BEING A PARENT WITH LEARNING DIFFICULTIES:

AN EXPLORATORY STUDY OF PARENTS' VIEWS AND EXPERIENCES OF LOCAL SUPPORT SERVICES

By

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Abstract

Recent changes in legislation across many countries have led to the principles of normalisation and anti-discrimination towards adults with (Learning Difficulties) LD; consequently, most are able to live within the community, develop relationships and start families (Llewellyn et al., 2010). Since the mid-1990s research with a social and human rights based approach has begun. There has been a growing interest in applying small-scale methods and approaches to research with parents with LD, such as case studies, action research, observational studies, life stories and ethnography (Cleaver & Nicholson, 2007). In relation to this, the aim of the present study is to explore the lived experiences and opinions of parents with LDs of the support they receive in order to inform policy and practice in Newtown[1] Local Authority. The goal is to improve the lives of parents with LD and to instil confidence within this group.

Working within a critical realist paradigm, in order to provide a contextual description of the experiences of parents with LD, I adopted a case study design and conducted semi-structured interviews with a sample of four parents. Qualitative data derived from semi-structured interviews were analysed and interpreted using thematic analysis (Braun & Clarke, 2006).

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[1] Pseudonym

This approach resulted in a number of suggestions for improving parents‘ access to support services and engagement with support services in Newtown. The main findings were that parents‘ experiences and views on the support they had received were heavily influenced by their relationships with support service practitioners, time spent with families by support workers, parents‘ ability to access information and parents‘ feeling valued and their opinions acknowledged. The findings suggest a need for improved family-centred planning by support service practitioners and for professionals to be provided with the resources needed to develop positive working relationships with parents with LD. I conclude by reflecting on the implications of these findings on the practice of support service practitioners and on the role of Educational Psychologists.

DEDICATION

I would like to dedicate this thesis to my husband, Rajinder Athwal and my sister Naveen Chaudhari, whose love, support and belief in me has made it possible for me to achieve my aspirations.

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CHAPTER 1

INTRODUCTION

In this Volume, I present research undertaken for the purpose of a three year (2009-2012) Applied Educational Psychology professional training programme with the University of Birmingham.

Volume One is structured in six chapters. In the present chapter, I set the scene for the empirical study by describing an overview of the structure of the remainder of the Volume. In Chapter Two, I present a critical review of policy relating to parents with learning difficulties. In Chapter Three, I present a critical review of research into support for parents with learning difficulties. In Chapter Four, I describe the methodology I adopted and the accompanying research methods. In Chapter Five, I present my findings and discussion. In Chapter Six, I conclude the Volume, by presenting my reflections on and critique of the research process and its findings.

1.1 Parents with learning difficulties

The Department of Health (2001) defines learning difficulty (LD) ~~a~~s the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), all of which started before adulthood, with a lasting effect on development" (DoH, 2001, p.14).

The number of parents with LD within the UK is currently unknown; Hatton and Emerson (2008) in their work for the Department of Health estimated that there were 828,000 adults with a LD in England. Despite not knowing the number of parents with LD in the UK, it is believed that this population is steadily rising (Ward & Tarleton, 2007). Both child and adult support services may find it challenging to appreciate and consider the needs of parents with LD and ensure the human rights of adults with LD and their children are being upheld.

1.2 Aims

The present study aimed to explore parents' views and experiences of local support services, highlighting examples of good practice and positive experiences of parents with LD, as well as exploring some of the needs and the challenges which they faced, with the further aim of informing practice with the research findings.

Key research questions were formulated within a critical realist epistemological framework and with reference to existing literature. The key research questions were:

- How do parents with LD perceive communication with support service professionals?
- How do parents with LD report that they are supported to meet their children‘s needs?
- What are some of the barriers to parents with LD receiving support?
- In parents‘ views, how may these barriers to support be overcome?
- What positive experiences of support services do parents with LD describe?

The study employed a case study methodology where qualitative data was gathered from multiple cases. Here, the ‗cases‘ comprised a small sample of parents with LD from Newtown. I chose to use semi-structured interviews as a means to explore how parents with LD view their experiences and the world around them.

A more detailed description of case study methodology, interview design, critical realism and the reasons why I adopted these approaches are presented in Chapter Four of this study.

1.3 Structure

In Chapter 2 of this study, I present a critical review of policy regarding parents with LD and the support they receive. Next, in Chapter 3, I present a critical review of research literature. In Chapter 4, I outline the chosen methodology and describe the rationale for the selection of a case study approach and provide an account of how it was applied. In Chapter 5, I present the findings derived from the thematic analysis of the transcribed interviews, and discuss these findings, drawing on theoretical knowledge, research, policy and professional literature to support my interpretation. In Chapter 6, I present conclusions, implications for future practice in supporting parents with LD, along with post hoc critical reflections on the assumptions informing study design and implementation. Feedback to Newtown Inclusion Support Service in relation to the key features and findings of this research are provided in a digestible public domain briefing (See Appendix One).

CHAPTER 2

PARENTS WITH LEARNING DIFFICULTIES AND THE SUPPORT THEY RECEIVE: HISTORICAL CONTEXT AND A CRITICAL REVIEW OF POLICY

2.1 Introduction

The aim of this critical review is to consider historic, as well as current British policy governing service delivery for parents with LD. I begin by reviewing policy initiatives from the early twentieth century, a time when adults with LD were treated as a homogeneous group and services were centred predominantly on the delivery of custodial care (Morris, 1969). I then progress to discuss how the view and treatment of adults with LD has evolved over the twentieth century leading to the development of current policy and practice guidance.

2.2 Historical Context

2.2.1 Early twentieth century

During the first half of the twentieth century parents with LD were often referred to within the literature as ‗idiots‘, ‗imbeciles‘ and ‗feebleminded‘ (Cleaver & Nicholson, 2007). At this time the worldwide ‗Eugenics Movement‘ influenced the public‘s feelings towards individuals with LD and informed social policy for many years (Porter & Lacey, 2005). In 1909, the UK saw the development of farm and industrial ‗colonies‘ to contain the ‗feebleminded‘ and prevent their proliferation (Porter & Lacey, 2005). In 1913, the Mental Deficiency Act promoted segregation and control of the ‗social inefficient.‘ Also, there is evidence of involuntary sterilisation of women with LD taking place to prevent them from having children (Fennell, 1995).

Research of particular influence on social policy at this time was conducted by Goddard (1912), who sought to provide proof of a link between genetics and LD. For example, in one of his most prominent studies, through the analysis of photographic evidence, Goddard (1912) noted that of 480 descendants of one ‗feeble-minded‘ woman who had children with a ‗normally‘ developing man, 143 were ‗feeble-minded‘ themselves, with only 46 descendants being considered ‗normal.‘ Kanner (1964) commented on how this caused widespread fear that society would be overrun with ‗socially inadequate‘ people.

At the time, with little research available on the interaction between environment and heredity, Goddard‘s work was accepted as scientific proof of the genetic transmission of LD. Goddard was later heavily criticised for his work on the basis of the particular methodology that he employed. For example, his ‗diagnoses‘ of ‗feeble-mindedness‘ rested largely on ‗surmises‘ based on looking at photographs spanning five generations and making assertions with little supporting evidence (Scheinfeld, 2012).

The manipulation of photographic evidence to make his results more significant was also noted (Raymond, 1987).

2.2.2 Later twentieth century

In the UK, the start of the National Health Service (NHS) in 1948 turned the majority of colonies, from the first half of the century, into hospitals overnight. However, the ‗subnormal population‘ remained segregated from the mainstream population. In education, the 1944 Education Act demonstrated no responsibility for educating children deemed ‗in-educatable‘ on the basis of an IQ test outcomes.

By 1959 eugenic views remained influential, while the 1959 Mental Health Act introduced the categories of ‗mild‘, ‗moderate‘ and ‗severe sub-normality‘ in the UK (Simmons, 1978). In 1952, Tredgold, in the preface to the *eighth* edition to his book wrote: ―Many of these defectives are utterly helpless, repulsive in appearance and revolting in manners...In my opinion it would be economical and humane procedure were their existence to be painlessly terminated.” (p. 8)

In 1991, Tredgold was criticised for relying heavily on statistics based on ‗official returns‘ which lacked accuracy and completeness of family histories (Mazumdar, 1991). Also, Mazumdar (1991) criticizes Tredgold‘s reliance on the use of diagrams, similar to family trees, to demonstrate how ‗good heredity‘ became ‗contaminated‘ by ‗morbid heredity‘. Mazumdar (1991) describes this approach as ―vulgar” (p. 56) and suggests that Tredgold lacked a *theory* of transmission and used the diagrams in ―a uncommitted”, anecdotal ―look-and-say” way (p. 56).

