects of Grounded Theory some authors like it and use it others feel they do not need to use it (Charmaz 2006).

Charmaz (2006) believes that although axial coding may help researchers explain their data it encourages them to apply an analytic frame to the data. In that sense relying on axial coding may limit what and how researchers learn about their studied worlds. If it helps or hinders is a question that remains under discussion in the qualitative inquiry world. Whether and to what extent it offers a more effective technique than careful comparisons remains debatable. At best axial coding helps clarify and extend the analytic power of the emerging ideas and theories. At worst it casts a technological overlay on the data and perhaps on the final analysis.

Glaser (1978) describes a process of theoretical coding which follows focused coding and is a means of conceptualising as to how substantive codes may relate to each other as hypotheses to be integrated into a theory or model. Theoretical codes specify possible relationships between categories the researcher has developed. Glaser argues that these preclude the need for axial coding because they weave the fractured story back together.

In many ways this approach is not dissimilar to that of Strauss and Corbin (1998) who describe the purpose of axial coding as beginning the process of reassembling data that were fractured during the open coding process. Categories are related to their sub categories to form more precise and complete explanations about the phenomena under study. A category is a problem, issue; event or happening that is significant to the participants. The
subcategories identified help to answer questions about the phenomenon such as when, where, how, why, who and the consequences therefore giving the concept greater explanatory power. This linking takes place at a conceptual level – giving an explanation or interpretation.

Answering the where, why, how, when, who type questions helps to provide contextualisation of a phenomenon i.e. to locate it within a conditional structure and identify the how or means through which a category is manifested. By answering these questions the researcher as they analyse the data is able to relate structure with process. Structure or conditions set the stage - create the circumstances in which problems, issues, happenings or events pertaining to a phenomenon are situated or arise. Process denotes action or interaction of a person or organisation in response to certain problems. Combining structure with process helps to get at some of the complexity that is so much part of - in this instance – life with a child with a disability.

Process and structure are inextricably linked and it is important to understand the nature of the relationship to each other and to the phenomenon. Strauss and Corbin (1998) describe axial coding as a scheme to sort and organise emerging connections via a combination of inductive and deductive thinking to present a paradigm or perspective. It helps to gather and order the data. The basic components being:

- **Conditions** – as related to the phenomenon under study - the structure, circumstances, situations
- **Actions** – strategic or routine responses directed at managing or handling the phenomenon, issue or problem
• Consequences of actions – outcomes related to phenomenon

Conditions arise out of time, place, culture, rules, social worlds, institutions and organisations etc. Actions may be direct or indirect, macro or micro or casual. The consequences will vary from individual case to individual case.

In this study the personal preference of the researcher, after hearing the Grounded Theorist Kathy Charmaz lecture at a conference and following much of her work, has been to utilise the terminology and process she has often described of line by line coding, codes, sub-categories and categories. This has demonstrated rigour in the data analysis through a staged and systematic approach. The decision to do this demonstrates not only the initial ‘deconstruction’ of the gathered data generated between the researcher and the participants but a means of making order from the chaos of qualitative research previously alluded to. Gradually through this process the data is brought back together or ‘reconstructed’ through the building of categories during it’s interpretation on the part of the researcher. By using coding in this way the data is displayed systematically and it therefore becomes informative. This assists in the interpretation of the data which in turn assists in the development of further questions or areas for exploration with future participants. Correlation of this information helps develop new knowledge and the implications drawn from the conclusion made by the researcher lead to new insights around the phenomenon under study. Data in its raw state does not make sense unless it is displayed and explained appropriately.
In proceeding to further axial coding the researcher demonstrates a complex texture of conceptual relationships built around the axis of the categories. The model of practice the researcher has developed is encapsulated and influenced by the factors holding and binding the categories together. The linking of these categories occurs on a conceptual level. These concepts serve as core variables and hold explanatory and predictive power. They act as interpretive frameworks and offer an abstract understanding of relationships present. They link together and inform the model of practice and demonstrate the socially constructed context of the study situation.

3.7 Trustworthiness, Validity and Rigour in Qualitative Research

Guba and Lincoln (1989) described the following criteria as validity issues when trying to establish trustworthiness or rigour in qualitative inquiry:

- credibility (internal validity or the need to demonstrate the truth value/s of multiple perspectives),
- transferability (external validity or applicability of findings to broader contexts),
- dependability of findings amid variability, (reliability or consistency) and
- freedom from bias in the research process.

3.7.1. The Issue of Quality

Lincoln and Guba (1985) had earlier identified credibility as an overriding goal of qualitative research reflecting the relativistic nature of truth claims in the interpretivist tradition. Since then the issue of quality in qualitative research has been discussed and
debated for almost a quarter of a century (Rolfe 2006). Whittemore et al (2001) joined the debate discussing the complexity and contradiction of applying such positivistic-based validity criteria to qualitative research as proposed by Guba and Lincoln (1989). They stated that qualitative research seeks depth over breadth and attempts to examine the subtle nuances of life experiences as opposed to aggregate evidence. The different philosophical approach of qualitative research to that of quantitative approaches calls into question the appropriateness of applying similar standards of quality – a view supported by Rolfe (2006). Verification of qualitative data can be difficult as the precise procedures used are difficult to replicate. No two researchers will ask the same questions in the same order or the same way, however, they can both study the same range of phenomena and generate analyses which inform each other and lead on to future studies, enhancing our understanding and knowledge of that range of phenomena.

3.7.2 Interpretation of the Data
To assure credibility the researcher must make a conscious effort to establish confidence in their accurate interpretation of the meaning of the data. The interpretation should reflect the experience of the participants. Some authors advocate independent coding by another person to ‘improve rigour in qualitative research’ (Barbour 2001); however as the interpretation of qualitative data can vary from reader to reader this may highlight disagreements and variation of understanding and possible alternative explanations rather than concordance between researchers or readers. Conducting ‘member checking’ (i.e. returning transcripts to participants for verification) may apply an ‘objective gloss’ to the study. This may increase the study’s
rhetorical impact – particularly for those readers who identify with a more positivist philosophical position (Rennie 2000). Although some say that the original transcript should be returned to the participant it is possible that they may wish to change the text and rewrite it in order to say what they want it to read rather than what they actually said. To overcome this, an alternative possibility is to send the participants a summary of the themes that are emerging from the initial analysis of the data to seek verification that these were the themes grounded in the basis of the discussions. The reality of the present for the participant differs from the past from which it emerges but each novel aspect of every new experience gives rise to new interpretations and actions. This will also ring true for the reader of the research. Comparison of the inductive data, comparison of the different statements of the participants around the same issues and discussion around the construction of those issues results in an analytical interpretation of the participant’s world and of the processes by which it is constructed, on the part of the researcher, i.e. this is the researcher’s interpretation of the data. Even then, the resulting understanding may be open to new interpretations (Rennie 2000).

3.7.3 Generalisability of Research
Qualitative research is contextual and subjective whereas the quantitative approach is generalisable and objective. Generalisability may not be a significant research goal of qualitative study. Transferability of findings to other populations i.e. what may happen in one place at any one time will also happen in another place or at another time, may not be the aim of the research. Payne and Williams (2005) referred to moderatum generalisation claims of qualitative study and urged researchers to
‘publish what they see as the extent of their moderatum generalizations and the grounds for their claims’ (p311).

Morse et al (2002) purported that validity and reliability are achieved when the researcher rigorously follows a number of verification strategies during the course of the research process – but this is a view that some may associate with a more positivist approach as in quantitative based research. Rolfe (2006) believed that any attempt to increase reliability involves a forced or artificial consensus and conformity in the analysis of the data, which is usually at the expense of the validity or meaningfulness of the findings.

3.7.4 Auditability of Research
One important aspect of validity in qualitative research is that of auditability. In order to defend their interpretation of the participants’ viewpoint an audit trail must be evident to demonstrate the interpretive process on the part of the researcher providing insight for the reader on how the salient interpretations were arrived at. Koch (2006) referred to the researcher providing a decision trail by which decisions about theoretical, methodological and analytical choices were discussed explicitly throughout the study. Whittemore et al (2001) also referred to a concept of thoroughness in qualitative research which they described as sampling and data adequacy as well as comprehensiveness of approach and analysis. The concept of data adequacy or saturation is also described by Morse and Richards (2002) as when there is no new information emerging from the data analysis. It implies attention to connection between themes and full development of ideas.
The overall conclusion seems to be that researchers within this field are no closer to establishing a consensus on quality criteria or even on whether it is appropriate to try to establish such a consensus at all (Sandelowski and Barroso 2002).

3.8 Philosophical Standpoint

Constructivist grounded theory as advocated by Charmaz (2006) is described as a contemporary revision of Glaser and Strauss classic grounded theory (Glaser and Strauss 1967 and Glaser 1978). It assumes a relativistic approach and acknowledges multiple standpoints and multiple realities of research participants and of the grounded theorist (i.e. the researcher). Thus, grounded theory from this perspective loses its positivist roots and moves further into the interpretative field of inquiry, positioning this within the historical, cultural, social situational and location context. It examines the perspectives and positions of the researcher (reflexivity) as well as those researched.

Qualitative study and grounded theory methodology appear to offer a best fit for the researcher’s own epistemological standpoint and philosophical position believing in multiple realities and the interaction of researcher and participant within the research process, as will be explained below.

3.8.1. Epistemology

Epistemology is a way of understanding and explaining how we know what we know. From a standpoint of believing in multiple realities and the construction of knowledge and understanding being based on the interaction of an individual with their world, the
author can be located in what Crotty (2003) described as the epistemological parameters of Constructionism.

3.8.2 Constructionism
Crotty (2003) stated that Constructionism is a view that:
'All knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their worlds, and developed and transmitted within an essentially social context.'

Crotty (2003 p42)

Crotty (2003) described Constructionism as the truth or meaning which comes into existence in and out of our engagement with the realities of our world. Meaning of that world is constructed by the person engaging in that world. Therefore, different people construct meaning in different ways – even around the same phenomenon (Darlaston-Jones 2007). The world, which in this study is the world of the team working with the child with a disability, is therefore a different place for each of the different professionals and the family interacting within it. Through this study, the author aimed to gain a better understanding of the social construct of key working within the context of multi-agency and multi-professional working, and interpret the meaning of the phenomenon of the key worker from the data generated by multiple participants of the study from their world viewpoint. This could also be described as an interpretivist standpoint. Qualitative researchers take the view that complete objectivity and neutrality are difficult to achieve and some may question if indeed they are necessary at all (Corbin and Strauss 2008).
3.8.3 Mutual Recognition between Researcher and Participant

The values, culture and experiences of both the researcher and participants (their own theoretical perspectives) will be integral to the research process. Crotty (2003) described this phenomenon as viewing the world through the lens of our culture. Only seeing the world through our own culture, however, may mean ignoring other things as viewed by those of a different culture – missing the obvious or less obvious. Unlike quantitative or empirical research, the researcher is not ‘divorced’ from the phenomenon under study. These are the assumptions that Crotty (2003) described when discussing the theory of knowledge as being ‘hidden’ within the researchers’ own theoretical perspective. These may well influence and bias the researchers’ approach and have the potential to overshadow the participants’ experiences. Along with an awareness of the influence of the researchers’ own culture, Allen and Skinner (2002) emphasised the importance of the researcher being open and sensitive to new ideas, new suggestions and new relationships that are evident in data generated by the participants. In doing so, it is hoped to facilitate receptivity on the part of the researcher to the participants’ perceptions and understandings of the phenomenon under study. Weaver and Olson (2006) referred to this as mutual recognition between researcher and research participant, which in qualitative research is fostered and valued.

3.8.4 The Researcher as a Research Tool

In this study, the researcher has a perspective of what a key worker should be and how the key working role should function, based on life experience, professional experience, knowledge, culture and beliefs. However, throughout the research journey this perception should not be allowed to overshadow those of the participants.
interviewed. As the facilitator and interviewer in the study, the researcher acts as the research tool therefore a pivotal instrument in the research process. The exploration of the participants’ viewpoint necessarily implicates the researcher’s own view of the world as well as the nature of the interaction between the researcher and the participant. In being reflexive, i.e. explicit in their influence on the research process, the researcher must recognise that their understanding of participants’ thoughts is necessarily influenced by their own way of thinking, assumptions and conceptions and in fact these are necessary in order to make sense of another person’s experience (Finlay 2002).

It is difficult for the researcher to understand fully what life means to the carers of a child with a disability. Despite many years of professional practice within the field, the researcher always has the ability to walk away at the end of each day to a life without those demands or intrusions. It is also true that the researcher has a particular professional view of the context of the study and may be unable to truly interpret or understand the professional viewpoint of a different team member or one who works for a different agency.

There are other philosophical standpoints that could have been employed when undertaking this research study for example a feminist or paternalist approach. These would have given the study a slightly different dimension but once again would not necessarily have included all perspectives of the whole team. For example, if taking a feminist perspective (Crotty 2003) on the role of the key worker the focus of the study would have changed but could have addressed the question: ‘Does the mother of a child with a disability automatically assume the role of the key worker in the team around the child?’ Thus undertaking research for women, the
mothers of disabled children could have been interviewed and asked how they view their role and what sort of activities they undertake in the management of their child beyond the normal day to day care and then this compared to the literature identifying the role of the key worker. This would have based the study within the advocacy model (Cresswell 2003) with the aim of empowering the parent and hopefully offering an outcome which may change practice. Similarly, the role of the father in the management of the child with a disability from a paternalistic perspective could have been examined (Denzin and Lincoln 2005).

Another possible approach from a feminist perspective would have been to explore the power differential for women who take a lead in the caring role. It is conceivable that the power differential may have been higher or different for them compared to a male lead. Many of the medical practitioners are male and it is possible that mothers of children with disabilities are treated differently when they attend appointments alone than when their partners are present.

However, the focus of this study was the practice of the multi-professional team around the child and although there is an awareness of the enormity of the role undertaken by parents in such situations, once again the focus was to look at the team as a functional unit.

3.9 Summary

This chapter has provided the justification for the theoretical basis and philosophical standpoint used. There are other methodologies available within the research arena but an investigation of research designs and methodologies has led to the selection of grounded
theory as the most appropriate. The following chapter will discuss in detail the method of the study.
Chapter 4.0: Method

This chapter will document the events of the research journey beginning with the research governance process. A discussion of the pilot study and its influence on changes made prior to the main study will follow. The sampling, methods of participant recruitment, data collection and analysis are stated.

4.1 Research Governance

The University of Brighton provided notification of sponsorship on 26th January 2006 (see appendix one). NHS ethics approval was given by Southampton & South West Hampshire Research Ethics Committee (A) on 28 June 2006 (see appendix two) following minor clarifications of the study proposal.

The key ethical considerations of the study were:

- Confidentiality within the focus groups
- Support for participants
- Potential for participants to raise child protection issues
- Lone worker issues for the researcher
- Data storage

Basingstoke and North Hampshire Foundation Trust Research and Development (R&D) Committee approval (NHS Approval) was given on 12 December 2006 (see appendix three).
4.2 The Pilot Study
Following receipt of research governance approvals a pilot study was carried out.

4.2.1 Aim of Pilot Study
The aim of the pilot study was:

- To receive feedback on the format and content of the information provided for the professional and parent participants (see appendices four and five).
- To enable the researcher to practice the research process.
- To assess the clarity of the focus group protocol regarding confidentiality (see appendix six).
- To test the process of interviewing and focus groups.
- To practice verbatim transcription of interview and focus group recording.
- To practice analysis skills using the constant comparative method.

4.2.2 Pilot Study Participants
Access to the participants for the pilot study was informal by personal telephone contact. Participants included five professionals from a health background and one parent participant. The participants were informed of the purpose of the research using information sheets and invited to an interview or to be involved in a focus group. Interviews and focus groups took place in a convenient location for participants, outside working hours.
4.2.3 Outcomes of the Pilot Study

The following changes were made as a result of undertaking the pilot study:

• The wording and order of the interview and focus group semi-structured question schedule was modified e.g. the introductory question was made more general to open and establish a rapport with the participant.

• The researcher learned to give participants time to respond to questions and to allow pauses in conversation.

• The researcher learned to allow each participant an opportunity to give input, in a focus group.

• The pilot study gave the opportunity to test skills of transcription and analysis of data using constant comparative method. The method of transcription was amended following these early experiences, to a more efficient process.

• The pilot study confirmed the researcher’s decision to run single agency focus groups. The issue of blame across agencies was raised by professionals. Discussion of other agency staff was open but often critical. Valuable data may have been lost if these issues were excluded.

• An extra microphone was required to enhance the quality of the digital data recorder as initial tapes were difficult to hear.

In addition to the outcomes above, participants of the pilot study were asked to give their opinions on their experience of the interviews and focus groups and feedback on the quality of information contained in the information sheets provided. There were no issues emerging from the pilot study which gave reason to seek further ethical approval.
4.3 Identification and Recruitment of Participants

Participants were selected because they had some familiarity with the phenomenon under study in as much as they shared the experiences of the situation and study context – i.e. they worked with children with disabilities or were a parent of a child with a disability.

4.3.1 Sampling Methods Used in the Main Study

The sample method selected for the study was purposive (Morse 2007). The purposive sampling criteria respected the need to expand the variability of the sample. Participants were selected because they provided access - in an interpretive sense - to the study context and subject. As the need for maximum variation in the study sample was desirable a range of professionals from each agency who had varying lengths of experience in post, were approached to participate. Parents of children of different ages and who had varying degrees of disability were invited to participate, therefore representing a variety of experiences related to the study context.

As the study progressed and data analysis took place theoretical sampling methods were then employed. These were used to build on and allow the researcher to explore the themes which were developing during analysis of the data generated from earlier interviews and focus groups (Mason 1996). For example, professionals working in the mainstream setting were under the impression that team working and the role of the key worker would be better placed within the context of the special school due to several factors some of which were more regular ad hoc contact with team members; teams co-located within the school; easier
communication channels; and regular face to face contact. This concept prompted an active move to recruit participants working in this setting to see if indeed this was the case in practice – one example of the shift to theoretical sampling. Another example of theoretical sampling was the move to seek the opinions of a range carers of social services provision. Some parents had a very negative view of social workers and the support they offered but it was unknown whether this was limited to just those families who had a severely dependent child and therefore it was important to take the strategic decision to seek the views of other parents who had children with different disabilities and needs of these services. Thus participants who had the appropriate knowledge and experience were selected due to the needs of the study to explore these new avenues. The sample was directly related to the emerging themes in the data analysis process.

4.3.2 Eligibility Criteria
Participant inclusion criteria were:
Either
1. Professionals working in a team with children with disabilities from the agencies of health, education and social services who were willing to participate.
   or
2. Parents/carers of a child with a disability who were willing to participate.

The complexity and classification of the disability of the child was deemed irrelevant in this study. All children whose disability met the definition from the Disability Discrimination Act 1995 (see chapter two) were included. This was felt to be a more inclusive approach, and provided the opportunity to generate data from parents of children with a wide range of conditions and abilities who
presented their families with a variety of challenges in day-to-day life.

Participant exclusion criteria were:
Either
1. Professionals who did not work with children with disabilities.
or
2. Parents of non-disabled children or those who were not willing to participate.

4.3.3 Access and Recruitment of Professional Participants
A lead person in each of the organisations in the study area that provided services for disabled children was approached for help with accessing potential participants; this person acted as a gatekeeper (Oliver 2008). [See appendices seven, eight and nine].

The gatekeepers for Social Services were the team leaders for Children with Disabilities Teams. Initial contact for Education staff was made to the Special Educational Needs Office of the Local Education Authority who gave a favourable response but advised that individual contact should be made with the Head Teachers of the schools included in the study. Schools known to have children with disabilities on their role were then purposively selected from the list of schools within the Health Trust area to be approached. The gatekeeper for the health team was the Disability Services Manager, a senior manager in the Child Health Directorate.

The gatekeepers in each area were sent a pack of information sheets, reply slips (see appendix ten) and return envelopes to pass on to all of the staff in their teams. The reply slips asked for the most convenient contact details for the participants e.g. telephone
numbers and/or email addresses and a convenient time when contact could be made. Individuals who were willing to participate in the study then returned the reply slip to the researcher. The researcher followed up these replies and made contact to arrange a convenient time and venue to hold a focus group or interview (see appendix eleven). Final signed formal consent was taken prior to the start of the focus groups and interviews.

4.3.4 Access and Recruitment of Parent Participants
Parent participants for the study were purposively selected from the paediatric therapy caseloads of the local Health Trust by individual therapists at the request of the researcher and recruited by letter (see appendix twelve), which included an information sheet, reply slip and return envelope. Once parent participants had expressed initial interest to participate in the study by returning their reply slip the researcher made contact by telephone to discuss the study and arrangements were made to undertake the interview. Final signed formal consent was taken prior to the interview.

4.4 Methods of Data Generation

The methods used in the study to generate data were focus groups and individual interviews.

4.4.1 Focus Groups
Professional participants where possible, participated in a focus group. There were some professionals, however, who were unable to make the appointed time of the focus groups who asked to be interviewed separately and an alternative appointment was made.
The Arrangements: Focus groups took place in a venue chosen by and convenient for each of the professional groups and the researcher travelled to them, e.g. a community room in a school, a day room in a social services day centre. Seating was arranged in a circle so that all participants, including the facilitator, could be seen by each other. Where possible a low table was included in the centre of the group where refreshments could be placed and the microphone was centred. If there was no table available the microphone was centred on the floor in the middle of the group.

The Process: The researcher acted as the facilitator and no other observers were present. All participants were requested to give written consent to confirm their agreement to take part in the study at the beginning of the focus group (see appendix thirteen). The focus group protocol including statements about confidentiality, respecting everyone’s views, allowing all individuals time to voice their opinion etc. was read out before discussion took place. Introductions were made and recorded so that the researcher was able to identify the participant speaking on the tape afterwards. Data were recorded using a digital recorder.

A semi-structured question schedule (see appendix fourteen) based on the evidence on key working in the literature and the aims of the study was available for use. This was not used exclusively as the group generated discussion through their own interaction and that discussion was not limited to the topics identified by the researcher. Questions and prompts were used in the group by the facilitator to bring the focus back to the phenomenon under study when necessary. These included clarification of points made, and requests to other group members for their views or ideas on the subject. Requests for input from other
group members were also made if one individual was dominating the group.

4.4.2 Individual Interviews
Parents were given the option of attending a parent focus group or having an individual semi-structured interview but all parents opted for a one to one interview. Six of the interviews took place in the parent’s home and two in a health setting as chosen by the parents. All the parents who responded were mothers and all were interviewed alone. The parent participants were requested to give written consent to confirm their agreement to take part in the study at the beginning of the interview (see appendix thirteen).

Parent interview questions explored their experiences of having a child with a disability and working with the team around the child as well as focussing on their perceptions of the key worker role. A semi-structured question schedule was available for the interview sessions but other issues and topics were also explored during the interviews (see appendix fifteen). All interviews were recorded using a digital recorder.

4.5 Data Management and Analysis

For ethical reasons the recordings of the interviews and focus groups were transferred to computer and stored in password protected files. These files will be destroyed following completion of the study in accordance with University and Trust policy.
4.5.1 Transcription
The content of each of the focus groups and interviews was transcribed by the researcher, verbatim (an example is given in appendix nineteen). Each transcription was given an identification number so that personally identifiable information of the participants was anonymised to all but the researcher. The printed transcripts were formatted to allow wide margins for notations and coding during analysis (see appendix twenty).

4.5.2 Analysis
Data analysis began as soon as data collection was completed for each focus group and individual interview. As described in chapter three section 3.6.3 the personal preference of the researcher was to begin with systematic line by line analysis of each transcript (see appendix twenty one). Each identified issue was assigned an initial code – a word or short phrase to identify what it represented to the researcher (Charmaz 2006). Initial codes were then grouped into sub-categories (see appendix twenty one). The sub-categories were then grouped into categories (see chapter six). Analysis of each transcript was compared to the others generated (constant comparative method) thus moving through the previously described staged process of analysis firstly deconstructing and then reconstructing the data to demonstrate the findings and interpretation of those findings, of the researcher. Each transcript analysed was used in an ongoing process to inform subsequent interviews and focus group topics. The development of interview topics during data collection in the interviews and focus groups is presented in appendix sixteen. Once there were no new categories emerging from the data gathered the researcher was able to work with the data categories to develop and conceptualise an understanding of the relationships within the data and build a
model of practice around the aims of the study - team working and the key working role (see chapter six). The interpretation and further conceptual development of the data revolved around the model of practice and the personal interpretation of the researcher was that there were influences acting on the model and the players within this model. These were interpreted as occurring at three levels and were inextricably linked but ever present within this context. They are described in more detail in chapter six (6.3).

4.6 Rigour

The issues of rigour and validity in relation to qualitative research have been discussed previously and the lack of consensus of opinion on how best to establish this noted. Appropriate sampling was used to recruit participants who had relevance to the context of the study. In analysis each code, sub-category and category can be traced back to the original data to ensure that the researcher’s interpretations and conclusions are firmly grounded in the data (Koch 2006). In addition, in the early stages of the study a summary of the initial themes from their group or individual transcript, was returned to the participants of the first focus group and first two interviews. The aim of this action was to seek verification that what was presented was a true reflection and representation of the discussions which took place during the sessions and to present the researcher’s interpretation of this. Participants were asked to comment if they felt the issues did not reflect their recollection of the discussion but no replies were received.

The researcher’s own reflexivity (see chapter eight) is presented to identify emic influences on the research process as a whole and a
resonance to the researcher’s own experience and clinical background.

4.7 Validity or Truthfulness

Each line of each coded transcript was numbered and all verbatim quotes can be tracked to the original participant. By presenting codes, sub-categories and categories the researcher has demonstrated the decision process and how categories have emerged and where concepts have developed. An audit trail has been used to establish the truthfulness of the data and researcher’s interpretation of the outcomes of the study.

4.8 Field Notes

Field notes were recorded in a notebook kept by the researcher immediately following each interview and focus group. These documented such issues as how the researcher felt the interview had gone; noted any issues that were raised which surprised the researcher (for example the strength of negative feeling against fellow professionals in the team around the child); and commented on the group dynamics. These were a valuable source of information to establish the importance of issues discussed across the teams and by individuals and helped give insight into the dynamics of team working. The field notes also provided additional material for personal reflection of the research journey.
4.9 Reflective Diary

In addition, the researcher kept a diary throughout the doctoral programme in which personal comments, notes, anecdotes and reflections about private experiences during the research process were documented. These notes were about much broader experiences than the field notes which focused on the interaction between research participants and were often written after a period of reflection allowing the researcher more time to think about and synthesise issues.

Both the field notes and reflective diary have provided useful material with which to compose the final chapter of this thesis.

4.10 Summary

A summary of the research process and methods used to address the aims of the study were presented here and used as a basis for the following findings.
Chapter 5.0: Findings

This chapter will begin by identifying and describing the characteristics of the study participants (see Table Five) and then go on to present the findings of the data. A detailed account of the professional background of participants can be found in appendices seventeen and eighteen. The author will present examples of quotes from the transcripts to support the process by which emergent categories were developed from initial codes and sub-categories. This process is represented diagrammatically in figures 4, 5, 6 and 7 throughout the chapter.

[An example of an interview transcript is given in appendix nineteen. Examples of initial coding and category development are given in appendices twenty and twenty one. The code of each transcript and line number is given after each quote e.g. Interview 1:119, and in the case of focus groups the respondent is represented by the letter ‘R’ and a number which corresponds to the code given to that participant by the researcher e.g. Focus Group 1 R1: 119.]

5.1 Characteristics of Study Participants

5.1.1 Parent Participants
A purposive sample of fourteen parents of children with disabilities on the caseloads of the paediatric therapists from the local Health Trust, were approached by letter to participate in the study. Eight agreed to be interviewed, a 57 % response rate. All the parent participants were mothers. The children of these parent participants had a wide variety of needs related to their impairments. Some were mobilising with assistance and others were fully dependent in all aspects of care and mobility.
Background of the Study Participants

The following table (Table Five) presents the numbers of participants involved in the study and their background.

<table>
<thead>
<tr>
<th>Background</th>
<th>Number in Sample</th>
<th>% of Total Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent</td>
<td>8</td>
<td>14%</td>
</tr>
<tr>
<td>Health Staff</td>
<td>12</td>
<td>22%</td>
</tr>
<tr>
<td>Children’s Services Staff (Social Care)</td>
<td>11</td>
<td>20%</td>
</tr>
<tr>
<td>Children’s Services Staff (Education)</td>
<td>24</td>
<td>44%</td>
</tr>
<tr>
<td>Total (=n)</td>
<td>55</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table Five: Background of Participants in Study [Original in Colour]
The children and young people ranged in age from four to eighteen years. Five of the parents lived in village locations whilst three lived in small towns. Six of the eight parents had children other than the child with a disability. All parents were living in the family home with a partner.

5.1.2 Health Staff Participants
A purposive sample of nineteen health staff working with children with disabilities, were invited to take part from the local Health Trust. Of these twelve agreed to participate in the study, a 63% response rate. Eight were Physiotherapists, one an Occupational Therapist, one a Hospital Play Specialist, one a Children’s Community Nurse and one a Doctor – an associate specialist in community paediatrics. Two focus groups of health staff and four individual interviews took place in healthcare settings. All the health care professionals worked in the local community covering urban (small towns), semi-rural and rural settings. Their caseloads included children who had involvement of a team across the statutory agencies. All health care professionals were of a senior grade and had been working in the field of paediatrics for some years. The characteristics of this study sample may reflect the lack of newly qualified professionals generally in this area of practice which may be more suited to those with experience. It may have been interesting to explore the opinions of newly qualified staff of team working and the role of the key worker in addition to those in this study that were well established in both the field and their own practice habits, but this was beyond the scope of this study which also hopefully reflects the reality of the teams in practice. It is worthy of note however, that the seniority of the staff and their longevity of service may well have affected their perceptions of the team around the child and the role of the key worker.
5.1.3 Children’s Services – Education Staff Participants

Five groups of education staff and two teacher advisors were approached and asked to participate in the study. All the groups agreed to participate. These included a team of teaching staff from a mainstream infant school (5 participants), a team from a children’s centre (5 participants), two Portage Home Visiting teams (11 participants), and teaching staff from a special school (2 participants). One teacher advisor also agreed to participate, however one further teacher advisor was invited to participate but declined. The staff teams were included in focus groups held in education buildings and the teacher advisor was interviewed on a one to one basis in a healthcare setting. Although most of the education staff had been qualified for some years there were at least two who had been qualified for less than five years.

5.1.4 Children’s Services - Social Services Staff Participants

Two local ‘children with disabilities’ teams were approached to participate in the study through their team managers. Although initially both team managers gave permission for their teams to be invited to participate one team manager subsequently took long term sick leave and the contact was lost. Therefore, only one team took part and all agreed to participate. This team included eight social workers and one Portage home worker who held a jointly funded post. All the participants from Children’s Services had been qualified for several years.

In addition, two occupational therapists working in Children’s Services were asked to participate and having agreed were also interviewed. The occupational therapists (both experienced practitioners) worked in the community visiting the child and family at home. They advised on equipment provision and adaptations to
buildings to address accessibility issues and accommodate the specific daily living needs of the children and their families. They had large caseloads and covered a wide geographical area crossing service boundaries of their colleagues in the health sector. All the social services participants were interviewed in Children’s Services buildings.

5.2 Emergent Subcategories and Categories

In total eight focus groups and fifteen interviews took place during the data generation period of the study. Following the analysis and initial coding of the first two or three focus groups and interviews emergent categories began to form. As data generation and analysis progressed the emergent categories were used to inform topics for subsequent focus groups and interviews as an on going process (see Development of Interview Topics during Data Collection appendix sixteen).

Once all the data analysis was complete the categories were grouped as follows by the researcher (see figures 4-7):

- Human Factors (Figure 4)
- Service Organisation and Delivery (Figure 5)
- Working Together (Figure 6)
- Communication (Figure 7)

Each of these categories will be addressed and presented in turn using evidence from the participants to support their construction from identified sub-categories, development and interpretation.
5.3 Category One: Human Factors

The impact of human factors was a major and significant category. It provides the backdrop on which services have to operate and function. The sub-categories listed below were developed from the coding identified during data analysis and demonstrated the complexity of this area of clinical practice. This was due on one hand to the individual presentation of the disabled child including the context of that child within their family, community and society; and on the other to the individuality of the professionals and uniqueness of the agencies working with that child and family.

5.3.1 Complexities of Family Life with a Disabled Child

5.3.1.1 Emotional Impact on Parents
Having a child is an emotional time for any new parent. The hope and expectations of a healthy baby are paramount. Having a child diagnosed with a disability can therefore have a major effect on the individuals within the family unit, when those expectations are shattered as many of the parent participants in the study demonstrated.

“... If you’re suddenly told... diagnosed... that your child has whatever condition, you’re in shock and you haven’t always got the inner strength to go looking for these things [information on condition] because something inside of you is denying that... they’ve got it wrong!” Interview 8: 400 [Parent]

“... It sent me into shock really... that was really difficult, although I suspected that there might be something wrong...you just always hope that, that isn’t going to happen...” Interview 13: 9 [Parent]
The parents described their journey since their child was born as an ongoing emotional rollercoaster. Despite often feeling that they had adjusted to a life which they had not expected, small things had the ability to trigger doubts that they were able to continue and cope. These emotions ranged in extremes from becoming sad and tearful across the whole spectrum of feelings to those of a suicidal nature.

“...it’s like a continual bereavement you know, you feel you’re over one hurdle and then something else comes along and hits you and you almost go through another bereavement period…” Interview 10: 157 [Parent]

“...I remember thinking I could just...I could just die now. I just wanted to die.” Interview 10: 368 [Parent]

5.3.1.2 Strain on Parents
Parents identified the strain on them of having a child with a disability.

“...sometimes it’s very tiring I think and then obviously it puts...it’s just the mental strain I think it’s really tiring there’s nothing worse than being tired and everything else seems worse doesn’t it?” Interview 13: 315 [Parent]

“...It was time, in some ways I would guess it [reference to time taken to contact professional team about child] was my saving grace that...it was what kept me propelled; also I do think that, that was, you know, that I had this mission em you know rather than just cracking up [laughter] …” Interview 11: 310 [Parent]

5.3.1.3 Impact on Family Life
For one parent the impact on family-life was not fully apparent until after the child died and the realisation of the true intrusion into family life became clear.
“I’d got really a good relationship with a lot of really… and I really missed that, because all of a sudden my life was...so busy and then nothing em you know it’s a big full stop… You have to totally rebuild your life after that and em we as a family struggled with that for a while, you know it is because you’ve been so geared to engineering life, all of a sudden it’s em you have to build up all these relationships again... between myself and my husband… Yeah and become a family again but em totally different family em it em, it was very difficult and em you know, lots of people that we’ve seen say you know, that most marriages don’t survive a child who either dies or suffered a long illness. And you know that could easily have been us at lots of different points…” Interview 11: 173 [Parent]

The health professionals admitted that it was difficult for them to comprehend the impact and individual experiences of having a child with a disability, on the parents and the family as a whole.

“I think it’s very difficult for any professional to truly understand their [the parents] world em looking after a child with a disability 24:7. I think it’s very, very difficult unless you are a mother and have a child with a disability. I can’t see how you could truly know… you’ve just got to do your best. Sometimes there are advantages in not being too involved; sometimes you can operate better looking as a …something at a distance.” Interview 5: 299 [Children’s Services Professional: Occupational Therapist]

The lack of understanding of their situation by professionals was also recognised by parents.

“The time you get with professionals, they can’t see what’s really going on, you know? You turn up to an appointment and you’re there for a reason and they’re there to see , you know, they’re only there, they’ve got a whole day booked in with different children and all they’re seeing is the notes for that child. They’ve got no idea of what it’s taken even to get to that appointment and what juggling you have to do with other
children and work even just to get... you know... to be there.” Interview 14: 688 [Parent]

5.3.1.4 Impact on Parental Relationships
Having a disabled child also impacted on parental relationships and the time available for parents to spend together, as a couple.

“[Husband’s] dad babysat on Saturday night for the first time in seven months so we managed to go out. We go out twice a year on our own – that would be nice if we could you know, even if it was here, a babysitting service or something, someone that we trust who isn’t scared of the condition - it’s more the epilepsy side I think but, but yeah that would be nice because it does put a strain on our relationship because whatever we do we’re always ... we’re never just together...” Interview 14: 633 [Parent]

“You can understand how families split up and you know, (husband) and I have had huge, you know a huge amount to deal with as well as many families have and you know his mum’s desperately ill and we’ve had that going on for the last four years and you know it puts a huge strain on our marriage.” Interview 10: 371 [Parent]

5.3.2 Child and Family Needs

5.3.2.1 Uniqueness of Need
The parent participants discussed the individual needs of their children revealing the uniqueness of each child and the impact on the family situation.

“... Routine is crucial, crucial to him to keep him on a level of maintaining his em, fits, and as a routine for him, he’s got used to... but he definitely needs to start his drugs routine at 8 o’clock. He has a big volume of drugs to get through and it can take half an hour to do it because you can not do all the drugs in one go.” Interview 8: 353 [Parent]
“She has very poor muscle tone so I will on a day to day basis I will always have to make sure I will hold her hand when we’re walking anywhere as she is quite unsteady and she can topple, em she will, she’s not yet out of nappies so I still have to use nappies with her em. She’s quite heavy she weighs nearly five stone now so she’s... I’m lifting her in and out of the car…” Interview 10: 6 [Parent]

“I have to lift him onto the bed. Em you have to help him get dressed which we are slowly...he, he can get his pyjamas off now, he can get his tee shirt on, his pants on but then getting him onto the toilet, helping him – giving him his toothbrush em and then getting him off the toilet, pulling his trousers up, getting his shoes and socks on…” Interview 12: 7 [Parent]

Although the professionals working with families which included a child with a disability recognised the need to be aware of the impact of that child on the whole family unit, they were concerned that the child’s specific individual needs may get lost within the wider family issues. The need to respect the family priorities sometimes presented as a dilemma between the members of the team.