2.2.3 Latter part of the twentieth century

By this time, a growing evidence base derived from behavioural research had begun to show that improvements in learning outcomes were possible at all levels of disability (Fuller, 1949; Tizard, 1952), and that the majority of adults with LD were socially and economically capable (Fuller, 1949). Furthermore, research had also begun to suggest that some 80% of adults with LD had children who were not ‗defective‘ (Charles, 1953). In England, these studies and the publication of *Changing Patterns* (Kugel & Wolfensberger, 1969), led to the emergence of a document entitled *Better Services for the Mentally Handicapped* (Department of Health & Social Security, DHSS, 1971). This document proposed a reduction of 50% of individuals with LDs in hospitals and laid the foundation for the expansion of community-based care services for individuals with LD. This shift was accomplished more fully by the 1991 NHS Community Care Act, whereby, local authorities became responsible for assessing the needs of individuals with LD, producing care plans and providing services in both the public and private sectors.

In parallel to those policy developments, researchers (Fuller, 1949; Rice & McDaniel, 1966; Brownfield & Keehn, 1966; Rice et al, 1967; Rice 1968) demonstrated that learning outcomes could be improved through the use of behaviour modification procedures to facilitate adaptive functioning and decrease maladaptive behaviour of individuals with LD. However, a review of behavioural research highlights a number of criticisms, including the investigation of very small samples of behaviour, and that procedures were often only partially recorded, which made evaluation of change over time very difficult to describe (Reid et al., 1991). None of the studies reported any follow-up measures or demonstrated long-lasting effects of behaviour modification. Also, the primary method of data collection was observation, with very few reports of inter-observer agreement. Thus, behavioural research at this time, although encouraging, did not provide a sound demonstration that substantial changes in behaviours could be achieved and/or sustained; however, as previously mentioned this research did influence government policy despite these limitations (DHSS, 1971).

Psychological research expanded rapidly throughout the 1960s-80s, introducing new ways of conceptualising mental handicap or LD. The results of this research enabled professionals to understand functioning in different areas of development (Uzgiris & Hunt, 1975; Hogg & Mittler, 1980; Kiernan & Jones, 1977). Subsequently, intervention was viewed in a more holistic way, and from an ecological perspective, incorporating an individual‘s social and physical environment (Hogg & Mittler, 1980).

2.2.4 More Recent Views

Over the past three decades, terminology used in this area has evolved to include ‗intellectual difficulties‘, ‗learning difficulties‘ or ‗learning disabilities‘. In this study, I chose to use the term ‗learning difficulties,‘ because organisations such as People First (2004) and The British Institute of Learning Disabilities (BILD, 2011) suggest that many people with learning disabilities prefer the term ‗learning difficulty‘ being used to describe their needs. According to BILD (2011) the two terms are used interchangeably within the domains of health and social care for adults. The term ‗learning disability‘ is used in many government documents in the UK (DoH, 2001; 2005; 2007; 2009; DoH & DfES, 2007; 2010; Ward & Tartleton, 2007).

The change in terminology is accompanied by a shift in attitude. For example, in the UK concerns have been raised as to whether there are ethical, moral and legal implications when denying adults with LD the right to live and contribute to their community, to enjoy sexual freedom and to start a family (Cleaver & Nicholson, 2007). From as international perspective, Denmark hosted the first international conference on parenting with LD, suggesting —that there is nothing unusual in the fact that some intellectually disabled individuals want to have children, and to many of them this is part of leading normal lives" (Danish Ministry of Social Affairs, 1996, p.6).

2.2.5 Summary

Historically, research has served both as a perpetuator of damaging views and a facilitator of change for adults with LD (Porter & Lacey, 2005). Changes in the perception of people with LD in the UK and across the world have been significant, with the last thirty years seeing many important changes in attitude, treatment and support offered. The research summarised above indicates that for many years the dominant view of people with LD was centred on a medical model, outlining an individual‘s impairment as the ‗problem‘ to be worked on or managed. More recently, a social model of LD has highlighted the external barriers to individuals with LD achieving equality, outlining structures within society as areas that need to be addressed.

The following section (2.3) examines current policy and practice guidance in the UK in more detail.

2.3 Current policy and practice guidance

The population of parents with LD is continually growing in number (Ward & Tartleton, 2007) and includes individuals with unique and complex problems. This diversity has led to policy advocating the need for person-centred planning.

Person-centred planning formed the core component of *Valuing People* (DoH, 2001) and has formed the basis of subsequent policies relating to parents with LD. Person-centred planning is individualised and aims to reflect the unique circumstances of each person with LD in both assessment and intervention (O‘Brien & O‘Brien, 2000). The difficulties associated with the practice of current policy, including the application of person-centred planning, are also discussed in detail within this chapter.

This section explores four pieces of key policy in the area and provides a critical review of the focal recommendations from each, as well as a review of the impact each policy has had on current practices of support for parents with LD.

2.3.1 The Lamb Inquiry (DCSF, 2009)

The Lamb Inquiry (DCSF, 2009) was launched as part of the New Labour Government‘s response to the 2007 House of Commons Education and Skills Committee report on Special Educational Needs (SEN). The aim was to examine the ways in which parental confidence in SEN assessment procedures could be enhanced. A key finding of this report was that parents felt that ‗good, honest and open communication‘ was one of the most central parts of promoting confidence and building good relationships with professionals; a second important component was access to the information they need, when they need it and in a way that was accessible to them.

A key recommendation from this report was that professionals working with parents should ensure that support is provided to parents based on their individual needs, to ensure fairness, especially for those ‗least equipped‘ financially or in terms of personal resources. Also, the report urged that the utmost should be done to ensure that children and parents are protected from discrimination, ―The system needs to feel more like one where everyone is on the same side" (p. 6.).

The Lamb Inquiry (DCSF, 2009) was designed to reflect the needs of *all* parents of children with SEN; it does not specifically address the needs of families in which parents have LD: a group who would particularly benefit from a more transparent and easily accessible system to improve the outcomes and life chances of their children. Building on the findings of *The Lamb Inquiry* (DCSF, 2009) and the New Labour Government‘s efforts to implement these recommendations, in the current study, I aimed to explore the views of parents with LD and their experiences of the support systems currently in place, particularly how ‗good, open and honest‘ they are from their perspective. My second aim was to explore the extent to which parents with LD feel their rights are met and how accessible information and support is for them.

2.3.2 Valuing People (DoH, 2001) *and Valuing People Now* (DoH, 2009)

The aims of *Valuing People* (DoH, 2001) and *Valuing People Now* (DoH, 2009) were to ensure that all people with LD were provided with the support they need to lead their lives as fully as possible, to engage in the same opportunities and take on the same responsibilities as everyone else, having their rights met and being treated with dignity and respect. In order to achieve this, *Valuing People Now* (DoH, 2009) recommended advocacy, person-centred planning, and support to give parents independence and control over their family‘s lives. It also emphasised the right for adults with LD to become parents and for adequate support to sustain the family unit.

A year after the publication of *Valuing People Now* (DoH, 2009), a summary report for the period between March 2009 to September 2010 (DoH, 2010) showed that despite there being examples of good practice in supporting parents with LD across many local authorities, there was still more to be done to ensure parents with LD could become effective carers, such as, to improve accessibility of information for parents with LD and provide access to advocacy for these families, to get the person-centred services they need. These suggestions were based on annual reports sent from 152 Learning Disability Partnership Boards from across the country. The reports were ‗signed off‘ by people with LD; however, it is not clear how these reports were communicated to adults with LD to ensure they had a clear understanding of what they were agreeing to. Indeed, some parents refused to ‗sign off‘ reports because they were ―too complicated to understand” (DoH, 2010. p. 25).

An inquiry into the rights of parents with LD (The Joint Committee on Human Rights, 2008) suggested there was significant disparity between the proposed aims of *Valuing People* (DoH, 2001) and the actual experiences of adults with LD. The Committee was particularly concerned that in *Valuing People* (DoH, 2001) there appeared to be limited targets for action which were measurable and few specific proposals for monitoring the impact of support. However, the inquiry was based primarily on written evidence in the forms of memoranda (over 200 were received) from service providers; there appeared to be little evidence of direct accounts from adults with LD, although this type of data is alluded to within the paper; ~~In~~ October 2007, we met with adults with learning disabilities, their supporters and families in a number of different settings” (p. 12). Despite this, there is no clear explanation of what data were collected during these visits or how they were analysed, nor is there any clear outline of how data from memoranda were interpreted.

A review of the implementation of *Valuing People* (DoH, 2001) was conducted four years later, entitled *The Story So Far* (DoH, 2005). This review revealed limited national progress, in very few areas. Positive findings were, for example, that parents with LD felt they were being consulted more in relation to service planning. Also, person-centred planning, when conducted well, was making a notable positive difference to the lives of adults with LD. However, it appears that this research is based on written feedback and questionnaires from support providers, with no direct work with the individuals with LD.