“It all depends what the family see as paramount need I think it’s all – well you could say everybody needs equal, like the little boy we keep going back to, I don’t think they [social services] see him as any more needy than anybody else in the family do they? But, the fact is that he is completely dependant on them for changing, for moving, for eating or anything, for everything and although he can speak and advocate for himself actually if they switch his wheels off or if they don’t charge his power chair up he can’t go anywhere....” Focus Group 3 R6: 153 [Health Professional: Physiotherapist]

When discussing the role of the key worker, the social workers described each member of the team as having ‘key worker’ responsibilities which would enable them to address the different
identified needs of the child i.e. different professionals offered different skills.

“... if it’s specifically about behaviour and it’s a behaviour plan that the child is working out, working through, then maybe that’s school, because school are working on that every day...” Focus Group 2 R7: 606 [Children’s Services Professional: Social Worker]

“...if it were health, predominantly health issues it might very well be led more by the health professional...” Focus Group 2 R6: 625 [Children’s Services Professional: Portage Worker]

The specificity of need for the child and issue within a family clearly influenced which professional was the most appropriate to contact for support possibly negating the need for a specific key worker role.

5.3.2.2 Immediacy of Support
Parents expressed the need for immediacy of support from the professional team particularly after being given a diagnosis or attending a medical appointment, so that terminology and implications could be explained to them.

“Those people [medical staff] are really difficult to track down. They’re very rarely office based you know, they’d be in surgeries or they’re doing their clinics or so in an ideal world I would really like to have somebody there to be able to, to speak to, for example when [the endocrinologist] told us about [child’s] Prader-Willi I think we had to wait... it was at least a month until we were able to speak to somebody and I just felt that was crazy and I would have liked to have made an appointment to see somebody the following day.” Interview 10: 565 [Parent]

“The diagnosis was at 10½ months. I think there must have been a lapse of at least six weeks before we actually got to see the first professional
and in that time we were like… just kind of left in the dark really with all the Scope information.” Interview 14: 521 [Parent]

5.3.2.3 Availability of Support
Parents also often expressed the need for support at all different hours of the day or night and felt that professional contact was often limited to ‘office hours’, leaving them to cope on their own without answers to their questions or support for their needs.

“Well there are going to be those moments, completely out-of-the-blue moments em where you just, something completely knocks you off your feet. And I know in the run up to (child) having her tonsillectomy and adenoidectomy I’d convinced myself she was going to die. And it would have been lovely to have been able to talk to somebody about that and say ‘God I’m feeling so morbid about it’. I’d like arranged her funeral and you know, she’s not going to come through there’s going to be some sort of complication because there always has been.” Interview 10: 407 [Parent]

5.3.2.4 Type of Need
Both social and medical needs of the child and family were identified by parent participants.

“This last year she has been very poorly and she’s had a tough time you know. You, you do come through it and you’ll probably look back in a few years and you’ll think well it wasn’t that bad but at the time it doesn’t seem that, you know? And when you’re tired mentally I think as well… em… I think that would be quite nice to have some, some respite care for her may be once a month, one day a month that somebody could have her, take her out to do things with her and just give us a complete break because I think that would just be nice for somebody to be there, just if you’ve got a problem or you need some help that there’s somebody to turn to I think. I don’t really feel there’s many people to turn to…” Interview 13: 423 [Parent]
“I think if you had that support all the way through from diagnosis it’s completely that, it is a support, it’s got to be someone that you might cry to, that you might em, even things like can you find out for me if you know, what’s going to happen at school this year, anything, somebody that you can just turn to and say look I need to know the answer to this and I just haven’t got the energy to go searching the internet or ringing x amount of people to try to find the answer could you do you think you could find out for me stuff like that, so I think yeah it would be a real valuable family friend as well…” Interview 14: 455 [Parent]

“I find probably the hardest thing which I’m hoping will be easier as she (sister) gets older is if we go out anywhere I need two of us. I can’t seem to do it on my own because I can’t look after her (sister) and help (disabled child).” Interview 12: 49 [Parent]

Similarly, when considering family support, professional participants also identified that there may be a need for a dual approach to the support role – potentially fulfilled by the key worker - one, which addressed the medical needs of the child and family (possibly a more professional role) and one which addressed more social need. Thus identifying that there may be a need for two separate individuals to undertake a key worker type of role.

“I mean does that need to be a professional role? Or do we need to be thinking wider than that, about self support? Not that we’re opting out of it but actually because it’s more appropriate would you be better off sharing that sort of thing, with someone who actually understood where you’re coming from? Because one of the hardest things when parents say to me is with the best will in the world I’m not in that position so what’s the balance between a ‘professional key worker’ who can help you with your appointments being in the same place at the same time and help you with understanding that Orthotics is, does this and the clinical psychologists do that and, someone to ‘off load’ on. I think there can be
Participants noted the need for clear boundaries around the role of the key worker particularly if there were to be two distinct elements to the role – social and medical.

“...if you’re going to have a professional key worker it seems to me inevitable you’ll have to put boundaries round it (Yes) and you see and that’s where, that’s where I think you either need both or perhaps some people need a professional and some people need the social key worker…” Interview 6: 340 [Health Professional: Medical Consultant]

5.3.2.5 Sibling Support
The need for support for the siblings of disabled children was expressed by all those parents who were interviewed who had more than one child, as well as some of the professionals involved in the team.

“I have been so keen to avoid (sister) looking back on her childhood and feeling that she was ever (disabled child’s) carer.” Interview 10: 460 [Parent]

“But the silly things that make all the difference. When we used to go to the other hospital they wouldn’t let me leave (disabled child) overnight, they wanted me to stay and I’ve got another child at home and it’s not very fair for him long term if I’m constantly not coming home, not coming home… and he doesn’t know where I am and what’s going on.” Interview 9: 388 [Parent]

“The other thing I would reinstate is more access for the other children in the families too. That used to work really well. At the moment I don’t think there’s enough support for other children. I know there’s the young carers groups, but you actually need something more.” Interview 5: 598 [Children’s Services Professional: Occupational Therapist]
5.3.2.6 Key Worker Support Role
Participants generally felt there was a need for a key worker role which would offer support to the child and family and could recognise its potential value in improving the wellbeing of the care givers. The key worker could assist in co-ordination of professional visits, organisation of appointments, attending case reviews and advocating for the child and family thus relieving some of the workload and worry from the parent.

“…taking some of the pressure off you know, primary carers, mum, dad, carers whoever, to try to co-ordinate that, there’s so many different people often going in and out of peoples’ doors and lives…” Focus Group 2 R3: 18 [Children’s Services Professional: Social Worker]

“…it would be less, less em assessments, less meetings; most things could be done collectively….cut down on the family’s time and stress levels…” Focus Group 2 R7: 675 [Children’s Services Professional: Social Worker]

5.3.3 The Influence of Personalities

5.3.3.1 Influence of Individual
It was felt that sometimes the individual professional working with the child and family could influence the parents’ acceptance of their situation and how the parents utilise their own coping strategies in times of need. There was a belief that the more capable families would contact the person they felt most comfortable with and that they could approach and already had a rapport with – no matter what the crisis they were facing.

“I think it was, in a way, it will come down to the same issues we have now that, where you have proactive parents who will, you know, look things up and will look for information and will read everything that you give them or whatever, they’d be great and you know, what are you
going to do about it… and use them [the key worker] really effectively whereas families who possibly are more in need of these things will just see them as some thing else …” Focus Group 3 R7: 663 [Health Professional: Physiotherapist]

The impact of individual personalities and the dominance of some on the dynamics of team working were referred to as tensions and on occasion difficult to tolerate by other team members.

“… it’s also about personalities and I think that does impact on it and that in turn is . . . would you say? It’s quite difficult to describe isn’t it? And it’s about, it sounds personal it’s not about that, I feel sure socially this person [referring to a Portage Home Visitor] would be absolutely great, but actually working with her is really very difficult because of the way she works” Focus Group 3 R6: 291 [Health Professional: Physiotherapist]

“…people still work in sometimes quite individual ways em; the risk of having a single team that is together all the time is that you get, of course you learn what peoples boundaries are and that sort of thing, but you also may be, if you have someone who works in a more individual sort of way you can run the risk of feeling that’s how that professional group works…” Interview 6: 192 [Health Professional: Medical Consultant]

The impact of individual personalities who could potentially undertake the role of the key worker was felt to be an influencing factor on the efficacy and nature of the role.

“… You have to be a very open minded sort of person. You’ve got to have the personality for it, very open minded, very objective . . . .” Focus Group 3 R8:503 [Health Professional: Hospital Play Specialist]

5.3.3.2 Influence of Previous Experience
The influence of the parents’ previous experiences with certain individual professionals was felt to have an ongoing impact on
coping abilities, needs and future relationships. Depending on the nature of the relationship the parents had with a particular professional they sometimes felt inhibited in their interaction.

“There’s always people that are better than others, it’s just I think, I think I’d find that if you’ve got a good personality people are much easier to approach than if you’ve got professionals that are very short or sharp or what ever … you think… I don’t really feel I can say what I feel and I think that’s quite important when you’ve got a child with a disability you need to be able to say what you feel. The previous consultant paediatrician was very good with that. You could say what you felt, he was very honest with you… for me I’d rather hear the truth because I think that’s much easier.” Interview 13: 394 [Parent]

This category (which is summarised in figure 4) has demonstrated how the nature of human factors i.e. individual personalities, coping abilities, knowledge and experience in addition to the complexity of family dynamics, relationships and practicalities of day to day living has the potential to influence the effectiveness of team working and the role of the key worker for the child with a disability. Participants provided data which suggested issues around current service provision which may not provide enough flexibility and individuality to meet the needs of the child and family. Human Factors has provided the context in which service organisation and delivery have to operate and these follow in category two.
Figure 4: Analytic Development: Category One Human Factors
5.4 Category Two: Service Organisation and Delivery

This was a major and seemingly significant category emerging form many interviews and focus groups which demonstrated how service delivery had the potential to impact on the team around the child. Category One – Human factors has provided the reader with a representation of the context in which service organisation and delivery has to operate. Participants provided data which suggested issues around current service provision which may not provide enough flexibility and individuality to meet the needs of the child and family and evidence for how the category was constructed will be presented in the subcategories and identified codes that follow.

5.4.1 Time & Caseload Constraints

5.4.1.1 Lack of Time

Lack of time was a factor that was referred to repeatedly as affecting individuals from all agency backgrounds during the study and was a cause of frustration for all – particularly when considering the nature of the role of the key worker.

“I think time is a real, real problem for them [parents] and us, because none of us have got the time” Interview 5: 167 [Children’s Services Professional: Occupational Therapist]

“As you can imagine with all those things going on there’s little time for a lot else - not just about going to all those places, its about you know sometimes I have to pick up the phone and change things or a ball has been dropped somewhere, it happens with so much going on it’s all sort of down to me really so I know I do spend an extraordinary amount of time in the whole caring, management of this and that’s not to mention the emergencies that pop up… which they do and it depends whether
it’s a mechanical emergency or whether she’s ill. So we deal with all that as well.” Interview 9: 122 [Parent]

“Well it should be quite a big responsibility [the key worker role] but the reality of it is one doesn’t have the time to actually do it properly” Interview 5: 193 [Children’s Services Professional: Occupational Therapist]

“…it needs dedicated time whether you’re a professional one… it needs even more dedicated time as it slides into the kind of social arena.” Interview 6: 370 [Health Professional: Medical Consultant]

Designated time to undertake the role of the key worker was identified as many professionals were unsure if they could commit to the role under current time pressures.

5.4.1.2 Size of Caseloads
Closely associated with the perceived lack of time was the pressure placed on clinicians due to the impact of the size of their caseloads and waiting lists.

“… The pressure of waiting lists, the pressure of having to get in and out, the pressure of seeing other people and there’s only so many hours in a day you know?” Interview 5: 169 [Children’s Services Professional: Occupational Therapist]

“I think time is the sort of biggest issue because there generally are quite possibly more children than there are spaces for people to get out.” Focus Group 8 R6: 76 [Children’s Services Professional: Mainstream School Teacher]

Staff described the emotional effect of having too many children and families with needs on their caseloads and not enough resources to meet demand.
“…no matter how, how much you might really, really feel for the family and really, really want to help them, you can not be all things to all people and we all have … we all have lots of families who have all sorts of need and actually even if you were a 24:7 person who could – who didn’t need a time boundary who just took calls at 3 o’clock in the morning from parents, you know there’s too many children to physically allow that to happen isn’t there?” Interview 6: 356 [Health Professional: Medical Consultant]

5.4.2 Access to Resource

5.4.2.1 Lack of Pooled Budgets
The lack of pooled budgets and lack of clarity over which agency pays for which service, provision or resource, as well as restricted and limited budgets, was frustrating for both parents and professionals.

“Probably the biggest one that seems to come up as a parent is around funding and where funding comes from. So although people are often very helpful about ‘oh yes well this, this might be good’ you know, it does come across as well may be health would fund that or education would fund that, and there are some areas where the boundaries don’t seem very clear …” Interview 1: 82 [Parent]

The lack of finance and resource led some professional participants to refer to feelings of inadequacy about the current service provision they could offer for these children and their families.

“I mean often I just feel totally inadequate the whole time by what we offer” Interview 5: 802 [Children’s Services Professional: Occupational Therapist]
“... There’s no way we can manage it you know? We just do the best we can... Can’t do it” Interview 5: 452 [Children’s Services Professional: Occupational Therapist]

Some parent participants demonstrated a resigned acceptance of the delays within the system due to financial and resource issues and the extended periods of time it took to receive services or resources from the different agencies.

“We’ve had all that in, but you know how long it all takes... a bit of time to sort out... they’re really busy aren’t they? ... Sometimes things take a long time but then you just have to learn to be patient because you’re not going to get it tomorrow. So you have to accept that…” Interview 13: 62 [Parent]

5.4.2.2 Influence of Access Criteria
In some agencies the restrictive criteria of access to services such as social work support and the complexity of the process to acquire resources for the child often led to professional frustration.

“...Frustrated because I actually went up [to social work team] and tried to refer them [family who have two boys with muscular dystrophy], and they said ‘No’ because they haven’t got a learning disability...” Interview 5: 408 [Children’s Services Professional: Occupational Therapist]

5.4.3 Influences on Services

5.4.3.1 External Influences
The influence of the negative public image of social services and social workers was commented on by participants with reference to families being reluctant to accept the need for their involvement.
“It’s just every time you see it on television, in the news it has a negative em . . . It’s child abuse or it’s they don’t see social services as helpful . . .”
Focus Group 3 R8: 582 [Children’s Services Professional: Mainstream School Teacher]

“No, I wouldn’t, I wouldn’t want it [a social worker] I think it’s that thing, I don’t know why maybe it’s that somebody that’s suddenly going to might not think you’re worthy, that you’re good enough and has that power of being able to take your kids away from you, you know, em always have that feeling that there’s an ulterior motive they’re not just there for you.” Interview 12: 215 [Parent]

Some parents found they had to have a social worker purely to access certain services for their child although they were very reluctant to do so.

“I had to have a social worker which I was very reluctant and unwilling to do but I had to have one in order to get respite services and I very much resented having to have a social worker and I also very much resented the social worker visits that I had to have because they added nothing and they were just an additional problem really but it was the only way she [the child] could have respite with having to go through, through the social worker.” Interview 11: 51 [Parent]

5.4.3.2 Legislative Constraints
The service organisation and delivery experienced by the social work participants was strongly influenced by legislative constraints on their role as well as the strong accountability they have to their employing organisation. They felt that their service was very much target driven and if those targets were not met income was affected.

“…accountable… certainly to the organisation they work for but also toward their client because that is who they are doing their job for but
however, you do have to think about em, your organisation which is bound by law, legislation, policies and procedures…” Focus Group 2 R1: 139 [Children’s Services Professional: Social Worker]

“… the key worker [in Social Services] is under a lot of pressure at that point to reach that target – of achieving 35 working days for their assessment because the county is judged on that performance and ultimately money is allocated … if we achieve performance targets…” Focus Group 2 R2: 112 [Children’s Services Professional: Social Worker]

Although all statutory agencies are bound by law, policies and procedures professional staff from other agencies did not comment on the impact of these or targets on their day to day practice. The social work team were very much focused on their statutory duties.

“When you’ve got child protection work going on and you’re involved in all the statutory duties around that and you’re perhaps in and out of court – the nature of that work takes precedent…” Focus Group 2 R5: 169 [Children’s Services Professional: Social Worker]

5.4.3.3 Public Accountability
Public accountability and media scrutiny presented another level of influence for the professionals and in the views of some, improved the ability of teams to work together.

“… we’ve had a couple of high profile cases in the past with child protection and things where they have…all the agencies really have been under scrutiny and probably that may make them work better together…” Interview 2: 313 [Health Professional: Physiotherapist]

5.4.3.4 Service Re-organisation
Participants described the influence of externally led service reorganisation and the bureaucracy of on-going change imposed
upon their employing agency, as impacting on the nature of their roles on a day to day basis.

“...change took place between children’s and adult services and it was decided for me to move into a generic adult team and so my role has to some extent changed in that I haven’t had the information to keep abreast of the developments in the child... children’s services but my caseload is only children with disabilities. But, it’s all about to be changed again” Interview 4: 16 [Children’s Services Professional: Occupational Therapist]

Parents found that the trust and relationship they had built up with professionals would be lost when changes due to service restructuring and re-organisation occurred and there was a lack of continuity of care for their child. It was also difficult when staff changed on a regular basis due to factors such as maternity leave, moving jobs or being moved by their organisation. Parents also had to cope with the changes in staff at each transition stage of the child’s life – for example when a child moved from pre-school into school the health visitors were no longer involved, or when a child transitioned from paediatric to adult services.

“... there is a transition period between the... between the cut off for a health visitor and then that person that nurtures you through until the next person then takes up when it gets to school age and the... you know there’s just... it doesn’t seem to have any... it’s all very airy fairy...”

Interview 10: 595 [Parent]

“I feel now that I’m out on a bit of a limb because (son) is obviously coming into adult care and that does frighten me because I know that the support of adult care won’t be as great as paediatrics that is one of my big concerns at the moment.” Interview 8: 17 [Parent]
5.4.4 Influence of Location

5.4.4.1 Geographical Borders
The impact of geographical borders appeared to present difficulties for successful team working with children with disabilities. Services from different areas had different criteria for service and resource provision which caused problems for some team members who had to justify to families why they may not receive provision when another child with a similar condition but from a different area qualified to receive the said provision.

“The one thing that can be quite difficult is where you’re working across borders – the school that (another physiotherapist) and I work in, we work with about – I can’t remember how many it is now probably about 4 or 5 different wheelchair services all of whom work differently so you’re having to say to children in the same class and their parents, well you can have that and actually if you live in (local town) you can have – you’ve got an appointment and it will only take this long and if you live in, come under (nearby city) then actually you’re going to have to wait another six months before you even get seen and quite rightly people don’t understand that. They don’t see why that child should be different to that child.” Focus Group 3 R7: 242 [Health Professional: Physiotherapist]

Parents also expressed frustration with regard to the lack of flexibility of service provision because of geographical border issues. One parent who lived on the border of two counties was restricted in her choice of preschool group for her disabled daughter.

“…From a parent point of view you know, the fact that we live here we’ve got a choice of we can either go an hour and a half this way where they still fall into the services or we can go twenty minutes or fifteen minutes this way where all of a sudden actually no we can’t help you but there’s nothing in our local area that meets the need.” Interview 1: 248 [Parent]
Another parent had to change the team working with her child because of a cross border issue.

“At the time it seemed a big frustration to have to change hospital in order to meet the system. I mean I’m very glad we did because of the care we get but at the time our closest hospital was only 20 minutes down the road but it’s across the county border so of course everything’s got to be under (local county) she’s got to be schooled in (local county) which is fine I mean we’re very happy em and we’re very happy with what everybody is doing but at the time I’d just established all those relationships at the local hospital which was 20 minutes down the road and they told me I had to change hospitals and start all over again which was a bit daunting for me …” Interview 9: 353 [Parent]

5.4.4.2 Co-location
The importance of co-location (i.e. where all team members use one office or are based in the same building) and shared service base was commented on as being helpful to improve contact, aid communication and assist in the co-ordination of the team working.

“The way we work here, we are all on the same floor aren’t we and we’re visible to each other and we can nip in to the office when we see somebody. We can nip in and say - oh what about something, what about so and so?” Focus Group 2 R8: 769 [Children’s Services Professional: Social Worker]

“There doesn’t seem to be the same forum of drawing people together if you’re not part of the centre (health centre) you know. Years ago our service use to work here at the health centre for a brief time and that was wonderful because we got to see speech therapy and health visitors so much easier than we do now.” Interview 15: 132 [Children’s Services Professional: Teacher Advisor]
The special school situation presented a positive model for team working with members of the team being housed in the same building.

“The younger side of services are pretty well co-ordinated and they all happen and everybody comes together or puts their report in and it’s all there and it all happens. Em, within a special school because you’re all under the same roof – you know most special schools function that way, but I’m not clear whether its that good when you’re actually out in the community at a mainstream school trying to get it all together. Em and I guess it depends on how good your SENCO [Special Educational Needs Co-ordinator] is.” Interview 2: 298 [Health Professional: Physiotherapist]

5.4.5 The Key Worker Role

5.4.5.1 Informal Key Worker Role
As there was no established key worker service in the study area the family were often thought to perceive certain professionals as their informal key worker even though the professionals did not see themselves in this role.

“…I don’t think the Portage Worker would see themselves as key workers. I think she’d see herself as a Portage worker with that family…” Focus Group 2 R6: 231 [Children’s Services Professional: Portage Worker]

“Yeah I don’t think it’s the Portage worker’s perception (that they are a key worker) I think it’s possibly the families’ perception…possibly” Focus Group 2 R8: 237 [Children’s Services Professional: Social Worker]

The perception of the health participants was that very few children had a key worker in any formal sense and often the families would simply turn to the most appropriate person in the team to address their issues and concerns. Sometimes this was the person they see most frequently and other times it was the person
most related to the issue at hand - potentially negating the need for a specific key worker.

“I pick whoever it is depending on what it is you know if she’s got an ENT (ear, nose and throat) problem I probably don’t ring the community nurse I might ring the consultant’s secretary in ENT, knowing that the right answer will come back from the right person so I decide that. I decide who I got to for the appropriate help.” Interview 9: 299 [Parent]

5.4.5.2 Parents as Key Workers
Some participants felt that the parent could undertake the role of the key worker however the impact of the emotional and psychological wellbeing of the parent or carer if acting as a key worker was a concern.

“One wonders if it’s a relation [in the role of key worker] or the parent themselves whether the emotional attachment would have an influence… [On how they carried out the key worker role]” Interview 4: 246 [Children’s Services Professional: Occupational Therapist]

The implication that if parents were in the key worker role they would advocate for what they wanted and not necessarily what the child needed was suggested.

“Parents can very much put their own words and their own needs forward and not give the child the opportunity to voice which way he wants to go” Interview 4: 530 [Children’s Services Professional: Occupational Therapist]

5.4.5.3 Cross-Agency Involvement in Key Worker Role
The long term stability of the choice of person in the key worker role would be very much dependent on the organisational structure of their employing agency. Participants felt that choice would be restricted if the key worker role was linked to a specific area or
profession although admitted that some professionals may find the task challenging.

“I think if it was just within the health professionals I think it would be OK. If we were going to include in the education staff then there might be more difficulties I’m not sure em partly because they have so much stuff any way they might not want it as an extra task em ‘cause it’s one thing for these things to function in a sort of unofficial way but when you start actually giving it to someone as a responsibility…” Interview 2: 178

[Health Professional: Physiotherapist]

However, the need for the key worker role to be fulfilled by staff from all agencies was felt to be essential due to the complex nature of the child’s needs.

“I wouldn’t want to see key working focus in one agency because I’ve yet to see any family whose problem is one agency’s. They might have problems with one agency but that’s not the same as saying the child’s difficulties don’t embrace more than one agency which they tend to.”

Interview 6: 510 [Health Professional: Medical Consultant]

Organisational differences in the management of social work staff highlighted how the allocation of the key worker in the social work team was done without consultation with any other members of the team or the child and family and may be seen therefore as an autocratic process.

“…as manager I would then select a key worker and that could depend upon people’s existing case load and whether they have space or it could depend on em… differing things that different people could offer to that service user…” Focus Group 2 R2:48 [Children’s Services Professional: Social Worker]

However, other participants from health and education backgrounds did refer to family choice when considering the key
worker role and stressed that the family need to feel comfortable with the chosen key worker.

“...They [the family] usually turn to the therapists because they have quite a lot of respect for the therapists perhaps the therapists see them more frequently”  Interview 6: 93 [Health Professional: Medical Consultant]

5.4.5.4 Context of Key Worker Role
Some participants had experience of key working in different settings e.g. respite care, school, nursery and child protection settings. As such the activities of the key worker appeared to be context dependent. There was an apparent lack of standardisation and consistency of the key worker role across the different settings.

“Within school settings I’m not sure they have, have the role in quite the same way and again the key worker tends to happen by default... It’s very often the learning support assistant that person who’s actually done more of the hands on bit who, who is very central to the child. The special needs co-ordinator will come and run things because they are professionally, I suppose at a different level... but actually it’s the learning support assistant who actually is the key...”  Interview 6: 227 [Health Professional: Medical Consultant]

5.4.5.5 Perception of Key Worker Role
The key worker was seen as a positive role in certain contexts e.g. with Portage home visiting, but the negative perception of the role of the social worker as a key worker was commented on by participants – particularly when dealing with child protection cases.

“You have quite a nice role [as a Portage Home Visitor] ...haven’t you? Your role is families...want...they [the parents] don’t always want the social worker in there...” Focus Group 2 R2: 246 [Children’s Services Professional: Social Worker]
The social workers described themselves as being at the high risk end of children’s services and intervention and suggested that all high risk, child protection cases should have a social worker as the key worker in this very specific context.

“...when you start talking about high risk, legal child protection stuff…obviously they would come straight across [to social work] wouldn’t they?” Focus Group 2 R9: 490 [Children’s Services Professional: Social Worker]

The key worker role was however, described by some participants as having the potential to be ‘burdensome’ and the need for this key person to have good skills and abilities and knowledge of the roles of the others in the team was essential.

“I think where it becomes burdensome for the professional is where it is outside of their sphere of professional interest em because actually it’s quite difficult em to understand other people’s roles…” Interview 6: 136 [Health Professional: Medical Consultant]

5.4.6 Key Worker Skills

5.4.6.1 Role Definition
The need for clear role definition and for core baseline skills for the key worker plus competencies brought from the professional role of the individual involved were seen as important.

“I think, I think we do need a structure and we do . . . we need what I would call I guess common boundaries (Yes) so no matter who you are, no matter who you’re key working for, there are things that you can do and things that you should not do . . . but it would seem to me if asked to have a key worker with core values who can’t then use their own competencies as well that seems to be a bit of a waste of skill really.”

Interview 6: 419 [Health Professional: Medical Consultant]
5.4.6.2 Key Worker Skills

The social work team felt that the role of the key worker included many of the skills and attributes needed in social work practice.

“I think you have to have em, obviously… good communication skills with your client and family but also be able to sort of network across the agencies really so it’s helpful to build up your local knowledge, helpful to know who’s who, it’s helpful to really get to know your child and family and look at every case individually em… good old social work attributes really…” Focus Group 2 R4: 67 [Children’s Services Professional: Social Worker]

Many of the participants (both professional and parent) believed they were undertaking tasks which could be attributed to a key worker role such as advocacy and co-ordinator – liaising with other team members, thus carrying out the role in an informal way.

“I think sometimes families phone me up and ask for advice because they’re not sure who to go to. So I won’t necessarily be doing something myself but I’ll say no it’s not me you need to speak to, you need to speak to so and so and hopefully that will point them in the right direction. So, from that point of view, sort of working as a key worker - just pointing them in the right area.” Focus Group 3 R10: 621 [Health Professional: Physiotherapist]

“I feel I can phone up the wheelchair service and say do you think it’s possible to get (wheelchair therapist) to give me a ring I’ve got a bit of a concern or I can say to the (school nurse) there’s a pressure sore what do you think it could be ?” Interview 8: 205 [Parent]
5.4.7 Training Needs

5.4.7.1 Core Training Needs

Although currently carrying out what they felt to be key worker activities in their day to day work many professional participants did not feel that their original professional training gave them all the necessary skills to undertake the key worker role in practice. They felt it would be helpful to have some sort of baseline training across all agencies so that all those carrying out the role would be doing so from the same basis.

“I think yeah, I think it would be a good idea to have some sort of induction to the (key worker) scheme and what it involves so that everybody was really clear that if they were the key worker their responsibilities were this… em, so that you knew exactly what you were responsible for and what could be, you know, given to somebody else to do…” Interview 2: 241 [Health Professional: Physiotherapist]

The social work team believed that as social workers they would be qualified to undertake a key working role following their basic training but were unsure if any of the other professional groups would have the skills, although they admitted that they lacked knowledge of the content of the training courses of health and education professionals.

“That is what we do, yes, case holders or key workers, that is… what we do.” Focus Group 2 R4: 203 [Children’s Services Professional: Social Worker]

“I see this key worker role as very much, quite social ‘worky’… and within the key worker role you’ve got a lot of other skills as well… there’s you know management skills, counselling skills there’s lots of other things that may well not be just within teacher training I don’t know. I don’t know
5.4.7.2 Parental Involvement in Training

Many of the professionals felt it would enhance the learning experience if parents were involved in shared training particularly about the role of a key worker and this sentiment was reinforced by parent participants.

“You need joint training with the parents” Interview 5: 293 [Children’s Services Professional: Occupational Therapist]

“You’ve got to tailor it [training] to the people on the course I think em, I would like to see a certain amount of parents with the professionals so the professionals get the parental side and view of things…” Interview 14: 364 [Parent]

The need for training was further reinforced by the fact that some parents did not fully understand the role of the key worker potentially for some being an abstract concept.

“[The key worker]… just somebody there to help you, support you and guide you through it…yes? I think… is the crutch of the help… it’s all so disjointed.” Interview 12: 195 [Parent]

“As far as I’m concerned it means that if you’ve got a key worker you can approach that person as being like your mentor…is that right? Interview 8: 309 [Parent]

“I have heard of a key worker but I haven’t really sort of…you know?” Interview 13: 278 [Parent]
The category of Service Organisation and Delivery (which is represented in figure 5) has identified some of the more strategic issues that have the potential to impact on team working and the role of the key worker in this context. Category three will address team working in more detail.
Figure 5: Analytic Development: Category Two Service Organisation and Delivery
5.5 Category Three: Working Together

This category demonstrated how the nature and practicalities of working relationships between members of the team, including the parents, had the potential to impact on the effectiveness of the management of the child. The team around the child was influenced in its practice not only by the individual human factors that have been described in category one but by operational constraints and boundaries of the service organisation and delivery of the statutory agencies of health, education and social services as described in category two.

5.5.1 Professional Role

5.5.1.1 Understanding Professional Roles
A clear understanding of professional roles was felt to be important to the team and to the way they worked together.

“I think an understanding of what all the professionals involved, do… What their roles are… that’s crucial as well.” Focus Group 3 R9: 380
[Health Professional: Occupational Therapist]

However confusion and lack of clarity over roles was expressed by parent and professional participants alike.

“You feel sort of disconnected from other people because you don’t really know their role or you don’t know sort of what training they do…” Focus Group 5 R2: 91 [Children’s Services Professional: Portage Worker]

“Sometimes you also don’t know who’s pigeon it is because of the cross over sometimes between… what’s Physio equipment, what’s OT equipment, different peoples… different roles em …” Interview 11: 243
[Parent]
The confusion was reinforced when the roles were not explicit and consistent across different agencies and in different geographical areas e.g. the occupational therapy role in health and social services. Parents could not understand why there should be an Occupational Therapist from Health Services and from Children’s Services and saw this as a duplication of provision.

“Even though we get disability living allowance, to get the grant for this… [housing adaptation], I had to go to social services... put us on another database so then she [the OT] comes out to see you so that’s another occupational therapist even though we already have (health occupational therapist)… it would be so much simpler if you just had well one OT. There’s your occupational therapist who knows your home, who knows the family who knows the child em, err, why can’t she do it?”

Interview 12: 267 [Parent]

5.5.1.2 Professional Identity
Reference was made by participants to team members being keen to be identified by their specific professional role. The comments which follow seem to suggest that the professionals do not see themselves as a team per se, but rather a collection of individuals.

“It’s like anything isn’t it? Everybody thinks their own little baby’s most important. Their own profession, whatever it be … is the most important thing… isn’t it?” Focus Group 3 R8: 745 [Health Professional: Hospital Play Specialist]

“I think one has to trust one’s colleagues more probably, actually in that you, you know, you can get very professionally in em… what’s the word I want? … You… protective of your own role and you actually probably need to be much more… well, you know… I don’t need to do that somebody else can do it just as well as I can.” Interview 5: 730 [Children’s Services Professional: Occupational Therapist]
One participant felt that she was the key worker for several of her cases but stated that she would not introduce her role to the family as such.

“I’ve never been into a house and said I’m your key worker. I’ll go in and say I’m your occupational therapist… I mean that’s what I am really” Interview 5: 285 [Children’s Services Professional: Occupational Therapist]

An approach such as this may indicate and reinforce the lack of formality surrounding the role of the key worker in this particular area.

5.5.1.3 Professional Respect
One of the identified factors felt necessary to promote positive working relationships in the team was the need for professional respect.

“So it’s time, communication and I think respect of everybody’s profession. So much of us think that we’ve got to be over protective of our profession.” Interview 4: 405 [Children’s Services Professional: Occupational Therapist]

“I do think we’ve continued a good relationship [with therapists working in school] and I think we use each others … you know…expertise …knowledge.” Focus Group 6 R2: 138 [Children’s’ Services Professional: Special School Teacher]

5.5.1.4 Professional Protectionism
The idea of professional protectionism and specific responsibilities arose with regard to the limits and competencies of each professional role. Some participants were found to be wary of other professionals stepping over the boundary into their domain of practice.
“You don’t want the Educational Psychologist to tell you what sort of antibiotics to use with a child just as we wouldn’t tell them what school to go to…” Interview 6: 183 [Health Professional: Medical Consultant]

The therapists working in Children’s Services supported a variety of teams from other agencies. Due to the variation of their core work it appeared there was often confusion about the boundaries of professional practice. Reference was made to the duplication of service provision and the feeling of being ‘checked up on’ by other team members indicating a possible lack of trust between professionals.

“…sometimes it [team working] doesn’t work so well and I think em, I think sometimes that there’s a doubling up” Interview 5: 109 [Children’s Services Professional: Occupational Therapist]

“If I’m going in and deciding on a course of action and then sometimes it can feel you’re being checked up upon by somebody else…” Interview 5: 134 [Children’s Services Professional: Occupational Therapist]

However, participants felt that although they did not always agree with the viewpoint of the other professionals in the team they recognised that they may have a different perspective, different skills and competencies to offer in the management of the child and support for the family.

“…If it’s seating I tend to let the therapists at the hospital do that, as far as the special seating is concerned….. I wouldn’t presume to be an expert on it.” Interview 5: 118 [Children’s Services Professional: Occupational Therapist]
5.5.2 Collaborative Working

5.5.2.1 Lack of Collaborative Working
Parents seemed to feel that the statutory organisations worked independently of one another with little collaborative working.

“You’ve got, you know, three different large organisations (if you want to call them that) all doing their own thing. There seems to be no ‘tallying up’ with this.” Interview 10: 606 [Parent]

Lack of collaborative working was particularly evident with regard to home visiting by the team. Parents found it difficult to manage the number of home visits as the professionals did not routinely share appointments, and tended to work independently of each other.

“I can’t really remember any joint visits at all but they were all made independently.” Interview 11: 100 [Parent]

This had a major impact on family life as described by one mother:

“At the time you know I joked about it… I did think about putting a sign up outside saying ‘Open House’ – I’d just leave the door open and em, just see how many people would walk through really. There were times when you’d think I don’t think they’d get any more cars on the drive because it just seemed to be a continual stream of people coming and doing things” Interview 11: 101 [Parent]

Some professional participants expressed a belief that no matter how hard they try to co-ordinate visits due to time pressures the onus of team co-ordination (key working) was still likely to fall to the parents.

“… however much you try and do joint visits between professionals either therapists, or Portage or nurses who ever it is because of time restraints
that’s only possible so much of the time that you still feel like that onus of all these different people and having to co-ordinate all these different people still tends to fall on parents.” Focus Group 3 R7:192 [Health Professional: Physiotherapist]

One participant stated that:

“I do still think we work in isolated pockets” Interview 4: 216 [Children’s Services Professional: Occupational Therapist]

The quote may suggest the participant’s perception of collaborative working may not be as effective as it could be and that there was still scope for improvement.

Team relationships did not appear to be very robust. In describing how one participant viewed the delicate nature of collaboration with other team members, she stated:

“I do find I have to tread on eggshells sometimes…” Interview 5: 158 [Children’s Services Professional: Occupational Therapist]

Positive working relationships were not uniformly experienced by all participants.

“It’s [team working] always been a positive experience for me em yes, I work with speech therapists and physiotherapists. I have worked with social services possibly that’s not such a positive em experience because they do tend to em… social services tend to be looking for problems rather than trying to make problems better err but my experiences with the other services have been quite positive.” Focus Group 5 R1: 34 [Children’s Services Professional: Portage Worker]

“I can’t see how you can work with a child with disabilities without working with everybody else and one of my most frustrating things moving out of the city to here was the amount of time I had to chase
people to talk to them and the reluctance of people initially wanting to work with one-another whereas in (midlands city) you had no choice to be honest.” Interview 15: 103 [Children’s Services Professional: Teacher Advisor]

5.5.3 Child & Family Focused Working

5.5.3.1 Lack of Child and Family Focus
Provision was perceived by some participants to be agency led rather than being focused on the specific needs of the child and family. This may lead to resources and provision of services being compartmentalised and contribute to the confusion felt by parents.

“They [the parents] get very confused about who’s who within all the different agencies that’s for sure and I find that I have to continually make myself check out ... do you know who this person is? Do you know who they belong to?... as it were ‘cause sometimes its just seen by a family as one whole system even though it’s lots of different systems and it’s intricate, to them it’s just a huge thing...” Focus Group 2 R3: 322 [Children’s Services Professional: Social Worker]

5.5.3.2 Impact of Policy and Procedure
Participants from the different service providers worked differently depending on their professional background. For example, different agencies had distinct procedures and protocols which staff had to follow. Sometimes these did not match across agencies and this occasionally resulted in dilemmas for other members of the team e.g. the doctor who sees the child as their ‘patient’. The doctor wants to support the parent in their request for a certain school for their child but they are unable to do so overtly because of another agency policy on the issue of specifically naming a
school in supporting reports for the Statementing of Special Education Need process.

“...when the parent comes and says ‘I want to go to the local special school’ it’s ever so tempting to, to not just talk about needs but actually try to kind of work it down the line of what the parents want...difficult, ethically quite difficult actually because the parents and child are your patients and they’re the ones you’re there to help and sometimes it’s a bit hard and across the agencies it’s harder to actually keep the role and have a clear understanding of what people can and can’t do.”

Interview 6: 159 [Health Professional: Medical Consultant]

5.5.3.3 Holistic Working

When comparing their role to those of the other professionals in the team around the child, the social workers felt they had a very good client focus with an overview of the management of the child and family. They believed they worked much more holistically than many of the other professionals.

“... I still feel the other agencies - our partners in education and health, perhaps don’t work so holistically.” Focus Group 2 R1: 698 [Children’s Services Professional: Social Worker]

However, many non-social workers thought they too were carrying out child and family focused roles – roles over and above their individual professional duties.

“Quite often you’ll come back from a visit or a phone call or something with a lot of – contact the doctor or, the orthotist or the wheel chair service or whoever, social worker whoever and that seems to be something in particular for the therapies. I think we tend to sort of be a bit of a gate keeper for... and that’s sort of just an accepted part of our role, whether we are knowingly sort of properly that or not.” Focus Group 3 R7: 602 [Health Professional: Physiotherapist]

193
5.5.4 Parent-Professional Interaction

5.5.4.1 Honesty Based Relationships
For some participants a parent-professional relationship built on a basis of honesty, trust and dependability was felt to be important.

“"I think approachable, somebody who is open, somebody who can be very honest...” Interview 10: 283 [Parent]

“I know my expectations are sometimes quite high. And em, I don’t like being treated like an ass. I’m an intelligent person and I don’t like being treated you know how some doctors em specialists treat people. I don’t ... I like to be told the truth.” Interview 10: 786 [Parent]

5.5.4.2 Impact of Acceptance of Disability
The parents interviewed were all at a unique place in their life long journey with their child with a disability. Their acceptance of their child’s problems and their innate capabilities to cope and ability to deal with these appeared according to some study participants, to have the potential to influence the way they worked with the professional team.

“It’s been a slow process over the last two, two- three years that... and I’ve now come to the realisation that I don’t think (child) will ever walk independently and there was no way I was ready to accept that three year’s ago. I wouldn’t have it and I have now, and I have to say it’s only been in the last year. It’s only been in the last year I could even say the word disabled... my son is disabled and feel Ok about it. I think that’s a real acceptance of it.” Interview12: 108 [Parent]

“... if you’ve got a parent who is either not accepting of the diagnosis or are unrealistic or are not motivated; each of those can present difficulties in terms of what we might see as aims for that child or opportunities for that child. If you’ve got a parent who for example is just not motivated it’s
really frustrating that sometimes, especially you really feel that child can’t fulfil their potential or won’t even have opportunity to have a go at fulfilling their potential.” Focus Group 3 R6: 22 [Health Professional: Physiotherapist]

Such complexities within family structures often resulted in difficult working conditions for professionals and the need for flexibility in their interaction and team working approach.

“I think it’s just, because often those are the families that are quite chaotic and quite difficult to get hold of and you have to be very flexible in order to work with them…” Focus Group 3 R7: 121 [Health Professional: Physiotherapist]

5.5.4.3 Continuity of Care
Understanding the needs of the child and family and giving support and advice was greatly appreciated by the parents. There was a belief for some that this was only achieved when there was continuity of care from the same professional over time.

“I feel that having generic teams has led to a down fall in continuity of care, you know, continuity of worker… does that make sense? I think it just goes hand in hand, you feel more familiar. It’s like for instance when mothers have babies they feel much better if they’ve had the same midwife turn up and the same health visitor turn up on two or three occasions… if you get to know someone in a very close way then you become a confidante as well as . . . you know and they see you as an ally and someone supporting you.” Interview 7: 70 [Health Professional: Children’s Community Nurse]

“I don’t know anyone that doesn’t trust (school nurse). She just puts you at ease and if she gives you the name of a person to get in touch with and you can’t she’ll do it for you. I think she goes above and beyond her role of a school nurse em. Outside of school as well you know I have rung her
a couple of times in the evenings – (son) is doing this – as a friend you 
know? But I’m fortunate that I have built up a relationship with her. But 
then (son) was only four and I think the continuity of the school nurse to 
be in one school for so long is beneficial to everybody. It’s when you get 
the chopping and changing isn’t it?” Interview 8: 457 [Parent]

5.5.4.4 Relationship Boundaries
In some cases the relationship balance became more personal 
when families had been known to services for many years and staff 
felt more accountable because they knew the family so well 
possibly altering the dynamics of the professional/patient 
relationship and potentially overstepping normal boundaries.

“… if you haven’t done something that… someone phoned you and it 
went out of your head and you didn’t do it, then you do feel much more 
accountable to, to the family because you know them so well...” 
Interview 2: 225 [Health Professional: Physiotherapist]

5.5.4.5 Parent Partnership
The professionals’ willingness to work positively with parents as 
partners was also stressed as important in the success of the 
relationship and could make the difference between a good or 
bad experience for the parent and child.

“At times it’s been quite a trial and certainly some services are, or some 
people that we have seen are em, are easy to talk to, are more 
approachable and make themselves more approachable em, and other 
em, others it’s been quite upsetting. At times and I feel very 
uncomfortable particularly the endocrinologist and it’s never a pleasant 
visit. It’s awful.” Interview 10: 113 [Parent]
5.5.4.6 Parental Capability

The capabilities of parents when negotiating the service maze was also felt to be an influencing factor on how relationships developed with the professional team and the outcomes for the child. Inequity of service provision led to obvious frustrations within the professional team and was felt not to be based purely on the assessed needs of the child but sometimes more on the capability and motivation of the parents.

“And if you don’t give them what they want they will come back to you time and time again until you do. And, a child who really, really needs that environment [the special school] who we’re all desperate for him to have it, because the family are not motivated and never shout and scream he won’t get that. And that’s really; well frustrating doesn’t really explain it, does it? And that is purely down to parent power if you like, and I think I absolutely agree with [other therapist] if you’ve got a patient – a parent who’ll come down on you heavy if you don’t do whatever I think sometimes there is, you know you are a bit more on your toes for that family.” Focus Group 3 R6: 47 [Health Professional: Physiotherapist]

5.5.4.7 Parental Engagement

The difficulty of engaging and enabling parents who were less able was presented as a challenge for some.

“I know a lot of our parents that are refugees or English isn’t their first language or whatever they’re just struggling with being parents and coping with the system without wanting to be anything more than that em but you know while English middle classes can be – can do it by themselves and demand it ... em but what I do know ... how you empower people who don’t see, don’t see that they need it cause I mean they are often the people who do need it but I don’t know how you get them to that stage.” Interview 2: 75 [Health Professional: Physiotherapist]
5.5.4.8 Relationship Power Imbalance

Some parent participants however, referred to situations which demonstrated a power shift in the interaction between the professionals and the parents. Parents were skilled in the care and management of their child and felt they had a role as an expert parent. One parent reported a positive experience on a hospital admission where she was asked for assistance by the acute nursing team as they felt they did not have the skills and expertise needed to manage the child because of lack of exposure to the situation.

“We always stay, always have stayed with him [during acute hospital admission] but I think that is us any way. It is difficult for some of the staff because each child is different with special needs. I do find a lot of the nursing staff don’t know how to use gastrostomies you know, along the way – not just (local hospital) I’ve had to show nurses... which I don’t mind but some people, you know it might be a bit of a shock to think oh you expect nurses to know but then not everybody knows.”

Interview 8: 286 [Parent]

5.5.4.9 Advocacy

An important part of the parent-professional relationship is that of advocacy. This had particular relevance to case conferences which could be daunting for parents, predominantly due to the potential power imbalance between the professionals and the parents.

“Yes advocate as well yes... like an ‘aide memoir’, because it can be very, very... you know...daunting for them [the parents] I assume, you know...of being in there [case conference] and they can then end up walking out thinking I wish I’d said that ...” Interview 7: 271 [Health Professional: Children’s Community Nurse]
5.5.4.10 Dependency

In some instances however the nature of the relationship between the professional and parent could conceivably lead to the creation of dependency of that parent on the professional.

“… maybe it’s to do with the model they’ve [the parents] been brought up with but they often seem to see em professionals as people that you just hand things over to and they take over rather than people you work with side by side with… and some of them to the point where they don’t seem to think…. where they’ve got to do anything at all and it’s all going to be done by the professionals for them.” Interview 2: 84 [Health Professional: Physiotherapist]

The perception of some participants is that the current system appears not to develop parental coping skills and strategies or enable the parents and families in the management of their child.

“Is there a better way, is there a way that’s slightly less dependent for them of sharing and off loading, because actually if you do continually bring things to a professional do you, do you really develop the same sort of problem solving skills and therefore is it part of the role of the key worker to help you develop the problem solving skills rather than just organise?” Interview 6: 326 [Health Professional: Medical Consultant]

However, parents were often the main point of communication and source of information across the team. They undertook a liaison role with different members of the team, passing on the latest outcomes of appointments and treatment, demonstrating a certain dependence of the professionals on the parents.

“It is kind of a full time job really trying to get it co-ordinated and get people to… people don’t speak to each other so I’m kind of the one in the middle that’s feeding back what one’s said you know to try and
5.5.4.11 Key Worker Relationship

Liaison such as this may be seen as one of the potential roles of the key worker and professional participants felt it was important to build positive relationships with families to enable them to trust and feel comfortable with their key worker.

“I actually feel that you would have to have a good relationship with the family to be their key worker so, some of that is going to be how much have you treated the family and got to know them and they’ve got to know you because they’ve got to trust you as well so…” Focus Group 3 R10: 527 [Health Professional: Physiotherapist]

“… it’s probably more important that it’s somebody [the key worker] the parents feel comfortable with… individual parents get attached to people…” Interview 6:117 [Health Professional: Medical Consultant]

The Working Together category (which is represented in figure 6) has identified some of the issues faced by the professionals delivering services as a team. The way they interact and their understanding of each other’s roles, skills and abilities has the potential to impact on the team dynamics and therefore the role of the key worker.
Figure 6: Analytic Development: Category Three Working Together
5.6 Category Four: Communication

Communication was a category which permeated all other areas of the study and demonstrated how interaction between team members; professional groups; parents; and service providers impacted on the effectiveness of team working. Communication was influenced by individual factors, organisation, delivery of services and the ways in which people worked together.

5.6.1 Communicating the Diagnosis

A specific area of communication that was commented on by both professionals and parents was that of communicating the diagnosis of the child. The professionals found that the way the diagnosis had been delivered to and received by the parent, had a long term influence on future trust and communication with the team.

“We know there’s angry parents out there who still talk about the way it [the diagnosis] was told to them . . . one particular one that always strikes me em you know, she can’t, they can’t, the family particularly, the mother can’t let go of that, how they were told and I think that their whole sort of life still revolves around that (yes) . . . . 10 years later.” Focus Group 3 R9: 61 [Health Professional: Occupational Therapist]

“You still get all these different emotions the, first… from the diagnosis point of view. I think the diagnosis stage was very badly handled any way, because when (child) was diagnosed it was a routine child development check at 10½ months. I was on my own just taking her to what I thought was a routine check up and err, the consultant did her assessment and err, we went back and sat at the desk and she said ‘oh yeah, it’s definitely cerebral palsy’. The words had never been mentioned before so suddenly that label was the… horrific… and it was like… and
she wrote down the number for Scope and told me to contact them for further information, that was it, end of consultation and I left the room in absolute tears em got back to the car and kind of broke down on the phone to my husband you know, I couldn’t get the words out. Em, so I thought that the diagnosis was really, really badly handled and you know I’d hate for anybody to go through that the way that I did.” Interview 14: 379 [Parent]

Delay in communicating a diagnosis was also felt to influence parent professional communication later in the child’s management.

“… looking back it’s quite interesting that some of the parents who we found may be a bit . . . not difficult but a bit not so on board, not so with the whole aims of treatment or so realistic, often they were quite late in diagnosis (yes) look back and see actually they weren’t, they didn’t have their, they weren’t diagnosed until they were over a year or two something like that, whether that was a complete coincidence?” Focus Group 3 R7: 69 [Health Professional: Physiotherapist]

Within the study some participants believed that the emotional and psychological well-being of parents differed if their child was diagnosed at birth from those diagnosed at a later stage and believed this had the potential to impact on relationships made with professionals.

“From the parents’ point of view because if it’s a head injury and/or an orthopaedic thing that’s happened as you say it’s a whole different type of grieving I think than if they’ve had that condition from day one and that can make it [the relationship with the professional] much harder because they don’t, you know... why do we need this and why do we need that... and they don’t always want it. Because they want what they used to have which was that normal child rather than the child they’ve got now.” Focus Group 3 R6: 230 [Health Professional: Physiotherapist]
Early intervention and communication following diagnosis was felt to allow a positive relationship to form and trust to build up between parent and professional. There was a belief that in early years services where there was good communication, team coordination worked better.

“I think early intervention works well again when everybody knows who’s who, who’s involved, where they live, where you get your resources from. I think where it doesn’t work is if you’ve got late diagnosis or something that happens later on and then becomes chronic and disabled – you know what I mean?” Focus Group 3 R9: 208 [Health Professional: Occupational Therapist]

5.6.2 Communication Across The Team

5.6.2.1 Numbers in the Team
The sheer numbers of people involved in the team around the child with a disability was evident from the comments of some of the participants.

“A huge army of people basically” Interview 11: 11 [Parent]

“She has a lot of multi-agency involvement in her life, everything from social services to health at the hospital. She sees a number of different consultants at different hospitals for different reasons em, probably about 15 or 20 people or so…” Interview 9: 14 [Parent]

The high numbers in the team around the child was sometimes felt to inhibit communication and good team working practice as one mainstream class teacher described.

“…a lot of people to deal with and its not always easy to, you know, obviously you don’t just say it once you say it more than, and it’s almost, it’s very difficult when you can’t get everybody in the same room at the
same time – it’s really difficult sometimes.” Focus Group 8 R9: 35
[Children’s Services Professional: Mainstream School Teacher]

Parents found they were repeating their ‘story’ several times due to the number of professionals that were involved with their child, often acting as a conduit for information between professionals.

“…well they always want to know what someone else is doing so I have to update each one on all the major happenings…” Interview 9: 218
[Parent]

5.6.2.2 Contact Difficulties
Confusion often arose about who in the team parents should contact. They also faced difficulty in actually making contact. Parents were often frustrated at the lack of response from professionals. They felt that if the person was away or on leave no-one would make contact to tell them or see if they needed assistance in the meantime until their own allocated professional returned to work.

“It’s a constant ... kind of making a list really of what I’ve got to do, who I need to contact and specially at the moment with everything that’s going on [referring to the house adaptation] em that trying to get hold of people at the moment is err... or trying to get people to actually return your communication is proving very hard at the moment ...so frustrating…” Interview 14: 46 [Parent]

5.6.2.3 One Point of Contact
Parents identified the need for one point of contact regarding their child.

“It would be really nice to have somebody – one point of contact that I could phone and say...that was at that meeting with me, attend the professionals with me, and takes away all that from me and says right
now I’ll go and do all this for you…we’ll get the physios input you know, re-looked at. We’ll do that and kind of let me just come out of the meeting and absorb what’s gone on without me having to rally it all around and start getting...do you know what I mean? Take that pressure off the parent it would be a … it would be really, really amazing, really beneficial.” Interview 14: 219 [Parent]

This view was supported by some of the professional participants who also felt that one key person should be the point of contact for the whole team.

“I’ve got a friend who is a class teacher who’s also a SENCO for a primary school and she tears her hair out because she’ll have speech in one day and the physio in another day and you know and, and they may or may not turn up for the annual review or they may not get their reports in for the annual review it makes it more difficult. It would certainly be easier for them if they could contact one person who would sort it all out…”

Interview 2: 281 [Health Professional: Physiotherapist]

Study participants agreed that the single point of contact for the team around the child should be the key worker.

“The concept [of the key worker] is also now unquestionable it’s just sort of, you know, the idea and we should be doing it... I think the parents should have a single person that can access all other information”

Interview 6: 104 [Health Professional: Medical Consultant]

“I guess key worker from a parents point of view I would be thinking of, the kind of the key person I would be in contact with so if I had any issues that come up they would be the first person that I’d maybe take it forward to… with, with a hope that they then are able to either if they know the answer or could find out from someone else…” Interview 1: 13 [Parent]
5.6.2.4 Key Worker and Communication
Communication skills were stressed as important in the key working role. Sometimes staff who found themselves in an informal key worker role acted as a conduit for messages to other services as they were the ones in touch with the parents.

“... they (the parents) tend to phone up and then leave us to sort of you know, approach... I mean we are always the point of liaison with the wheelchair service, with the special seating service, with em often with the OT although she’s the one who tends to do the social services OT stuff...”  Interview 2: 211 [Health Professional: Physiotherapist]

5.6.2.5 Proactive Communication
Some parents were seeking proactive communication from the team – even if all was going well they would have appreciated a regular telephone call just to have contact with someone and to know that someone was concerned for their well-being.

“You know it sometimes would be nice if you got a call once a month or once every six weeks or whatever to say ‘Hi everything OK?’ And you could say ‘Yeah fine’, you know I kind of think there have been times that battling with certain things - not just with (disabled son) but other things, take you away from your son a little bit and you just lose control and then you think your whole world’s tumbling around you and you wish someone would come and say... Do you need help? Do you need a little bit of help to get you back on the road again?”  Interview 8: 327 [Parent]

5.6.2.6 Team Communication
The need for time for the team to communicate and meet in order to build up relationships was a constant thread throughout the data.
“…we try to invite people to our team meetings and we try to find out about… networking a lot of the time… finding out information…” Focus Group 2 R7: 336 [Children’s Services Professional: Social Worker]

Joint training was seen as providing an opportunity to network, communicate and to share information and meet personnel from other agencies.

“Multi-agency training as well I think is a factor because that’s when you do a lot of your networking…” Focus Group 2 R9: 361 [Children’s Services Professional: Social Worker]

However, with reference to networking, the social work team did perceive that the effort to do this was one sided on their part and not matched by the staff of other agencies.

“…I do feel sure that other agencies need to make more of an effort too and come to us.” Focus Group 2 R4: 338 [Children’s Services Professional: Social Worker]

5.6.3 Inter-Agency Communication

5.6.3.1 Lack of Common Language

It was apparent that each professional group and agency staff had its own terminology and cultural language. The language used by one group of professionals meaning something quite different to another. The lack of common understanding of shared terminology across the professional interface and across agencies had the potential to cause confusion when working as a team. The issue of terminology had particular relevance within the study with regard to the role of the key worker.
“...I’ve always seen the social worker as the case holder. And, the key worker I’ve always thought could be chosen from anywhere...” Focus Group 2 R6: 192 [Children’s Services Professional: Portage Worker]

“...when it’s a child protection case the family may have a totally different perception of your role as a professional doing that key worker role because of the nature of what is going on in and around that family which may bear influence on them...” Focus Group 2 R5: 215 [Children’s Services Professional: Social Worker]

5.6.3.2 Cross Agency Communication
When discussing the relationship and interaction between agencies the difficulties of managing communication across a tripartite relationship were evident. Health professionals referred to good communication channels with education staff but mentioned social services staff as ‘a complete world unto themselves’, indicating a more difficult relationship across this agency interface, and between education and social services staff.

“It’s historical, it’s historical and it’s not going to change unless they have a culture shift. I don’t think the two [Education and Social Services] do get on because that’s . . . I don’t think they understand each other it’s not . . . that’s not necessarily typical of anybody in it (No) but it is a basic lack of understanding...” Interview 6: 474 [Health Professional: Medical Consultant]

Parents too noted limited contact across agencies between the professionals who were treating their child.

“... I mean occasionally they might talk to each other for some reason but it’s quite rare. It’s normally me that has to do the instigating so I, I manage everything and feedback everything...” Interview 9: 241 [Parent]
Virtual teams (i.e. teams that were not structured in any formal sense but included professionals from different agencies who had some involvement with the child and family on an individual case basis) were presented as a helpful way of communicating with a team around the child but there was no mention of parents or children being involved with the process. The parents were not portrayed as being level players in the team; one participant described them as giving:

“...their slant on what they’ve heard and what they want to hear”

Interview 4: 62 [Children’s Services Professional: Occupational Therapist]

This comment may suggest professional ‘scepticism’ regarding the information given by the parents about their child, or their child’s management.

5.6.4 Face to Face Contact

Some participants felt that there was a great deal of value in face to face meetings where specific needs could be discussed with the whole team although once again the child and family did not appear to be routinely included in this forum.

“... that’s a very good meeting, good use, you get a lot of different professionals there and you can discuss specific children with specific problems... you get it all sorted out there” Interview 5: 65 [Children’s Services Professional: Occupational Therapist]

Some parents were disappointed at the lack of time there was for direct communication in the form of face to face contact with their professional team. This was more noticeable once the child moved out of the pre-school age group when many parents found they almost lost contact and were left out of the loop with regard to
what was happening with their child’s management. As a result parents felt that there were unilateral decisions being made about their child and their child’s care and they were not being involved and included as part of the team around the child.

“One or two blips along the way with em... well head teachers at schools making decisions, taking things away that I thought might be beneficial ...” Interview: 8 24 [Parent]

“If I’d known (the physiotherapist) was going to be there [at school] yesterday I would have stayed around or come back to see her. Em I sometimes feel that communication is a bit poor I know people are really busy I appreciate that but when it’s your children you want to know what’s going on.” Interview 13: 143 [Parent]

In a lot of cases the parents were quite protective of the professionals in the team almost making excuses for their lack of face to face contact or input due to heavy caseloads and increasing work pressures. Some stated that they did not feel they wanted to disturb the professionals as they knew they were busy.

“That’s another thing you do detect and certainly with (health visitor) and I’m not dropping her in it at all but certainly there were times when I felt guilty for calling on her because her work was, you know, her workload was huge.” Interview 10: 294 [Parent]

“You know people do, do their best but people are busy and there isn’t much time and I think it’s a shame really and it’s not anybody’s fault I think it’s just services just keep being cut and they just get more and more stretched.” Interview 13: 231 [Parent]

Most team members recognised the importance of being able to meet face to face and one head teacher in a special school setting described how team working was much more integrated
when all members of the team, including the parents, were actively involved in communicating and planning during meetings.

“…when we all get together especially with the parents as well it’s much more powerful you get much more integrated working really…much more consistency which is what we are aiming at”  Focus Group 6 R1: 68  
[Children’s Services Professional: Special School Teacher]

The social work team were concerned at the changing nature of their role which they felt had led to a reduction in available time for face to face contacts with their clients.

“…I think there’s more and more paperwork involved – there has been over the years em, and people feel they are spending more time in front of a computer than they are face to face with families”  Focus Group 2  
R2: 39 [Children’s Services Professional: Social Worker]

The need for more face to face contact with the whole team around the child was felt necessary as individual professionals saw themselves as one small part of a much bigger jigsaw.

“… it would be more helpful, helpful occasionally you know even once a year or something that you actually saw the service as a whole so you saw where your bit of the service fitted into their overall service and what else you know what they are providing maybe would help you understand better I don’t know.”  Interview 2: 330 [Health Professional: Physiotherapist]

5.6.5  Information Sharing

5.6.5.1 Information Sources
For parents an important part of communication was to have appropriate and timely information about their child’s management, however, parents commented on the lack of
forthcoming information from the professional team and often found other parents a valuable alternative source – parent to parent communication.

“I think I probably find the biggest breakdown in communication is somebody to tell you what’s out there be it in funding you know…information. All… everything I have found out about is by talking to other mums…em.” Interview 12: 171 [Parent]

“… I think sometimes another parent giving another parent some advice-that have been through it - is probably more helpful than what a doctor or a professional… because they think it’s just something else to be… you know…” Interview 8: 375 [Parent]

Although they were often not given written information by the professionals about their child’s condition, parents felt it may be useful to have something to take away from appointments.

“Leaflets are certainly helpful so that it’s something you can take away and you’re not always going to remember everything that someone’s said to you in a meeting or you know, sort of feel you can, but you might pick up a few bits on it, so sort of some leaflets to almost take away and go over what’s been said would be quite helpful…” Interview 1: 118 [Parent]

Professionals felt that if sufficient information was given at the appropriate time it would help resolve many of the crises faced by the families and prevent the need for contact on an out of hours basis. The information however, would have to be individualised for each child indicating a need for greater flexibility in resource provision than is currently available. With regard to information supply an in depth knowledge of the child and family situation would assist in making decisions about crisis care, and this may not
be possible for staff members who were not that child’s regular professional carer or key worker.

“I used to have my phone on perpetually and I would answer any calls and would deal with them and that would be probably about the most efficient way of doing it only because... not that I like the interruption ... no-one abused it ... they only phoned me up when it became a real emergency and there was no, you know, they couldn’t work their own way through it. One, I kept it down because I would be giving them loads of information anyway and give them support...” Interview 7: 97 [Health Professional: Children’s Community Nurse]

Interestingly this was demonstrated to be a two way process as some parents were pro-active in seeking out information about their child’s condition and were keen to share this with members of the team supporting their child.

“... because they had a lot more em just by the volume of children they dealt with and there was a couple of consultants who were quite pioneers in what they were trying to do with regards the epilepsy and em so I actually went out to the States, but I also had telephone contact with quite a few that then gave me information that I was able to feed into my consultant here who did take that advice and who did take the telephone calls from him so that was really good.” Interview 11: 41 [Parent]

5.6.5.2 Impact of Lack of Information

Some participants perceived that they may miss out on information that was discussed between staff from another agency and team members or parents in a different location and that this had the potential to impact on the outcome of service provision for the child. This was a communication issue that stemmed from a team location issue as has been previously mentioned in earlier
categories. Those who worked predominantly in the home setting stated:

“Where I feel we are put at risk... is that all the assessments of a disabled child mainly take place in a hospital or schools so all that health information around sort of hip stability, posture, spine what’s going on, what’s the paed... paediatrician’s decision, we’re not part and parcel of that... We could end up prescribing something that was detrimental to the child because we haven’t got the full information... So being left out of that loop I feel places us at risk...” Interview 4: 41 [Children’s Services Professional: Occupational Therapist]

“...that’s the challenge to make sure em, that when you’re very much relying on people talking to you and telling you things, your colleagues that you’ve got to work with have all got to feed information in as well as take it out haven’t they?” Interview 5: 520 [Children’s Services Professional: Occupational Therapist]

5.6.5.3 Information Sharing

The health team did identify the need to share information about the children they were working with.

“I do have a lot of contact with education and social services... I have direct contact with schools and preschools usually over individual children...” Interview 6: 29 [Health Professional: Medical Consultant]

However, they expressed concerns that parents have to go to several people before they find the right person who has the information they need and that occasionally the team does not share appropriate information possibly because of the complexity of data protection and confidentiality.

“...we don’t really share, we’ve got no authority to share on behalf of anybody else, I think is one of the problems” Interview 6: 109 [Health Professional: Medical Consultant]
The need for shared information to allow a key worker to have a clear understanding of local policy for accessing resources was felt to be essential.

“Well social services generally have got their, their way of doing things haven’t they, so you obviously have be aware of what’s local in your area and how things are done and there must be some sort of protocol or whatever so you know how you access things. If it’s a novel situation then obviously you’ve got to feel your way but I think if you’re going to assume that role of key worker as an official role then I would hope there would be some sort of resources that tell you what the protocol was for doing that, so that you didn’t waste a lot of time doing it wrong.”

Interview 2: 138 [Health Professional: Physiotherapist]

5.6.5.4 Incompatible Information Technology Systems
Information sharing and communication were often felt to be hampered by the lack of connection and compatibility of Information Technology systems across agencies. This presented issues of safety and confidentiality when using systems such as e-mail, telephone and post. The preferred method of communication was face to face.

“… One of the issues I think we have [in health] is we get a lot of email contact from education in particular, social workers a little bit, em they tend to use email quite freely and we are not in a position to be able to reply to lots of that so we end up trying to catch people to talk to them… if it’s appropriate to share…” Interview 6: 51 [Health Professional: Medical Consultant]

5.6.5.5 Lack of Joint Documentation
Information sharing for the team was also problematic because there was no system of joint documentation in place. Records centred on the child and family and held by them, were not
evident, each professional or agency holding their own records often in separate locations. Even when notes were in the same location they were not accessed, as one participant suggested...

“...how often has someone on call or someone who err, from the ward yeah? Have ever run round to the CCN (Children’s Community Nursing) office to get out the nursing notes to have a look at what’s been said and what’s gone on for the last six months?” Interview 7: 186 [Health Professional: Children’s Community Nurse]

Effective communication seems to have been influenced by many factors included in the earlier identified categories of this study. It was evident from the data that it was an essential overall element in team working and in the potential success of the role of the key worker. The category of communication is represented in figure 7.
Figure 7: Analytic Development: Category Four Communication

- Communication the Diagnosis
  - Numbers in team
  - Contact difficulties
  - One point of contact
  - Key Worker and Communication
  - Proactive communication
  - Team communication

- Communication across the Team

- Inter-Agency Communication
  - Lack of common language
  - Cross-agency communication

- Face to Face Contact
  - Face to face contact

- Information Sharing
  - Information sources
  - Impact of lack of information
  - Information sharing
  - Incompatible Information Technology Systems
  - Lack of joint documentation

Codes
- Diagnosis

Figure 7: Analytic Development: Category Four Communication
5.7 Summary

The findings of the study have been analysed through a process of coding, development of subcategories and grouping into categories.

The individual needs of the children with disabilities and their families demonstrate the complexity of this context and area of clinical practice. The way services are currently organised and delivered influences the effectiveness of provision and outcome for the child and family and demonstrates the need for a key worker who is adaptable and has a wide range of skills. The way in which the team work together can shape the experience of service provision for the child and family and a key worker has been suggested as a potential linchpin in such a team. The effectiveness of communication at an individual level, across professions and teams, and across agency boundaries influences and impacts on effectiveness on the way teams work together.

These identified categories provide and support the fundamental basis of team working and the potential role of the key worker. The conceptual development of these categories will be demonstrated in the following chapter in an attempt to restore some order to the fragmentation of the data that has occurred during the analysis process as is typical with grounded theory methodology. The implications of these findings for future clinical practice will be also discussed in the text that follows.
Chapter 6.0: Discussion

This chapter will consider the main findings of the study. The categories identified i.e. Human Factors; Service Organisation and Delivery; Working Together and Communication have for purposes of clarity, been presented as separate entities in chapter five. However, in the reality of day to day practice while attempting to meet the diverse clinical needs of service users they do in fact all overlap, interact and impact on each other and it should be recognised that they are therefore inextricably linked. Identifying how these categories are linked has been through a process of conceptual development (or axial coding) via inductive thinking. This process emphasises the causal relationships of the phenomenon – the causal conditions or events; the context i.e. the location or background of the variables and conditions of influence; the action strategies – i.e. the purposeful activities performed in response to the phenomenon and conditions; and the consequences of those actions be they intended or unintended.

The discussion of the main findings of the study will begin by critiquing the issues around current service provision within the context of the four identified categories of this study from both a parental and professional perspective (see figure 8). Identification of common ground between the stakeholders of this service and their differences will be related to current literature throughout the discussion. This will be followed by an analysis of the needs of the child and family which are not met through current service provision. Suggestions and recommendations for changes in service delivery to address these needs will then conclude with a model of practice which also identifies the conceptualisation of the data analysis.
Ideas are also presented throughout the text of some of the more immediate changes to practice which could be made. These changes could provide a more positive foundation upon which to implement the key worker role and a key worker service and enhance team working within the boundaries of current service provision.

Recent literature and policy which was not part of the original development of this study that has been published since it’s onset and has significant relevance to the study context will then be presented.

The chapter will then go on to present factors as identified by study participants that may mitigate against proposed change and development in the future. The chapter will conclude with a summary.
Figure 8: Discussion Route

[Original in Colour]
6.1 Criticisms of Current Service Provision

6.1.1 Human Factors: Individual Personalities

The nature of individual personalities and dominance of some individuals in a team had a powerful influence on working relationships and often presented tensions during interactions between team members. Both parents and professionals discussed the influence of strong or difficult individuals they had come across in the team. Some felt that this influence could change the situation and make the difference between a family’s ability to cope with a problem or not. Hinojosa et al (2001) identified the influence of individual professional identity particularly when assuming the key worker role and Mukherjee et al (1999) discussed the fact that the individual may not actually be aware of such influences in practice. In this study both positive and negative influences were referred to – some resulting in enablement of the family and others the opposite, sometimes creating a dependency of the family on the professional. This may be due to the professionals’ inability to ‘let go’, or a ‘need to be needed’ – as previously described by Mitchell and Sloper (2002).

With this influence in mind a hierarchical approach to the management of the child and a lack of regard for the parents’ strengths by the professionals in the team may reduce the effectiveness of key working and partnership with the child and the family. The individual personality, qualities and nature of the key worker will inevitably influence their effectiveness when working with the family. Service providers should respect the need for flexibility when allocating the key worker and recognise the possible need for change if the relationship between the family and the key worker becomes problematic.
6.1.2 Human Factors: Professional Ideology

Professionals interviewed within this study were often found to be loyal to their own ideologies and occasionally less than accepting of others. This appears to stem predominantly from the fact that different professionals are employed by different agencies. This is an issue which has also been identified in literature as having a major influence on the effectiveness of team work and the role of the key worker (Appleton et al 1997, Mukherjee et al 1999, Vetere 2007). However, the majority of this literature focuses on overcoming these inter-agency barriers and there has been little suggestion of a radical shift from the current situation of multiple agencies to a single all inclusive agency - suggestive of a Children’s Federation - supplying services to children with disabilities and their families.

A children’s federation could see the amalgamation of all employing statutory agencies into one single organisation with one culture and philosophy to which all employees subscribe. Radical as it may seem this may be the only way to eradicate these barriers, whether perceived or real, and improve the dynamics of team working, creating a more favourable climate for true collaborative working. Shared pre-registration training may also help to overcome some of these cultural barriers and this is now beginning to happen in a small way with the Common Learning Programme (University of Southampton 2003).

6.1.3 Service Organisation and Delivery: Agency Silos

It became clear during this research that the three main statutory agencies appeared to operate in very different ways which may, as in the Goodley and Tregaskis (2006) study, be described as institutional. Participants, both parent and professional, described
the agencies as operating from isolated silos with the cross agency interface creating functional difficulties for the team. This factor reinforces the differences between professionals as has been mentioned earlier in this chapter. Townsley et al (2004a, 2004b) referred to this problem as causing professionals to be less likely to be committed to working together particularly when problems or difficulties arise. The complexities of the organisational systems were influenced in part by politics, policies and philosophies which constructed particular cultures within each organisation – a factor recognised in previous studies by May (1996a, 1996b) and Sloper (2004). The diverse cultures and philosophies of professionals from the three main statutory agencies were identified by professional participants of this study as having a bearing on their ability to work with other members of the team employed by those agencies. Establishing a key worker service on such a foundation of lack of trust and supportive working is likely to prove problematic for anyone undertaking the role.

6.1.4 Service Organisation and Delivery: Professional Language
Each agency and group of professionals appears to have developed its own terms of reference and language. This has also been recognised in an earlier study by Holloway (1997). One of the evident factors in this study data was that the language and certain words and phrases used by the different professional team members from different organisations meant different things to different people, e.g. the use of acronyms which often led to confusion. Time was needed to discuss and learn the language used by staff from different agencies and to develop a shared understanding and terminology common to those across the team. From a parent viewpoint they relied very much on professionals in an advocacy role particularly with regard to case conferences, to
explain and interpret the language and terminology used during such meetings. This need gives an indication of how ingrained into practice specific language has become and how difficult it is for a lay person such as a parent to fit in and understand proceedings in this situation. It also raises the issue of the need to change such practice so that parents can feel true inclusion in the team. The influence of professional language on team work and in particular the role of the key worker could be a potential area for future study and is suggestive of a gap in current knowledge.

6.1.5 Service Organisation and Delivery: Bureaucracy
The influence of the unique bureaucracy within each agency on the effectiveness of the roles of team members was felt sometimes to be restrictive by professional participants and cause a shift away from a child centred service. Within the literature the key worker role is described as facilitating better access to services (Townsley et al 2004b) however the key worker may be in no better position to secure services than any other team member if established bureaucratic processes prevent this. The concern of some participants was the extent that the key worker role in itself would merely introduce yet another layer of bureaucracy for the family and complicate an already complex system – a potential risk also noted in the work of Braye (2001). As a result participants questioned the value of the key worker – a negative perception of the key worker role which is not explored in the current literature and may be worthy of further investigation.

Navigating the complex bureaucratic maze of regulations and access criteria of the current agency silos was found to be arduous for most of the participants both parents and professionals. This does not reflect the rhetoric of current policy around provision of
seamless services for children with disabilities and identifies the inflexibility of current service provision.

An understanding of the bureaucracy of service access criteria was felt to be lacking across the agencies and such information did not appear to be readily available, transparent or shared across the team - findings which support those in the earlier study of Townsley et al (2004a, 2004b). Many in the team simply found out what other service criteria were when they had a complex case they wished to refer and were then refused access. For a key worker lacking this information and knowledge will cause frustration for them, the child and family and the team.

Many parents identified difficulties in understanding who ‘belonged’ to which agency and who they should contact with particular issues and problems or for specific information due to the complexity of the current bureaucratic systems, thus identifying an unmet training and education need for them.

Sainsbury (1998) and BDF Newlife (2007) both identified inconsistencies of bureaucratic systems across the country with regard to access to, and funding for, equipment for children with disabilities and called for a more unified approach in this context. This issue highlights the need to invest in ongoing provision over the long term for children with disabilities. These children are surviving to a much older age because of the developments in neonatal care where advances in medical practice have been significant and as a consequence they are becoming dependent on community services where developments and investment in resources has been limited.
The influence of access criteria on team working and the role of the key worker are not well documented in the current literature possibly supporting the suggestion that there may well be local bureaucratic variations and little national consistency of threshold for qualification of services and provision. This is an area where further investigation could prove useful when developing services for children with disabilities.