In relation to the findings outlined in this section, in the current study I was interested in exploring the direct views of parents with LD in relation to the impact of *Valuing People Now* (DoH, 2009), by asking parents in Newtown about their experiences of becoming parents and whether these were in line with the expectations set out in

Valuing People (DoH, 2001) and *Valuing People Now* (DoH, 2009). Specifically, I hoped to explore their experiences of person-centred planning, accessing information and advocacy.

2.3.3 Good Practice Guidance on Working with Parents with a Learning Disability (DoH, 2007)

The Good Practice Guidance (DoH, 2007) highlights a number of fundamental characteristics of good professional practice when working with parents with LD:

- information provided in an accessible format;
- improved co-ordination of referral and assessment procedures which are clear to follow;
- support specifically planned to meet the individual needs of parents with LD and their families, based on assessments of both their strengths and areas of need;
- long-term support where appropriate; and
- access to advocacy.

The Good Practice Guidance advocates early identification of needs, suggesting that agreed criteria, procedures, and pathways should be established between children‘s and adult social care and maternity services when pregnancy is confirmed. Also, consideration should be given to developing positive communication between agencies for appropriate person-centred care planning. *The Good Practice*

Guidance (DoH, 2007) was developed following group discussions with parents with LD from several areas across the country and incorporated analysis of the 2004 national survey of people with LD in England. It is unclear how the group discussions were analysed, or the extent to which assertions made within *The Good Practice Guidance* (DoH, 2007) were supported by evidence provided by parents. In relation to the 2004 National Survey which was used as evidence, it is unclear how many parents responded or whether the survey was accessible to all parents with LD in the format it was disseminated.

In their *Seventh Report* in 2008, The Joint Select Committee on Human Rights noted that *The Good Practice Guidance* (DoH, 2007) had intended to help local authorities to fulfil their duty to provide equal opportunities for disabled people. However, the guidance was criticised by The Ministry of Justice (2009) for not clarifying local authorities' duties to act in line with the right to respect for privacy and family life, or outlining the balance that must be achieved to defend any intrusion of that right, under Section 6 of the Human Rights Act (1998).

The Joint Select Committee was also critical of the fact that successful support depended on both the effective dissemination of the guidance by central government and also its successful application by local authorities, NHS Trusts and other professionals” (p.29); neither of which may prove dependable.

The Ministry of Justice (2009) issued a response to the Joint Committee on Human Rights. Within this response, The National Co-Director for Learning Disabilities acknowledged that *The Good Practice Guidance* (DoH, 2007) ~~h~~ad been disseminated so far to professionals within adult services and further dissemination was needed to ensure that professionals working in children's services were informed of its recommendations" (p.32). It was argued that dissemination had been achieved through a series of seminars run by a single independent parents' network; however, these conferences had been heavily oversubscribed with the result that there were not enough staff to deliver training in order to meet the growing demand. The Committee expressed further disappointment that the distribution of this pivotal guidance had thus far relied solely upon the efforts of independent parenting networks. They called upon the New Labour Government to outline clearly its suggestions for making sure that all professional departments of the local authority should be aware of *The Good Practice Guidance* (DoH, 2007) and that all appropriate professionals were trained in its dissemination.

In relation to *The Good Practice Guidance* (DoH, 2007), in the current study, I am interested in exploring whether parents with LD in Newtown feel they are able to access the support set out in *The Good Practice Guidance* (DoH, 2007). In Newtown, there is a local support service (OfL[2]) for parents with LD who base their services around *The Good Practice Guidance* (DoH, 2007), with the central aim of delivering person-centred planning for whole families. OfL work is conducted in partnership with other professional agencies involved with families, including statutory agencies and third sector organisations such as social workers, school staff, educational psychologists and health professionals. I aim to explore the extent to

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[2] Pseudonym

which parents I interview consider their needs and the needs of their children are being fully met at a local level. I aim to elicit examples of good practice, as well as perceived barriers and suggestions for improvement.

2.3.4 Summary

In 2009, The Minister for Care Services acknowledged that, although momentous progress had been achieved in the creation of policy such as *Valuing People Now* (DoH, 2009) and *The Good Practice Guidance on Working with People with a Learning Disability* (DoH, 2007), work was still necessary to disseminate and implement these policies effectively.

Within the context of these and other policy developments, there is an ambitious target for service providers. With the aim of developing independence, and the control exercised by people with LD over the support made available to them and to safeguard in cases where they may become vulnerable, the task is ambitious because of a) the ever increasing numbers of people involved and b) the population of parents with LD includes individuals with a wide range of difficulties which can, in some cases, impede the development and maintenance of relationships with other people (Cooke & Richards, 2008).

Within Newtown specifically, there has been considerable evidence of increasing pressure on local services and carers, rising restrictions on local budgets have meant that agencies such as OfL have made redundancies and waiting lists have been created, with the need to ‗discharge‘ families when a crisis has passed (Durose, 2011).

Overall, it was positive that the New Labour Government itself had recognised that more needed to be done to apply policy successfully to maintain the rights of adults with LD. The 2010 Conservative-Liberal Democrat Coalition Government has begun to build on these policies through the publication of the Green Paper "Support and Aspiration: A New Approach to Special Education and Disability" (DfE, 2011). A primary objective of The Green Paper is ―To provide the best quality of life possible to the most vulnerable children and young people in our society… identify and meet children‘s needs early by ensuring that health services and early education and childcare are accessible to all children; work in partnership with parents to give each child support to fulfil their potential; and join up education, health and social care to provide families with a package of support that reflects all of their needs" (section 5). This message builds on key points raised previously in policies such as *Valuing People* (DoH, 2001) and *Valuing People Now* (DoH, 2009) and suggests that support for vulnerable children can be achieved through improved coordination of services; further transparency in the planning and delivery of services; and parents having ―real choice over their child‘s education and the opportunity for direct control over support for their family" (DoH, 2009, p. 134). However, the slow rate of progress in this area and the increasing strain on local resources has remained a concern.

2.4 Turning policy into practice

In this section, I aim to explore the extent to which policy discussed previously is being implemented. The evidence here is very limited, as so few studies have addressed outcomes of person-centred planning and policy implementation in the UK.

Tarleton et al., (2006) investigated the implementation of policy for supporting parents with LD, with the aim of identifying and communicating positive practice within the UK. 13 parents with LD and 20 professionals were included in the project, which utilised a range of research methods such as web-based questionnaires and telephone interviews with professionals and case study methodology with parents. The study identified that the majority of professionals in mainstream services lacked any experience of working with parents with LD, which led to a general —negative attitude from many professionals involved” (Tarleton et al., 2006, p. 198). This often led to parents‘ late, (often at crisis point), referral to adult support services. Many professionals identified lack of resources as obstructing their capacity to support parents with LD; also they suggested that time restrictions meant support provided was often short-term. Despite this, parents were required to acquire the skills they needed quickly and utilise them independently (Tarleton et al., 2006). Support during pregnancy was not being provided for those who were particularly vulnerable, such as parents with LD (McConnell et al., 2006). Moreover, on average, parents with LD received little social support from friends, family or community networks (McConnell et al., 2008).

In 2010, a study conducted by Simpson and Price found that support offered to parents with LD is largely short-term, in contradiction to policy recommendations discussed previously (DoH 2001; 2005; & 2007). They suggest that short term support can do more harm than good, with withdrawal of support leaving parents with LD at high levels of risk. They also argue that parents with LD are supported by staff who are not trained to a high enough standard; they argue for better pay, conditions and training of staff who support parents with LD. They also suggest that families, who make up the majority of carers for parents with LD, are not being supported enough within their local communities. They conclude that —people with learning disabilities and their advocates are beginning to realise that a policy framework, which promised much, is not delivering for a significant group of people" (p. 185). Simpson and Price (2010) used case study methodology with four cases included; however, it is unclear how data were analysed and interpreted. No quotes were used as supporting evidence and the extent to which assertions made by the researchers were supported by the evidence gathered remains unclear.

Hoole and Morgan (2011) conducted a focus group study with people who have LD; it was unclear how many parents were included. Through a thematic analysis of recorded data, they found that participants perceived a significant power imbalance between themselves and support staff, and felt that they were often not listened to, which led them to feel frustrated and angry. Adults felt they had little control over their lives. Overall, the researchers felt that the focus group was passionate about their rights and expectations and wanted a greater level of involvement in service planning.

Forrester-Jones et al., (2010) reviewed research relating to the employment of people with LD in the UK: a priority area in policy such as *Valuing People* (2001) and *Valuing People Now* (DoH, 2009). They concluded that fewer than 10% of adults with LD were known to be employed. They suggest that a ―lack of readily accessible, reliable and representative data presents a major barrier to monitoring the effectiveness and efficiency of employment services in terms of outcomes for people with learning disability" (p. 57).

These findings suggest that policy has remained ahead of practice and that fundamental principles outlined in policy have not been implemented adequately. Whilst, the policies discussed in the previous section are ―not statutory and therefore not enforceable by law" (Tarleton et al., 2006 p.197) they are defended by current legislation such as the 2010 Equality Act. Such legislation requires services to make appropriate modifications to meet the individual needs of parents with LD; where they do not, they could be viewed as compromising children‘s rights to live with their family. However, Beresford (2008) argues that whilst the drive in policy is towards person-centred planning, aligned with ideas of ‗choice‘ and ‗control‘, there is a significant ignorance of financial implications. ―It is impossible to see how true self-directed support, accessible to all, within a broader customised system of personalised social care will ever become a reality without some fundamental rethinking about who pays and how much money will be needed" (Beresford, 2008, unpaged).

CHAPTER 3

PARENTS WITH LEARNING DIFFICULTIES AND THE SUPPORT THEY RECEIVE: A CRITICAL REVIEW OF RESEARCH

3.1 Introduction

It is important here to examine the extent to which the research has, to date explored the experiences of parents with LD. This section is divided into sections which aim to critically review:

- factors associated with adequate parenting (section 3.2);
- risk factors commonly associated with parents who have LD (section 3.3);
- service provision for parents with LD (section 3.4);
- perceived barriers to support for parents with LD (section 3.5); and
- limitations of research with parents with LD (section 3.6).

3.2 Determinants of adequate parenting

In 1957 Winnicott introduced the phrase ‗good enough parenting‘ in relation to judging the adequacy of parenting approaches. It was suggested that being a ‗good enough‘ parent was adequate and that to provide the appropriate support to families who could be facing significant difficulty, professionals needed to recognise the contexts where parenting skills may *not* be ‗good enough‘. While Winnicott has been criticised on the grounds that the term ‗good enough‘ parenting sends the message that 'second-best' parenting is all that is required" (Tomison, 1998, p. 2) the notion continues to have currency in informing decisions about parenting capacity and child care placements.

A general consensus as to what constitutes ‗good enough‘ parenting has been identified, this includes that children are:

- well fed;
- relatively clean;
- warm;
- dry;
- given chance to sleep regularly;
- given clear boundaries;
- cared for by adults who respond to their requests and needs;

- loved; and
- safe

(Budd, 2005; Sellars, 2011)

Observing and monitoring parenting behaviours appears central in making judgments about what constitutes ‗good enough‘ and ‗not good enough‘ parenting ability; however, there remains uncertainty and inconsistency about how practitioners reach their decisions. In 2009, Taylor et al., aimed to investigate what factors service professionals considered when making judgments about parenting capacity. They found that even when presented with a wide array of information about a parent, often professionals made decision based on a limited range of factors such as boundary setting and housing conditions. Taylor et al., (2009) concluded that training and resources may need to be further targeted to ensure that clear and consistent judgment models are used. Taylor et al.,‘s (2009) study used a sample of health visitors from one Scottish health board. The results should be interpreted with caution as they are not representative of the approach used by all UK health visitors. Also, an experimental design was employed, whereby the study was based on health visitors‘ responses to vignettes (hypothetical scenarios) which, the authors themselves admit, could not fully replicate the context in which decisions are made. Additionally, the results were analysed statistically with little interpretation, and failed to illuminate the decision-making process and rationale behind health visitors‘ judgements.

In terms of how this impacts parents with LD, with over 800,000 parents with LD estimated to be living in the UK (Hatton and Emerson, 2008), the question remains, *how can parents with LD be supported to be „good enough' parents?* This is an important question, as lack of support services for parents with LD has been identified as a key issue affecting court decisions concerning placement of children (Tarleton et al., 2006). Furthermore, there is evidence to suggest that parenting programmes can have a positive impact on a range of parenting skills for parents with LD (Wade et al., 2008; Coren et al., 2011). Research by Coren et al., (2011) should be interpreted with caution. It comprised a systematic review of randomised control trials involving clinical samples only. The authors themselves admit that the quality of evidence reviewed was ‗moderate' to ‗low' and that no qualitative information was considered. Also, in Wade et al.'s (2008) systematic review of research pertaining to the efficacy of parenting programmes, they comment that the research they reviewed was of ambiguous quality, with ―limited generalization data, short-to-moderate follow-up periods, small sample sizes, a lack of information about fathers with intellectual disability, and limited data on treatment intensity and concurrent intervention" (p. 363). Both studies report positive outcomes of parenting programmes on the quality of parenting by adults with LD; however, there is little evidence highlighting which specific elements of parenting programmes produced positive effects; both authors strongly suggest the need for further research in this area.

In a study conducted by Tarleton and Ward (2007), parents with LD recognised that they required support to meet their individual families' needs, at particular stages of their children‘s development. Their study did not discuss how this might be achieved; however, research from New Zealand involving interviews with parents with LD suggests that on-going assessment and planning at each stage of children‘s development is key to supporting parents with LD to be ‗good enough‘ (Conder et al., 2010).

It is understood that there are many theories that contribute to our understanding of human development and it is recognised that parents will require increased or decreased support at different stages of a child‘s life. Masten et al., (2008) suggest that there are developmental tasks at different stages (see Appendix Two for Masten et al.,‘s developmental tasks) with which parents may require additional support. For example, in their children‘s early childhood, parents with LD may require more support with forming attachment bonds with children, while in ‗middle‘ childhood they may require help with teaching their children to socialise and progress educationally.

Masten et al., (2009) base their synthesis of developmental tasks on a review of research in the field (including that of Havighurst, 1972; Bowlby, 1982; & Erikson, 1968) alongside longitudinal studies, involving gathering data (observations in clinical settings) and mapping individuals across developmental stages. A criticism of their approach may be that they did not map one individual‘s progress through all of the developmental tasks; instead they mapped a selection of participants‘ progress through ‗key‘ areas. Also, participants were observed in clinical settings which may have affected their ability to demonstrate progress reliably. Despite this, there is general consensus regarding the key developmental tasks described by Masten et al., (2009) (for example, Roisman, 2009; Gewirtz & Edleson, 2007). In relation to these developmental tasks, –children‘s chances of achieving optimal outcomes will depend on their parents‘ capacities to respond appropriately to their needs at different stages of their lives" (DoH, 2009, p. 128).

3.2.1 Assessment of parenting skills

There are many approaches which can be applied to assess parenting skills. A review of the literature suggests that these approaches are based on a model of risk and strengths assessment (Bigby et al., 2007; Sellars, 2011), whereby, it is understood that each parent‘s strengths and difficulties will be individual and therefore should be individually assessed. In cases where there are known risks, as in the case of some parents with LD, the risk and strengths assessment should be carried out at the earliest point possible, as a preventative measure, to ensure that appropriate support is offered before ‗crisis point‘ (DoH, 2000).

The Framework for Assessment (Department of Health, 2000) is often used as a tool for targeting support where there is significant need. *The Assessment Framework* (Department of Health, 2000) provides guidance to practitioners when undertaking an assessment of the risks and strengths all children and their families experience, including applicability to parents with LD (see Figure 1). *The Assessment Framework* is a standard tool which is currently used by most professionals working with children for the purposes of assessment and referral (White et al., 2009).

This framework seeks to address strengths and potential areas of risk in the following areas:

- a child‘s developmental needs;
- the capability of the child‘s parents or carers to respond to his/her needs; and
- the role of the child‘s wider family and environmental factors on the child and his or her family.