6.1.6 Service Organisation and Delivery: Organisational Drivers
The drivers within an organisation - National (e.g. Department of Health 2004a, Department of Health et al 2008), Local (e.g. NHS South Central 2009), Political, and Economic - also emerged as a strong influence on team working from the professionals' perspective. For some it was important to meet targets and deadlines to gain financial support, often citing lack of timely response from other agency professionals as causing a breach in these targets. This often resulted in feelings of frustration at the lack of support from other team members however; these targets were not necessarily shared across the team and were particular only to one group, i.e. the social workers. There is little evidence within the literature identifying the impact of targets on team working and the role of the key worker. It would be interesting to map the current national targets and drivers of the different agencies to see if these are compatible, consistent and how they may influence team practice and the role of the key worker.

6.1.7 Service Organisation and Delivery: Funding
Funding streams and how to access them were identified by parents and professionals as complex. This finding was similar to one of the outcomes of the study by Townsley et al (2004b) who found that funding complexities were prevalent even within the well
established multi-agency teams. Participants within this study reported that discussions about funding responsibility appeared to delay provision for an inordinate amount of time. Many of the parents demonstrated resilience and stoicism to the complexities, delays or absence of service provision and resource allocation due to funding issues for their child and family – a resigned acceptance of the way things were. One possible cause for the lack of provision of resources has previously been identified by Sainsbury (1998) who raised the issue of the lifelong challenge of disability and the need for sustained family support and appropriate funding. The study by BDF Newlife (2007) echoed these findings, identifying poor investment in this area of health and social care, and a lack of strategic support for these children and their families.

The lack of shared budgets and the lack of clarity over who pays for which provision, service or resource was a great frustration for all concerned in this study – both parents and professionals. Carey (2003) referred to the budget being an important factor in team culture which has the power to impact on everyday practice and this was evident in this particular context and borne out by the participants in this study. Once again although the literature identifies this as an issue in this context there appears to be no suggested resolution to the on going problem. However, one solution may be for the team around the child, co-ordinated by a key worker, to complete comprehensive reports and present a prediction of the likely needs of that child and family over a period of time, providing evidence of the likely cost factors of supplying a service to meet those needs – a truly child and family centred approach. This may assist budget holders to set and manage their budgets more appropriately and prevent delays in provision for the child and family.
What is clear from the study is that there is a lack of clarity for provision and the process for getting funding for resources. This results in delays in supply which affects the well being of the child and family with the potentially longer term impact of increasing the cost of the statutory provision.

6.1.8 Service Organisation and Delivery: Location
The impact of geographical borders on access to services and service provision is not a factor which features predominantly in the current literature. Participants of this study demonstrated the inflexibility of the current system with regard to location in more ways than one. The geographical boundaries of the statutory agencies did not map each other which resulted in some families receiving services from different agencies that often worked from different areas and had access criteria that varied from one area to the next. Inequity of service provision between one geographical area and another resulted in some children receiving provision and others not - such bureaucratic parameters resulting in a postcode lottery where service provision was concerned. The postcode lottery phenomenon is something which is referred to with regard to equipment provision in the work of BDF Newlife (2007) and is perceived as common particularly in the healthcare sector. The consequence of this situation was that parents and families were disadvantaged, spending more time travelling with their child or changing service providers and developing new relationships with yet more professionals who were undertaking their child's care, thus adding to their stress and undermining their emotional well being.

The geographical location of the team also appeared to influence team working relationships and the potential success of the key
worker role. Some professionals identified better working relationships when in an inner city team than in a team which was spread across a rural area. When service providers were co-located and used a shared service base this was found to be helpful and improved communication and contact. Co-location of team members may therefore provide an opportunity for informal team building activities and a shared sense of belonging that is not found across current team members who use separate bases. This was certainly the perception of those participants of this study who worked predominantly in the mainstream sector of education. This perception was the reason for the shift from purposive sampling to theoretical sampling during the data generation period of the study. Those participants who only worked with one or two children with disabilities who attended a mainstream school were of the opinion that collaboration between team members and the potential for key working would be much better placed in a special school setting whereby the team around the child were working more closely together and spent more time co-located during their day to day work. When interviewed the staff of the special school felt this was true to a certain extent however still reported that there were difficulties across certain agency boundaries – particularly that of social care - a feeling mirrored in the mainstream setting. This once again emphasised the impact of the team members being employed by different agencies, having different cultures, targets and philosophies. All of which influenced the way the team worked together. Co-location, along with employment of staff within one organisation, may assist the key worker particularly in the aspects of their role related to communication and co-ordination of services.
Geographical border issues provided a prime example of the lack of flexibility of current service provision and the lack of understanding about the family situation. A co-located team co-ordinated by a key worker, with good communication, cooperation and collaboration may be able to discuss service provision more flexibly and offer solutions to apparently unreasonable situations making decisions as a team and improving the outcome for the child and family.

6.1.9 Working Together: Team Organisation & Membership
As a combined multi-agency service provider for children with disabilities and their families, the team around the child had no evident organisational structure in this study. One consequence of this was that there was no tangible aim about what it was they were trying to offer service users. McConachie (1997) and Yerbury (1997) similarly identified this factor and reported it as being a major structural problem in team work leaving the team without clear goals or objectives. In order to develop shared objectives and aims there has to be an established means of co-ordination and team leadership. The team members in this study were not managed in any formal sense of the word. It can be seen by the background of the different participants that there were multiple stakeholders involved in this area of practice but no clear leader. The introduction of a team leader or team manager should assist in the provision of structure to the team and help to provide some co-ordination of those involved. This may be seen as part of the role of a key worker but may be more of a strategic management role.

6.1.10 Working Together: Understanding Roles
There was a lack of understanding about the various roles of the professional team members. This was expressed by both parents
and professionals many who were senior and had been working in the clinical field for many years. This lack of understanding of roles has been identified in other studies (May 1996a, 1996b, Yerbury 1997) but in this context could be a potential barrier to both effective team working and effective key working. For the participants in this study there appeared to have been little or no time to share training when role definition of those in the team could have been discussed. Roles were also not explicit or consistent across the agencies, which presented difficulties for parents. Both parents and professionals often saw this as a duplication of practice and professionals often cited this as a potential area for tension. This echoes the issues of professional boundaries and responsibilities referred to in the work of Robinson and Cottrell (2005) who described team members as potentially colliding as individual tasks were redefined. Some participants in this study described a feeling of service duplication and a sense of being ‘checked up on’ by someone of the same profession but working for another agency. However, many saw the benefit for the child and family of having a range of expertise in the team. These issues could be addressed in structured team building which included parents, if investment in this activity, in terms of time and money, were made.

6.1.11 Working Together: The Key Worker Role

One of the main roles suggested in the literature about the team around the child and the primary focus of this study was that of the key worker role. Importantly the need for training for key workers was identified by many of the participants of this study – parents included. It was felt that regular contact was not the only qualification needed but that it was more about having the appropriate skills to fulfil the role. Many may see this as an
expensive and consequently prohibitive resource which may be a reason why implementation of the role is not more common. Many of the skills identified by participants paralleled those recognised in the current literature (Boarder 2002, Care Co-ordination Network UK 2004) and demonstrated the variety and diversity of expertise required for the role. One of the problems however, was that the role of the key worker meant different things to different participants. This problem is reflected in much of the current literature (Emmanuel et al 2002, Carey 2003, Riddell-Heaney 2003, Sloper 2004). This can lead to limited success and confusion when working with others who have a different perspective. Across this study there was no clear understanding of exactly what the role encompassed and many participants suggested that it would be very much dependent on the individual who undertook the role. This finding indicated an obvious lack of prior training for the participants of the key worker role. It also highlighted a need for consistent understanding of the job profile across all the professional groups including the parents of children with disabilities to ensure equity of provision for the child and family.

Parents used examples of situations they had experienced to demonstrate how they would approach the professional they felt most comfortable with and who they felt could deal most appropriately with their need at that time, irrespective of team structure, and potentially bypassing the appointed key worker if there was one. This independent action may well potentially negate the need for a key worker. There appears to be a certain logic and reasoning behind this action – why go through a third party if you can speak to a more appropriate person direct and get an answer to your question without delay? This would be particularly true if the key worker employed had little knowledge or
experience of the area of practice and highlights the need for knowledge, education, training, a clear understanding of professional roles and services for any key worker as advocated by Appleton et al (1997). This would suggest a need to research teams where there is an established key worker and to compare this with a team where there is no identified key worker to see if the outcomes for the child and family are significantly different. To date there is minimal evidence of this nature available.

The key worker role was described in the health context with the health professionals identifying ‘health competencies’ that would give them adequate skills to carry out any health elements in the role. This approach suggests the concept of the key worker for these staff is based very much within a medical model of disability. These findings mirror those of Hinojosa et al (2001) who documented the differences of delivery of care by professionals from different agencies. These findings were also supported by Meeks (2001) who reported on social workers who based their intervention in the context of social care. The impact of the professional’s background and their philosophy relating to the employing agency can not therefore be underestimated for the consistency of the key worker role.

6.1.12 Working Together: Relationships
Positive working relationships were not uniformly experienced by all team members. Some relationships were felt to be precarious demonstrating the strength of feeling across professional boundaries and the enormity of the task to improve these. For those who did feel they experienced more positive team working the support from the team was felt important when services were under pressure due to staffing shortages. Staff described the ability to
‘share the load’ across the team and offer alternatives until such time as those services were back to full capacity again - a demonstration of true collaboration between team members. Abbott et al (2005) described this as a role release or transfer and an opportunity for role expansion whereby professionals can train in the concepts and language of other professionals to provide better co-operation and collaboration between staff of different agencies. Many of the participants referred to the concept of sharing the load of the co-ordination and management of the child, with the key worker having a lead responsibility as opposed to the lone responsibility for the management of care of the child.

6.1.13 Working Together: Parent Partnerships
Despite the wealth of literature claiming parent partnership and family centeredness as the way forward within this context of practice (Rosenbaum et al 1998, McConachie 1999a, Pickering and Busse 2010), the lack of kudos and inclusion of the parent in the team within this study was a concern. There was evidence of a distinct gap between actual practice, the reality of partnership working and the desire to do so. Some professionals appeared to be reluctant to engage with parents in this way - a not uncommon phenomenon also reported on in a study by Hinojosa et al (2001). The disparity of power and authority was a particular challenge for parents although also recognised by professionals. In the health care team much of this seemed to stem from the strongly hierarchical medical model of practice and the important role and status given to the medical expert.

The lack of respect for the parent within the team and inequity of their representation on the team resulted in an imbalance in the working partnership. This potentially created an element of
dependency for the parent on the professionals. It seemed to suggest that the parent was not being empowered to help their child and that knowledge and skills were not shared across the parent-professional boundary. Parents felt that they were not always recognised or respected as an equal partner in the team – a phenomenon previously referred to as being sidelined by Limbrick (2007). There was a sense of paying lip service to the concept of parent partnership but the reality demonstrated a lack of conviction to the idea – a finding which reflects the work of Kirk and Glendinning (2004). This finding may give an indication of lack of confidence on the part of the professionals to sign up to the parent-partnership approach and the need for training and development in this area.

Parental involvement in team training was raised by parent and professional participants in this study. Parents felt they had a valuable perspective to give and were keen to be involved in the training of professionals. Parents may be able to help professionals understand the reality of living with a child with a disability and be able to demonstrate some of the effects of the professional intervention and intrusion into family life as suggested in the work by Quinton (2004). Many studies identify that parents are an important part of the team around the child (Rosenbaum et al 1998, McConachie 1999a, Pickering and Busse 2010) but they do not identify training as a specific role for the parents. Parental involvement in training could be extremely powerful for many clinicians who may only see the child in a clinical setting and lack understanding of the reality of family life. This could be something that could be implemented within current working practice and a key worker may be the ideal person to involve parents when they feel they are ready to participate.
The nature of the parent-professional relationship was identified as a critical element in securing a positive outcome for the child. A relationship built on openness, equality, trust and honesty was felt to be essential. The importance of enabling communication by being approachable was expressed by many of the parents who had all experienced very negative interactions with certain professionals since their child was born. They detailed accounts of how this affected them, their understanding of what that professional said and their reluctance to return to see that professional again. Being treated with respect was valued and appreciated by the parents but this was not always their experience.

Similarly the nature of the partnership between parents and professionals could greatly influence the success of the key worker role. A key worker must take care to balance the support given to a child and family to enable them to develop and utilise the skills they have to manage their situation however, if the professional remains influenced by the hierarchical medical model of practice and the professional as the expert, this may stifle the parental coping skills.

A successful relationship took time to develop and once again parents commented on how difficult this could be if practitioners kept leaving, moving on, or were moved by their organisation - an issue also identified by Emmanuel et al (2002) who found this a factor which impacted on the success of the key working system.

Transition periods in the child’s life often led to problems when the personnel dealing with the child changed. One consequence of this was that the parent had to constantly repeat their ‘story’ and give information about the child’s management, an issue also
identified by The Dartington Hall Trust (2004). This often re-opened old wounds for the parents and impacted on their emotional well-being. Where this relationship went to the opposite extreme and the professional remained consistent over a period of years there was a potential for dependency on a particular favourite professional. Not only did this cause problems when the child came to transition into adult services – the parents reaching crisis state as they would no longer have access to that professional; but it also had the potential to restrict the development of coping strategies for the parents. Skills they would need once the child outgrew paediatric services at age nineteen. The development of a contract laying out a gradual reduction of services from the paediatric professional team over the transition period to adult services may be helpful for families and young people in this situation. Information detailing service availability in the adult sector may also smooth the transition period. A key worker may be supportive at this time. Currently the availability of transitional services between paediatrics and adult service providers are not well developed and this is an area of practice that has great potential for improving the outcomes for young people in their care and management as they progress into adulthood.

6.1.14 Working Together: The Core Team

In reality the high numbers of children on professional caseloads makes it impossible and unnecessary for all professionals to be permanent members of one team. The support needs of the child and family were identified as changing over the lifetime of the child so it is inevitable that team membership would also change. Their involvement with a high number of children would necessarily mean professionals would be ‘members’ of multiple teams and the need for attendance at all meetings and case conferences would
be an unrealistic expectation. Staff would be overloaded and workload stress could result in their capability decreasing to the detriment of the children and families. One co-ordination strategy offering more flexibility to the service user was explored by Tait et al (2002), who described the need for a ‘core’ team and this would appear helpful in this context. According to Tait et al (2002) children with complex needs require a small individualised cooperative and collaborative team to provide effective support. Tait et al (2002) suggested that entry and exit of workers to the team around the child would be based upon and dictated by specific and unique needs of each child and family at a particular moment in time rather than there being a predetermined team structure. This idea demonstrates the need for flexibility in service provision in this context which may not be currently present. The core team would be required to take an active role in decision making and have knowledge of the context and detail of the child and family. The high numbers of professionals involved with the child identified by participants in this study would suggest however, that a core team would need to keep in touch with peripheral practitioners who may have intermittent contact with the child and family – a potential liaison role for a key worker. By reducing the size of the current teams some of the pressure on parents; the impact of multiple assessments and numerous home visits and appointments, could be reduced. A review of team membership may be necessary. If professionals are members of multiple teams a reduction in current workload levels may be necessary to enable them to fulfil their roles effectively. This would require an investment in human resources in order to share the workload.
6.1.15 Working Together: Specific Roles

Some team members had very specific roles related to issues of safeguarding children such as child protection. Many participants referred to the very negative nature of the work that social workers carried out, including the social workers themselves and the negative public image and stigma the service had. This made parents particularly reluctant to engage with those services and professionals, presenting a clear barrier to successful team working and potential implementation of the key worker role – particularly when the social work team referred to a ‘key worker’ specifically for child protection work. This point was also identified in the work of McConachie (1999a), in her evaluation of multidisciplinary services for disabled children. It was described as a great irritation for many families; a view wholeheartedly supported by the parents in this study.

6.1.16 Communication: Team Communication

Communication permeated all areas of the study and was perceived by both parent and professional participants as being influential on the effectiveness of team working and the nature of the relationships between those who were working together. Somewhat surprisingly communication per se is not specifically highlighted in many of the studies exploring team working and the role of the key worker. However there is a sense that it is implied as being crucial to the effectiveness of the role through information sharing and the key worker acting as a first point of contact (Kirk and Glendinning 2004, Gurr 2006).

The difficulties of managing team communication across all the inter-agency interfaces, was identified as a real problem in this study. This may have been due to the lack of formal team
leadership or co-ordination as well as the influence of cultural language across the agencies.

Once a diagnosis had been given for the child communication with the large number of professionals in the team became the next problem faced by the parents. As Limbrick (2007) reports children and families with complex needs are those for whom the plurality of intervention is itself a problem or in danger of becoming a problem. Over-burdening the family becomes counter-productive for the child. Within this study the high number of visiting professionals to the family home was identified as difficult for the parents to manage. Parents cited many of the professionals identified in the work of Beattie (1999) focusing on the team around the child. Some listed as many as twenty individuals involved with their child. This has already been expressed as a concern regarding the intrusion into family life (Quinton 2004) but it is also time consuming for the parent and child as they found few of the visits were co-ordinated with two or more professionals due to lack of team communication. This concept demonstrates the fact that in this context it is the whole family who are recipients of services and not just the child with the disability re-emphasising the need for recognition of Rosenbaum et al’s (1998) child and family centered approach. Support for the family at the particularly sensitive stage of diagnosis could be more co-ordinated if the team were managed in a more formal way. A particular professional could be identified as a key worker to visit the family immediately or at least very soon after a diagnosis has been given to provide support and information.

Most participants valued face to face communication between team members but often the parents were not included in this
team interaction – once again giving an indication of how the reality of parent partnership does not reflect the current policy in this area. However, some professionals were concerned at how the changing nature of their roles meant less and less time for face to face contact with the child and family – whether this was in meetings or clinical contact on a day to day basis. Many participants referred to the desire to meet regularly as a team, a suggestion that would support the need to invest time on team building activities as described by Dukewits and Gowin (1996).

6.1.17 Communication: The Key worker – One Point of Contact
Certain agencies felt they had better connections with some more than others and this was referred to more as a problem of relationships than with technology. Parents identified this as an issue and were very aware of the limited contact between staff from some agencies, a gap which they often had to fill. This often detracted from the parenting role and was very time consuming. They often requested someone to help with this task and expressed a desire for one point of contact through which communication could flow. This reflects the findings of the National Service Framework for Children, Young People and Maternity Services (DOH 2004a). Many of the professionals also supported this view finding communication with other team members difficult and time consuming. The core concept of the current literature of the key worker being ‘a single point of contact’ (Braye 2001, Limbrick 2001, Boarder 2002, Townsley et al 2004a, 2004b) was recognised by the study participants and both professional participants and parent participants referred to this as a crucial element of the role and something that would make a huge difference in practice. However this may be impossible to achieve within the scope of current workloads and lack of compatible information technology
systems across the agencies. A long term investment in both staffing resources and technology may provide a solution. Communication was seen in this study as an essential element of effective team working, team collaboration and key working.

The child and family are vulnerable and at risk of advice and information overload from so many sources. Contradictions about treatment, medication, surgery and general management of the child’s condition may go unresolved. To have one key person – a key worker - through which information and communication is channelled, plus regular face to face team meetings would therefore be a major improvement.

However, there were some participants, both professional and parents, who expressed a certain level of doubt about the notion of ‘one point of contact’ – an issue which has not arisen in the current literature. Some study participants believed that to have one identified person as the key worker could potentially limit parental interaction with the team if, for example that key worker was absent from work when the parent needed support. The parent may not feel empowered to talk to any of the other members of the team in the same way as the key worker and any issues may remain unresolved until their key worker was available. Parents also expressed the need for independence in their choice of who to approach to discuss certain issues. They felt they would be selective depending on the issue when choosing who to go to for help – thus possibly negating the need for a key worker. In addition some professionals actually felt that there was little difference in a key worker role and their current day to day role. Many believed they had taken on an unofficial key worker role and were doing much of what might be expected of someone in that
role. The need for someone else to join the team as a key worker therefore would be unnecessary.

6.1.18 Communication: Information Technology
Communication was often hampered by the lack of compatibility of information technology systems both within and across agencies, and concerns about data protection. One such example was that of different email systems in different agencies. Importantly, this lack of communication impacted on the establishment of shared goals, aims and objectives for therapeutic intervention with the child and family. For some professionals they feared that this placed them at risk and potentially endangered the child, their intervention being based on only part of the wider, but not necessarily shared, assessment of the child. Team members needed to be in an informed position, and have access to reliable information in order to manage their intervention with the child and family. A consequence of this resulted in parents being placed in the position of becoming the information conduit for the professionals. This situation was not uncommon and has been identified in other studies such as Kirk and Glendinning (2004) where parents were found to perform multiple roles associated with that of the key worker including communicating and passing information between members of the team.

6.1.19 Communication: Regularity of Contact
The regularity of professional communication with parents was raised by parent participants in this study as a concern. They were actively seeking proactive contact from the professional team however many of the team members worked in the community and were therefore difficult to communicate with. In effect this proved problematic for both parents and professionals. The issue of
part time staff was also highlighted with relation to the problems of contact when team members only worked one or two days a week. The lack of communication from some professionals was however defended by several parents who claimed that because of perceived high caseloads the professionals were very busy. Sometimes parents did not make the effort to contact the professionals as they did not want to disturb them, despite having needs and issues to be addressed. The parents here took a passive stance giving an indication of a resigned acceptance of the current deficiencies in the system of provision for these children and their families. Implementation of the key worker role has the potential to resolve this issue for parents. The key worker could initiate regular pro-active contact with the family as advocated in the studies of Mukherjee et al (1999) and Barton and Clarke (2005), to help improve communication channels.

6.1.20 Communication: Documentation

When discussing the issue of communication with other team members particular reference was made by the professional study participants to patient documentation. The lack of cohesion of patient records across agencies was noted as a frustration in team working and indicated a lack of seamless service provision – a goal of much of the policy documentation since the publication of the Court Report (Department of Health and Social Security et al 1976). Although staff commented that sharing information could be difficult because of patient confidentiality, parent held paper records were felt to be a possible solution to this issue and one which could be implemented within current practice in the short term. However, parent held records may still continue to result in duplication of recording systems as professionals need to be able to produce case notes when requested as evidence for litigation
purposes. In the future the use of electronic record keeping may assist in communication across the team including the parents (providing there are inter-agency access agreements in place and systems are compatible). If access was openly permitted for parents to see their child’s record and indeed add to these the use of electronic systems may help to resolve some of these issues.

6.1.21 Communication: Shared Experiences and Information Sources

It was very clear in the study that the impairment or disability did not just affect the individual child but also impacted on the life of the entire family. Carpenter (2000) questioned whether or not professionals had real insights into how a child with a disability impacted on family life. They often made assumptions about family needs whilst not truly understanding the parent experience. Parent and professional participants in this study identified this as an issue. The parents felt that professionals did not understand how difficult even the easiest things in life could become once you had a child with a disability. Professionals admitted that due to their lack of personal experience they may not be the best people to offer certain advice to parents. It was apparent that some things may be better suited to being discussed in a communication forum with someone who had the shared experience, i.e. someone with insider knowledge - a parent to parent interaction. This coping strategy is also identified by Ware and Raval (2007) as used by fathers of children with life limiting conditions.

Parents in this study also found that professionals did not communicate more general information to them and this factor was also recognised in the recent studies of Goodley and Tregaskis (2006) and Koshti-Richman (2009). Goodley and Tregaskis (2006)
stated that the information that parents gained outside of their involvement with professionals clearly armed them with critical knowledge about their right to access additional services for their children. Koshti-Richman (2009) found it troubling that many parents were unaware of their rights to benefits such as Disability Living Allowance and Carer’s Allowance as the professionals they were dealing with assumed someone else would tell them about financial support.

The parent to parent interactions in this study were identified as ad hoc. There was no formal forum for regular parent to parent contact in which useful sharing of information could occur. This demonstrates a gap in service provision not only in this study context but possibly on a wider scale for children with disabilities and their families which could be directly related to the lack of key worker provision.

Information supply is clearly a function identified in the literature as one of the roles of the key worker (Limbrick-Spencer 2000). The identification of a need for parent to parent interaction did not mean however, that the role of the professional was in any way diminished or negated but highlighted the need to recognise the valuable contribution parents themselves could make to other families.

6.2 Child, Parent and Family Needs

The needs expressed by the parents in the study ranged from emotional support to instrumental and practical support. These included support at the time of diagnosis of their child to timely...
provision of equipment to assist in their child’s day to day care, to provision of another person to assist in family outings.

The variance in level of need identified demonstrated the individuality of requirements of each child and family, a factor which has been demonstrated in many of the earlier studies pertaining to children with disabilities and their families (Greco and Sloper 2004, Kirk and Glendinning 2004, Ware and Raval 2007).

Both social and medical needs were highlighted but professional team members felt they often had limited resources and facilities available to address these. Team members with a better knowledge of services provided by other agencies may be able to signpost the family to more appropriate sources of help and support. However, in the first instance this knowledge would have to be shared with the team members in particular a key worker and team building activities alongside joint training would provide a forum in which this could happen.

The concept of there being a key worker role for health matters and a key worker role for more social issues [sometimes referred to as direct assistance (Carpenter 2000)], was identified by both parents and professionals as quite different things. This highlighted the differing nature of the needs of the child and family and the requirement for a versatile approach to support. This concept challenges current literature on the nature of the key worker services which does not identify these particular needs as distinct entities within the key worker role, but to the participants within this study they clearly existed.
Both parents and professionals interviewed in the study expressed a need for some form of support for the sibling of the child with a disability. Care for the whole family, beyond just the child with a disability, has been recognised in much of the literature about key working (CCNUK 2004). The lack of family-centeredness and family focus of care meant there was little support for siblings in the current system. Some professionals were somewhat cautious however, fearing that if they had to address the issues across the whole family the disabled child’s needs may become swamped and lost and this presented them with a dilemma – possibly indicating a lack of flexibility on their part and a lack of shared aims and objectives across the team including the family. This finding reinforces Carpenter’s (2000) belief that within current outmoded support systems there is still discrimination against family involvement. Professional respect for the parent and shared goal setting would assist in identifying and addressing the wider family needs.

One factor discussed by parents was the need for support at different times of day and night and the limited availability and lack of flexibility within current service provision to address this need. Parents referred to this as a ‘24:7’ need. Parents could never be certain when questions or concerns about their child would arise and they expressed a desire to be able to contact someone to discuss their issues – particularly when this was out of office hours or at weekends. It is unlikely that current resource funding would enable a 24:7 service provision. A key worker would be contracted to a set number of hours in any one working week and therefore would only be available to the family at certain times – indicating that a family may need access to more than one person as their key worker. A more financially viable option may be for staff to
work more flexibly over a seven day week with adjusted hours to cover an extended period of the day and early evening. This would involve new employment contracts which could be introduced as staff change over time. To offer a seven day week service would mean for many professionals currently working in this area a major change in working routine and in working culture. Many services in acute settings are already familiar with this working practice and it may be appropriate to consider this in the future for community services. However, this change to working practice may be attractive to current full-time staff wishing to work compressed hours, part-time workers or those who have young families and find child care cover costly and difficult to obtain. Therefore such a change in working practice may be favourably received by the current workforce.

Parents found that the current system often meant a long wait for a reply to a question or information request about their child’s condition which caused a rise in anxiety and stress. Even during office hours logistical issues about communicating with the team arose. As identified by Quinton (2004) support is complex to assess, to get right and deliver and would suggest a need for greater flexibility in the support systems currently on offer. Support giving is a balance between enabling individuals and families to make the most of their potential and supporting those in difficulty.

It was apparent from the study findings that the impact of having a child with a disability was not just centred on the moment of diagnosis but for the parents occurred over a lifelong journey. Parents were repeatedly upset as they were reminded of the needs of their child at different stages of their growth and development right up until transition into adulthood and beyond. Feelings such as
these are apparently not uncommon in parents and carers of disabled children and young people as reported by Yerbury (1997), MENCAP (2003) and Stevenson (2009). However, the support mechanisms for the family particularly following diagnosis appeared at worst non existent and at best delayed, leaving the parents anxiously searching a variety of sources of information about their child’s condition. This situation is reflected in other studies of parental experiences (Ware and Raval 2007) indicating a clear need for support at this time.

Professional participants noted that throughout the child’s life the parent had changing information needs. The need for information about the statutory processes such as the Statementing process for Special Educational Need, grant application for housing adaptations, and entitlement to benefits were often apparently unmet. The consequence of this was that parents were often unprepared for interaction with certain professionals and had to do a lot of investigative work on their own. The practice of information giving was explored by Mitchell and Sloper (2002) who found that the parents in their study identified similar concerns. This gap in service provision possibly highlights a need for a key worker, however, in the short term information could be provided more proactively by current team members.

Information for the parents about their child’s condition was also felt to be lacking. Parents felt it would be helpful to have leaflets that they could take away following a consultation with a professional to allow them to absorb information when they were ready. Professional participants agreed that if sufficient and appropriate information was supplied for the child and parent it may reduce the need for support such as a key worker would
provide. The need for distinct information pertinent to the child was once again recognised emphasising once more the individuality of each child and uniqueness of family circumstances.

6.3 Conceptualisation of Findings

When examining the findings of this study it becomes apparent that the causal relationships between the categories identified and presented in chapter five and discussed at length above begin with the impact of the child’s impairment. How this affects the stakeholders concerned in the team around the child can impact on the outcomes for that child and family. The effectiveness of the working relationships in the team around the child – be they parent to professional or professional to professional is then greatly influenced and related to the personal culture of individuals. This is often related to the nature of organisational cultures identified within this study which appear to act as a barrier to effective team working. Finally the whole system is related to the influence of societal views and how people react and accept children with disabilities and their families.

6.3.1 Impact of Impairment
The impairment of the child not only affects their physical ability due to the pathology of the condition and the severity of affectation but also how this affects their ability to function in every day life. This will impact on the child’s level of dependency and thus influence how much help and support they need from their carers. The impact of the child’s impairment affects not only the birth parents or those identified to care for the child, but the siblings and wider family members. The personal impact on carers has proven to be varied and the parental voice within this study has
identified many reactions to having a child with a disability in the family. Many of the parental responses have been on a personal level (i.e. feelings of guilt, sadness, and suicidal tendencies) but others have affected relationships with partners and other family members. The actions of carers in response to the child with a disability vary from an inability to cope, emotional and physical exhaustion, dependency on professionals, to resilience and strengthening of character during their constant battles with the 'system'. The 'disabled' family are all recipients of services and the longer term impact of this is sometimes not evident until the child passes away. The consequences of the parental responses and actions in relation to the child appear to influence and affect the interaction and relationships with the professional team around that child. What we begin to see is the 'ripple effect' such as occurs when a pebble is dropped into a calm pond. The child is represented by the pebble and gradually it affects a wider and wider group of people. If the parents react with anger at their situation and relationships become turbulent this can impact on wider relationships across the team – the water in the pond becomes very choppy. The nature of the child’s impairment will affect the reaction and actions of the professionals in different ways. This may depend on their level of experience, if they have had contact with this type of impairment before, and external issues such as their current work pressures and stresses. The nature of the child’s impairment will also influence what services the family are eligible for and the criteria for service provision in certain agencies.

6.3.2 Impact of Individual Culture
The second level of influence which appears to relate the findings is one of individual characteristics and culture. Everyone in the team
around the child has their own individual culture. This may be related to upbringing, religion, moral culture, experience, education, training and social standing; or it may be based on their professional background. However a combination of all these factors will influence how they react in this particular context and what actions they take as a result of being part of the team around the child. As has been seen in the study the personalities of some individuals can greatly influence the success or failure of a relationship either between a parent and a professional or between two professionals. This in turn will influence the role of the key worker, the nature of the team work and subsequently the outcome of the experience for the child and family. Individual culture will also be influenced by organisational culture and once again this has been evidenced within the study. The suggestion of one employing organisation would reduce the conflict of this influence to a certain extent as all professionals would be employed by the same organisation therefore would hopefully have the same cultural philosophy linked to that organisation.

6.3.3 Impact of Societal Views

The third and final overarching level of influence identified within this study is that of how society views not only children with impairments and families who have disabled children but also the role of the professionals working with those children and the services provided by the statutory organisations. In addition to this the nature of acceptance of disability in the wider community – accessibility, ease of gaining help and support on a local level, availability of local provision suitable for children with disabilities, will influence the consequences for the families. One very clear influence identified within the study was the role of the social worker and the negative perception of the role that was
felt both by parents and social workers themselves. The influence of society’s views was very unhelpful and consequently parents were downbeat about having to have contact with them.

This conceptual level development once again re-emphasises the complexity of this area of clinical practice. It is difficult to represent every aspect diagrammatically - a complex web would be ideal however it would mask the detail of the underlying structure of any proposed model. An attempt has been made to give a simple representation of a suggested model of practice in Figure 9 which is included in the recommendations for service development section that follows.

6.4 Recommendations for Service Development

Despite the variety and scope of current service provision for children with disabilities and their families and the dedication of many of the professionals working within the study context inconsistencies, lack of flexibility, difficulties and gaps in service organisation and provision have been identified by study participants – both professionals and parents.

6.4.1 Definition of a Key Worker

When focusing on the role of the key worker in the team around the child confusion felt by the participants of this study both parents and practitioners, may reflect the lack of a definitive definition of the key worker within the literature and possibly indicates the need nationally for a clearer agreed definition from which all professionals and agencies can work.
As a result of the data generated in this study the following is a suggestion of a definition for a key worker:

'A key worker is an identified, named individual from the team around the child with a disability who has received training and has a clear understanding of the remit and scope of the role. The key worker should be known to the child and family and can act as the first point of contact for them and the team. The key worker maintains regular proactive contact with the child and family taking a holistic family-centred approach to their needs. A key worker advocates for the child and family and provides information to meet the individual and changing needs of the child and family over time. The key worker offers support when needed but also signposts and facilitates or enables the family to utilise their own strengths in caring for and supporting their child. The key worker works for the child and family in the first instance but co-ordinates services across all agencies and organisations involved in the team around them.'

6.4.2 Model of Practice
The model identified in Figure 9 presents a key worker role co-ordinated model of practice upon which to build the team around the child. This has been developed as an outcome from the findings of this research study.

Support for the model emerging from this study data includes the following factors:
• Single Employing Agency
Development of a single employing agency (a Children’s Federation) for all staff working with children with disabilities and their families may help to overcome cultural barriers which are currently identified as inhibiting collaborative working practice.

• Shared Location
A team which shares a work base location will have better opportunity for personal interaction and regular communication on an ad hoc basis as well as the opportunity for social interaction and networking which will enhance the understanding of one another’s roles.

• Shared Communication Channels
Improved documentation in the form of parent held records as well as professional records, and communication systems including information technology, is one significant area that would greatly advance team working and collaboration.

• Team Building/Team Training
A team employed by one agency and housed within the same service base could facilitate joint training and team building activities more readily than those who are employed by different agencies and work in different locations. Team building has been seen to take an extended period of time and a programme of work addressing this issue could be developed within the employing agency. Identification of a team leader or co-ordinator will give the team structure and clear management.
• Clear Team Objectives
Clear team objectives have been shown to be important. Having a collective goal and team philosophy could enhance team ownership and recognition and promote collaborative working.

• Child and Family Focus
The role of the child, parent and family within the team has been shown to affect the outcome and communication of information throughout the team. Parent partnership and recognition of parental expertise is a key to the development of knowledge and skills across the team.

• Needs Led Service Provision
The team around the child would need to carry out joint assessments to ascertain the needs of the child and family. These need to be co-ordinated to prevent duplication or omission. The team could then discuss priorities for the child and family at that time so that the family are not overwhelmed by intervention and the most appropriate people have contact with the child. A plan of management including identification of the anticipated future needs could be made which would alert commissioners of services and budget holders for demands on their provision.

• Prediction of Financial Needs
Following diagnosis of the child a long term financial needs prediction could be made based on assessment by the team using nationally standardised, recognised and accepted assessment tools. The financial needs prediction could identify likely service and resource needs of that child over a period of time - this may be for example in pre-school years, school years and through transition. Once established this could be reviewed on an annual basis. The
assessment could identify equipment resources, in particular 24 hour postural management equipment that the child is likely to need e.g. sleep system, seating, standing support, wheelchair provision or mobility equipment.
Figure 9: Key Worker Co-ordinated Service Model

- Child and Family (Human Factors)
- Key Worker (Communication)
- Team around the Child (Working Together)
- Single Employing Organisation (Service Organisation and Delivery)
- Impact of Societal Views
- Impact of Individual Culture
- Impact of Impairment
- Private, Voluntary and Charitable Sector Organisations
This would be alongside other equipment to assist in the child’s care and management at home – special bed/cot, bathing/toileting equipment or more specific medical equipment e.g. ventilators, oxygen supply etc. The team could also assess the family’s need for hands on support or short breaks which could also be costed. Identification and ring fencing of budgetary allocation for each child would provide a more child centred approach and prevent delays in supply of equipment to meet identified needs and prevent deterioration in the child’s condition, support the family and prevent frustration for both parents and professionals currently caused by delays due to disagreements as to who is responsible for funding. The prediction of financial needs could be managed by the key worker in collaboration with the child, family and team who could identify current priorities for the child.

- Hands on support

Hands on support (direct support) for the child and family could potentially be offered via a scheme of National Care Support akin to the 100 Hours Project (Limbrick-Spencer 2000). This could be open to anyone who is cleared by current safeguarding procedures and has received appropriate training. Members of the scheme could offer a set number of hours of support for example 100-200 over a period of one or two years working with a child and family. Not only could they act as an additional pair of hands to assist in a day trip or outing but they themselves could benefit from an improved understanding of citizenship duties, community issues, disability awareness and family dynamics. This could be something that is well respected in future employment application and may even encourage some people into the caring professions.
• Transparent Access Criteria
Service criteria need to be accessible, transparent and available to all concerned with the child. These need to be fair and equitable not only in one locality but across the country so that a child and family would receive the same level of service wherever they lived. Accessibility of information is important and this needs to be within the local community so that it can be easily disseminated to those who need to know.