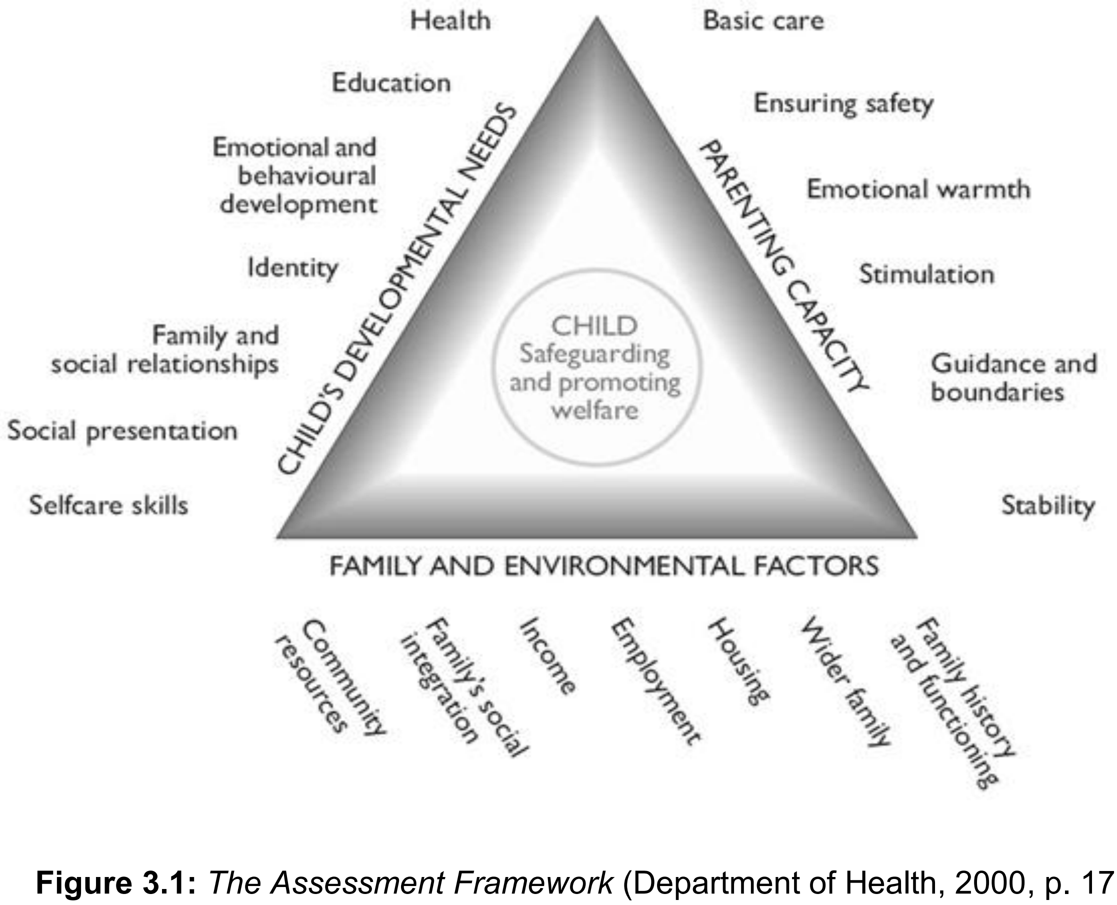

Figure 3.1: *The Assessment Framework* (Department of Health, 2000, p. 17)

The three domains, comprising the three sides of the triangle, create a foundation on which practitioners can develop an understanding of situational factors for a child. *The Assessment Framework* has practice guidance (Department of Health, 2000).

Cleaver and Walker (2004) conducted a research project spanning two years and incorporated a questionnaire-based survey with support service staff and interviews with families receiving support. It is unclear how many participants were involved or how data were analysed and interpreted. However, they found that *The Assessment Framework* (DoH, 2000) enhanced the quality of social work practice in the UK and facilitated multi-agency working. Also, they found that implementation of *The Assessment Framework* (DoH, 2000) had improved the understanding of parents with LD of the assessment process, and had facilitated their involvement at every stage of the assessment process.

One of the core underlying principles of the framework is that it highlights the interaction between internal and external factors, drawing on research by Schofield (1998). Schofield (1998) argued that support service professionals such as social workers required a framework for recognising areas of strength and difficulty and supporting families, taking into account their ‗inner‘ and ‗outer‘ worlds. Whilst there may be contemporary evidence (such as Martinez-Torteya et al., 2009 and Sternberg et al, 2006; Rutter, 2006) to support the need to consider internal and external factors when assessing and planning family support, Schofield (1998) relied heavily on research from the 1960s and 1980s, referring to the work of Winnicott (1964), Rutter

(1985) and Bowlby (1988). The article provides slender supporting evidence for the assertions that it makes, yet is referred to repeatedly within *The Assessment Framework* practice guidance (DoH, 2000).

A criticism of implementing *The Assessment Framework* (DoH, 2000) for assessing parenting skills is that this approach remains subjective in nature and open to the interpretation of the person(s) completing the assessment. As with most subjective assessment approaches, use of *The Assessment Framework* relies on description and narrative accounts causing interpretive demands on both the assessor and reader, and so can lead to unreliable accounts of the complex interplay between individual and environment (White et al., 2009). Researchers have found that practitioners' experiences with families, both personal and professional, can adversely affect their judgments and influence their assessment of a family's needs (Voight et al., 1996). Also, application of *The Assessment Framework* (DoH, 2000), can often be biased towards negative aspects of parenting, thus steering child care away from a focus on preventive and positive experiences, towards an inherent inspection of harm (Newman 2004). Finally, the application of the same framework to every parent suggests that they are a homogeneous group, when in reality parenting practices differ considerably, according to culture, with different considerations of what constitutes appropriate and good parenting across different ethnic groups (International Society for the Prevention of Child Abuse and Neglect, ISPCAN 2006).

3.2.2 Summary

Professionals working with families need to be aware of how their own experiences and judgements might affect ―their interpretation of the parenting practices within a multicultural society” (Maiter et al., 2004 p. 316). These limitations have led to recognition of the need for practitioners to develop their skill set, to identify ‗good enough‘ parenting, and where this is not apparent, to trigger ‗appropriate responses‘ to support families in providing children with the most positive start possible in life (Attree 2004). Ideally, holistic and impartial assessment of all factors which affect a family is necessary (Taylor et al. 2000); however it appears that assessment is often confused by premature judgement formation and decision making (White et al., 2009).

3.3 Risk factors associated with parents with LD

3.3.1 Stressors for all parents

Stressors to which all parents are vulnerable, such as large numbers of offspring, marital disharmony, marital violence, poor mental health, poor childhood experiences including abuse, substance misuse, lack of social support and poverty are found to be more predictive of poor parenting than parental intelligence (Booth & Booth, 1996;

Dowdney & Skuse, 1993; Cleaver & Nicholson, 2007). Unfortunately families headed by a parent with LD often experience a combination of these factors. For example, research shows that parents with LD are often socially isolated (Llewellyn et al., 2010) and economically disadvantaged (Bloomfield & Kendall, 2010).

3.3.2 Children taken into care

UK studies suggest that approximately 46% of parents with LD are not currently responsible for looking after their children (McConnell et al., 2008). Also, court studies in the United States, England, and Australia suggest that ―children of parents with LD are ‗overrepresented‘ in child welfare proceedings, representing approximately 15 to 25% of all children placed by the courts away from their family home" (Booth et al., 2005a p. 357; Llewellyn, McConnell & Mayes, 2003). These statistics could be indicative of a support gap for parents with LD and/or that parents with LD are at greater risk of being judged as inadequate parents.

In one local authority, Booth et al., (2005b) found that approximately one case in every six of care proceedings involved (at least) one parent with LD. ―In three quarters of these cases the children were removed" (Booth et al., 2005b, p. 12). However, this study does not explain what risks children were exposed to, whether risks were directly associated with the parent with LD, other family members or external factors, where the children were placed instead or under what circumstances.

Booth et al., (2005b) also found that at a national level, there appears to be wide variation in the experiences of parents with LD across different local authorities. However, Booth et al., (2005b) fail to explain why these differences occur, for example, whether they are due to variation in assessment procedures or local differences in support for vulnerable parents.

The statistics associated with children of parents with LD going into care have influenced current UK policy (e.g. *Good Practice Guidance on Working with Parents with a Learning Disability*, DfES, 2007) and are cited in many other influential documents (see Tarleton et al., 2006 writing on behalf of the *Baring Foundation* and Ward and Tarleton, 2007). I would argue that these statistics should be interpreted with caution and that more information is required before conclusions can be drawn regarding the reasons for high numbers of children of parents with LD being involved in care proceedings. Also, further research is necessary so that appropriate preventative measures can be developed and implemented to reduce this number. Many studies in this area rely on quantitative measures which, although they provide useful data regarding population trends, offer little explanation for these findings or indicators of ways of improving future practice.

In summary, research indicates that parents with LD are less likely to have been offered support with their parenting skills before court proceedings have begun, and that if support has been accessed by parents, they are increasingly likely to be held responsible for the failure of support rather than appropriateness of services being the focus for challenge (McConnell et al., 2008).

3.3.3 Child abuse and neglect

There is limited current research in this area; however, following Lord Lamings Inquiry (DoH, 2003) all health professionals have been advised to be attentive towards potential signs of abuse or neglect such as social disadvantage, domestic violence, mental illness and the risk that potential perpetrators of abuse pose to children (DoH, 2003). Unfortunately, parents with LD may often face social disadvantage and are particularly vulnerable to forming relationships with partners who become abusive towards their children (Sellars, 2011).

Sellars' (2011) study, although open to criticism for having a small sample size (16 interviewees), provides in-depth information on how (now-adult) children experienced an up-bringing in a family headed by a parent with LD. Overall, it found many instances where abuse involving children of parents with LD originated outside of the home.

The National Library of Health (2007) reports that the occurrence of abuse by parents with LD is uncommon; children are more prone to be removed from parents with LD on the basis that they are at risk of harm due to neglect. This statement is based on research by Booth and Booth (2004) which involved reviewing court records and conducting statistical analyses on rates and reasons for removal of children from parents with LD. There was no information provided in their study relating to whether families had received support prior to referral to court, making it difficult to conclude whether alleged neglectful behaviour reflected lack of access to support, poor quality support or non-engagement with support services.

We know that some parents with LD are able to raise their children to become functional members of society with little or no intervention from social care agencies (Llewellyn et al. 2010); despite this, there appears to be little or no evidence describing the experiences of children in families with a parent with LD, who are *not* taken into care. This type of research may offer further insight into factors which, from their perspective, protect children or facilitate positive childhood experiences.

3.3.4 Increased developmental delay and behaviour disorder

Research suggests that as a group, children of parents with LD are at increased ~~ri~~sk for developmental delay and behaviour disorders” (McConnell et al., 2008 p. 35). For example, Keltner et al., (1999) reported that 16 of 38 (42%) 2-year-old children showed signs of developmental delay in a North American study. In line with these findings, McConnell et al., (2003) found that in Australia, between one third and one half of a study of 37 children aged 0-5 years old demonstrated developmental delay of a minimum of 3 months. It is important to note that these studies are few in number and based almost entirely on small clinical samples; therefore, results should be interpreted with caution.

Studies dating back to the early 1980s have demonstrated that the risk of developmental delay for children of parents with LD can be reduced with access to suitable support structures. For example, in one clinical study, ~~c~~hildren were randomly assigned to one of two treatment conditions: a comprehensive educational day care intervention from birth through to age 5 years or a no-treatment" control (Campbell et al., 2001 p. 239). After one year, follow up investigations demonstrated ~~a~~ significant difference in general cognitive ability, with a mean treatment-related difference of 11 IQ points" (Campbell et al., 2001 p. 239). This study did not report any effects past the one year follow-up investigation, making it unclear whether the difference in IQ was sustained over time.

Studies into developmental delay and behaviour frequently fail to consider factors external to the home. For example, one Danish research study (Faureholme, 2007) interviewed 23 children of parents with LD and reported a number of interesting findings in relation to the development of behaviour problems. The study found that children of parents with LD often face oppressive and derogatory behaviour from their local community throughout childhood (Llewellyn and McConnell, 2005). Young adults reported high rates of exclusion on many levels, including in school and the wider community, despite some having stable, continuous and comprehensive support from local services. The evidence shows that environmental factors and social conditions play an important role, but are largely ignored within the literature, so that their significance cannot be determined.

In summary, children of parents with LD are at an increased chance of being subject to child care proceedings and subsequently removed by child welfare authorities, than any other group of children (Booth et al., 2006). As well as stressors faced by all new parents, families where parents have LD are more likely to be socially isolated (Emerson et al., 2005), vulnerable to victimization from partners who are abusive (McGaw, 1998) and at increased risk of engaging in neglectful behaviour towards their children due to their own limited knowledge and resources (Tymchuck, 1992). However, studies have historically shown that outcomes for children of parents with LD can be significantly improved with appropriate support and services (McConnell et al., 2008); including access to parenting programmes (Feldman, 1994) and parent support groups (Booth & Booth, 2003).

3.4 Service provision for parents with LD

New Labour Government policy and research (including *Finding the Right Support,* Tarleton et al., 2006; *Good Practice Guidance on Working with Parents with a Learning Disability*, DoH, 2007; *Valuing People,* DoH, 2001; and *Valuing People Now*, DoH, 2009) recommend a number of key support strategies, based on extensive consideration of issues and practice in supporting parents with LD and their children, which need to be available for parents with LD at a local level. These are described in Table 3.1 (source: Tartelton et al., 2006, p. 397).

Support Strategies	**Description**
Multi-professional and multi-agency working	supported by joint training and strategy development, care pathways and protocols for joint working, including clarity over different professionals' roles and boundaries, as well as, multi-professional forums for discussion and support.
Key workers	to support parents with learning difficulties and their families.
Training	for staff in generic and family support services – on identifying and supporting parents with learning difficulties and for staff working in specialist adult learning difficulty services – about child protection.
A range of support services	which can be provided, and funded, long term.
Early intervention	supporting parents during pregnancy is widely regarded as the most effective means of promoting health and well-being in the developing child.
Group support	through parent groups, this also helps to increase social networks.

Partnership working with parents	both in relation to bringing up their children and also in the delivery of training or planning for the development or delivery of support services.
Close working with mainstream services	including identification and creation of effective systematic links between generic services, such as maternity services, doctors, schools, mainstream parenting projects and specialist learning difficulties teams, so that early intervention is more readily available.
Easy to understand information	Information and advice about all aspects of parenting, on the support available and about child protection and judicial processes should be presented in a clear and accessible format.
Advice	in multiple areas, including advice on parenting, benefits and how to handle problems in relation to poor housing, harassment and so on.
Skills teaching	and other focussed help as necessary.
Consistency and clarity	from the professionals involved about their expectations of them as parents.
Advocacy	whether professional or voluntary, to support parents, particularly if they are involved in child protection or judicial processes.
Encouragement and affirmation	so that parents can gain the confidence to engage positively with services and demonstrate that they can be good enough parents with support.

Table 3.1: Summary of key support strategies for parents with LD (Source: Tartelton et al., 2006, p. 401)

It is important to note that the studies, from which these support strategies were synthesised, mostly drew on data from support service professionals such as social workers and health visitors, with disproportionally less data gathered from parents and families themselves. Also, little information was provided on how data were analysed and interpreted, for example, illustrating the saliency of certain support strategies over others.

3.5 Barriers to support

It is well documented that many parents with LD will require long-term, carefully coordinated and regularly reviewed support (Booth & Booth, 1996; Tarleton et al., 2006; McConnell, 2008). It is suggested however, that parents with LD rarely approach children‘s social care services for help when they are experiencing difficulty. An apparent deterrent to seeking support is that parents with LD fear they may lose care of their child or they may not wish to be involved with learning disability services because of associated stigma (Cleaver and Nicholson, 2007). The Cleaver and Nicholson (2007) study was commissioned by the Department of Health to inform assessment and intervention practice. Findings are based on reviews of social worker case files and review of court case files, and 50 interviews with family members where a parent had LD; these interviews were followed up a year later. Data analysis involved both quantitative and qualitative approaches. Although not all families were available for follow-up interviews, the findings are valuable and illuminative. The extent to which the findings were considered or applied by the Department of Health remains unclear.

Despite these barriers to support, local authorities have a responsibility to ―let families know how to contact them and what they might expect by way of help, advice and services" (HM Government, 2005, p.79). It is to be recognised that more needs to be done to address the challenge of overcoming the negative expectations and poor experiences that many parents with LD have had of professional services

(Booth & Booth, 1996; McConnell, 2008). For example, research suggests that parents with LD experience negative community and professional attitudes no matter what their circumstances, and often both family members and professionals involved immediately question parents‘ capacity to raise their children successfully (Booth & Booth, 1996; Mayes et al., 2006).

Research suggests that mothers with LD prefer to seek support from family networks such as parents and siblings, rather than formal support services (Llewellyn & McConnell, 2002) because family support is perceived to increase parents‘ confidence in their parenting and ‗support is consistent with their own values and ideals" (Llewellyn, 1995 p. 5). However, the amount of support accessed from family networks varies between individuals with some parents not receiving any support (Llewellyn & McConnell, 2002).

Mansell and Beadle-Brown (2004) used a combination of interviews with parents, focus groups with practitioners, and questionnaires with ‗significant others‘ to investigate barriers to meeting the support needs of parents with LD and service constraints in the UK. A number of service limitations were found to be barriers to parents with LD accessing support including ‗limited time, staff, and funding; lack of suitable parent education resources; limited practitioner skills; and negative attitudes" (p.11).

3.6 Limitations of research

It has been highlighted throughout this literature review that the studies referred to are open to criticism on various levels. Limitations include the samples used, gender bias towards mothers and methods used to gather data. These will now be addressed in turn, as will researchers' epistemological position and the implications of research in this domain for educational psychology practice.

3.6.1 Sampling

Much of the information cited about parents with LD derives from clinical samples, which leads to selection bias. Samples of those parents who receive support from clinical services are unlikely to be representative of the wider population of parents with LD. This could mean that the findings of such studies reflect only the experiences of a small percentage of parents with LD, since the whole population has not been proportionately represented. This may also mean that the findings of studies which draw upon clinical samples cannot be generalised to the rest of the population; they lack external validity. However, this type of data is often used to make general statements about parents with LD and more should be done to ensure that findings are interpreted and reported with more caution.

3.6.2 Gender

The focus of research so far has been on parenting, although in reality this has predominantly involved seeking the views of mothers alone. The experiences of fathers with LD have been largely ignored (Llewellyn et al., 2010). A search of a regularly updated Australian database (www.healthystart.net.au) of empirical literature from around the world identified 445 publications about parents with LD, only two of which referred to fathers with LD. Feldman (1994) conducted a meta-analysis involving 190 parents, across 20 studies. In this sample, again, only two fathers were included, despite the majority of studies referring to ‗parents.‘ As a result, there is a gap in the literature where researchers should explore the experiences of fathers with LD, seek their views and give them a voice.