• 7 Day Per Week Service Access
A review of current working practice and a shift away from traditional office hours on a Monday to Friday basis would be valuable in offering more flexibility of service provision to children and their families.

• Non-statutory Agency Partnerships
Involving voluntary agencies, charitable organisations or any other providers of services to the child and family in team meetings and planning will be important to ensure a holistic approach and co-ordinated care for the child.

• Key Worker Provision
Within this model the key worker has a pivotal role in co-ordinating the care and management of the child and in bringing together all the stakeholders in a collaborative approach. The team will need to undertake training on the role of the key worker as this study has shown the perception of the role varies from individual to individual. This would need to include a clear definition of expected duties and the core competencies required of the role. A team who are employed by a single agency may relieve some of the pressures currently experienced by key workers.
in engaging with workers from agencies other than their own and improve access to budgets and resources as these would again be under the control of one agency.

Early identification of a key worker for the family could enhance team communication, information sharing and support for the family.

Addressing these identified factors would provide a sound foundation for the key worker role and effective collaborative team working. With a strong foundation team members would be able to anticipate and respond locally and pro-actively to challenges and offer more flexibility and individuality with which to address the changing needs of the child.

6.5 Recent Literature

During the time it has taken to undertake this study there has been continued publication of research and policy documentation on children’s service provision, the team around the child, key working and management of the child with disabilities.

6.5.1 Children’s Trusts

Notable examples which have relevance to this study include the work of Helen Wheatley (2006) who produced a good practice guide for children’s services in the development of services for disabled children. In this guide Wheatley used evidence gained from pathfinder Children’s Trusts which were established in 2003 and tasked with improving partnership working across statutory agencies. Of the thirty five Trusts established across the country one third of these focused on services for disabled children. These trusts defined a specific group to focus on and these tended to be those
children with the most complex needs. As a result a whole population of children with needs (moderate and mild) were potentially excluded from the pathfinder pilot study. These children may have presented different issues to services and it will be important in the future to include them in further pilot studies or trials. The Trusts were able to adopt their own approach suited to local needs so that many differing styles of working were observed across the sample pathfinder group. This in theory provided the potential to be completely flexible and focus the service provision on the identified needs of the child and family.

Despite the amalgamation of the three core agencies of health, social care and education in the pathfinder trust development much of the reported work in Wheatley’s paper concurs with the evidence generated within this study. For example when summarising the outcomes of the project it is noted that the creation of children’s trusts arrangements presented authorities with a huge challenge. Even in areas where there was a history of good partnership relations across agencies it was felt to take a long time (years) to get the foundation right. There was a suggestion that change would be required across all partnership agencies at a strategic level as well as operational level. However, the project did not push the boundary just that little further and actually employ the staff in the teams in one single organisation. This project over the longer term may have presented an ideal opportunity to do so and to map the outcomes for both staff and families. Many of the problematic issues identified by the areas involved in the pilot were due to the fact that there remained three employing agencies all of which supported their own philosophies, cultures and language.
One of the factors identified as causing tensions in the teams of the trusts was the lack of clear understanding of roles and responsibilities across the agencies. It was noted that it was very unusual for any one individual to have a working knowledge of all three key services which constitute the core of a children’s trust. The key worker role may be likened to the children’s trusts manager role as they too have to develop skills in understanding all services. This is an interesting finding when considering what is being asked of a key worker who undertakes the role of co-ordinating the team around the child currently without any training. When considering the management role of the children’s trusts there was no indication of the influence of the affiliation of the manager (to any one particular agency) on the rest of the team or of the outcomes for the child and family and no comparison across the pathfinder trusts of any differences because of this.

Funding and budgetary control had proved to be a challenging area in the pathfinder trusts with the incompatibility of regulations and guidance evident across the different agencies. Once again one organisation holding one budget may be the only solution to resolve this issue or alternatively a budget linked to each and every child identified as having a disability as has been suggested in this study.

The membership of the pathfinder trusts was not given in any detail and it is difficult to ascertain whether all services were included in the pilot – for example wheelchair services, Orthotic services, integrated children’s equipment stores – all of which play a very important part in the life of a child with a complex disability and their family.
Some of the pathfinder areas found it difficult to co-locate the teams during the set up of the children’s trusts. The barriers identified within the Wheatley study have been suggested as lack of suitable buildings, lack of commitment from all agencies, sustainability, staff terms and conditions and realistic timescales. Wheatley describes service integration as a long term, complex project involving major structural and cultural change for organisations and the individuals within them. Co-location of the team around the child was a factor that was felt to influence the effectiveness of team working and potentially the role of the key worker in this study too however, the author believes that if the team were employed by a single organisation some of these identified barriers would be easier to overcome and potentially co-location would be easier.

Wheatley identifies that the role of the key worker continues to cause confusion among staff and families. One of the pathfinder areas had been piloting using both designated and non-designated key workers however there was an identified need to secure long term funding for the key worker project to ensure it would continue, indicating that it would be difficult to sustain within current resources and without further investment. One finding of the pilot was that the status of key workers needed to be promoted across the agencies to ensure they had the authority to negotiate on a family’s behalf. This gave a possible indication of the lack of training about the role of the key worker and lack of understanding and respect for the role. There was little evidence in the study to indicate whether any of the pathfinder trusts had any training prior to the pilot and this may have been one aspect that would have been useful to include.
6.5.2 NHS Next Stage Review

The authors of the final report ‘High Quality Care for all. NHS Next Stage Review’ (Department of Health 2008) came to the conclusion that services need to be more effectively designed around the needs of children and families and delivered not just in health settings but also in schools and children’s centres. This study agrees with those conclusions and also demonstrates that services should be designed around the individual needs of the child and family however, it has also shown that there is more to consider than just the way services are delivered.

The Department of Health (2008) report once again identifies the need for a lead professional for the child and family and talks of a partnership approach. Organisation of services around children and their families, not the other way round, may be the only way to achieve a truly patient centred seamless approach but this requires greater flexibility in services than is currently available.

6.5.3 Government White Paper

Since embarking on this study there has been a general election and change of government. July 2010 saw the publication of a government white paper Equity and Excellence: Liberating the NHS (Department of Health 2010). The white paper contained some suggested radical changes to the NHS and the way services are commissioned. Following consultation and listening exercises this white paper has lead to a new Health and Social Care Act.

The white paper included elements which support the findings of this study and these include:
• Involvement of service users in decisions about their care: ‘no decision about me without me’ (p3) – akin to parent (and child) partnership.

• Personalised care to meet individual needs i.e. patient focused care – noting the individuality of the patient and providing flexible care to meet those needs. The paper notes the expectation that patients are expected to fit around services rather than services around patients suggesting that the current system is inflexible as has been suggested within this study.

• Joint working and joint provision across all agencies with seamless provision across boundaries. Reiterating the original outcomes of the Court Report (Department of Health and Social Security et al 1976).

• Accessible information and support.

• Improvements in information technology.

• Provision of personal health budgets – although the nature of these and whether they will cover disabled children’s services is not yet clear the concept seems similar to that which is proposed in this study.

One notable change to provision of services which could influence key working in the team around the child suggested in the white paper was the introduction of ‘any qualified provider’. Any qualified provider could alter the dynamics of the structure of the team around the child. In the future it may be more common to see service providers including professionals working for voluntary agencies, charitable organisations and private companies rather than the statutory agencies of health, education and social care and the key worker for the child may come from any of these providers and need to liaise across potentially even more agency
or organisational boundaries. The impact of this change and the implications for collaborative team working will need to be closely monitored as the change in system may just increase some of the problems that have been identified within this study to the detriment of the child and family.

The white paper signified radical change in the way in which health and social care services are provided and it may prove in the longer term to be a missed opportunity within this climate of change and economic influence restructuring to look at children’s service provision and the potential for redesign to provide a more flexible approach to meet the needs of the child with a disability and their family.

6.5.4 Department of Education Green Paper
The Department for Education (2011) have produced a green paper exploring a new approach to special educational needs and disability. Within the document once again the emphasis is on seamless services across organisational boundaries, collaborative working and the identification of a key worker or lead professional to co-ordinate the care for the child and family. The paper talks of more transparency in the provision of services and more choice for parents over their child’s education and support. Reference is made to the bewildering bureaucracy of the current special education system – just one aspect of the disabled child’s life, and the need for clearer information and advice. Recognition is made of the uniqueness of each family’s situation and the need to receive the right support for their situation. Within the document there is discussion regarding the provision of personalised funding by the year 2014 giving parents ‘greater control over their child’s support, with trained key workers helping them to navigate
services’ (p8). Although the finite details of how this personal budget would be managed and what services it would be expected to cover for the child are not yet clear, the responsibility on the key worker to guide the parent is likely to be substantial and indicates a need to have knowledgeable people in the key worker role who understand the child’s condition and likely future needs, as well as the provision available from other services. It would appear therefore that the training of key workers and a clear understanding of the role is likely to become even more important than anticipated and the responsibility of the role crucial to positive outcomes for the child and family. In preparation for this change the introduction of training needs to be planned now.

It can be seen that the subject of team working and the role of the key worker remains current in the context of services to children with disabilities and their families. The focus remains on working together across organisational and agencies boundaries with a key worker in a co-ordinating role. It is therefore important that we have an understanding of why there are not more key workers available to these children and their families and what it is about the current systems that prevent the role becoming more prevalent in practice.

6.6 Factors Mitigating against Change and Development

It is evident from the study findings that change is needed in a number of areas of practice to improve the outcomes for the child with a disability and their family. However, during the research process, interaction with participants highlighted particular logistical factors which may potentially present barriers to the recommendations and subsequent reform of these services.
6.6.1 Professional Culture
Understanding the limitations of cultural boundaries and finding ways to work across the different cultures of health, education and social care is important for future development of collaborative teams. Caution may need to be exercised with regard to professional culture barriers (expressed as medical, social, educational models of practice). These barriers reflect the different world views, agendas and priorities of team members and include how those practitioners see themselves. These may need to be understood and negotiated in order to make significant change or progress in breaking down existing barriers. The true potential of a key worker system may be unachievable until such time as these cultural barriers are overcome. Potentially one of the only ways to achieve this may be by the merger of Children’s Services (in particular social care) and Health.

6.6.2 Time Pressures
Time pressures on staff were a particular concern when discussing the role of the key worker. Unless service provision was more flexible the key worker role may be too much for professional to undertake in addition to their current high caseloads and work demands. To undertake the role effectively one professional could only be a key worker for three or four families at most. This standard may be difficult to achieve due to the high numbers of children on caseloads and currently involved in services.

6.6.3 Financial Constraints
Financial constraints for service providers are also seen to be a mitigating factor in service development particularly the role of the key worker. Development of the role does not include additional funding to release time for professionals to carry out the duties of
the role, or to provide extra resource for services or equipment for the children and their families. The key worker would be working within current financial and resource constraints which may limit the effectiveness of the role. Without investment it is unlikely that the key worker role will become more common in this context of practice.

6.6.4 Resistance to Change
Change can be viewed as threatening (Handy 1985). Change that is necessary within this context involves professionals from multiple agencies and thus from differing professional cultures and these may be the two elements which present barriers to the change process. Cultural beliefs are what underpin the whole organisational system. For change to happen within the context of this study staff will have to think outside of their experience of the ‘norm’, what some refer to as institutional inertia (Spurgeon and Barwell 1991). Although apparently willing and motivated, it is difficult to anticipate how staff will react to any proposed change and professional cultures may dominate the change process.

6.7 Summary and Conclusion
Clearly there is much that can be recognised as good practice on the part of individual professionals within the team around the child in this context. An effective team can be described as being a group of people working collaboratively (not collectively) towards a shared goal. The assumption appears to be that if the individuals were proficient then the team of which they were a part would be effective. However, due to the multiplicity and complexity of service provision in this context it became apparent in this study that these highly trained and experienced individuals when
grouped together delivered a less than efficient team performance into which a key worker role could be introduced.

Identification of underlying problems with regard to team working has implications for service delivery and if these are not addressed barriers whether perceived or real will remain. Both the professional and parent participants of this study agree that the current service provision is problematic in a number if ways and that there is a major need for redesign of services.

The key worker role has been seen as a solution to some of the current service delivery problems but it can not be viewed as a solution in isolation. There are other key factors which appear to contribute to the fundamental problems experienced by both professionals and families in this practice context. Unless these fundamental problems are also addressed the key worker will continue to be unable to meet all the needs of the child and family.

Some of these problems may be addressed in the short term but others require central funding and may need much longer to resolve. The shorter term solutions may include the involvement of parents in training and team building activities, co-ordination of teams by a team leader; information provision for parents and support focused at time of diagnosis. In the longer term solutions may include financial investment in services to provide more staff thus reducing workloads releasing time to undertake the key worker role effectively; adequate funding for the timely purchase of equipment for children with disabilities; sustained and ongoing training and support for key workers.
Staff will need to have shared responsibility for the change and be supported through the process. The model of changing behaviour described by Cole (1997) may be a useful way of looking at the task ahead. That is: the need to unfreeze existing behaviours and gain acceptance of the change; change the behaviour and adopt the new way of looking at the service; refreeze behaviours to reinforce the benefits of the new way of delivering the service. However, the context in which these changes are necessary is one of constant flux and any fixed outcome may be too rigid to achieve. Flexibility in service provision and ways of working have been the mainstay of all the discussion throughout this study and any solution may have to be adaptable and flexible enough to meet the individual needs of the children and their families for whom these services are provided. At all stages the child and family must be central to the process and the outcomes and benefits for them of any changes to service provision mapped.
Chapter 7.0: Conclusions

This chapter will address the main conclusions of the study. The aim of the study will be revisited to verify that the findings have achieved the original aims and objectives previously set out in this text. The significance of the study will be identified and the key findings and novel contribution to knowledge relating to practice, given. The study limitations will be identified. The implications for practice and proposed methods of dissemination of findings will then be acknowledged. This section will include some elements of successful change in practice already achieved as a result of the study. Recommendations for future research as have developed throughout this study will be noted and the chapter will conclude with identification of how the outcome of this research may have relevance in a wider population.

7.1 The Aim of the Study

The aim of the study was to explore and interpret the experiences and understanding of the team around the child with a disability including professionals and parents, of multi-agency, multi-professional team working and in particular the role of the key worker.

The objectives of the study were to:

- Review current and relevant literature relating to the study context and subject
- Investigate views of the professional team on the role of the key worker for children with disabilities and their families.
• Investigate the views of the parents, of children with disabilities, on the role of the key worker.
• Explore the experiences of parents, of children with disabilities, working with the professionals who care for their child.
• Examine the wider needs of parents of children with disabilities in relation to the role of the key worker.
• Develop guidance for key workers in current and future service provision

The anticipated outcome of the study was to create original knowledge which would better inform and underpin professional practice and provide evidence for change management.

The study has clearly addressed these areas of investigation. The responses of the study participants have provided data which the researcher has interpreted using grounded theory methodology. The codes, sub-categories, categories and concepts developed during analysis represent the areas of the study context where there are perceived difficulties in the way services are currently provided and evidence of the researcher’s interpretation of how these are related. Although not insurmountable, in their current form these difficulties have the potential to inhibit and constrain the success of the implementation of a key working service for children with disabilities and their families thus identifying potential reasons why this role is not more prevalent within this practice context.

7.2 Significance of Study

This study was conducted in a qualitative research paradigm using the principles of grounded theory methodology.
The study sought to explore, examine and interpret the experiences and understanding of the team around the child with a disability of multi-agency, multi-professional team working, with particular focus on the role of the key worker. The team around the child included professionals from multi-agency statutory organisations and parents of children with disabilities.

The study has relevance to current practice and is significant due to the concept of team working, service co-ordination and the introduction of key workers for disabled children and their families which is topical within current government policy and legislation focusing on children.

### 7.3 Key Findings: Novel Contribution to Knowledge Relating to Practice within the Clinical Field

This study has provided novel contributions to knowledge relating to practice in two key areas. These are:

- The presentation of the unique voices of parents of children with disabilities and the professional team that support them

- The need for the concept of key working in the team around the child with a disability to be flexible in it’s delivery to meet the individual needs of that child.

This study has provided evidence to demonstrate the scale of the challenge – not only for the individual undertaking the role of key worker, but to the implementation of key working services within the current rigid system of statutory provision for children with
disabilities and their families - a potential major contributing factor to the failure of many attempts to establish key working in the past.

7.3.1 The Voice of Parents of Children with Disabilities
The voice of service users is a powerful tool in the evaluation of service provision. To hear the raw experiences of how services are provided to the parents and families who have children with disabilities can be a sobering encounter. The parental journey begins with the delivery of a child they had hoped to be healthy only to be told their child has a disability. This very first contact with a health professional appears to colour their view and future relationships with professionals for years to come. Many will never forget how they are told of their child’s diagnosis and it will shape their destiny and how they will react and cope in the future. The impact of their child’s impairment is dramatic – not only for them as individuals but for their family and the dynamics across family relationships. They begin an emotional rollercoaster ride. The impact of the impairment is felt not only in the child but in the family as a whole – husbands, wives, partners, siblings, grandparents and others. It impacts on the social and economic wellbeing of the whole family. The whole family are recipients of the services provided for the child.

The family have to build relationships with an army of professionals many of whom they have never heard of prior to having a child with a disability let alone understanding exactly what the professionals’ role is in providing care for their child. They report having to fight constant battles with bureaucracy and rigid rules and regulations about how services can be provided. They are given constant reminders of what their child can not do. They find they live the wrong side of the border to receive services provided
elsewhere. They feel isolated from others and seek support from those who have had similar experiences – those who can really understand what they are going through. They have too much or too little information and little of it seems pertinent to their child's unique presentation. They are often not consulted and professionals make unilateral decisions about the care their child should receive. They don’t understand the language used and there is no-one there at the time they need someone to explain it all. They have to wait to reach crisis point before help arrives when if it came sooner they could cope more easily. If they weren’t resilient at the time of their child’s birth by the time they are transitioning to adulthood they have developed resilience through a basic need to survive.

This study has provided a forum for parents of children with disabilities to have a voice and be heard. Many of those who took part stated that this was their first opportunity since their child was born to talk about their experiences. They have a strong voice and constructive thoughts and ideas about how services can be improved. They want to be part of the team to share training with professionals to help them understand what it is really like as a family living with a disability and this study has given them that opportunity and in doing so has made a novel contribution to the knowledge in this field of practice.

The parents that took part in the study demonstrated a lack of understanding about what the role of the key worker was and collectively they had at best little experience or at worst no experience of working with a key worker. All the parents felt they had experienced a time since the birth of their child when someone in the role of a key worker would have been of support to
them however they identified that they had different needs – all unique to their child and their personal situation that could not necessarily be met by one person alone. They expressed concern that it would be difficult for one person to be available at the times when they felt their needs were greatest - often outside office hours or at weekends. Sometimes the help that was needed was an extra pair of hands or a shoulder to cry on. At other times it was a more formal role to explain professional jargon or act as an advocate for the child and family. There was also a hint of scepticism that the key worker may end up being yet another person they would have to liaise with increasing the burden of communication. This feeling may have been due to the lack of understanding and experience of the role and is certainly not the aim of the key worker system.

In the study the parents were supported by the voices of many professionals who work with them in managing and caring for their child. Theses voices have also provided a novel contribution to knowledge within this clinical field. In practice professionals do not often get the opportunity to discuss their feelings about the system in which they work. The strength of feeling across the professional team about many aspects of their collaboration (or lack of it) with colleagues from other agencies was enlightening. It demonstrates that there is much ground work to do prior to establishing a key worker service that would be effective and efficient.

The study has also provided information on the perception of the key worker role from a professional and parental perspective. The indications are that there is a fundamental lack of understanding of the role and that a programme of training would be required alongside other changes to practice such as team building
activities and joint training, to support the role prior to its implementation.

7.3.2 A Flexible Approach to Key Working
The data generated and the interpretation of that data has given an indication of the variety of underlying problems within the current system of multi-agency provision for children with disabilities and their families. These include poor team working, and a lack of regard for the individual needs of the child and their family but predominantly an inflexibility of the current system of service provision.

The research has shown that the context of clinical practice in this area is extremely challenging due to the nature and number of stakeholders involved in the team around the child; the individual needs of the child and family; and the organisation and delivery of services to the child and family. Support for the child is needed from a multitude of service providers and the child’s unique needs can not often be resolved by input from any one agency alone. This may be where the difficulty lies. Trying to match and marry up provision of services from multiple providers who have different criteria for provision, different targets to meet and different philosophies and cultures may be an impossible task.

This study has identified that although suggested as a way of providing co-ordinated services to children with disabilities and their families' implementation of the key worker role in current practice may be inhibited by problems affecting the process and effectiveness of team working and service delivery across the statutory agencies of health, education and social care. For many
reasons there appears to be no sound foundation of collaborative team working upon which to base key working.

As a consequence of the pattern of current service provision parents stated that they experienced both gaps and duplication in provision for their child and family. Many of the professionals were found not to trust each other and often assessments were duplicated. Lack of clarity of funding streams led to confusion over responsibility for and supply of resources and equipment for the child. Lack of availability and transparency of access criteria for services resulted in frustration for the child and family and the professional team working with them. The overall inflexibility of current service provision and lack of application of services to meet individual need led to problems in collaborative team working and affected the outcome of care and management for the child and family.

Lack of integrated, collaborative working, shared location, differences in practice and barriers to working together have been found to have the potential to cause problems for the effectiveness of team working. Such factors underpin the success of the key worker role and many of these are particularly difficult to address. Provision of a key worker for every family with a disabled child may therefore be a somewhat unrealistic goal within the rigid bounds of current practice and resource provision.

7.3.3 Model of Practice

The model of practice shown in chapter six (Figure 9) which has been developed following data generation, analysis and interpretation during this study is a new theoretical construct and shows a conceptual framework of one employing agency in which
provision of services to meet the individual needs of the child with a disability and their family, including and embracing key working could be successful. The model demonstrates the complexity of this area of practice and the conceptual influence of the child’s impairment, individual culture and the impact of societal views on those who work in the field.

The study has provided evidence to show where current service providers need to rise to the challenge to improve outcomes for the child with a disability and their family. The unification of the statutory agencies to form one umbrella organisation supporting the child and family would better facilitate collaborative team working in clinical practice, thus providing a sound basis upon which the key worker role can operate. An investment of time in team building activities needs to be allowed so that professionals can develop an improved understanding of each other’s roles and develop trust based relationships. Training is needed to establish a baseline profile of the key worker role. Training should involve parents as partners and professionals need to develop skills in accepting parents as equal members of the team. Support should be provided for families following the diagnosis of their child. Consideration should be given to more flexible working practices to cover a seven day working week with extended hours of availability each day. Once team building has taken place the team should be based within one location to improve communication channels. Clear team objectives should be established and a team leader identified to co-ordinate team activities. The service should be based on the needs of the child and family. Members of the team should assess and identify potential future financial requirements for the child and family and resources should be provided in a timely manner.
It can be seen that despite policy, legislation and research supporting the role of the key worker and promoting seamless services for children and their families, little has changed over the years in the way services are organised and provided. This study has given an indication as to why that might be and has provided practitioners and policy makers with ideas of how to move service provision forward for the benefit of service users and those involved with service provision.

To resolve much of what has been identified in this study as problematic may take radical reform i.e. bringing together all the statutory agencies into one organisation. If however, the underlying problems were addressed the situation may become more favourable for the key working role to be implemented and the position more common place in practice. The suggested model of practice (Figure 9) could provide a positive way forward for the concept of key working turning the rhetoric of the past decades into reality on practice.

7.4 Limitations of the Study

7.4.1 Participants
One notable limitation of the study was the lack of involvement of fathers as parents of children with disabilities. All parent participants were mothers. This may reflect the usual high involvement of mothers with service providers who offer intervention for their child but to give further diversity to the data in future every attempt should be made to include fathers in the participant sample.

Similarly the study failed to acknowledge the voice of the disabled child. The understanding of children of how services are co-
ordinated around them to meet their needs may also be an area for future research.

Representation of all potential members of the team around the child was not achieved within this study and of those professionals who were represented often there were only small numbers e.g. a single medical consultant. It may be possible that greater variation in data and recommendations may have been achieved with wider and larger representation. This has particular reference to those involved in the team around the child from the voluntary sector including charitable organisations. It is also important to note that due to the proposals in the government white paper (Department of Health 2010) private providers of services may well become partners in the team around the child and play an important role in their care and management in the future. It would be essential therefore to involve them in any future research set in this context.

7.4.2 Study Context
There were many change processes being undertaken within the research context during the research period particularly with regard to budget cuts and change to organisational structures. This may have had an influence on the morale of the professional participants, shaping their responses to the study questions.

7.4.3 Research Design: Methodology
Some qualitative researchers may feel that a literature search prior to undertaking data generation may stifle a research study however, the background knowledge gained by completing the search prior to the study did in fact enhance the data generation in this context. Due to the structure of the Professional Doctorate
programme the literature search and review for this study began at the beginning of the academic programme.

New topics which were raised by participants in the data generation period were later explored by the researcher in available literature. Grounded theory methodology was therefore found to be a useful tool in this particular study context.

The use of a note taker during data collection may be useful in future to provide an objective view of the interview and focus group processes.

7.4.4 Generalisability
This thesis explored the concept of the key worker within the context of the team around the child with disabilities and their family. The research was undertaken in the local community and is therefore pertinent to this specific group of participants. The outcome is therefore rather more suggestive than conclusive and would have to be tested further before being claimed applicable to a wider population with similar characteristics.

Beyond the context of this study there may be many families who have children with similar disabilities however, exact replication of this study would be difficult to achieve because of the nature of the study sample involved. Nevertheless much of what has been expressed by these individuals may be experienced by others, although how they deal with these experiences will be dependent on their own personal characteristics. The study continued until saturation was reached and so the experiences may well be relevant to other groups of people.
7.5 Implications for Practice

Having a child with complex needs dramatically changes family life. A key worker would need to be available, dependable, responsive, flexible and able to react in a timely supportive manner. Having regular team meetings and team planning, with shared goals and good communication and documentation were seen as being important when building trust and confidence in the team management from the parents’ perspective. These activities would prevent the need for the parent to keep repeating the same information to a multitude of professionals. Thus the key worker role has the potential to reduce the stress often felt by parents and would boost their confidence that the system was working for them. However, as previously indicated much needs to change within current practice to enable the key worker role to be effective.

The ideal situation for true team collaboration to occur would be if all professionals working within a team were employed by a single organisation or by one agency. This would have the potential to minimise any perceived barriers or differences in philosophy, focus or culture. Having clear and transparent access criteria shared across the team would relieve some of the frustrations experienced by staff when appealing for support with children on their caseload. This situation becoming a reality within the short term is highly unlikely; however this could remain an objective for future gold star standard service provision for children and their families.

To implement the key worker role in the shorter term however, there needs to be strategic sign up and investment in team building activities prior to the establishment of the role. Team building could
also include shared activities with parents of children with disabilities and when appropriate the children themselves. Co-location of workers in the team, shared Information Technology (IT) and documentation would all be helpful in supporting a team to operate effectively together and improve the usefulness and efficiency of the key worker role.

These changes are significant in the world of the statutory agencies and although steps have been taken to bring together social services and education under the umbrella organisation of Children’s Services, many participants still reflected in their views that the two organisations remain very disparate each retaining its own identity. In the meantime the health service as an organisation remains isolated sustaining yet another culture. Professionals potentially do not see themselves as members of one team - they do not currently represent the same organisation, they have different policies, procedures and paperwork all of which reinforce their sole identity and do not support collaborative team working centred on the child and family.

7.6 Dissemination and Implementation

This study provides evidence of current practice which is problematic for practitioners and has the potential to affect the outcome of intervention for the child and family. The categories and concepts developed in the data analysis provide information regarding specific areas or activities of practice that could be addressed during a change management programme to improve the working relationships of the team around the child.
The researcher has a responsibility to the research participants to disseminate the findings of the research study (see appendix twenty two) and use professional autonomy to lead change and inspire others to change. This can be done through professional and parent networks and interagency forums as well as through composition of articles for professional journals. As has been identified there are many stakeholders in this area of practice and all need to be receptive to participate in change which may prove to be one of the biggest challenges to address. However, the clinical setting has a culture which actively promotes practice development and is supported by legislation and policy as well as a desire on the part of many parents to be more involved in team working and service development.

7.6.1 Celebrating Success
As a result of this study a group of parents have become involved in joint training with professionals in the local area. This has proved to be a very powerful tool and has provided another dimension to the professional understanding of living with a child with a disability. It has given professionals an opportunity to discuss with the parents the implications for the family unit and for family life of having a child with a disability - a perspective which is not often explored during clinical consultations where time is short. It has also provided a more holistic picture of the problems faced by these families beyond the medical and social needs of the child alone. It is hoped that this activity can be built on, grow and become the norm in training practice.

The research study has provided the researcher with time to talk with professionals from other agencies and has improved understanding of the issues particular to their organisation that are
faced on a day to day basis. This has provided an opportunity to build and develop relationships and it is hoped that if this were to become the norm for team building it would have the same positive outcome for a wider group of staff.

7.7 Recommendations for Future Research

Further study is however required to focus on the needs and indicators for a flexible service as well as team building activities and strategies for those involved in the team around the child. The views of the child and family should be explored and included in the research, particularly those of fathers and the child themselves. Inclusion of a wider scope and higher numbers of professionals may also be valuable.

7.8 Conclusion

The findings of the study have identified that the individuals involved in delivering and receiving the services for children with disabilities provide the foundation and context upon which the services have to operate. They strongly influence how the services function on a day to day basis by the very nature of their personalities and their unique professional culture. As can be seen by the data presented there is no uniformity across the individual stakeholders concerned and the basis of their own experience will affect the efficacy and outcome of both service delivery and reception of that provision by service users. The issues around the organisation and delivery of services demonstrate the complexity of strategic administration of provision and resource in this context. It is clear that current systems are restrictive in certain contexts and inflexible with regard to the needs of the child and family.
There are some areas of the country that have a key worker system in place and some of these appear to functional well. However, some of the available literature on the phenomenon does report that a poor team foundation affects the nature of delivery of services to the child and family. The fact that on a national scale, less than one third of families with a disabled child have a key worker would indicate that there may well be problems on a national scale establishing the role and this study may have given some indication as to what those problems might be not only in the study locality but potentially in other areas too. Some of the issues identified by this study are unlikely to be rectified at a local level (e.g. shared IT systems across agencies). Many require national governmental investment in the statutory agencies as a whole. The potential merger of all three statutory agencies although idealistic is unlikely without major reform. Practitioners must therefore be reconciled that some issues are likely to remain unresolved in the near future and beyond. However, there is much that can be achieved on a local level.

This study identified that the concept of key working in the team around the child with a disability holds much promise with regard to positive outcomes for the child, family and professional. However, for the key working philosophy to achieve its full potential investment in team development, through training and team building, needs to take place. Targeting important areas of role definition and interaction between team members to clarify and provide a baseline from which to develop the concept of the key worker will be essential. However, there may be other elements of team working which may improve service quality and may be
more critical to improving the experience of children and their families, for example, improvement of communication.

Although this study represents a snapshot in time, policy, politics, and economics all influence the way the team works and the context in which they work, and as such, there is constant change to be added to the complexity of this field of clinical practice.

This research was clinically appropriate in that it was patient-focused as well as being timely with regard to the subject of the key working role. It is important, therefore, to use the knowledge gained through this research to embed new practice to improve outcomes not only for the child and family but to improve the working relationships and role satisfaction of the professional group.
Chapter 8: Reflections of a Research Journey

In this final chapter I will present my research journey, discussing the complex issues and challenges I have faced along the way. In the dual role of ‘researching practitioner’ I have been an integral part of the research process – gathering, analysing and interpreting the data. It is therefore appropriate to present this reflexive discussion written in the context of the first person. Reflexivity requires an awareness of the researcher’s contribution to the construction of meanings throughout the research process, and an acknowledgement of the impossibility of remaining ‘outside of’ one’s subject matter while conducting research. Reflexivity urges us to explore the ways in which our involvement with a particular study influences, acts upon and informs such research (Nightingale and Cromby 1999).

8.1 The Study

The aim of the study was to explore and examine the perceptions of the team around the child with a disability, of the role of the key worker. The specific aims and objectives of the study have been identified in previous chapters and these were based on an interest in the following areas:

- The perception of the team around the child of the role of the key worker.
- The skills and knowledge required to undertake the role of the key worker.
- The nature of the current practice of team working and its affect on the potential key worker role.
The impact on effective team working of the current system of statutory provision for children with disabilities.

This area of interest arose for me over a period of time working with children with disabilities and their families. The concept of the key worker within the team around the child had been discussed and had appeared in literature and policy for several years however, I had not worked in a team that operated this system and although proposed as a means of co-ordinating services the evidence showed very few families had access to such a supportive resource. Through informal discussions with professional colleagues and parents it was clear that the perception of the role of the key worker varied from person to person and there was no clear definition or job profile for such a person. Although staff believed they were doing many of the elements of a key working role in their day to day job much of this depended on individual personalities and there was little apparent consistency across the professionals from the different agencies.

The study was based within a qualitative paradigm using a grounded theory approach. In qualitative research the aim is to interpret the world as others see it. By using grounded theory the multiple realities of the participants could be explored and explanatory models developed from the data generated.

The data were collected through interviews and focus groups. Although these were guided by questions I wished to explore there was flexibility in my methodological approach to allow participants an opportunity to tell their stories and present their view of the world with regard to the study phenomenon.
8.2 Consent to Participate

8.2.1 Influences on Participation
My professional role, managerial status and previous contact with many of the participants may have influenced their decision to take part in the study. Initial contact was made through my supervisor and for parents it was clearly stated that participation or non-participation would not influence in any negative way, the future care their child would receive. Some participants may have felt obliged to take part whereas others may have seen this as an opportunity to expose the shortcomings of the service and systems to someone who may have had the power to take action on their behalf.

Being a researching practitioner and team manager presented the ethical dilemma of possible coercion of my own team and work colleagues to participate in the study. It is unlikely that voluntary participation or refusal was possible in this situation (Archbold 1985). In order for participants to make a free choice about participation in the study, support was requested from my supervisor to act as the named person on the invitation to participate in the study, to prevent feelings of undue pressure or coercion from those who knew me. This hopefully reduced the impact of me as a researcher within my own practice. I was also aware that once the study was completed I would return to a professional role working as a clinician with many of the participants involved in the study. I was conscious of the desire for them to be honest in their replies to questions and their presentation of the reality of the situation for them but also their possible concern that they may not wish to influence future contact with me and the service I provide.
8.3 Role of the Researcher Practitioner

As an ‘insider-researcher’ (Dearnley 2005) carrying out research within the practice environment it was important to reflect on the implications of this and how it affected the research outcomes. Going into this research project I had insider knowledge of the professional practice settings, an understanding of the roles and responsibilities of the participants, knowledge of professional practice and knowledge of organisational cultures. However, I recognised that this knowledge was based on my own experience and acknowledged my own presuppositions and how difficult it was for me to distance myself from the research context.

8.3.1 Preconceptions and Pre-understandings
My own preconceptions and pre-understanding of the participants’ situation and study context undoubtedly influenced my own understanding and interpretation of their views. It was difficult to separate my own knowledge, culture, pre-reading and professional experience, particularly having worked in the field of paediatric neuro-disability for several years and having a role within the social context of the situation under investigation. My role both within the research study and outside of this arena also presented issues particularly with regard to the nature of my relationships with the participants whether they were professional colleagues, team members or parents of children receiving services from colleagues in my profession and organisation. The power dynamics of these different relationships whether formal or informal, may have affected the participants’ reactions and responses during their interaction with me.
8.3.2 Therapeutic Relationships

Certain qualitative methods, in particular interviews, are suggestive of a therapeutic relationship in clinical assessment and intervention – they involve the participant entering an aspect of their life and giving an interpretation of it. Data collection/generation is in fact an intervention. As I was known to many of the participants as a physiotherapist I had to assume a ‘different’ role during my research activity. This involved dressing differently. I would normally have worn a uniform that identified me as a physiotherapist. To reinforce the change in my role during interviews and focus group facilitation I did not wear uniform.

In future research studies it may be more appropriate to purchase the services of an independent facilitator for interviews and focus groups to prevent the social desirability factor of participants’ responses i.e. participants wanting to present themselves to me the researcher – as a known clinician - ‘at their best’ (Bowling 1999). This may also minimise the impact of the researcher being a representative of one of the agencies under scrutiny. However, in this study personally acting as the facilitator did provide me with the opportunity of ‘immersion’ in the data during the whole research process (Holloway 1997). Comments received about the physiotherapy service and health services in general varied – some being very positive others more critical. I did not feel that participants were inhibited in their responses by knowledge of my clinical position outside the research arena.

During the course of the research the children of the parent participants were not on my clinical caseload. However, I often had knowledge of the families involved in the study due to discussions with other team members involved in their care.
Therefore there may have been particular issues over the participant/researcher relationship as the researcher was known as a clinician to most of the participants. Because of this fact the participants may have been unprepared to assume an important self-protective role in the research situation. If, as a clinician researcher, I had been caring for the participant’s child, a power differential would be present and ‘official’. These particular parent participants may have been subject to anxieties and vulnerabilities due to the emotional strain of their family circumstances. Many of the parent participants were under intense emotional strain and the interview situation often exposed raw emotions. At this time it was difficult not to assume a counselling support role as opposed to that of researcher – again presenting a conflict of roles for the researching professional. One parent that I interviewed stated that this was one of the very first opportunities she had been given (and her disabled daughter was almost six), to sit down and discuss her experiences and proffer her thoughts on the support ‘system’ in all that time.

The parent participants may have assumed I was able to influence the care their child received and it was important to be aware of this during the interview process. Two examples of such issues were one parent commenting on the need for the child’s wheelchair to be repaired and asking me to follow this up with the wheelchair service and another parent asking if she could change her therapist. Although not part of the researcher’s specific role I had to note these two requests and act on them on returning to the clinical setting. This made me conscious that my personal knowledge did at times influence the interviews and focus groups. The examples given also presented issues of confidentiality across the research/clinical boundary as participation in the study was
confidential. I was however, able to resolve both issues without compromising confidentiality during routine processes in the clinical situation.