Llewellyn et al., (2010) suggests that what is known about fathers with LD is very limited, but that they face their own unique challenges is apparent. It could be concluded that the research in this area is not representative of the population of parents with LD and is subject to sample selection bias.

3.6.3 Epistemological approaches to research

Historically, the field of learning difficulties has been dominated by positivist research (Skritic, 1991, 1996). These approaches view ‗reality‘ as an objective entity which exists and can be understood entirely independently of the subject. Research until the late 1990s was almost entirely centred on comparing groups of adults with LD with the typically developing population in ―some experimental condition” (Turnure, 1990 p. 187). 22% of research studies conducted between 2000 and 2001 were based on survey design. These approaches can be criticised for their lack of attention to individual differences and environmental/contextual factors. The limited nature of quantitative findings generated by positivist approaches results in meaning being extrapolated by the researcher, which is highly susceptible to interpreter bias and ‗solutions‘ being generated without an in-depth understanding of the needs of the participants. This bias influences policy, decision-making and practice in the provision of support services for parents with LD. Evidently, when considering the treatment of parents with LD in the past, this has been the case, where research based on intelligence testing heavily influenced the public‘s views about individuals with LD and contingent social policy for many years (Porter & Lacey, 2005), ultimately leading to the oppression and maltreatment of this group.

Alternatively, Howie (1999) advocated a developmental as opposed to deficit approach to the way in which the needs of parents with LD are conceptualised. She argues for a shift away from the use of categorical labels, to recognising a continuum reflecting different levels of support needed by parents with LD and a shift from simply studying individual variables, to include systemic influences. Such a shift would add to the ecological validity of findings and offer meaningful information for future practice.

To add to the validity of findings, researchers must move beyond simply charting environmental and systemic factors and explore the way in which individuals *perceive* environment and systemic factors promote or hinder their development as parents. In support, Howie (1999) suggests a fundamental change is needed: in contrast to the objectivism of behaviourism and positivist research approaches, there should be a focus on the subjectivities, the meanings that people construct and the relationships between subjects and their environment.

Over time, calls for a paradigm shift towards a more participatory and qualitative form of research have been made (Goodley & Moore, 2000; Chappell, 2000), to provide a meaningful influence on policy (Chappell, 2000). Research should aim to improve the lives of parents with LD (Chappell, 2000), and in order to do so, should incorporate a combination of qualitative approaches such as participant observation, focus groups and interviews, with active involvement of parents themselves (Walmsley & Johnson, 2004). For this reason, it is important to consider an array of epistemological positions when conducting research into the experiences of parents with LD, in an attempt to bring balance to an area of research which has, to date, been heavily skewed towards describing only that which is observable.

Adopting a Critical Realist (CR) position affords an alternative way to approach research with parents with LD. For example, researchers from a positivist stance often rely on outcome measures which, as previously discussed, can fail to account for environmental and contextual factors and generate a limited understanding of the experiences of participants. Constructivist research may focus on how parents with LD view the support they have received from services, with a central focus on the language participants use to discuss it. However, a focus on language may not be appropriate for research with those who have limited language skills (Porter & Lewis, 2001). CR may focus on the mechanisms through which the views of parents with LD should influence practice, in relation to the support they receive, by adopting methods which do not rely extensively on language ability but remain qualitative in nature. In line with a CR approach, more recently, researchers have sought ways to access the voices of parents with LD through, for example life testimonies; using narrative life history accounts (Atkinson & Walmsley, 1999); and research studies based on structured and un-structured interview approaches (Cambridge et al., 2002; Emerson et al., 2000).

3.6.4 Implications for Educational Psychology practice

In a review of the Functions and Contribution of EPs in England and Wales by Farrell et al., (2006), it was noted that EPs ―work for a significant amount of time at the ‗systemic‘ level in order to increase the capacity of schools and other organisations" (p. 13), and display considerable skill in this area. Also, ―a dataset compiled by the

National Association of Principal Educational Psychologists illustrates a wide and extensive range of EP work within multi-agency teams across England and Wales at universal, targeted and specialist levels of service provision" (National Association of Principal Educational Psychologists, NAPEP, 2005 p. 23). EPs can be facilitators of, as well as advocates for, provision within local services' (Senior Policy Advisor with the Youth Justice Board, Farrell et al., 2006, p. 117) and display a commitment to supporting children's' education through focussing on the interacting systems in a child's life. One EP referred to by Farrell et al., (2006) noted that ―We have an aptitude to raise people's awareness about how a system works; we have a particular overview across development and contexts. Our perspective is particularly about how systems interact and how the child is included within and across those" (Farrell et al., 2006, p. 75).

EPs focus on consultative working alongside parents, teachers, health professionals, child and adult social services as well as other professionals. This breadth of focus places EPs in a strong position to facilitate understanding of the needs of parents, children and families who are affected by LD and to promote understanding within the professions and communities who support these families. Furthermore, EPs are skilled researchers who could add to the evidence-base in this area through the conduct of robust research, drawing on a range of methods, approaches, theories and perspectives.

3.7 Concluding Synthesis: Policy and research: what we already know and what remains to be explored

A key finding of *The Lamb Inquiry* (DCSF, 2009) was that parents felt that ‗good, honest and open communication‘ was most important for promoting confidence and building good relationships with professionals; a second important component was access to the information they need, when they needed it and in a way that was accessible to them.

In light of this, in my own research, one of my aims, in relation to what remains to be explored, is to inestigate the views of parents with LD and their experiences of the support systems currently in place, particularly how good, open and honest they are from their perspective. A further aim is to explore the extent to which parents with LD feel their rights are met and how accessible information and support is for them.

The aims of *Valuing People* (DoH, 2001) and *Valuing People Now* (DoH, 2009) were to ensure that all people with LD are provided with the support they need to lead their lives as fully as possible, to engage in the same opportunities and take on the same responsibilities as everyone else, having their rights met and being treated with dignity and respect.

In relation to the findings outlined in this section, in the current study I was interested in exploring the expressed views of parents with LD in relation to their experiences of becoming parents. Specifically, I hoped to explore their experiences of person-centred planning, accessing information and advocacy.

The Good Practice Guidance (DoH, 2007) highlights a number of fundamental characteristics of good professional practice when working with parents with LD, including easily accessible information, person-centred planning and long-term support where appropriate.

In the current study, I was interested in exploring whether parents with LD in Newtown felt they had received long-term support, when needed. I aimed to explore whether the extent to which parents I interviewed considered their needs and the needs of their children were being fully met at a local level. I aimed to elicit examples of good practice, as well as perceived barriers and suggestions for improvement.

Hoole and Morgan (2011) found that participants perceived a significant power imbalance between themselves and support staff; they felt that they were often not listened to, which led them to feel frustrated and angry. Forrester-Jones and Melling (2010) found that “lack of readily accessible, reliable and representative data presents a major barrier to monitoring the effectiveness and efficiency of employment services in terms of outcomes for people with learning disability” (p. 57). Also, there is evidence to suggest that parenting programmes can have a positive impact on a range of parenting factors for parents with LD, including contributing to a sense of empowerment (Wade et al., 2008; Coren et al., 2011).

Within the current study, I sought to ask parents about their own experiences of support when becoming a parent and during early stages of parenting, where parenting programmes are thought to have the most impact. I wanted to explore whether they were able to access such support and factors which facilitated or hindered their engagement with such support. Also, I was interested in how parents viewed their relationship with support service professionals, for example, whether they believed they were listened to.

In relation to lifespan developmental stages, –children‘s chances of achieving optimal outcomes will depend on their parents‘ capacities to respond appropriately to their needs at different stages of their lives” (DoH, 2009, p. 128). In this current study, I was interested to explore the extent which parents with LD considered the needs of their children to be met through the support they were receiving, whether they could identify stages in their children‘s lives or developmental tasks where they perceived they needed help, and whether they were able to access this successfully.

Research indicates that parents with LD are less likely to have been offered support with their parenting skills before court proceedings have begun, and that if support has been accessed by parents, they are increasingly likely to be held responsible for the failure of support rather than appropriateness of services being the focus for challenge (McConnell et al., 2008). In the present study, what remained to be explored was the extent to which parents considered support to have been offered in a preventative capacity, early in their children‘s lives before crisis points, or whether they perceived services to be largely reactive.

The quality of such support often makes the difference between whether children remain in the family home or are taken into care (Booth & Booth, 1996). I intended to explore what parents considered to be the quality of support they had received from professionals and what factors influenced their views.

Local authorities have a responsibility to —let families know how to contact them and what they might expect by way of help, advice and services" (HM Government, 2005, p.79). I was interested to explore whether parents with LD were aware of the support available to them and what types of support they were accessing, along with the factors which facilitated or hindered this process.