8.4 Methodology

In qualitative research and grounded theory methodology, presentation of the research to the subject can be problematic in that the researcher does not want to influence the participant’s behaviour or responses by explaining in detail what is being studied (Archbold 1985). I chose the research topic and facilitated the interviews and focus groups using an interview schedule. Therefore I must question how much I was influencing and pre-empting the participants thoughts and responses whilst at the same time introducing the subject matter of the research and area of investigation. This could be interpreted as a major source of bias. To overcome this, I tried during the interviews and focus groups to present open questions to participants in a way which enabled them to give their perception and interpretation of the phenomenon under study.

8.4.1 Pilot Study Experience
The pilot study provided useful experience of interviewing and facilitating a focus group. At the beginning of the study I found it difficult at first when participants hesitated and paused for long periods to think about their answers. Initially I wanted to fill these gaps. This was difficult to identify on a two dimensional paper transcript but when replaying the tapes of the interviews I felt I began to change in the later interviews and allowed the pauses to extend until the participant was ready to speak again. On reflection when listening to the tapes the silences appeared to give
an indication sometimes of the importance of an issue and intensity to the response. My reflections here are supported by Lydall et al (2005) who also report the difference between listening to participant stories and transcribing them and how when listening to the tapes the emotions were very powerful but appeared lost to a certain extent when written on paper.

8.4.2 Clarification of Meaning
I found I gave examples to qualify the answers given by participants and used vignettes – for example the key worker co-ordinating an appointment with the wheelchair service. This process helped to clarify the meaning of the participants’ responses and also brought to life situations alluded to in the questions. This process assisted in increasing the credibility of the research data. Participants were not sent verbatim copies of the transcripts to check so by feeding back, summarising and repeating what the participants had said during the interviews this ensured I had correctly understood the meaning of information that they had supplied and prevented opinions being based purely on my own assumptions.

8.5 Support Mechanisms for the Researcher

During the research process I met regularly with my supervisors who provided me with a forum to discuss my research journey. In verbalising my thoughts and experiences I found that I was able to be more reflexive about the process and my part in it.

8.5.1 Emotional Challenges of the Research Experience
The interviews and focus groups were often emotional experiences for me as a researcher. The initial enthusiasm for the research study
often gave way to feelings of despair and helplessness for the experiences the parents in particular, were presenting. Although initially I did not think participants would become distressed I was surprised at the level of emotion and passion about services that emerged. During the parent interviews it was evident that there had been experiences which had left very strong impressions and the emotions of those were in actual fact still quite raw. Many of their accounts were deeply personal and upsetting and it may have been that when initially consenting to participate in the study they may not have appreciated the impact discussing their personal journey may have on them. Many I felt appreciated the opportunity to talk about their experiences since the birth of their child. For many this was the first time they had done so. All were reminded that they could stop and withdraw at any time but none chose to do so. Even so I was deeply sorry that I had unearthed deep memories and caused the participants distress.

Equally frustrating but from a different perspective were the experiences of the professionals. The intensity of feeling about other professionals in the team surprised me. This was particularly evident in the social work focus group which was one of the first I facilitated and in some ways I would have liked to revisit this group later in the study. This may be something I bear in mind for future studies and adjust the method and ethics application to allow for a second interview with participants.

There was a general feeling of over work and frustration amongst professional participants at the limitations of the policies and procedures within the system and the impact these had on the care and management of the children with disabilities. However, most were looking to improve and change for the better which
gave me hope that this willingness could lead to effective change management in the future.

8.6 Dissemination of Knowledge

The volume of data produced through the interviews and focus groups presented me with a difficult decision – how was I to do justice to all the participants and represent their voices. Since I began my journey I have presented my research at various forums (see appendix twenty two) as a way of disseminating this information.

I have also involved parents in training alongside professionals in an attempt to address the professional/parent power imbalance and give them the opportunity of presenting their perspective. It has been a very powerful tool.

I hope that I can continue to use the data and present articles for professional journals which will continue to highlight the issues of team working and the role of the key worker in the team around the child with a disability.

8.7 Personal Change

At the onset of this journey the exciting challenge of undertaking research in an area of personal interest, as a practising therapist was intellectually stimulating and promised personal and professional development. To explore an area of clinical practice presented an opportunity to bridge the practice-research gap.
I believe my choice of study was clinically appropriate, patient and outcome focused and current with regard to political, organisational, professional and policy context.

The research study provided an opportunity to develop transferable skills and to question and analyse current practice methods not only within the research context but within wider clinical practice too.

Development of discipline and time management skills with regard to the combination of study and professional life has been essential. I feel I am now more reflective about practice and often more analytical about day to day challenges not only in the workplace but of life in general.

8.8 Practice Change

During the time it has taken to complete this study the need for key workers and effective team working in this context has continued to be at the forefront of policy and political drive (NHS Confederation 2008, Franklin 2009, and NHS South Central 2009). It is a need which from all perspectives is described almost without question as essential in the care and management of a child with a disability (Vetere 2007, Dempsey and Keen 2008, Cameron 2009, Koshti-Richman 2009). However, the study has made it apparent that implementing such a role on a foundation of poor team working will not lead to success. The study has provided an understanding of the issues faced by clinicians and professionals as well as families, when supporting a child with a disability. It has also provided a model which has identified the factors which need to be addressed prior to the establishment of the key worker role. Both
the parent group and professional participants in the study are committed to improving the situation; however, change will require strategic commitment on the part of all organisations who are involved with children with disabilities.

8.9 Summary

The experience of this research journey has provided the opportunity to acquire and apply a high level of transferable skills which can be directly attributed to clinical practice and personal professional context. It has helped develop research and organisational skills whilst at the same time provided a challenge to current practice models and processes. The experience of data generation with professional colleagues and parents has opened new avenues in the field of clinical practice and has encouraged a desire to continue with further studies within this context.
References


[Last accessed 16/02/2010]


Available from:

http://dfes.gov.uk/everychildmatters/downloads.cfm

[Last accessed 23/01/05]
[Online] London, HMSO. Available from:
[Last accessed 23/01/05]


Available from: [http://www.canchild.ca](http://www.canchild.ca)

[Last accessed 29/09/08]


- NHS South Central. (2009). Progress towards achieving the vision – one year on. NHS South Central, Newbury.


Appendices
Appendix One

Brighton University Research Governance Approval
Dear Chair

University of Brighton research sponsorship

I am writing to confirm that the University of Brighton will act as research sponsor as required under the Department of Health’s Research Governance Framework, for the project entitled ‘The perceptions of service users and professionals of the role of the “keyworker” in the management of children with disabilities’ to be carried out by Julia Graham.

If there are any general questions about the university’s approach to research governance, please contact Ronnie Boyce-Stevens, Academic Research Officer on 01273 644184 or V.Boyce-Stevens@brighton.ac.uk

Yours sincerely

[Signature]

Professor Ann Moore PhD, GradDipPhys, FCSP, DipTP, CertEd, FMAACP
Director of Research
Appendix Two

Ethical Approval Confirmation
Dear Mrs Graham

Full title of study: The perceptions of service users and professionals, of the role of the ‘key worker’ in the management of children with disabilities.

REC reference number: 06/Q1702/19

Thank you for your letter of 14 June 2006, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for other Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Application</td>
<td></td>
<td>30 January 2006</td>
</tr>
<tr>
<td>Investigator CV</td>
<td>1</td>
<td>23 January 2006</td>
</tr>
<tr>
<td>Investigator CV</td>
<td>1</td>
<td>23 January 2006</td>
</tr>
<tr>
<td>Protocol</td>
<td>1</td>
<td>23 January 2006</td>
</tr>
</tbody>
</table>

An advisory committee to Hampshire and Isle of Wight Strategic Health Authority
<table>
<thead>
<tr>
<th>Document Type</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Covering Letter</td>
<td>31 January 2006</td>
</tr>
<tr>
<td>Letter from Sponsor</td>
<td>28 January 2006</td>
</tr>
<tr>
<td>Compensation Arrangements</td>
<td>01 December 2005</td>
</tr>
<tr>
<td>Interview Schedules/Topic Guides</td>
<td>23 January 2006</td>
</tr>
<tr>
<td>Participant Information Sheet: - Parent</td>
<td>13 June 2006</td>
</tr>
<tr>
<td>Participant Information Sheet: - Professional</td>
<td>13 June 2006</td>
</tr>
<tr>
<td>Participant Consent Form</td>
<td>23 January 2006</td>
</tr>
<tr>
<td>Response to Request for Further Information</td>
<td>14 June 2006</td>
</tr>
<tr>
<td>Reply Slip</td>
<td>13 June 2006</td>
</tr>
<tr>
<td>Focus Group Protocol</td>
<td>13 June 2006</td>
</tr>
<tr>
<td>PALS Information Leaflet</td>
<td>04 May 2006</td>
</tr>
<tr>
<td>Letter from Christine Marsh-Jenks</td>
<td>02 June 2006</td>
</tr>
<tr>
<td>Letter to Education Department</td>
<td>18 January 2006</td>
</tr>
<tr>
<td>Letter to Social Services - Alton</td>
<td>18 January 2006</td>
</tr>
<tr>
<td>Letter to Social Services - Basingstoke</td>
<td>18 January 2006</td>
</tr>
<tr>
<td>Letter to Health Division</td>
<td>23 January 2006</td>
</tr>
<tr>
<td>Letter to Disability Services Manager</td>
<td>13 January 2006</td>
</tr>
<tr>
<td>Letter from Education Department</td>
<td>26 January 2006</td>
</tr>
<tr>
<td>Letter from Disability Services Manager</td>
<td>24 January 2006</td>
</tr>
<tr>
<td>University of Brighton, Interim Guidance on Research Governance in Health</td>
<td>20 April 2005</td>
</tr>
<tr>
<td>University of Brighton, Research Governance Risk Assessment Checklist</td>
<td>01 December 2005</td>
</tr>
<tr>
<td>University of Brighton, Academic Supervisor Checklist</td>
<td>01 December 2006</td>
</tr>
<tr>
<td>Copy of e-mail response from Social Services</td>
<td>31 January 2006</td>
</tr>
</tbody>
</table>

Research governance approval

You should arrange for the R&D department at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain final research governance approval before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

An advisory committee to Hampshire and Isle of Wight Strategic Health Authority
With the Committee’s best wishes for the success of this project

Yours sincerely

Mr Edward Carter
Chair

Email: GM.E.hio-au.SWHRECA@nhs.net

Enclosures: Standard approval conditions

Copy to: Professor A Moore
University of Brighton
Clinical Research Centre for Health Professions
Aldro Building
49 Darley Road
Eastbourne
East Sussex
BN20 7UR
Appendix Three

Letter of R&D Approval
Dear Mrs Graham

Re: Final NHHT Research & Development Approval Confirmation

Study title: The perceptions of service users and professionals of the role of the key worker in the management of children with disabilities

R&D Ref No: 2006/MACH/03 (Please quote in all correspondence)

Thank you for submitting the final ethics approval letter to R & D. This letter confirms that your above research proposal has North Hampshire Hospital NHS Trust approval to commence.

The conditions of this approval require you as Chief Investigator to ensure the following:

- You are required to be aware of and adhere to your responsibilities, as detailed in the protocol and Clinical Trials Agreement, as well as comply in full with ICH GCP, Research Governance and current EU Legislation.
- All staff involved with this project are familiar with the Research Governance Framework for Health and Social Care and the Data Protection Act.
- All staff that will be involved with NHHT NHS patients and/or have access to identifiable patient data have substantive/honorary NHHT contracts.
- All data must be collected and stored in accordance with ICH GCP and/or MRC Guidelines for GCP in clinical trials.
- All essential documents are to be stored and maintained in a project file, which may be subject to monitoring by R & D. Original copies of Patient Consent forms must be stored safely.
- All serious adverse events that occur at the North Hampshire Hospitals NHS Trust are to be reported in writing to the Ethics Committee and copied to R & D within 7 days.
- In order to ensure that the Trust recoups the agreed income, all activity must be notified to the R & D accountant, Carole Eden (ext 4809, carole.eden@nhht.nhs.co.uk).

Please note that this Trust approval (and your ethics approval) only applies to the current protocol. Any changes to the protocol can only be initiated following further approval from the Ethics Committee via a protocol amendment. All correspondence to the Ethics Committee must be copied to R & D in order to maintain your NHHT R & D approval and indemnity status.

I am enclosing details of your responsibilities as Chief Investigator and would be grateful if you would return the signed Chief Investigator Agreement to Katy O'Donnell at the above address before commencing the study. Please contact Katy O’Donnell, R & D Manager, if you require further information.

On behalf of the Trust I wish you every success with the study.

Yours sincerely,

Dr John Ramage
Director of Research & Development

Hospital switchboard 01256 473202
www.northhampshire.nhs.uk

336
Appendix Four

Professional Participant Information Sheet
Participant Information Sheet

‘Key working and the role of the key worker’

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being carried out and what it will involve for you. Please take your time to read the following information carefully. Talk to other people about the study if you wish.

Part one tells you the purpose of this study and what will happen if you take part. Part two gives you more detailed information about the process of the study. Please contact me if there is anything that is not clear or if you would like more information. My contact details are available at the end of this information sheet. Take time to decide whether or not you wish to take part.

Part one:
The researcher is a paediatric physiotherapist working at the North Hampshire Hospital and this study is part of a Professional Doctorate course that she is currently undertaking at the University of Brighton.

As a physiotherapist working with children with disabilities who have a range of complex needs, the researcher is aware of the high number of professionals that may be involved with the child and family at any one time.

It has been identified that less than one third of the families who have a child with a disability have a ‘key worker’. This means that the responsibility of coordinating all the input from professionals and services currently tends to fall on the family.

The researcher would like to examine the perceptions of these service users and those professionals involved in the care of children with disabilities, of the role of the key worker and why they think that so few families have access to such a person.

On behalf of the researcher I am writing to invite professionals from health, social care and education to participate in the study. Parents of children with disabilities will also be invited to participate.

- Taking part in this research is entirely voluntary. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw from the study at any time without giving a reason.

- If you do take part in the study you will be asked to take part in a single agency focus group which will be audio-taped. The focus group will last between one and two hours and, will take place in a location and at a time convenient for you and other members of the group. If you agree to participate in the study by returning the enclosed reply slip, you will be contacted by the researcher who will be able to answer any further questions you may have about the study. The researcher will offer you a choice of dates and venues for the focus group meeting. You would be
asked to give your preferences. The focus group will then be arranged and confirmed in writing.

- By the very nature of the focus group information disclosed will only be confidential between the members of the group. You will be asked not to discuss this information outside of the group situation. All information gathered will be anonymised and held securely - remaining confidential to the researcher. Some quotes may be used verbatim but the information you give will not be personally identifiable.

- Following the focus group if you feel that you have raised issues that have not been addressed or you have a complaint about the way you have been dealt with during the study and you would like to discuss these with the Maternal and Child Health Divisional General Manager, at the North Hampshire Hospital, a private appointment can be made.

- Any disclosure made during the group session with regard to unprofessional behaviour or of a child protection nature will be taken through the appropriate channels by the researcher to the appropriate authorities identified in the Child Protection Policy Guidance of the North Hampshire Hospital NHS Trust.

- If there are issues raised which you wish you discuss in more depth on a one to one basis an interview can be arranged but this will not be expected of you.

- I cannot promise that the study will help you directly but the information you give may help improve service co-ordination for families with children with disabilities in the future.

- Once the study is complete if you would like to receive a summary of the study the researcher would be happy to supply you with this.

- If the information in Part one has interested you and you are considering participation, please continue to read the additional information in part two before making any decision.

Part two:

- If the study is stopped for any reason you will be informed as to the reason.

- You can withdraw from the study at any time without prejudice and you do not have to give a reason. You retain the right to decide if any information you have given prior to withdrawal can be used by the researcher.

- If you have a concern about any aspect of the study you should ask to speak to the researcher who will do her best to answer your questions (Tel: 01256 314916). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital. In the unlikely event that you are harmed during the course of this study, you may have grounds for legal action but you may have to pay your legal costs.
Any information that you give during the course of the study will be tape recorded and coded to protect your identity. The researcher is the only person with access to the coding system and all tapes will be stored securely maintaining confidentiality. All tapes will be destroyed following completion of the study after a period of five years.

This study has been given favourable ethical opinion for conduct within the NHS by the Southampton & South West Hampshire Research Ethics Committee A.

All participants will be given a copy of this information sheet and signed consent form to keep.

Thank you for taking the time to read this information and considering participating in this research study. If you would like to be involved please complete the reply slip and forward in the stamped addressed envelope provided and you will be contacted by the researcher who can discuss the study in more depth and answer any questions you may have.

Dr Virginia Jenkins – Prof. Doc. Research Thesis Supervisor
Senior Lecturer in Physiotherapy
University of Brighton
School of Healthcare Professions
Robert Dodd Building
49 Darley Road
Eastbourne
BN20 7UR

Tel: 01273 643653
Email: v.s.jenkins@bton.ac.uk

Enc. Reply slip and SAE
Appendix Five

Parent Participant Information Sheet
Participant Information Sheet

‘Key working and the role of the key worker’

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being carried out and what it will involve for you. Please take your time to read the following information carefully. Talk to other people about the study if you wish.

Part one tells you the purpose of this study and what will happen if you take part.

Part two gives you more detailed information about the process of the study.

Please contact me if there is anything that is not clear or if you would like more information. My contact details are available at the end of this information sheet. Take time to decide whether or not you wish to take part.

Part one:
The researcher is a paediatric physiotherapist working at the North Hampshire Hospital and this study is part of a Professional Doctorate course that she is currently undertaking at the University of Brighton.

As a physiotherapist working with children with disabilities who have a range of complex needs, the researcher is aware of the high number of professionals that may be involved with the child and family at any one time.

It has been identified that less than one third of the families who have a child with a disability have a ‘key worker’. This means that the responsibility of coordinating all the input from professionals and services currently tends to fall on the family.

The researcher would like to examine the perceptions of these service users and those professionals involved in the care of children with disabilities, of the role of the key worker and why they think that so few families have access to such a person.

I am writing to invite parents of children with disabilities to participate in the study. I will also be inviting professionals from health, social care and education to participate.

- Taking part in this research is entirely voluntary. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw from the study at any time without giving a reason. A decision to withdraw at any time or a decision not to take part will in no way affect the service provision you currently receive.

- If you do take part in the study you will be interviewed and that interview will be audio-taped. The interview will last approximately one hour and, will take place in a location and at a time convenient for you. This will be arranged by telephone and confirmed in writing. You will also be given the option of joining a focus group of about 5 or 6 other parents if you would prefer. The focus group would take place at a location
convenient to the participants and arranged by the researcher in
discussion with you. The focus group session will also be audio-taped.

- By the very nature of the focus group information disclosed will only be
  confidential between the members of the group. You will be asked not to
discuss this information outside of the group situation. Any disclosure
made during the group session with regard to unprofessional behaviour
or of a child protection nature will be taken through the appropriate
channels by the researcher to the appropriate authorities identified in the
Child Protection Policy Guidance of the North Hampshire Hospital NHS
Trust.

- All information will be anonymised and held securely by the researcher -
  remaining confidential. Some quotes may be used verbatim but the
information you give will not be personally identifiable.

- Any disclosure of information made during the interview or group session,
  with regard to unprofessional behaviour or of a child protection nature,
will be taken through the appropriate channels by the researcher to the
appropriate authorities identified in the Child Protection Policy Guidance
of the North Hampshire Hospital NHS Trust.

- Following the interview if you feel that you have raised issues that have
  not been addressed or you have a complaint about the way you have
been dealt with during the study and you would like to discuss these with
the Patient Advice and Liaison Service (PALS) a leaflet is enclosed
explaining how you can contact the PALS team.

- I cannot promise that the study will help you directly but the information
  you give may help improve service co-ordination for families with
children with disabilities in the future.

- Once the study is complete if you would like to receive a summary of the
  study the researcher would be happy to supply you with this.

- If the information in Part one has interested you and you are considering
  participation, please continue to read the additional information in part
  two before making any decision.

**Part two:**

- If the study is stopped for any reason you will be informed as to the
  reason.

- You can withdraw from the study at any time without prejudice and you
do not have to give a reason. You retain the right to decide if any
information you have given prior to withdrawal can be used by the
researcher.

- If you have a concern about any aspect of the study you should ask to
  speak to the researcher who will do her best to answer your questions
(Tel: 01256 314916). If you remain unhappy and wish to complain formally,
you can do this through the PALS team. Details are enclosed. In the
unlikely event that you are harmed during the course of this study, you
may have grounds for legal action but you may have to pay your legal
costs.
Any information that you give during the course of the study will be tape recorded and coded to protect your identity. The researcher is the only person with access to the coding system and all tapes will be stored securely maintaining confidentiality. All tapes will be destroyed following completion of the study after a period of five years.

This study has been given favourable ethical opinion for conduct within the NHS by the Southampton & South West Hampshire Research Ethics Committee A.

All participants will be given a copy of this information sheet and signed consent form to keep.

Thank you for taking the time to read this information and considering participating in this research study. If you would like to be involved please complete the reply slip and forward in the stamped addressed envelope provided and you will be contacted by the researcher who can discuss the study in more depth and answer any questions you may have.

Dr Virginia Jenkins – Prof. Doc. Research Thesis Supervisor
Senior Lecturer in Physiotherapy
University of Brighton
School of Healthcare Professions
Robert Dodd Building
49 Darley Road
Eastbourne
BN20 7UR

Tel: 01273 643653
Email: v.s.jenkins@bton.ac.uk

Enc. Reply slip and SAE
Appendix Six

Focus Group Protocol
The perceptions of service users and professionals of the role of the 'key worker'
in the management of children with disabilities

Focus group protocol

Welcome to this focus group and thank you for participating in the study. I greatly appreciate the time you have given to be here.

Although we may not all agree with the comments made I would ask that you all respect each other’s opinions and value each other’s contributions.

As you are aware I will be taping the discussions and I would appreciate it if we could allow only one individual to speak at any one time so that when I come to transcribe the tape I do not miss valuable comments made by anyone. I will endeavour to allow time for everyone to contribute.

Due to the nature of the group situation the information given by any one member will only be confidential within the group. I ask that you do not disclose what has been said within the group to anyone outside this room.

I must advise all group members that any disclosure of information with regard to unprofessional behaviour or information of a Child Protection nature made during the course of the session will have to be taken to the appropriate authorities under the guidance of the Child Protection Policy of my employing Trust the North Hampshire Hospital NHS Trust.

If following the group session you feel you wish to make more detailed contribution please do ask for another appointment. If you feel that you have unresolved issues or cause for complaint you can be offered an individual appointment with the PALS service team/ Maternal and Child Health Divisional General Manager.

Thank you
Mr Robin Thomas  
Assistant County Education Officer  
Children and Families Branch  
Hampshire County Council  
County Education Office  
Education Department  
The Castle  
Winchester  
Hampshire  
SO23 8UG

18th January 2006

Dear Mr Thomas

Re: ‘The perceptions of service users and professionals, of the role of the ‘key worker’ in the management of children with disabilities’

I am a clinical specialist paediatric physiotherapist working for the North Hampshire Hospitals NHS Trust. I have worked in the field of paediatric disability for over twenty years now being predominantly based in the community setting working closely with staff from Education and Social Services agencies. I am currently undertaking a Professional Doctorate course at the University of Brighton and it is in relation to this that I am contacting you now.

Over the forthcoming two years I aim to carry out a qualitative study the title of which I have given above. For that study I would like to carry out focus groups of staff from not only Health settings but Education and Social Service settings too. I will also be interviewing the parents of children with disabilities. I hope to explore the perceptions of all the groups on the ‘role of the key worker and key working’ in itself.

Key working is something that has been discussed in policy and legislation with regard to children with disabilities since the mid nineteen seventies. In the recently published National Service Framework for Children, Young People and Maternity Services (DOH 2004) it was identified that less than one third of families with a disabled child have a key worker. I do not feel that in this geographical area we have a well-established system of key working for these children although I am aware that the different agencies involved with these children work very differently and some agencies may have internal key worker systems established.
I am writing to ask your permission in principle to approach staff in some schools and pre-school units to see if they would be willing to participate in one of the focus groups. These will take place outside of school hours in a venue convenient for staff and last approximately 1-2 hours. Staff would be given information explaining the study and asked to sign a consent form that would state that they could withdraw at any stage from the study without prejudice and that all data would remain confidential and anonymised in the final study write up.

I am about to submit my proposals to the Local Research Ethics Committee and I cannot proceed until they have given me permission to do so. It would be helpful to have your response so that I could include it in that submission.

On completion of the study I would be happy to forward a copy to your department for your records.

If you would like to discuss this matter in any further detail please do contact me on 07850 446103 (Mobile) or 01256 314916 (Work) or 01420 588659 (Home).

I look forward to hearing from you.

Yours sincerely

Julia Graham MCSP MSc
Clinical Specialist Paediatric Physiotherapist
Dear Julia,

Further to John Tyler’s telephone conversations with you, I wanted to thank you for the courtesy of letting us know about your forthcoming research in Hampshire schools. I understand that John has explained that schools are autonomous in dealing with such matters and you would need to approach each school to seek the agreement of the headteacher and governing body to carry out your research involving members of their staff. I’m certain the majority, if not all, would be very interested in your research. However, it is unlikely that headteachers would want to direct colleagues to take part outside school hours and therefore it will depend on the circumstances of individual members of staff.

I would be very pleased to receive a copy of your study on completion and may I take the opportunity to wish you every success with the research programme.

Best wishes,

Yours sincerely,

Felicity Dickinson
Deputy Branch Manager (Children and Families)

Director of Children’s Services
John Coughlan
Appendix Eight

Letter to Health Gatekeeper
Response from Health Gatekeeper
Dear Fiona

Re: Professional Doctorate in Physiotherapy

As you are aware I am about to embark on my thesis for the Professional Doctorate in Physiotherapy course I am currently undertaking at the University of Brighton.

The title of my study will be …

‘The perceptions of the multi-professional team working with children with disabilities, including parents and carers, on the role of the key worker.’

I aim to interview parents of children with disabilities and run focus groups for staffs of the Health, Education and Social Services agencies. I am about to submit my ethics application form for the study and wanted to recruit your help. One of the main ethical concerns for the inclusion of parents in the study is that during interview they may become distressed if they feel that there are gaps in or lack of provision of services for their child. Similarly staff may feel frustrated at the possible perceived or real lack of resource for the children with disabilities on their caseload. I wanted to ask if you would be willing to meet with any parent or staff member should they wish to take their concerns further following their participation in the study and if so would you be willing to offer an individual appointment if they should request it, to allow them a forum in which they can discuss their issues with a senior manager on the Child Health Team?

I look forward to hearing from you and thank you for your continued support for my studies.

Yours sincerely

Julia Graham
Paediatric Therapy Services Manager
24 January 2006

Dear Julia,

Thank you for your letter of 23rd January 2006 requesting support to enable you to undertake your study on the perceptions of service users and professionals of the role of the key worker in the management of children with disabilities.

I believe this will be an extremely valuable piece of work and I have no hesitation in approving your request to approach staff in the health setting who may be willing to participate in focus groups.

Yours sincerely,

Fiona Corshill
Disability Services Manager
Appendix Nine

Letters to Social Services Gatekeepers
Response from Social Services Gatekeeper
Ms Wendy Davey  
Children with Disabilities Team Leader  
Hampshire County Council Social Services Department  
Sun Alliance House  
37-41 Wote Street  
Basingstoke  
Hampshire RG21 7LU  

18th January 2006  

Dear Ms Davey  

Re: ‘The perceptions of service users and professionals, of the role of the ‘key worker’ in the management of children with disabilities’  

I am a clinical specialist paediatric physiotherapist working for the North Hampshire Hospitals NHS Trust. I have worked in the field of paediatric disability for over twenty years now being predominantly based in the community setting working closely with staff from Education and Social Services agencies. I am currently undertaking a Professional Doctorate course at the University of Brighton and it is in relation to this that I am contacting you now.  

Over the forthcoming two years I aim to carry out a qualitative study the title of which I have given above. For that study I would like to carry out focus groups of staff from not only Health settings but Education and Social Service settings too. I will also be interviewing the parents of children with disabilities. I hope to explore the perceptions of all the groups on the ‘role of the key worker and key working’ in itself.  

Key working is something that has been discussed in policy and legislation with regard to children with disabilities since the mid nineteen seventies. In the recently published National Service Framework for Children, Young People and Maternity Services (DOH 2004) it was identified that less than one third of families with a disabled child have a key worker. I do not feel that in this geographical area we have a well-established system of key working for these children although I am aware that the different agencies involved with these children work very differently and some agencies may have internal key worker systems established.  

I am writing to ask your permission in principle to approach staff in your team to see if they would be willing to participate in one of the focus groups. These will
take place outside of normal office hours in a venue convenient for staff and last approximately 1-2 hours. Staff would be given information explaining the study and asked to sign a consent form that would state that they could withdraw at any stage from the study without prejudice, and that all data would remain confidential and anonymised in the final study write up.

I am about to submit my proposals to the Local Research Ethics Committee and I cannot proceed until they have given me permission to do so. It would be helpful to have your response so that I could include it in that submission.

On completion of the study I would be happy to forward a copy to your department for your records.

If you would like to discuss this matter in any further detail please do contact me on 07850 446103 (Mobile) or 01256 314916 (Work) or 01420 588659 (Home).

I look forward to hearing from you.

Yours sincerely

Julia Graham MCSP MSc
Clinical Specialist Paediatric Physiotherapist
Dear Mr Roley

Re: ‘The perceptions of service users and professionals, of the role of the ‘key worker’ in the management of children with disabilities’

I am a clinical specialist paediatric physiotherapist working for the North Hampshire Hospitals NHS Trust. I have worked in the field of paediatric disability for over twenty years now being predominantly based in the community setting working closely with staff from Education and Social Services agencies. I am currently undertaking a Professional Doctorate course at the University of Brighton and it is in relation to this that I am contacting you now.

Over the forthcoming two years I aim to carry out a qualitative study the title of which I have given above. For that study I would like to carry out focus groups of staff from not only Health settings but Education and Social Service settings too. I will also be interviewing the parents of children with disabilities. I hope to explore the perceptions of all the groups on the ‘role of the key worker and key working’ in itself.

Key working is something that has been discussed in policy and legislation with regard to children with disabilities since the mid nineteen seventies. In the recently published National Service Framework for Children, Young People and Maternity Services (DOH 2004) it was identified that less than one third of families with a disabled child have a key worker. I do not feel that in this geographical area we have a well-established system of key working for these children although I am aware that the different agencies involved with these children work very differently and some agencies may have internal key worker systems established.

I am writing to ask your permission in principle to approach staff in your team to see if they would be willing to participate in one of the focus groups. These will take place outside of normal office hours in a venue convenient for staff and last approximately 1-2 hours. Staff would be given information explaining the study and asked to sign a consent form that would state that they could withdraw at
any stage from the study without prejudice, and that all data would remain confidential and anonymised in the final study write up.

I am about to submit my proposals to the Local Research Ethics Committee and I cannot proceed until they have given me permission to do so. It would be helpful to have your response so that I could include it in that submission.

On completion of the study I would be happy to forward a copy to your department for your records.

If you would like to discuss this matter in any further detail please do contact me on 07850 446103 (Mobile) or 01256 314916 (Work) or 01420 588659 (Home).

I look forward to hearing from you.

Yours sincerely

Julia Graham MCSP MSc
Clinical Specialist Paediatric Physiotherapist
Derek and Julia Graham

From: "Rowley, Mark" <mark.rowley@hants.gov.uk>
To: <graham121@btinternet.com>
Sent: 31 January 2006 08:41
Subject: Role of key worker study

Julia, thank you for your letter outlining the study you are undertaking which looks like a useful exercise from a multi agency perspective. I can confirm that I am happy for you to approach staff. I will mention it at our team meeting this Thursday.

Regards

Mark

Mark Rowley
Team Manager, Children with Disabilities, Alton / Aldershot
Park House
High Street
Alton
GU34 1EN

Tel 01420 545680
Fax 01420 543515
Email mark.rowley@hants.gov.uk

31/01/2006
Appendix Ten

Reply Slip for Participants
The perceptions of service users and professionals of the role of the ‘key worker’ in the management of children with disabilities

Reply Slip

I …………………………………………………………………. (Please print name)

Give my consent to be approached by the researcher (Julia Graham) to discuss the above named study in more detail with the view to participation.

My details are as follows:

Address:

Telephone number:

E mail:

The best time to contact me is:

Signed………………………………………………………………………………….
Appendix Eleven

Letter to Professionals willing to Participate in Study
Date

Dear

Re: Key Working and the Role of the Key Worker

I am a paediatric physiotherapist working at the North Hampshire Hospital in Basingstoke. I am currently studying for a Professional Doctorate in Physiotherapy at the University of Brighton. I have been given permission by the Assistant County Education Officer/ Team Leader of the Children with Disabilities Team/ Divisional Manager MACH Division, to approach you as a professional working with children with disabilities. I have full Local Research and Ethical Committee, and R&D approval for this study to proceed.

You have very kindly recently returned a reply slip regarding the above study and have agreed to be approached to discuss your participation in the study. I am therefore writing to thank you for your interest in the study, identified above, which is to investigate the role of the key worker and your perceptions of this role.

If you would like to ask any further questions or would like further information regarding the study please do not hesitate to contact me on the number or at the address (postal or email) given above. I will be making contact with you within the next few days to arrange a convenient time for you to take part in a focus group.

I am grateful for your time and look forward to meeting you.

Yours sincerely

Julia Graham
Paediatric Therapy Services Manager
Appendix Twelve

Letter of Invitation to Parents to Participate in Study
Date

Dear

Re: Study - ‘Key working and the role of the key worker’

I would be grateful if you would have time to read the enclosed information about a study that I am currently undertaking as part of a Professional Doctorate course at the University of Brighton.

I feel as part of the study it is important to hear and represent the voices of parents and carers of the children with whom we work. I believe that you have a valuable contribution to make and would value your comments on how you feel the different statutory agencies work together. Participation involves being interviewed by me at your convenience and having the interview recorded so that I can accurately reflect what you say. All information given is treated in the strictest confidence and no-one will be identifiable in the final thesis write up.

If you would be happy to participate please follow the instructions given and return the reply slip in the envelope provided to my supervisor at the university. You are in no way compelled to take part and non-participation will not affect any services that your child currently receives.

Thank you for taking time to read this letter.

Yours sincerely

Julia Graham
Paediatric Therapy Services Manager
Maternal and Child Health Division
Basingstoke and North Hampshire Foundation NHS Trust
Appendix Thirteen

Participant Consent Form
Study Number: 06/Q1702/19

Participant Consent Form

Key Working and the Role of the Key Worker

Name of Researcher: Julia Graham

- I confirm that I have read and understand the information sheet, dated June 06 version two, for the above study. I have had the opportunity to consider the information; ask questions and have had these answered satisfactorily.

- The researcher has explained to my satisfaction the purpose of the study and possible risks involved. I have had the principles and procedure of the study explained to me and I understand these fully.

- I am aware that I will be required to participate in an interview or focus group which will be audio-taped.

- I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

- I understand that any confidential information will be seen only by the researcher and will not be revealed to anyone else.

- I agree to take part in the above study.

Name of Participant (please print) Date
Signature

Name of Person taking consent Date
Signature
(If different from researcher)

Researcher Date
Signature

When completed, one copy for participant; one copy for researcher site file
Appendix Fourteen

Question Schedule for Focus Group
Questions for Focus Groups: Key Working and the Role of the Key Worker

Introduction
Please can you describe for me your current role and how you are involved with working with children with disabilities.

Section One: Understanding of the Key Worker Role

1. What does the term ‘key worker’ mean to you?

2. How would you describe the role of the key worker?

3. What are the sorts of skills/attributes/qualities needed by someone undertaking the role of a key worker?

4. Who should/could undertake the role of the key worker?

5. What sort of status do you think a key worker should have to be effective in their role?

6. Who should a key worker be accountable to?

7. In your opinion are there certain occupations that may constrain an individual’s ability to be a key worker and if so why?

8. What support mechanisms do you feel a key worker would need to facilitate their role?

9. How can key workers have authority to access services from different agencies?

10. How independent from their professional background and employing agency do you think a key worker could be?

11. What sort of challenges does the role of the key worker present to existing professional cultures?
Section Two: Experience of the Key Worker Role

12. What experiences have you of carrying out a key worker role?

13. What key worker activities do you think you are doing at the moment?

14. What sort of training would you need/does a key worker need, to be effective in the role?

Section Three: Current Practice

15. If you are currently working in a multi-professional team how do you ensure you communicate with all the other members of that team?

16. Do you believe the current system of interagency working to be effective – if so how, and if not, what is it that impedes cross agency working? Is this at a practice level or at a strategic level?

17. Within the current interagency system of working what would you change to enable effective key working to take place?

18. How do you think the outcomes for the child and family would change if there was a key worker system in place for all children within our area who have a disability?
Appendix Fifteen

Question Schedule for Parent Interviews
Questions for Parents: Key Working and the Role of the Key Worker

I would like to explore some of your experiences of working with the team of people that have been involved with your child. First of all can you tell me a little about your son/daughter?

How many professionals are working with you and your child and family at the moment?

How do you communicate with all the members of this multi-professional team?

How do you think the team members communicate with each other?

Do the team members visit together?

How do you feel that team members could work better together?

What does the term ‘key worker’ mean to you?

How would you describe the role of the key worker?

Have you any experience of working with a key worker? Is that within this area or elsewhere?

What are the sorts of qualities needed by someone undertaking the role of a key worker?

Who should undertake the role of the key worker? Are there any people you feel should not be a key worker?

What sort of key worker activities would be helpful to you and your child?

What, if anything would help you understand how to use a key worker?

What is it about the current system of provision that is most difficult for you, your child and family?

Do you think having a key worker would be helpful for you and your child and family?

How do you think life for your child and family would change if there was a key worker system in place?
Appendix Sixteen

Development of Interview Topics during Data Collection
### Development of Interview Topics during Data Collection

<table>
<thead>
<tr>
<th>Focus Group/Interview Number</th>
<th>Background of Participants</th>
<th>New Participant Led Interview Topics</th>
<th>Comments</th>
</tr>
</thead>
</table>
| Interview Three | Health Physiotherapist | Lack of understanding of professional roles by parent  
Parental emotional journey  
Interagency conflict - silo working  
Influence of co-location  
Intrusion into home life  
Acceptance of disability  
Key worker role increases bureaucracy  
Impact of impairment on family and relationships  
Specialist nursery – better team work  
Negative image of social workers | Purposive participant: professional working with disabled children  
Reinforced ‘journey’ of child and parent |
|---|---|---|
| Focus Group (2) | Children’s Services Staff: Social Care Social Workers | Issue specific key worker  
Specialist key worker role in child protection  
Terminology means different things to different people  
Difference in special schools compared to mainstream  
Statutory duties  
Professional training gives key worker skills – different to other professionals | Theoretical sample: impact of negative social work image |
| Focus Group (3) | Children’s Services Staff: Education Teachers - Mainstream School | Time factor for key work role  
Differences in key worker role in different settings/contexts  
Negativity of social work role  
Impact of impairment on support given  
Lack of training preparation for disabilities in teacher training  
Poor interagency relationships | Theoretical sample – mainstream versus special school staff qualifications, skills and expertise |
| Focus Group (4) | Children’s Services Staff: Portage Home | Powerlessness of role  
Lack of understanding of role | Theoretical sample - key worker context influence on role |
<table>
<thead>
<tr>
<th>Focus Group (5)</th>
<th>Health Therapists: Occupational Therapist, Physiotherapist, Hospital Play Specialists</th>
<th>Impact of impairment on parents and family Professional cultures Inter-professional relationships influence working as team Key worker = abstract concept Lack of child centred services</th>
<th>Theoretical sample - key worker context influence on role Dropped challenges to key worker role that currently exist as participants were readily describing these in their discussions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview Four</td>
<td>Children’s Services Staff: Education Specialist Teacher Advisor</td>
<td>Communication difficulties across agencies Power imbalance between professionals and parents Professional dominance – regularity of visit creates dependency</td>
<td>Theoretical sample – interagency working, professional cultures Dropped question about current system of interagency working as participants were describing what was and was not effective and what changes they would make therefore no need to repeat</td>
</tr>
<tr>
<td>Interview Five</td>
<td>Parent</td>
<td>Training need for parents on key worker role Logistical need for extra hands – key worker role Impact of impairment on parental relationships Impact on employment Role of mother versus father</td>
<td>Theoretical sample – parent partnership, child centred services, professional cultures</td>
</tr>
</tbody>
</table>
| Interview Six | Parent | Concerns about transition  
| Need for pro-active support not crises management  
| Changing professionals – lack of consistency  
| Impact on siblings  
| Parent to parent support  
| Communication issues with team | Theoretical sample  
| professional/parental power imbalance, influence of diagnosis |
| Interview Seven | Parent | Rigidity of service provision – rules/regulations  
| Need to think outside of the box  
| Impairment focused family | Theoretical sample – service provision not child centred, impact on siblings, parent/professional imbalance, negative image of social workers |
| Interview Eight | Parent | Physical demands (24 hour)  
| Key worker accessibility | Theoretical sample – parent to parent support, impact on siblings, influence of individual personalities |
| Interview Nine | Parent | Balance of work and family life  
| Information needs  
| Constant battles | Theoretical sample – logistical support, negative image of social workers |
| Focus Group (6) | Children’s Services Staff: Education  
| Children’s Centre Staff | Individuality of need  
| Whole family involvement  
| Language/jargon  
| Lack of commitment to team work  
| Limitations of key worker role  
<p>| Shared responsibility of team | Theoretical sample – influence of personalities, parent/professional relationship, availability of key worker |
| Focus Group (7) | Children’s Services Staff: Portage Home | Lack of regular team contact | Theoretical sample – differences in professional training – impact on |</p>
<table>
<thead>
<tr>
<th>Interview</th>
<th>Role</th>
<th>Issue</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview Ten</td>
<td>Children’s Services Staff: Occupational Therapist</td>
<td>Duplication of service provision</td>
<td>Theoretical sample - influence of personalities, lack of trust, lack of joint meetings/training, influence of diagnosis on future relationships. Statutory duties</td>
</tr>
<tr>
<td>Interview Eleven</td>
<td>Parent</td>
<td></td>
<td>Theoretical sample – emotional journey for parent, communication issues, influence of staff changes, information needs, parent to parent support</td>
</tr>
<tr>
<td>Interview Twelve</td>
<td>Children’s Services Staff: Occupational Therapist</td>
<td></td>
<td>Theoretical sample – inequality of parent/professional relationship, team information sharing needs, parent as key worker, influence of individuals</td>
</tr>
<tr>
<td>Interview Thirteen</td>
<td>Health Staff: Paediatrician</td>
<td></td>
<td>Theoretical sample – individuals in team, professional and organisational cultures, creation of dependency, key worker availability, lack of contact with team, key worker role in different contexts</td>
</tr>
<tr>
<td>Interview Fourteen</td>
<td>Parent</td>
<td></td>
<td>Theoretical sample – self select key worker related to need, parental</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------</td>
<td>----------------------------------------</td>
<td>----------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td><strong>Interview Fifteen</strong></td>
<td>Health Staff: Children’s Community Nurse</td>
<td>Theoretical sample – key worker related to need, parent/professional relationship, and information needs, financial constraints, organisational bureaucracy.</td>
<td></td>
</tr>
<tr>
<td><strong>Focus Group (8)</strong></td>
<td>Children’s Services Staff: Education Special School Teachers</td>
<td>Theoretical sample - integrated working in special school, interagency/inter-professional relationships, geographical boundary issues</td>
<td></td>
</tr>
</tbody>
</table>
Appendix Seventeen

Participant Background: Interviewees
## Appendix Seventeen

### Participant Background: Interviewees

<table>
<thead>
<tr>
<th>Interview Number</th>
<th>Parent/Professional Designation of Participant</th>
<th>Employing Agency</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>Parent</td>
<td>N/A</td>
</tr>
<tr>
<td>Two</td>
<td>Health Physiotherapist</td>
<td>Health</td>
</tr>
<tr>
<td>Three</td>
<td>Health Physiotherapist</td>
<td>Health</td>
</tr>
<tr>
<td>Four</td>
<td>Specialist Teacher Advisor</td>
<td>Children’s Services (Education)</td>
</tr>
<tr>
<td>Five</td>
<td>Parent</td>
<td>N/A</td>
</tr>
<tr>
<td>Six</td>
<td>Parent</td>
<td>N/A</td>
</tr>
<tr>
<td>Seven</td>
<td>Parent</td>
<td>N/A</td>
</tr>
<tr>
<td>Eight</td>
<td>Parent</td>
<td>N/A</td>
</tr>
<tr>
<td>Nine</td>
<td>Parent</td>
<td>N/A</td>
</tr>
<tr>
<td>Ten</td>
<td>Occupational Therapist</td>
<td>Children’s Services (Social Care)</td>
</tr>
<tr>
<td>Eleven</td>
<td>Parent</td>
<td>N/A</td>
</tr>
<tr>
<td>Twelve</td>
<td>Occupational Therapist</td>
<td>Children’s Services (Social Care)</td>
</tr>
<tr>
<td>Thirteen</td>
<td>Consultant Paediatrician</td>
<td>Health</td>
</tr>
<tr>
<td>Fourteen</td>
<td>Parent</td>
<td>N/A</td>
</tr>
<tr>
<td>Fifteen</td>
<td>Children’s Community Nurse</td>
<td>Health</td>
</tr>
</tbody>
</table>
Appendix Eighteen

Participant Background: Focus Groups
# Appendix Eighteen

## Participant Background: Focus Groups

<table>
<thead>
<tr>
<th>Focus Group Number</th>
<th>Professional Designation of Participant</th>
<th>Employing Agency</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>R1: Physiotherapist&lt;br&gt;R2: Physiotherapist&lt;br&gt;R3: Physiotherapist</td>
<td>Health&lt;br&gt;Health&lt;br&gt;Health</td>
</tr>
<tr>
<td>Two</td>
<td>R1: Social Worker&lt;br&gt;R2: Social Worker&lt;br&gt;R3: Social Worker&lt;br&gt;R4: Social Worker&lt;br&gt;R5: Social Worker&lt;br&gt;R6: Portage Worker&lt;br&gt;R7: Social Worker&lt;br&gt;R8: Social Worker&lt;br&gt;R9: Social Worker</td>
<td>Children’s Services (Social Care)&lt;br&gt;Children’s Services (Education)&lt;br&gt;Children’s Services (Social Care)</td>
</tr>
<tr>
<td>Three</td>
<td>R1: Head Teacher&lt;br&gt;R2: Teacher (Year Two)&lt;br&gt;R3: Teacher (Year One)&lt;br&gt;R4: Teacher (Reception)&lt;br&gt;R5: Teacher (Reception)</td>
<td>Children’s Services (Mainstream Education)</td>
</tr>
<tr>
<td>Four</td>
<td>R1: Portage Worker&lt;br&gt;R2: Portage Worker (Team Lead)&lt;br&gt;R3: Portage Worker&lt;br&gt;R4: Portage Worker&lt;br&gt;R5: Portage Worker&lt;br&gt;R6: Portage Worker</td>
<td>Children’s Services (Early Years Education)</td>
</tr>
</tbody>
</table>
| Five  | R1: Physiotherapist  
R2: Physiotherapist  
R3: Hospital Play Specialist  
R4: Occupational Therapist  
R5: Physiotherapist | Health |
|---|---|---|
| Six  | R1: Early Years Centre Worker (Centre Leader)  
R2: Early Years Centre Worker  
R3: Early Years Centre Worker  
R4: Early Years Centre Worker  
R5: Early Years Centre Worker | Children’s Services (Early Years Education) |
| Seven | R1: Portage Worker  
R2: Portage Worker (Team Lead)  
R3: Portage Worker  
R4: Portage Worker  
R5: Portage Worker | Children’s Services (Early Years Education) |
| Eight | R1: Head Teacher  
R2: Nursery Teacher | Children’s Services (Special Education) |
Appendix Nineteen

Example of Transcript

Parent Interview Example
Parent Interview Example

JG: What I want to explore is some of your experiences of having a child with a disability and having to work with the group of professionals that you have got to work with. You were just chatting about some of the people you’ve had contact with so to start off can you give us an idea of the sort of people you’ve got contact with …

KB: Em, so if we start with physiotherapists, occupational therapists, Orthotists, orthoptists and em and the … what … I can’t remember his title, I can’t think what it’s called … the eye consultant the one above the orthoptist. We see the orthoptist three times a year and once a year we see her boss. Then we have, obviously at the moment social services, the em … the HA (housing association) department of the council currently. [Is that housing?] Yes. They’re kind of the extension side of things (extension to the house) em and then related to that we’ve got the county appointed architect we’re liaising with constantly and em then we have the teacher adviser from the LEA (Local Education Authority), then we have the LSA’s (Learning Support Assistants) in school and obviously the SENCo’s (Special Educational Needs Co-ordinator’s) and head teachers and class teachers em … Then I deal with, at the Rainbow Centre (centre for conductive education) I have various conductors – conductive education as well em, so we have reviews with them and obviously contact every fortnight when we go. I think that might cover everything apart from your normal dental people and things like that, that everybody needs.

JG: You were saying about an orthopaedic appointment?

KB: Oh yes we see an orthopaedic consultant now as well at S (local tertiary centre) for the first time so yeah now I’ve kind of gone out of region as well. So three different hospitals A (local hospital), B (local secondary hospital) and S (local tertiary hospital)

JG: Gosh, what about wheelchair services has she got a wheelchair?
KB: Yeah that’s em, I’ve never had contact directly with the wheelchair service, em the wheelchair’s always been
provided by the OT (occupational therapist) and the wheelchair services if they’ve needed to do anything have
contacted school directly and done it and they’ve actually come out to home em, and we had the guy that when we
had D’s (child) new trike, came out and do the assessment, mobility and that sort of thing.

JG: Quite a lot of people.

KB: Mmm yes

JG: Quite a lot to work with. How do you manage to communicate with them all?

KB: Em, well, I’m finding it more difficult as time goes on really em, it’s … most of it’s the phone, I don’t think I’ve seen
any of them or a lot of them in person for about at least six months em, yeah mainly telephone. Email where I can to
check if I need something in writing, to support something or to refer back to … try and get things done in email. Em
and, it’s a constant kind of making a list really of what I’ve got to do, who I need to contact and specially at the
moment with everything that’s going on (referring to house extension plans) em that trying to get hold of people at the
moment is err . . . or trying to get people to actually return your communication is proving hard at the moment . . . so
frustrating so err . . .

JG: Do you sort of keep a central file of everybody’s contacts and who they are?

KB: Yeah . . . I’ve got a filing cabinet in there (pointing to hallway) with a… the whole . . . the bottom drawer has to do
with D (child) and I’ve got a whole section on therapy, I’ve got . . . oh I forgot the paediatric consultant of course, as
well, because I haven’t met her yet it’s a new one. Em, I’ve got a section on the LEA (local education authority), I’ve
got a section on the extension, I’ve got a section on social services, em therapy reports em, school . . . kind of contacts
so em I’ve got quite a bit of paper work out there.
JG: You need an admin officer as well to go with it all (laughter)

KB: It’s just lucky that you know in a way that I don’t work full-time because I don’t know whether I would be able to manage with a full-time job because obviously you have to contact people within business hours because they’re not available outside of them em, and if I wasn’t at home you know kind of 70% of the time, then err I don’t know how I’d manage and also with the amount of time that we spend going to appointments I don’t think anybody would employ me any way because I’d be forever out of the job, so the job that I’m doing now fits in really well. I’ve got four jobs at the moment I doing Monday afternoon, Tuesday afternoon, Thursday afternoon, Friday afternoon delivering local newspapers to the paper boy and girls …

JG: Oh right yeah

KB: So like you know I get 2,500 papers delivered to me. I’ve got about 20,000 leaflets in the dining room that I sort over the week end to go with the papers but it suits me because I can go straight from whichever area I am in go straight to school to pick up

JG: Yes, yes.

KB: So it’s working very well.

JG: Because you’ve not only got D (disabled child) you’ve got two younger girls as well

KB: Yes I’ve got C (2nd child) who’s coming up to six and is showing quite . . . em signs of dyslexia so at the moment I’m now liaising with em the SENCo and the reading class specialists at school to get her some individual sessions which they’ve just kind of identified the need as well, that I’ve asked for, so C’s (second child) struggling slightly on the learning
side of things. And A (3rd child) is four and I got her letter on Saturday that she’s got her place at (named school) from September so yeah, she’s at playschool or preschool three mornings a week and all day on a Wednesday so yeah.

JG: So not only that you’re also a taxi driver for the girls as well.

KB: Yes. (Laughter) Completely! I spend my life in the car now I’ve got my blue tooth at least I can phone people and discuss things on the phone yeah I’ve kind of given everyone instructions now if I’m not on my home phone number please phone me on my mobile because my car is like my second office at the moment (laughter) and I’m quite happy to speak to people in the car

JG: Yeah . . . needs must. Do you think those people are all aware of the other people that are involved with D (child) and what is going on with her?

KB: No I don’t at all. I don’t think that any of them realise the amount of appointments that you know that we go through, em, my calendar is kind of full of, because obviously when you’ve been to one appointment you always make six monthly appointment then or yearly or three monthly whatever it is. So my calendar has got, you know dates, times the person we are seeing and where we are seeing them not only for the benefit of me but if anything should happen to me, J (husband) wouldn’t have a clue. Where . . . because I do the kind of you know, he’s got his full time job and I do the more kind of routine appointments if you like. He comes to S (tertiary centre) because you know we felt that that was the first, the start of something quite big, to see the orthopaedic surgeon. So em, yeah so I don’t think that anybody could unless you’re, unless you are in the situation where you are the parent of a child with a disability. I don’t think you can think about the amount of appointments that are em routinely booked in because you’ve also got the add hoc ones, whenever I kind of see D’s (child) deteriorating in a certain area I’ll be straight on the phone to which ever professional I think that you know, needs input into that and em there we go we get another range of appointments em, the follow ups and also em, with her health as well I mean she had tonsillitis again the week before last and that in the past has set off her seizures so you’ve got the epilepsy kind of kicking in so you have to monitor that so you’re back
and forward to the doctors even though they tell me it’s a virus and send me away and later I’m back again because I can’t let it go on for any length of time em, but they tend to be pretty good they kind of just take it. You know I’ve got my torch . . . I’ve bought a Mag light torch so I can see the back of her throat and when it gets to a point that I think no I’ve got to get something done they take my judgement on it and just help me out. So yeah it’s em, you know from an outside . . . I know social services should have an idea of all the professionals that their patients see from adult down to children you know the input that people have but I don’t know whether they know how frustrating and how time consuming it is trying to actually get to see those em . . . people and then trying to organise the outcome of it. What then happens next then the follow ups and em, the loss of schooling time and things like that which always has an impact on learning and catching up and err . . . it’s em yeah it is kind of a full time job really trying to get it co-ordinated and get people to . . . people don’t speak to each other so I’m kind of the one in the middle that’s feeding back what one’s said you know to try and relate . . . to get my . . . to get what needs to happen across em and err the one last Monday is a prime example of it. I’ve got to rethink after that the initial appointment with the orthopaedic consultant. He said to us on Monday I’m now going to impact on physiotherapy and orthotists and I’ve not got to re-look at all of that kind of thing and start again really. Em . . .

JG: Is the plan to do some major surgery?

KB: The plan is that we go back in six months and have another hip x-ray done and check gait analysis. The frustrating thing was the initial referral came from B (local secondary hospital) for us to go to him because he’s top of his field and when we got there he said oh well we need to do some gait analysis where we put some dots on D’s (child) legs . . . well we’ve done all that in movement clinic, we’ve had three lots of that over the past two years so he wasn’t aware that that had actually happened so he hadn’t had any of the files for that em and nobody had sent previous hip x-rays across to him either so he had no, no point to monitor the movement against the hip x-ray on Monday so I kind of felt for him because you know he had the referral through but none of the back up information that needed to go and now we’ve got to go back in six months because it will give him a chance to get all of that information and study it and for him to take another hip x-ray and see what the progression is, if it’s very quick or whether it’s nice and slow, if it’s very
quick then yes em surgery will be em imminent but it will be multi-level they won’t do . . . they’re finding now that the
muscles take a year to recover each time they prefer to do hip knee and ankle at the same time so it’s only got the one
year of recovery rather than three but we want to avoid that at all costs and em he was em he wants us to have a
major physio input in that six months because he felt that D (child) was so tight that there was no need for it that she
wasn’t getting the right programme and not enough input, so therefore I come back and try and follow all of that up
JG: Wasn’t the consultant J that referred you down to S (local tertiary centre)
KB: Yes it was J (consultant paediatrician) and CP (physiotherapist). CP sat in and she was the one I asked J asked her
for her opinion for which one and it was her that obviously suggested that Mr U (consultant orthopaedic surgeon) was
the better with children, the bed side manner em because the other one is quite frightening (laughter). He was
fantastic. He came across as very confident very experienced in what he was saying and em explained everything in
lay mans terms for us and D (child) and err . . . yeah
JG: It would have been better if that information had gone with you to the clinic?
KB: Well definitely he could have checked her gait analysis and the way she was walking em and hip x-ray from the
date we last had it he could have seen what the movement was and whether or not we need to be talking about
surgery or not em. Obviously the main thing is that we can’t let her hip go completely uncovered and at the moment
it’s on the edge. Her right leg is coming in so badly …
JG: Is she having a lot of pain with that?
KB: She’s having more pain when I try and put her feet in the right position and make her walk as she should be. It’s
more comfortable for her to be walking in that position at the moment so it’s obviously putting more strain on all the
muscles of her ankle. It’s awful because she’s walking on the outside of her foot which is hurting her little toe it’s all
impacting on the fact when J (husband) saw her the other day em walking in bare feet because he doesn’t see her
walking in bare feet a lot you know he’s always . . . he said her toe looks almost black you know where she’s walking
and all of that weight, her heel’s completely up, all the weight’s being taken on a couple of her little toes and that’s it

JG: Which is not where it’s supposed to be?

KB: No so em, so yeah it’s then setting up another round of appointments that weren’t kind of scheduled in with your
routine ones you know ad hoc ones all extra time and all out of school time

JG: Yeah, yeah, yeah. It’s really difficult to find the right balance.

KB: I’d like a better flow of communication between them all em I’ve kind of looked at the whole idea of key workers
before on the when I did an Early Support course for the Early Years study em and I don’t think, I can’t see that you can
all sit down in a room together and do your routine appointments twice a year because it doesn’t work. The monitoring
of different things moves quicker on some than others and it would take you know you could probably sit there for two
days by the time everybody’s covered their part of everything em so I can’t see that that would ever be a possibility but
having said that em a flow of communication is . . . if people were aware of the amount of appointments and what the
outcomes were and follow up reports that everybody was having to attend to and also if you know the OT’s and
physio’s work quite closely together – that’s obviously the health side of it and the . . . so they know what’s going on with
each other em. It would be nice if social services knew from a health point of view because they come along and they
say ‘oh yeah you’ve got you know . . . the child’s got CP (cerebral palsy) therefore she’s unable to do this and that, but
then I don’t think, you know ‘cause every child’s different, in different degree’s of it, capabilities are all different and
again that impacts on the amount of other professionals that you’re seeing. Em, but then I don’t know whether social
services have got their resources to follow that kind of paper work . . . I think something like a computerised system

392
where all of the information is available to the professionals working with that child and they can pull up that information
and know that there is an... you know who's having input what that input is. May be something along those lines. It
would be really nice to have somebody – one point of contact that I could phone and say, that was at that meeting
with me, attend the professionals with me, and takes away all that from me and says right now I'll go and do all of this
for you, we'll get the physio's input you know relooked at. We'll do that and kind of let me just come out of the meeting
and absorb what's gone on without me having to rally it all around and start getting... do you know what I mean. Take
that pressure off the parent it would be a... it would be really, really amazingly really, beneficial. That person who's
then feeding back is going to know that even if they haven't got an outcome yet they are dealing with it, it's not just
kind of being left em yeah and let us kind of get on with other things in life. Really...it would be good.

JG: What sort of skills do you think a person like that would need?

KB: Well they'd need a lot of people skills because they would be dealing with a... parents and children they'd have a
lot of input into the children as well so they've got to be approachable and they've got to be em, understanding of the
family situation, they've got to be a caring sort of person but they've also got to be em professional and not be scared
to talk to other professionals because I know that whenever you go, if anybody gets on their backs, they kind of get
their backs up if somebody goes to them and says look we need to do this, this and this, most of them em are very
defensive of their roles and em you know will probably say 'oh that's not possible because blah' So that person's going
to have to be a strong person to say well actually we need this to happen em there are, you know there must be ways
of doing it but it's... you got to have sort of a person that can be approached, by the parent and by the professionals
and be able to deal with both sets em to get the right outcome really so they've got to be a strong willed person and
they've got to kind of get the bit between their teeth and run with it to get, to get the outcome em and I think they've
got to be a hard worker because I think it is extremely tough. When you've got numerous families with all different... em circumstances they've got to be a strong person I think you know to kind of go into those circumstances as well em.
JG: Do you think it’s somebody who has, that could do it, who has a professional role already who is on the team or do you think it needs to be somebody who is totally separate from that professional team?

KB: Em I don’t know I can see that an independent would be clearly that because they’re not going to be bias towards any of the professionals. So for me I think that would work better but then are you then introducing another person into the whole family contact but then . . . the family shouldn’t need all the contact that they’ve been having obviously you’re going to see . . . the family have got to be involved with the appointments with the professionals but if you haven’t got to keep chasing things by the phone and everything then maybe an independent would be the way to go that their main focus is to get things moving for families so they haven’t got to then go out and do their own physio role or whatever it is with the key worker role in the background. One’s always going to take over the other so I think that em from a purely logistical point of view an independent person, somebody that’s actually appointed you know em for that reason is probably the best person because they can get their teeth into exactly what they’re supposed to be doing and use, spend all their time doing that really.

JG: If it was somebody who did have a professional role do you think it would be easy for them to go say, say it was the physio they obviously work for the health agency. Do you think it would be easy for them to go to social services or education and say this child needs x, y and z can you supply it?

KB: Yeah I think whenever you . . . em I still think that a lot of em systems regard your normal kind of not office type person but somebody . . . if a key worker for instance wasn’t a professional that had been you know just appointed for that role I still think they would be looked at differently to a professional. I think a professional is always going to be more effective because they have that knowledge and respect em and I think they would . . . as soon as you kind of put down that you know you’re an occupational therapist or you’re a physiotherapist you’ve got a certain amount of weight behind it and the other people think well actually they do know what they’re talking about because they’re trained in this area so err the key worker coming in that doesn’t have any of those qualifications on the physical side, coming in and just kind of you know requesting things may just be kind of put to the bottom but then that would all
have to be done with the profile of the position, people would have to be told . . . not told but you know trained in that or advised in the fact that this person is as important as anyone else because they’re working on behalf of the family and they’re liaising with all the professionals, so they’re still getting all that input – just because they haven’t been trained in it themselves that physiotherapist is still giving them the advice and input that they need all they are doing is taking the pressure off the family and relaying it and getting things to happen yeah I can certainly see that you know a person that’s been in their job for so many years suddenly gets somebody coming in that’s not a professional and says well this needs to happen could get their back up but somebody who is a professional well they can kind of work together sort of thing

JG: Yeah.

KB: It’s the perception of the role I think definitely

JG: Do you think people might need quite a bit of training of what that role is about?

KB: Yeah definitely. Yeah you couldn’t just em . . . when I attended this particular course and we got on to the key worker role the em . . . the balance in the room was completely put out it was, it was . . . there was a lot of people who kind of dismissed it completely – ‘Oh we tried that in the past – didn’t work’. That was it case closed as far as they were concerned. Em, so blinkered –

JG: Were they professional people?

KB: Yeah they were professionals because you had a mixture of parents, social services, OT’s, physio’s and . . . I think that might have been it, there might have been a couple of SENCo’s (Special Educational Needs Co-ordinators) in there em and yeah I mean you do have . . . and it was driven home the whole time that this was a new programme, this was in light of the em the government study after the death of . . . I forgotten her name now . . .
JG: Victoria Climbié?

KB: Yeah em and that you know it’s not the same as how it was working before this is what, you know, this is all been done in pathfinder groups to establish it and help direct it so you get the ones that thought it was a really good idea, mainly the newer ones because they hadn’t come across it before and are open to system changes and I think em those that had been there for years and years and years were just sort of like well actually we don’t really want to change it all again we’re forever having changes and you can completely understand that you know there’s always restructures there’s always changes to policy there’s always . . .you know and it affects the way they work so they’re constantly having to change and you can completely understand where they are coming from but they were completely negative about the whole thing and you know wouldn’t even consider it. And em you know it’s quite easy. . . we did a lot, we had that initial discussion and then did the role play part of it and really helped to . . . when you visualise it I think that really helped them a lot more the em the one that sticks in my mind is the balloon exercise where you have the parent sitting down on the chair and every professional has a balloon and the family members have a balloon and they try and give them to the parent and everybody is trying to give the parent their balloon and eventually she starts dropping balloons and the kind of whole reason behind it is that the balloons that get dropped are kind of family ones because the professionals are you know you will take my balloon you will have this input from me and the kind of family lot are pushed to the side lines and it was very em I say very visual but kind of light hearted way of doing it but it did get the message across really. And the people that were negative sort of went well yeah you can actually see now how many people you know these people have to contact and so that’s it, it is the way forward and they started coming round a bit to the idea. But yeah the training would have to be completely right to get everybody on board and it would have to be completely consistent because you couldn’t have the key worker doing one thing for one family and not for another em, you know it’s em like the adaptations at the moment you know it’s all post code lottery again. Some councils will completely fund 100% no matter what the cost is and H (local county) won’t, so I just, I just feel that there’s so much inconsistency with everything to do with you know disabilities that something like a key worker role would have to be you know across board, doesn’t matter if you are in Scotland, up north, down south, in.
Wales everybody doing the same thing. You shouldn’t have to go and live in a borough that you will help you more than the one that you are living in. I don’t think that’s fair.

JG: Yes. Just going back to training there for a minute... do you think the training would be best organised with professionals and parents together em because some parents may not understand what this role is about if it was introduced or do you think that parents should have separate training?

KB: I felt a little bit intimidated em, even guilty you know as if I was putting more on them. As if I was making their life harder em and again we have had these discussions during the group and you will get ... you ... you couldn’t have a newly diagnosed parent on this type of course because there’s so much that they’re absorbing and you kind of throw them into that ‘there you go now lets learn about this’ em it would be awful and there’s also em you’ve got, I mean everybody’s from different backgrounds and without trying to sound discriminating or anything you’ve got a parent or set of parents who perhaps aren’t great at reading or writing and the academic side of things you couldn’t then put them on a course with professionals because I feel that the level would be too high and they wouldn’t get anything out of it. You’ve got to tailor it to the people on the course I think em, I would like to see a certain amount of parents with the professionals so the professionals get the parental side and view of things but I feel the parents would have to be chosen particularly, you know very wisely and willing to be on the course with the professionals but I do think it’s necessary for the parents to be involved all the way along the way along any way whether it be like half a day on a Saturday morning type course or even just more kind of informal chat session course you know an evening for 2 hours where there’s tea and biscuits – stuff like that because I do feel that everybody needs ... but it would have to be presented in a completely different way to the professionals err so yeah you got to get, the training is very crucial I think and you couldn’t have one training format for everybody it just wouldn’t work.
JG: Mm yeah. You touched a little bit about em, the sort of early diagnosis stage there when you mentioned parents.
Looking back on your years you know being mum to D (child) have you come through various emotions and
experiences on that journey from diagnosis stage?

KB: Mm yes and it changes as D (child) changes you know you still get all these different emotions the first ... from the
diagnosis point of view. I think the diagnosis stage was very badly handled any way. Because when D (child) was
diagnosed it was a routine child development check at 10½ months up until that point the checks had always been,
the outcome was oh yeah she’s a little stiff in her legs and then at 10½ months I was on my own just taking her to what I
thought was a routine check up and err the consultant did her assessment and err we went back and sat at the desk
and she said oh yeah it’s definitely cerebral palsy. The words had never been mentioned before so suddenly that label
was the horrific ... and it was like ... and she wrote down the number for Scope and told me to contact them for
further information, that was it end of consultation and I left the room in absolute tears em got back to the car and kind
of broke down on the phone to my husband you know I couldn’t get the words out. Em so I thought that the diagnosis
was really, really badly handled and you know I’d hate for anybody to go through that the way that I did. Em, so then
you’ve got the confusion about where suddenly has this come from. You’ve got the ‘Oh my God what does it mean
does it mean she’s going to die early or anything? Because you don’t know about the conditions until you start
researching them. You know if you went out to the, you know, the kind of the ordinary person on the street and said ‘OK
what’s cerebral palsy?’ None of them would have a clue unless they’ve got contact with somebody so then you’ve,
but you’ve also got that ‘Oh my god I must research it I must know everything that there is to know about it so there you
go you start your phoning straight away and, and your internet researching, your library search, what is this, what ... I
mean you’ve got then referrals to all sorts of people that you’ve never had any contact with before you don’t know
what they’re going to do, what they can do, what they’re input – you know how their input is going to affect anything
and then I say you’ve got ... at the back of it you’ve got a lot of why, why us sort of thing, you’ve got that going on,
what have we ever done to deserve this, you know what has she done, she’s a baby why put this on her em and then
you’ve got the guilt perhaps I did something in pregnancy I must have caused this you’ve got all those emotions going
on. And then when you start telling family and friends em you’re kind of almost ashamed because you feel that it is
something that you've caused and that's . . . so you have to start telling people and they're like well why? You know you've got all the questions then and you can't answer everything and you've got the em kind of the sympathy from them as well and as I say you've got that angle and the emotional upset and trying to understand it. As she gets older and you get the joys from em . . . one of her first diagnoses when she was about 14 months was one of the so called kind of experts told us she would never be able to hold a pencil she said she'd never be able to write her name and em . . . I'm a little bit kind of bloody minded if you like and the fact that somebody tells me that she can't do something we'll go back and do our hardest to prove them wrong. So from that point onwards you know there were crayons everywhere in our house, there were places to draw everywhere you know. You will, you will write, you will be able to hold a pencil and obviously she's proved them wrong in that point and also they said if she didn't sit up before her second birthday she would never walk unaided and she sat up the week before her second birthday. I think we were like yeah we've got that milestone although you know so it's quite obvious now that she probably will never walk unaided but it was that sort of you know you're working towards those deadlines and each time you get to that milestone it's joy and then when she started school and her speech has always been good because where in the toddler stages other children are focusing on their physical side obviously she couldn't so she was focusing more on her speech and communication so her vocabulary has always been excellent and her clear communication has been brilliant and she speaks far better than a lot of children her age em so you've got that kind of flip side emotions so the joy and happiness and then when you get, even when you get to a point where em she had surgery on her eye when she was 2½ so just getting to those, getting past those and being discharged from that particular consultant is like 'Oh Ok cross that one of the list' . . . sort of thing although she sees another one now just for follow up but em getting past those things because OK we won't have to do that again she won't need surgery again, get rid of that em. And so just on the social side she's just em very, you know she's very outgoing, she's got a lot of friends em but then when you get to the bullying stage that we had last year that was awful again you know em we had em the mickey taking em the pushing her on her frame em and obviously the pushing her, running with her round the playground on her frame her legs can't carry on . . . keep up with them. These kind of things and we're going to have to keep going into the school to sort things out and then deal with her being upset at home, not sleeping em so now she's actually got sleep hormone pills that she has to have every night now she can't . . . I don't know whether it's something to do with the epilepsy she
has the em, em... oh what's the scan... EEG that's it and err yeah it's, she's very... her body is physically tired but her
brain won't switch off. She's responding really well to these tablets it's brilliant

JG: Do you think if you'd had somebody like a key worker right from the beginning who could have sat down and
talked to you about, you know what was going on, what all the words meant, who the people were; that would have
helped?

KB: Oh definitely, yeah definitely. Someone who could calmly sit down and go through all your questions and explain to
you exactly what it means and em just say this, this is what will happen next. Just absorb this sort of thing if you've got
any other questions just give me a call whenever em I think access to that person is very important I think because you
know when a question... when a parent raises a question or suddenly has a question they want to know the answer
now they don't want to wait three days or anything like that it's there it's in their mind and they must know it now you
don't get past that bit em but I think if you had that support all the way through from diagnosis it is completely that, it is
a support, it's got to be someone that you might cry to that you might em, even things like can you find out for me if,
you know what's going to happen at school this year, anything somebody that you can just turn to and say look I need
to know the answer to this and I just haven't got the energy to go searching the internet or ringing around x amount of
people to try and find the answer could you, do you think you could find out for me stuff like that, so I think yeah it would
be like a real valuable family friend as well I think that they, the relationship the bonds there would be you know
amazing em... as long as you're allocated a key worker that you like (laughter)

JG: Do you think it's important that you could change who, how would you know I suppose who to choose from but
even if you had the right to say look I'm not getting on with this person?

KB: Oh yes I think you definitely need to I don't think you can be forced to work with any particular professional or
anybody that you don't like or don't respect or don't trust I think that with the care from any aspect you've got to be
completely comfortable with that person otherwise you know from my point of view it would be like well I'm sorry I'm not
going anywhere, near them you know D’s (child) not going anywhere near them we just don’t do that appointment ...

Until you allocate somebody else. Every parent’s got the right to say no I don’t want to work with that person em please could you allocate somebody else.

I also think the key worker’s got that right as well. If the family’s been particularly I don’t know em – doesn’t work well with that key worker em but I think she’s got to say well actually I feel threatened when I go round there or whatever I don’t... I would like somebody else to take on this family. I think it works both ways.

JG: You mentioned something that you had to go out and seek out a lot of information. And obviously you weren’t given a leaflet or a booklet at the time do you think that’s something... a lot of people can’t take in a lot of what’s been said to them especially at diagnosis stage but do you feel you, well you obviously need something because you went away and sought it out but if somebody didn’t have the skills or access to the internet and things do you feel something to actually take away in your hand would have been helpful, whether it was about the condition or the professionals that you might then come into contact with.

KB: I think, certainly at diagnosis stage it would need to be... condition... em because you sit there and from my point of view as soon as she said the words cerebral palsy that was it, wall went up, not now listening to anything else because round and round in my head was going cerebral palsy, cerebral palsy I don’t know what that means is she going to die does that mean she’s not going to live past twelve or something like that all those sort of things. At that particular point I wasn’t, I didn’t even have any thoughts about the professionals that were going to come involved in it because I don’t think you can have any kind of yeah perception of what’s going to be involved but I think had they given me a scope leaflet that scope sent me em you know just a general, I mean obviously scope do varying amounts of information when I phoned yeah I got absolutely everything that they could give me. Just that first one about you know just a small summary of what the condition is and em you know the helpline number for Scope because any questions you have initially you can just pick up the phone and ask them just that one little A5 booklet a couple of pages – this is what it is, this is what it’s going to mean em this is the helpline number just a few FAQ’s just bullet points of this, this, this that would have been really useful because when you get home and people are... especially when you are telling people as
well, family members and you say well she’s got . . . and they say well what does that mean . . . well I haven’t got a
clue. I really don’t know. Because J (husband) was obviously I phoned him at work and said oh she’s got this and he
said well what’s that? And I said I don’t know, no body told me, I’ve got a phone number here I’ve got to phone, so I
couldn’t even tell my own husband what it meant you know, you know her dad, em, because I didn’t know myself so I
think, I think that’s really important. I don’t think you can tell a parent their child’s got something and leave it at that you
know because if you go out onto the street and ask somebody what muscular dystrophy is, multiple sclerosis, any of
them unless you come into contact with them, you don’t know.

JG: So when the consultant gave you the diagnosis there was no contact from anybody else after that – the next day or
. . . ?

KB: No. It was em . . . it was, I think she did a referral to the physiotherapist at the hospital em but the routine letter came
through sort of weeks later with D’s (child) first kind of physio appointment em and fitting for Piedro boots em and that
was I mean that was probably at the time they did an assessment for a Kaye walker so it was well passed – she was over
a year old. The diagnosis was at 10½ months I think there must have been a lapse of at least six weeks before we
actually got to see the first professional and in that time we were like . . . just kind of left in the dark really with all the
Scope information

JG: Wading your way through it all (laughter)

KB: Yeah... through it all

JG: OK so just reflecting on the current system with the different agencies and things if you were able to change
anything about the way the system works or doesn't what would you change?
KB: I’d like people to return my phone calls … anybody to return my phone calls, even if you know somebody’s away
don’t leave it until they come back, somebody – whoever’s taken it just pick up and phone and say such and such is
away you know is there anything you need urgently or can it wait until they come back, just an acknowledgement that
they’ve got my message that you know I haven’t just been deleted off the face of the earth. That would be really nice.
Em I mean the other thing you know that – the other kind of wishes are you know just kind of pie in the sky, I suppose it’s
never going to happen because the money’s not there it would be so nice for families not to constantly battle or have
to constantly battle for everything be it equipment be it a bedroom be it a school place be it anything I’m fed up of
every change that D (child) has, every new need is you know, even if you get the agreement that yes she needs it but
then to actually physically get it is a battle and it’s so draining for you know, and it’s so hard, everything takes so long
and err yeah that would be what I would change. When things are identified lets just do them, when the need is there
let’s fulfil it no matter what it is that would be, you know, the ideal.

JG: And that would make a big difference to D (child) and you?

KB: Yes. You know… em; it would completely take the pressure off everything. If you knew the family that whatever
needs D (child) has from now to you know when . . . It doesn’t matter if she’s a child or an adult really. If she needs a
motorised wheelchair – just get one. If she needs em, a ramp lets just get one. If you knew that whatever she needs you
would just get it you know. As long as it’s been identified by the particular professional that it’s a requirement, provide it
… just give it to her. But it’s all this who’s going to pay for this who’s going to pay for that you know this funding has been
removed so now somebody else has got to pay for it and they’re refusing to pay for it because they don’t believe it
comes under their umbrella em . . . that, that is what I’d like to change

JG: If there was one pot of money for all agencies

KB: A central pot
JG: It may help; it may not be all the answer but is it because there are health monies, education monies, social services monies?

KB: Yeah I think it probably is. I mean I don’t know if any of the agencies have got a surplus at the end of their financial year. I wouldn’t think so, but I mean it may be the case that somebody’s you know under spent somebody else could have really valuably used that money but I also feel that there isn’t enough money for the agencies you know we wouldn’t have this problem if there was. If social services had or you know the council had, it could basically say whoever needs an adaptation the money will be there for it, in terms of physio and OT if the child needs a certain amount, a piece of equipment – the money should be there for them, to cap it is em, I think it’s unfair on the agencies because you could say the facts must be there year on year of what’s been spent and the fact that some people have to wait until the next financial year because the money has run out. I can’t believe, the government should be saying well obviously you need more money because you couldn’t fulfil this; this and this so let’s give you some more money. You know. It does annoy me because they keep harping on about you know all we are doing extra for disabled people. We’re making them you know the promotion is all about inclusion and independence but yes inclusion if you are in a particular borough because that borough more than this one. And so you know that to me would be the most important thing that central money I don’t know whether – because then you’d have to have some sort of central agency looking after that money and you’d have a new department again then you know that everybody would have to go to, em but it might stop all of this – well I don’t know if that comes under health or social or what have you. They have their clear you know physio and OT they’ve got their equipment budget and anything that’s kind of slightly outside the scope there is a central pot for it, take that from there no arguments. Same with social services you know they’ve got their clear money for carers to go into help, things like that and then anything like the adaptations anything like that well it’s not quite comes under social services it certainly doesn’t come under health, the council only got this amount that then comes out of a central pot, an overflow if you like that people can tap into.

JG: Yeah, yeah, one of the things that one of the other parents I’ve spoken to has mentioned is about respite . . .
JG: One of the things they said ever since you know, my little one was born – as much as I love them I never had time for myself or for the other children. It’s been a big impact. Have you ever been offered any sort of respite care?

KB: Actually when we moved into the borough and went to social services at PH (social services address) to let them know we’d moved into the borough and find out what we needed to do next as it were, they actually did a kind of a little assessment and said oh she doesn’t need respite. She was only 2½ at the time and em the social worker completely kind of said you know we don’t need to do anything with you that was it. That was the last contact we had with them, until we started the . . . well actually when we did the ramp and the rails at the stairs at the old house em but that was from Ads (alternative social services office) because there wasn’t enough cover . . . you know resource at A (local social services office) anyway.

Em but there’s never been any kind of further assessment as she’s got older. I’ve often, I mean I would em I wouldn’t want to kind of send her away we’ve always, we’ve always treated her the same as the other two you know we’d do family holidays you know apart from you ask for the extra assistance on the plane and things like that but as she’s getting older she’s em, she’s getting more frustrated because she’s more aware of her condition, her capabilities err and the kind of the temper sides coming out the frustration, the shouting ‘I hate you’ which is, you know all children go through that any way but em it seems more prolonged I think it would also be nice for her if there was somewhere like a respite centre perhaps that she goes for the day or just an overnight or . . . she loves sleep-overs but none of her friends will invite her to sleep-overs because parents are too scared so she’s never had a sleep over with friends, everybody always sleeps over here. You know she hardly gets invited to birthday parties em she certainly doesn’t get invited to go and play at peoples houses because most of them have got stairs and they just kind of you know avoid it you know just don’t ask her, she might be best friends with people em so she has been best . . . she’s had lots and lots of friends over the years you know whenever D (child) has a birthday party she invites absolutely everybody because they are all her friends but hardly gets any back because it’s the parents like don’t understand the condition you know and won’t approach me so she just gets left out so it would be nice yeah, it would be nice for us to have a break. The other thing is
em we’ve only got J’s (husband) dad in A (local area). My mum’s dead and my dad lives in London. J’s (husband) mum lives in Cyprus so we don’t have babysitters’ em we had J’s (husband) dad babysat on Saturday night for the first time in seven months so we managed to go out. We go out twice a year on our own that would be nice if we could you know, even if it was here, a babysitting service or something someone that we trust who isn’t scared of the condition it’s more the epilepsy side I think but, but yeah that would be nice because it does put a strain on our relationship because whatever we do we’re always we never it just together we’re always a family everything that’s done it’s like always together and things like birthdays, valentines day we just put the children to bed and have a meal at home so you know we can’t go anywhere else. So that would be nice. Also when the children were younger instead of having respite it would have been nice to have a helper because when I had A and C (sisters) and they were little, in the double buggy in school holidays I couldn’t take them out anywhere because I couldn’t push the wheelchair and double buggy on my own and J (husband) was obviously you know he was at work em so unless I could go with another adult, another group of friends or something I just couldn’t do days out to theme parks or even to the park really it was difficult. That would have been nice. JG: Because respite comes in all sorts of forms really doesn’t it. It doesn’t have to be going away to a respite home?

KB: No exactly so and as she’s getting older I keep thinking more and more about it and thinking well actually a break would be you know, as much as I don’t, I wouldn’t want it to be, I wouldn’t want her to seem like we’re sending her away em you know and just kind of be a family without her because she’s the first born as well, you know she’s the oldest, she’s the big sister and she bosses everybody else around. So but yes some time to ourselves would be nice every now and again.

JG: Yes and that’s quite a common theme actually. Everybody says ‘it’s not because we don’t love them.

KB: No not at all I certainly wouldn’t want them to think that em because at the moment she has got to the stage where her whole everything’s … I mean obviously with the extension it’s all gone so pear shaped, so she’s now blaming herself
she’s saying ‘oh well if I wasn’t disabled you wouldn’t have these problems and em I’m useless I can’t help you, I wish I could help you but I can’t’ and em you know all these things are coming to the forefront now.

JG: It just shows you how cognitively aware and alert and sensitive she is.

KB: Very, very sensitive to feelings and the way. So yesterday she peeled all the veg. for me which was a real big help because I was sorting my leaflets for work (laughter) so em yeah…

JG: Well I’ve come to the end of my questions. Is there anything else you feel a burning desire to say?

KB: No I think we’ve kind of touched err, em the main things I think you know if it did ever happened the main things were consistency, and err training available and the age old thing of money really are the only things that are going to make a difference.

And without the money everything else . . . you’ve got to have the money to have the key worker in the first place, because that role would have to be paid role em I think everything else kind of em is driven by it really people are working in such tight constraints and unfortunately the family are at the end of it all.

JG: And yet I think they are so crucial and their views and as you say their input in the likes of training just to make professionals aware of what you’re going through … it’s so important.

KB: Yeah. The time you get with professionals they can’t see what’s really going on you know you turn up to an appointment and you’re there for a reason and they’re there to see, you know they’re only there, they’ve got a whole day booked in with different children and all they’re seeing is the notes for that child, they’ve no idea of what it’s taken even to get to that appointment and what juggling you have to do with other children and work even just to get you know to be there
JG: Well thank you very much for that.
Appendix Twenty

Example of Thematic Analysis

Sample of Initial Coding
Parent Interview Example
(Showing Researchers Coding Notes)
anybody could unless you’re, unless you are in the situation where you are the parent of a
child with a disability. I don’t think you can think about the amount of appointments that are
em routinely booked in because you’ve also got the add hoc ones, whenever I kind of see
D’s [child] deteriorating in a certain area I’ll be straight on the phone to which ever
professional I think that know, needs input into that and em there we go we get another
range of appointments em, the follow ups and also em, with her health as well I mean she
had tonsillitis again the week before last and that in the past has set off her seizures so you’ve
got the epilepsy kind of kicking in so you have to monitor that so you’re back and forward to
the doctors even though they tell me it’s a virus and send me away and later I’m back again
because I can’t let it go on for any length of time em, but they tend to be pretty good they
kind of just take it. You know I’ve got my torch . . . I’ve bought a Maglight torch so I can see
the back of her throat and when it gets to a point that I think no I haven’t got to get something
done they take my judgement on it and just help me out. So yeah it’s em, you know from an
outside . . . I know social services should have an idea of all the professionals that their
patients see from adult down to children you know the input that people have but I don’t know
whether they know how frustrating and how time consuming it is trying to actually get
to see those em . . . people and then trying to organise the outcome of it. What then
happens next then the follow ups and em, the loss of schooling time and things like that
which always has an impact on learning and catching up and err . . . it’s em yeah it is kind of
a full time job really trying to get it co-ordinated and get people to . . . people don’t speak to
each other so I’m kind of the one in the middle that’s feeding back what one’s said you
know to try and relate . . . to get my . . . to get what needs to happen across em and err the
one last Monday is a prime example of it. I’ve got to rethink after that the initial appointment
with the orthopaedic consultant. He said to us on Monday I’m now going to impact an
physiotherapy and orthotists and I’ve not got to re-look at all of that kind of thing and start
again really. Err . . .
JG: Is the plan to do some major surgery?
KB: The plan is that we go back in six months and have another hip x-ray done and check gait analysis. The frustrating thing was the initial referral came from B (local secondary hospital) for us to go to him because he's top of his field and when we got there he said oh well we need to do some gait analysis where we put some dots on D's (child) legs... well we've done all that in movement clinic, we've had three lots of that over the past two years so he wasn't aware that that had actually happened so he hadn't had any of the files for that em and nobody had sent previous hip x-rays across to him either so he had no, no point to monitor the movement against the hip x-ray on Monday so I kind of felt for him because you know he had the referral through but none of the back up information that needed to go and now we've got to go back in six months because it will give him a chance to get all of that information and study it and for him to take another hip x-ray and see what the progression is, if it's very quick or whether it's nice and slow, if it's very quick then yes em surgery will be em imminent but it will be multi-level they won't do... they're finding now that the muscles take a year to recover each time they prefer to do hip knee and ankle at the same time so it's only got the one year of recovery rather than three but we want to avoid that at all costs and em he was em he wants us to have a major physio input in that six months because he felt that D (child) was so tight that there was no need for it that she wasn't getting the right programme and not enough input, so therefore I come back and try and follow all of that up.

JG: Wasn't the consultant J that referred you down to S (local tertiary centre)

KB: Yes it was J (consultant paediatrician) and CP (physiotherapist). CP sat in and she was the one I asked J asked her for her opinion for which one and it was her that obviously suggested that Mr U (consultant orthopaedic surgeon) was the better with children, the bed side manner em because the other one is quite frightening (laughter). He was fantastic. He came
Appendix Twenty One

Example of Thematic Analysis

Initial Coding and Development of Sub-Categories

Parent Interview Example
<table>
<thead>
<tr>
<th>Line Number</th>
<th>Initial Coding</th>
<th>Sub-Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 - 25</td>
<td>Range of professionals involved with care</td>
<td>Parent professional interaction</td>
</tr>
<tr>
<td>26</td>
<td>Seen at three different hospitals</td>
<td>Access to resource</td>
</tr>
<tr>
<td>33</td>
<td>Service provision through school</td>
<td>Access to resource</td>
</tr>
<tr>
<td>35</td>
<td>Additional services for specialist equipment provision</td>
<td>Access to resource</td>
</tr>
<tr>
<td>43</td>
<td>Communication difficult</td>
<td>Communication/parent professional interaction</td>
</tr>
<tr>
<td>44</td>
<td>Lack of face to face contact</td>
<td>Communication</td>
</tr>
<tr>
<td>45</td>
<td>Telephone contact</td>
<td>Communication</td>
</tr>
<tr>
<td>45</td>
<td>Email contact</td>
<td>Communication</td>
</tr>
<tr>
<td>47</td>
<td>Constant responsibility</td>
<td>Impact on family</td>
</tr>
<tr>
<td>49</td>
<td>Regular communication</td>
<td>Communication</td>
</tr>
<tr>
<td>50</td>
<td>Frustration at lack of response from professionals</td>
<td>Parent-professional interaction</td>
</tr>
<tr>
<td>54</td>
<td>Large amount of documentation and records</td>
<td>Communication</td>
</tr>
<tr>
<td>57</td>
<td>Information classified according to agency involved</td>
<td>Communication</td>
</tr>
<tr>
<td>57-58</td>
<td>Services involved in care</td>
<td>Collaborative working</td>
</tr>
<tr>
<td>65</td>
<td>Time consuming to contact professionals</td>
<td>Impact on family</td>
</tr>
<tr>
<td>65</td>
<td>Lack of flexibility of availability of professionals</td>
<td>Access to resource</td>
</tr>
<tr>
<td>68</td>
<td>Difficult to balance work and parental responsibility</td>
<td>Impact on family</td>
</tr>
<tr>
<td>68</td>
<td>Time needed to attend appointments</td>
<td>Impact on family</td>
</tr>
<tr>
<td>68</td>
<td>Difficult to hold down job</td>
<td>Impact on family</td>
</tr>
<tr>
<td>69</td>
<td>Part-time work</td>
<td>Impact on family</td>
</tr>
<tr>
<td>69</td>
<td>Flexibility of job role needed to allow balance of commitments</td>
<td>Impact on family</td>
</tr>
<tr>
<td>Line Number</td>
<td>Initial Coding</td>
<td>Sub-Category</td>
</tr>
<tr>
<td>------------</td>
<td>---------------------------------------------------------------------------------</td>
<td>---------------------------------------------------</td>
</tr>
<tr>
<td>86</td>
<td>Sibling also has special needs</td>
<td>Family needs</td>
</tr>
<tr>
<td>86</td>
<td>Sibling also has special needs</td>
<td>Family needs</td>
</tr>
<tr>
<td>89</td>
<td>Younger child at a variety of sessions at preschool</td>
<td>Family needs</td>
</tr>
<tr>
<td>95</td>
<td>Need to be mobile to meet needs of family but needs to be contactable for professionals</td>
<td>Family needs</td>
</tr>
<tr>
<td>104</td>
<td>Full calendar of appointments</td>
<td>Individuality of need</td>
</tr>
<tr>
<td>106</td>
<td>Need for good documentation and organisation</td>
<td>Communication</td>
</tr>
<tr>
<td>109</td>
<td>Mother does all this and needs clear information in case anything should happen to her</td>
<td>Impact on family life</td>
</tr>
<tr>
<td>110</td>
<td>Father works full time</td>
<td>Family life</td>
</tr>
<tr>
<td>111</td>
<td>Some appointments shared – more important for child than others</td>
<td>Impact on family life</td>
</tr>
<tr>
<td>113</td>
<td>Need to experience the situation to understand demands</td>
<td>Impact on family life</td>
</tr>
<tr>
<td>117</td>
<td>Mother monitors child’s status</td>
<td>Expert parent/collaborative working</td>
</tr>
<tr>
<td>118</td>
<td>Takes action to prevent problems</td>
<td>Expert parent/collaborative working</td>
</tr>
<tr>
<td>120</td>
<td>Awareness of mother to impact of general health of child</td>
<td>Expert parent/collaborative working</td>
</tr>
<tr>
<td>123</td>
<td>Expert parent</td>
<td>Collaborative working</td>
</tr>
<tr>
<td>128</td>
<td>Lack of understanding by professionals</td>
<td>Child &amp; family focused working</td>
</tr>
<tr>
<td>130</td>
<td>Loss of education</td>
<td>Impact on family life</td>
</tr>
<tr>
<td>131</td>
<td>Impact on child</td>
<td>Impact on family life</td>
</tr>
<tr>
<td>131</td>
<td>Increased demands to catch up</td>
<td>Individual needs</td>
</tr>
<tr>
<td>132</td>
<td>Parent acts as prime co-ordinator and liaison officer between professionals</td>
<td>Communication/collaborative working</td>
</tr>
<tr>
<td>142</td>
<td>Beginning of a journey towards major surgery</td>
<td>Individuality of need</td>
</tr>
<tr>
<td>Line Number</td>
<td>Initial Coding</td>
<td>Sub-Category</td>
</tr>
<tr>
<td>-------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td>145</td>
<td>Lack of communication between centres</td>
<td>Communication/collaborative working</td>
</tr>
<tr>
<td>148</td>
<td>Repetition of information and assessment</td>
<td>Information sharing</td>
</tr>
<tr>
<td>151</td>
<td>Delayed intervention due to information gathering</td>
<td>Information sharing</td>
</tr>
<tr>
<td>155</td>
<td>Complex surgery</td>
<td>Individual needs</td>
</tr>
<tr>
<td>155</td>
<td>Extended timescale intensive input</td>
<td>Individual needs</td>
</tr>
<tr>
<td>159</td>
<td>Parent needs to liaise and follow up</td>
<td>Impact on family</td>
</tr>
<tr>
<td>164</td>
<td>Shared care and decision making</td>
<td>Collaborative working</td>
</tr>
<tr>
<td>168</td>
<td>Good relationship with consultant</td>
<td>Parent-professional interaction</td>
</tr>
<tr>
<td>169</td>
<td>Easy to understand</td>
<td>Communicating the diagnosis</td>
</tr>
<tr>
<td>174</td>
<td>Prognosis of condition</td>
<td>Collaborative working</td>
</tr>
<tr>
<td>176</td>
<td>Child in pain</td>
<td>Information sharing</td>
</tr>
<tr>
<td>181</td>
<td>Altered gait pattern impacting on other parts of the body</td>
<td>Individual needs</td>
</tr>
<tr>
<td>183</td>
<td>Medical need impact on other aspects of life</td>
<td>Child’s needs</td>
</tr>
<tr>
<td>192</td>
<td>Communication</td>
<td>Impact on family</td>
</tr>
<tr>
<td>200</td>
<td>Role of KW</td>
<td>Communication</td>
</tr>
<tr>
<td>201</td>
<td>Child’s needs demand different regularity of input</td>
<td>KW Role</td>
</tr>
<tr>
<td>204</td>
<td>Need to be aware of appointments and value of these</td>
<td>Access to resource</td>
</tr>
<tr>
<td>207</td>
<td>Some professionals work closely together</td>
<td>Parent- Professional interaction</td>
</tr>
<tr>
<td>210</td>
<td>Cross agency working needed</td>
<td>Collaborative working</td>
</tr>
<tr>
<td>211</td>
<td>Cross agency working needed</td>
<td>Collaborative working</td>
</tr>
<tr>
<td>Line Number</td>
<td>Initial Coding</td>
<td>Sub-Category</td>
</tr>
<tr>
<td>-------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>---------------------------------------</td>
</tr>
<tr>
<td>213</td>
<td>Individuality of child</td>
<td>Child &amp; family needs</td>
</tr>
<tr>
<td>216</td>
<td>Shared IT system</td>
<td>Information sharing</td>
</tr>
<tr>
<td>220</td>
<td>One point of contact</td>
<td>Key worker role</td>
</tr>
<tr>
<td>221</td>
<td>Support for parent</td>
<td>Key worker role</td>
</tr>
<tr>
<td>222</td>
<td>Someone to activate outcomes of appointments</td>
<td>Key worker role</td>
</tr>
<tr>
<td>224</td>
<td>Relieve pressure off parent</td>
<td>Key worker role</td>
</tr>
<tr>
<td>227</td>
<td>Parent get on with parenting</td>
<td>Impact on family</td>
</tr>
<tr>
<td>232</td>
<td>Skills of KW</td>
<td>Key worker role</td>
</tr>
<tr>
<td>232</td>
<td>People skills</td>
<td>Key worker role</td>
</tr>
<tr>
<td>234</td>
<td>Understand wider family unit</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>235</td>
<td>Caring professional; Assertive</td>
<td>Key worker role</td>
</tr>
<tr>
<td>238</td>
<td>Professionals can be defensive of role</td>
<td>Professional role</td>
</tr>
<tr>
<td>241</td>
<td>Approachable</td>
<td>Key worker role</td>
</tr>
<tr>
<td>243</td>
<td>Strong willed</td>
<td>Key worker role</td>
</tr>
<tr>
<td>244</td>
<td>Determined</td>
<td>Key worker role</td>
</tr>
<tr>
<td>246</td>
<td>Appreciate different needs of families</td>
<td>Child and family focused working</td>
</tr>
<tr>
<td>254</td>
<td>Lack of bias from independent person</td>
<td>Key worker role/professional role</td>
</tr>
<tr>
<td>255</td>
<td>Extra person for family to cope with</td>
<td>Communicating across the team</td>
</tr>
<tr>
<td>258</td>
<td>Relieve family of some responsibility</td>
<td>Key worker role</td>
</tr>
<tr>
<td>260</td>
<td>Conflict of role if doing KW role and professional role</td>
<td>Key worker role/professional role</td>
</tr>
<tr>
<td>262</td>
<td>Independent person one goal – KW role</td>
<td>Key worker role</td>
</tr>
<tr>
<td>276</td>
<td>Respect for professional role</td>
<td>Professional role</td>
</tr>
<tr>
<td>Line Number</td>
<td>Initial Coding</td>
<td>Sub-Category</td>
</tr>
<tr>
<td>-------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>-----------------------------------</td>
</tr>
<tr>
<td>279</td>
<td>Knowledge of specialist area</td>
<td>Key worker role</td>
</tr>
<tr>
<td>280</td>
<td>KW without professional background may not get respect needed</td>
<td>Key worker role</td>
</tr>
<tr>
<td>284</td>
<td>Understanding of KW role by whole team</td>
<td>Training</td>
</tr>
<tr>
<td>289</td>
<td>KW role supported by other professionals</td>
<td>Training</td>
</tr>
<tr>
<td>290</td>
<td>Impact of professionals defensiveness</td>
<td>Professional role</td>
</tr>
<tr>
<td>291</td>
<td>Shared responsibility</td>
<td>Collaborative working</td>
</tr>
<tr>
<td>295</td>
<td>Important to have correct perception of role</td>
<td>Training</td>
</tr>
<tr>
<td>301</td>
<td>People influenced by past experience of KW role</td>
<td>Influence of personalities</td>
</tr>
<tr>
<td>302</td>
<td>Lack of open-mindedness to role</td>
<td>Influence of personalities</td>
</tr>
<tr>
<td>316</td>
<td>Difficulties of conflict between new staff willing to change and those long established staff stuck in ways</td>
<td>Influence of personalities</td>
</tr>
<tr>
<td>325</td>
<td>Need for training to assist change of opinion</td>
<td>Training</td>
</tr>
<tr>
<td>330</td>
<td>Demonstrate impact of large team on child, parent and family</td>
<td>Complexities of family life</td>
</tr>
<tr>
<td>335</td>
<td>Practical demo during training changed some professionals perception</td>
<td>Training</td>
</tr>
<tr>
<td>337</td>
<td>Need for training</td>
<td>Training</td>
</tr>
<tr>
<td>343</td>
<td>Consistency in KW service</td>
<td>Key worker role</td>
</tr>
<tr>
<td>345</td>
<td>Postcode lottery</td>
<td>Access to resource</td>
</tr>
<tr>
<td>345</td>
<td>Equity of service</td>
<td>Access to resource</td>
</tr>
<tr>
<td>345</td>
<td>Consistency</td>
<td>Access to resource</td>
</tr>
<tr>
<td>355</td>
<td>Intimidated</td>
<td>Parent-professional interaction</td>
</tr>
<tr>
<td>Line Number</td>
<td>Initial Coding</td>
<td>Sub-Category</td>
</tr>
<tr>
<td>-------------</td>
<td>----------------</td>
<td>--------------</td>
</tr>
<tr>
<td>355</td>
<td>Guilt</td>
<td>Complexities of family life</td>
</tr>
<tr>
<td>355</td>
<td>Impact of shared training on parent</td>
<td>Training</td>
</tr>
<tr>
<td>358</td>
<td>Parent journey</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>358</td>
<td>Difficult to take in lots of information just after diagnosis</td>
<td>Communicating the diagnosis</td>
</tr>
<tr>
<td>361</td>
<td>Individual ability of parents</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>363</td>
<td>Training adapted to meet individual needs</td>
<td>Training</td>
</tr>
<tr>
<td>365</td>
<td>Shared training in some instances to give parental perspective</td>
<td>Training</td>
</tr>
<tr>
<td>369</td>
<td>One size fits all approach not ideal</td>
<td>Child and family focused working</td>
</tr>
<tr>
<td>373</td>
<td>Need to be flexible about training</td>
<td>Training</td>
</tr>
<tr>
<td>379</td>
<td>Journey involves different emotions</td>
<td>Child and family focused working</td>
</tr>
<tr>
<td>380</td>
<td>Delivering bad news at diagnosis</td>
<td>Communicating the diagnosis</td>
</tr>
<tr>
<td>380</td>
<td>Poorly handled diagnosis</td>
<td>Communicating the diagnosis</td>
</tr>
<tr>
<td>381</td>
<td>Unexpected news</td>
<td>Communicating the diagnosis</td>
</tr>
<tr>
<td>386</td>
<td>Communication</td>
<td>Communicating the diagnosis</td>
</tr>
<tr>
<td>386</td>
<td>Lack of support and follow up</td>
<td>Communication</td>
</tr>
<tr>
<td>388</td>
<td>Lone parent</td>
<td>Face to face contact</td>
</tr>
<tr>
<td>389</td>
<td>Communication with other parent</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>390</td>
<td>Bad experience of diagnosis</td>
<td>Communication/Information sharing</td>
</tr>
<tr>
<td>391</td>
<td>Confusion</td>
<td>Communicating the diagnosis</td>
</tr>
<tr>
<td>392</td>
<td>Lack of understanding</td>
<td>Information sharing</td>
</tr>
<tr>
<td>393</td>
<td>Unknown future</td>
<td>Information sharing</td>
</tr>
<tr>
<td>393</td>
<td>Need to seek information</td>
<td>Communicating the diagnosis</td>
</tr>
<tr>
<td>394</td>
<td>Need to seek information</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>Line Number</td>
<td>Initial Coding</td>
<td>Sub-Category</td>
</tr>
<tr>
<td>-------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>---------------------------------------------------</td>
</tr>
<tr>
<td>396</td>
<td>Lack of understanding by ordinary man</td>
<td>Information sharing/Individuality of need</td>
</tr>
<tr>
<td>400</td>
<td>Referrals to team – roles and input unknown</td>
<td>Training</td>
</tr>
<tr>
<td>403</td>
<td>Why has this happened</td>
<td>Child and family need</td>
</tr>
<tr>
<td>403</td>
<td>Guilt, blame, ashamed, sympathy.</td>
<td>Complexities of family life</td>
</tr>
<tr>
<td>410</td>
<td>Emotional turmoil</td>
<td>Complexities of family life</td>
</tr>
<tr>
<td>414</td>
<td>Prove experts wrong</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>418</td>
<td>Prediction of abilities</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>418</td>
<td>Determination to enable child</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>419</td>
<td>Milestones very important</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>422</td>
<td>Small achievements have big impact</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>425</td>
<td>Excels in other areas</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>427</td>
<td>Emotional journey</td>
<td>Complexities of family life</td>
</tr>
<tr>
<td>429</td>
<td>Goals to aim at before moving on</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>432</td>
<td>One less professional contact in her life</td>
<td>Communication across the team</td>
</tr>
<tr>
<td>433</td>
<td>Impact of child’s disability on school life and social well being</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>437</td>
<td>Constant reminders of limitations</td>
<td>Complexities of family life</td>
</tr>
<tr>
<td>442</td>
<td>Need for parental support and specialist support through medication</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>449</td>
<td>KW Objective stand point</td>
<td>Key worker role</td>
</tr>
<tr>
<td>449</td>
<td>Explain give information</td>
<td>Key worker role</td>
</tr>
<tr>
<td>450</td>
<td>Answer questions</td>
<td>Key worker role</td>
</tr>
<tr>
<td>453</td>
<td>Access 24:7</td>
<td>Access to resource</td>
</tr>
<tr>
<td>456</td>
<td>Support</td>
<td>Key worker role</td>
</tr>
<tr>
<td>Line Number</td>
<td>Initial Coding</td>
<td>Sub-Category</td>
</tr>
<tr>
<td>-------------</td>
<td>---------------------------------------------------------------------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td>457</td>
<td>Help with emotional journey</td>
<td>Child and family focused working</td>
</tr>
<tr>
<td>459</td>
<td>Energy draining</td>
<td>Complexities of family life</td>
</tr>
<tr>
<td>462</td>
<td>Build relationship</td>
<td>Key worker skills</td>
</tr>
<tr>
<td>462</td>
<td>Valuable family friend</td>
<td>Key worker role</td>
</tr>
<tr>
<td>462</td>
<td>Choice in allocation of KW</td>
<td>Collaborative working</td>
</tr>
<tr>
<td>469</td>
<td>Parents/family need choice</td>
<td>Child and family focused working</td>
</tr>
<tr>
<td>470</td>
<td>Respect and trust</td>
<td>Collaborative working</td>
</tr>
<tr>
<td>471</td>
<td>Comfortable relationship</td>
<td>Collaborative working</td>
</tr>
<tr>
<td>475</td>
<td>Parents and professionals have rights</td>
<td>Collaborative working</td>
</tr>
<tr>
<td>489</td>
<td>Diagnosis stage need for simple brief information about condition</td>
<td>Communicating the diagnosis</td>
</tr>
<tr>
<td>491</td>
<td>In shock when given diagnosis</td>
<td>Communicating the diagnosis</td>
</tr>
<tr>
<td>494</td>
<td>Couldn’t think ahead. No idea of impact for future</td>
<td>Communicating the diagnosis</td>
</tr>
<tr>
<td>500</td>
<td>Need contact for support initially</td>
<td>Face to face contact</td>
</tr>
<tr>
<td>501</td>
<td>Simple straight forward information clear and concise</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>504</td>
<td>Family need information</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>508</td>
<td>Communication to partner</td>
<td>Child and family focused working</td>
</tr>
<tr>
<td>510</td>
<td>Need support and follow up</td>
<td>Face to face contact</td>
</tr>
<tr>
<td>512</td>
<td>Lack of familiarity with condition</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>517</td>
<td>Consultant referred to team – delay in follow up</td>
<td>Collaborative working</td>
</tr>
<tr>
<td>521</td>
<td>Impression of wasted time for child</td>
<td>Collaborative working</td>
</tr>
<tr>
<td>523</td>
<td>Family in limbo</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>534</td>
<td>Communication very important</td>
<td>Parent-professional interaction</td>
</tr>
<tr>
<td>Line Number</td>
<td>Initial Coding</td>
<td>Sub-Category</td>
</tr>
<tr>
<td>-------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>-------------------------------------</td>
</tr>
<tr>
<td>535</td>
<td>Acknowledgement of parent contact</td>
<td>Parent-professional interaction</td>
</tr>
<tr>
<td>541</td>
<td>Constant battle to meet needs and get services</td>
<td>Access to resources</td>
</tr>
<tr>
<td>544</td>
<td>Physically draining</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>545</td>
<td>Parent exhausted</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>545</td>
<td>Sense of despair</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>551</td>
<td>Relieve family strain</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>553</td>
<td>Meet needs of disabled child</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>555</td>
<td>Provide equipment</td>
<td>Access to resources</td>
</tr>
<tr>
<td>556</td>
<td>Arguments over finance</td>
<td>Influences on services</td>
</tr>
<tr>
<td>558</td>
<td>Criteria for funding equipment needs which agency should pay?</td>
<td>Influences on services</td>
</tr>
<tr>
<td>563</td>
<td>Need for central funding</td>
<td>Influences on services</td>
</tr>
<tr>
<td>569</td>
<td>Needs for shared funding</td>
<td>Influences on services</td>
</tr>
<tr>
<td>571</td>
<td>Lack of money</td>
<td>Influences on services</td>
</tr>
<tr>
<td>573</td>
<td>Funding enough to meet needs</td>
<td>Influences on services</td>
</tr>
<tr>
<td>576</td>
<td>Advance planning</td>
<td>Child and family focused working</td>
</tr>
<tr>
<td>577</td>
<td>Long wait due to lack of funding</td>
<td>Influences on services</td>
</tr>
<tr>
<td>580</td>
<td>What government say they are doing and what the effects are, do not match</td>
<td>Influences on services</td>
</tr>
<tr>
<td>580</td>
<td>Rhetoric and reality</td>
<td>Influences on services</td>
</tr>
<tr>
<td>583</td>
<td>Central funding</td>
<td>Influences on services</td>
</tr>
<tr>
<td>584</td>
<td>Central agency</td>
<td>Influences on services</td>
</tr>
<tr>
<td>585</td>
<td>One department one budget one set of criteria</td>
<td>Influences on services</td>
</tr>
<tr>
<td>588</td>
<td>Standard core items them extras to be funded out of central pot</td>
<td>Influences on services</td>
</tr>
<tr>
<td>Line Number</td>
<td>Initial Coding</td>
<td>Sub-Category</td>
</tr>
<tr>
<td>-------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>-----------------------------------</td>
</tr>
<tr>
<td>607</td>
<td>Lack of recognition child’s needs change over time – need for re-assessment</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>613</td>
<td>No review of new needs</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>615</td>
<td>Family holidays need assistance</td>
<td>Child and family focused working</td>
</tr>
<tr>
<td>617</td>
<td>Child frustration</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>617</td>
<td>Increased awareness</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>621</td>
<td>Impact on social life</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>622</td>
<td>Fear of other parents</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>625</td>
<td>Physical barriers</td>
<td>Complexities of family life</td>
</tr>
<tr>
<td>628</td>
<td>One way friendships</td>
<td>Complexities of family life</td>
</tr>
<tr>
<td>631</td>
<td>Lack of family support</td>
<td>Complexities of family life</td>
</tr>
<tr>
<td>633</td>
<td>Impact on parents relationship</td>
<td>Complexities of family life</td>
</tr>
<tr>
<td>636</td>
<td>Family and carers sacred of epilepsy</td>
<td>Complexities of family life</td>
</tr>
<tr>
<td>637</td>
<td>Relationship strained</td>
<td>Complexities of family life</td>
</tr>
<tr>
<td>639</td>
<td>No time for each other</td>
<td>Complexities of family life</td>
</tr>
<tr>
<td>639</td>
<td>Limited support to allow time as a couple</td>
<td>Complexities of family life</td>
</tr>
<tr>
<td>641</td>
<td>Need for physical hands on help</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>643</td>
<td>Restricted family activity</td>
<td>Child and family focused working</td>
</tr>
<tr>
<td>654</td>
<td>Respite handled in correct way for child</td>
<td>Child and family focused working</td>
</tr>
<tr>
<td>655</td>
<td>Child is part of family – she has her status and place</td>
<td>Child and family focused working</td>
</tr>
<tr>
<td>664</td>
<td>Child blames self for problems that parents have with agencies and provision</td>
<td>Child and family focused working</td>
</tr>
<tr>
<td>671</td>
<td>Child’s awareness and sensitivity to parents emotions</td>
<td>Child and family needs</td>
</tr>
<tr>
<td>Line Number</td>
<td>Initial Coding</td>
<td>Sub-Category</td>
</tr>
<tr>
<td>-------------</td>
<td>----------------------------------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>678</td>
<td>Need for consistency</td>
<td>Access to resource</td>
</tr>
<tr>
<td>678</td>
<td>Training</td>
<td>Training</td>
</tr>
<tr>
<td>680</td>
<td>Money</td>
<td>Influences on services</td>
</tr>
<tr>
<td>681</td>
<td>KW as paid role</td>
<td>Key worker role</td>
</tr>
<tr>
<td>682</td>
<td>Professionals currently constrained</td>
<td>Time and caseload constraints</td>
</tr>
<tr>
<td>683</td>
<td>Family come last</td>
<td>Child and family focused working</td>
</tr>
<tr>
<td>688</td>
<td>Busy schedules – professionals do not notice wider picture</td>
<td>Time and caseload constraints</td>
</tr>
<tr>
<td>692</td>
<td>Juggling act to care for child</td>
<td>Complexities of family life</td>
</tr>
</tbody>
</table>
Appendix Twenty Two

List of Thesis Dissemination to Date
List of Thesis Dissemination to Date

- European Academy of Childhood Disability Conference
  Monaco 2005 Poster Presentation
- Undergraduate Occupational Therapy Course (BSc)
- Post Graduate Occupational Therapy Course (MSc)
  University of Brighton 2009, 2008, 2007 Oral presentations
- MSc Paediatrics Module Queen Margaret University Edinburgh (4 days) January 2009 Oral presentations and facilitation of interactive group learning
- Association of Chartered Paediatric Physiotherapists
  Introduction to Paediatrics Conference. March 2009 Basingstoke. Oral Presentation
- South Central SHA Children and Young People’s Network
  Transitional Care Study Day March 2009 Oral Presentation
- SUADE Conference University of Brighton April 2009 Oral Presentation
- 5th Colloquium in Qualitative Research University of East Anglia May 2009 Oral Presentation