International research shows that many parents with LD are hesitant to ask for help and afraid to receive services, while others refuse to engage with support offered (Traustadóttir and Sigurjónsdóttir, 2010). Parents with LD often receive services from a variety of agencies, and parents do not always agree with the advice they are given. As part of the present study, I hoped to explore the extent to which parents with LD had engaged with services and whether their engagement had been facilitated or hindered by the way they consider professionals to perceive them for example, and/or they had refused to engage due to a difference of opinion with service professionals and how this had impacted their access to support.

The synthesis presented above forms the basis for my five research questions:

1. How do parents with LD perceive communication with support service professionals?
2. How do parents with LD report that they are supported to meet their children‘s needs?
3. What are some of the barriers to parents with LD receiving support?
4. In parents‘ views, how may these barriers to support be overcome?
5. What positive experiences of support services do parents with LD describe?

In Chapter 4, table 4.6 demonstrates how interview questions are linked to the above research questions and presents the associated rationale for question choice, aligned with the above concluding synthesis.

In the present study, I intended to generate knowledge which could be used to improve the lives of parents with LD. I sought also to instil confidence in interview participants (parents with LD from a community sample) by a adopting an appropriate methodology, (with supporting rationale), considering ethical implications that need to be addressed and how these could best be resolved when working with parents who have LD. I endeavoured to design a study which could explore the lived experiences of parents with LD as closely as possible through careful consideration and selection of data collection procedures, methods and tools and considering criteria for the trustworthiness of findings. My approach is presented in detail in Chapter Four.

CHAPTER FOUR

METHODOLOGY

4.1 Local context

Presenting a portrayal of the research context is integral to Critical Realist (CR) epistemology and case study methodology. The context defines the degree to which theoretical assumptions and findings may be generalised to future cases. In relation to this, a description of the geographical and historical context of the present study is provided below.

4.1.1 Demographic trends

The study was undertaken in Newtown Local Authority characterised by social and ethnic diversity, within the Midlands. There are no trustworthy official statistics regarding the current number of people with LD in the UK, or indeed within this Local Authority. In a recent *Draft Commissioning Strategy for People with Learning Disabilities in Newtown*, the numbers of people with learning disabilities known to services was 850 adults with severe or profound leaning disability, and an estimated 3,139 adults with mild or moderate learning disabilities (Draft Commissioning Strategy, 2004 -2007). However, by utilising prevalence rates founded in entire populations (in comparison to people known to services) and applying these across the Newtown population, it is suggested that locally, there are approximately 1,698 people with severe LD and 8,490 with mild LD in Newtown (Gaughey & Hickson, 2008). Both national and local evidence suggests that these numbers will increase, taking into account the relationship between higher prevalence of learning disabilities and social economic deprivation (Disability Rights Commission, 2004). Newtown has been ranked as the 12th most deprived Local Authority (LA) out of a total of 354 (DCLG, 2010) in England. The area in which I conducted the present study was within one of the most deprived areas in the LA, falling within the lower 10% of the most deprived areas in England (DCLG, 2010).

4.1.2 Historical context

Enabling people with LD to live a fulfilling life within a community continues to be a significant challenge within most health and social care services budgets, including Newtown. Whilst across Newtown, there are independent and private sector providers supporting day opportunities, the Local Authority supports the majority of parents with LD. Newtown Local Authority has undergone a number of changes over the past 12 months due to the national economic decline. As a result services have faced significant reductions (approximately 20-30%) in staff and resources.

During informal discussions with key workers from a voluntary agency who support parents with LD, it was suggested that many paid workers have been made redundant, whilst workload has continued to increase for those who remain employed. One worker reported feeling unable to provide the level of support that parents with LD require because she simply has too many cases to manage. A social worker reported similar difficulties, where budget restraints have eroded her perceived quality of support for parents with LD.

When presented with the research brief, both the agencies expressed a professional interest in ascertaining the views of parents with LD within this current economic climate, in hope of providing evidence to highlight the need for an increase in staffing.

4.1.3 Policy and guidance

This section identifies the key themes that have influenced the emerging strategic model of support for people with LD in Newtown. Table 4.1 presents a number of published policy and strategy documents which relate to the support of parents with LD Newtown.

Policy/guidance document	**Key points**
The Newtown Plan (2008)	• Promoting lifelong learning; • Creating wealth / revitalising the Newtown economy; • Transforming Newtown‘s Environment; • Improving health; and • Creating a safer Newtown.
Towards 2010 – Building the Future Together	• Improve health outcomes of those with significant need; • Empower people to better manage their own health and well being; and • Increase locally accessible support services that meet local people‘s needs.
Report to 2010 - Special Needs (2005)	• People with LD want and should have access to mainstream services; • People with LD have health and care needs are more challenging than the general population; • Currently, the needs of people with LD are not well met at present in either sector; and • There is evidence of an increasing demand for services and support across all sectors from this client group.

Best Value review “A Place to Live” (2010)	• All service users are able to influence decisions that affect their lives and are part of the decision making process; • People with a LD live safe and secure lives as part of their community; • All service users will be offered opportunities for real community experiences and involvements; • All people with a LD are treated with the same dignity and respect as members of the wider community; • All service users have help to speak up for themselves or an independent person to speak on their behalf if they cannot do so themselves; • Service users will be supported by staff skilled and knowledgeable in the field of LD; and • High quality, approved service provision is available which meets the vision of Valuing People.

Table 4.1: policy and strategy documents which relate to the support of parents with LD Newtown

Table 4.1 begins to identify some of the priorities for action based on several reviews and commitments made locally. There are a number of common themes throughout these policies, which are:

- health promotion and well-being;
- equality of access and choice;
- individual control;
- improving information;
- partnership working; and
- high quality services.

These key themes have influenced the strategic model of support for people with LD in Newtown.

4.1.4 Support structures

In Newtown, there is number of structures in place which parents with LD can access for support. Some services are specific to parents with LD, whilst others are available for all parents. The structures and services are described in Table 4.2.

Service	**Description**
Newtown Integrated Support Service	Newtown Integrated Support aims to provide support for children and young people (from birth to 25 years) with special needs, including those with disabilities and their families.
Newtown Housing Options Team	The Housing Team provide parents with information about the housing options available to them and support access to support.
Newtown Community Care Team	The Community Care Team has dedicated housing officers to assist parents with LD in accessing housing and support alongside the Housing Options Team.
Newtown Learning Disability Team	The Community Learning Disability Team offer support and advice for people with learning disabilities who live in Newtown.
Newtown Supporting People Team	The Supporting People programme funds support to assist people to live independently in the community. This may be living in a shared house, a group of flats, or on their own.
OfL (pseudonym)	The remit of this Newtown based service is to support and improve quality of life for people with learning difficulties by enabling access to support. They are a registered charity who work to ensure parents with LD are valued and assisted to live their lives as fully as possible, ensuring they enjoy the same rights and opportunities as non-disabled people" (service leaflet, p. 2).
Newtown Parent Partnership	Parent Partnership provides a free, confidential and impartial service for all parents and carers of children with special educational needs in Newtown" (service leaflet p. 1).
Newtown Children's Centres	There are a number of children's centres which parents with LD can access for support. Staffing typically includes a Centre manager, family support and parental outreach coordinators, family support workers, fathers worker/family support worker, maternity support workers, citizen's advice bureau advisor, who together deliver a preventative support service to families. The range of work with parents includes advice, befriending, advocacy and parenting skills courses.

Newtown Social Care Services	This service is available to all parents with a branch dedicated to parents who are ill or disabled (including learning disability) and support parents by offering advice, information or practical help across a variety of areas.

Table 4.2: Support structures in place in Newtown

4.1.5 Role of Educational Psychologists

A significant part of the EP role in Newtown is to work within systems models of human behaviour (Burnham, 1988; Dowling & Gorell-Barnes, 2000; Dowling & Osborne, 2003), with an emphasis on contextual influences on the extent to which individual young people develop: importance is placed upon the complex interplay between individual characteristics and environmental conditions (Dowling, 2003). In Newtown, systems theory is applied in educational contexts to seek explanations of how young people's "behaviours and experiences are influenced by the educational establishment of which they are part, as well as the influence of the relationships between school and home" (Dowling, 2003. p. 46). Whilst the EPs' clients are usually pupils, the breadth of the EP role extends beyond focussing on the individual child and within a systemic framework, EPs in Newtown support children and families headed by parents with LD through a wide range of approaches; for example, through attendance at multi-agency meetings and parental consultation, EPs provide guidance, advice, training and support to school professionals and parents with regard to pupils and families experiencing a wide range of needs.

4.2 Aims

Key research questions were formulated within a Critical Realist (CR) epistemological framework, in line with case study methodology and with reference to existing literature. The present study aimed to explore parents‘ views and experiences of local support services, highlighting examples of good practice and positive experiences of parents with LD, as well as exploring some of the needs and the challenges which they faced, with the further aim of informing practice with the research findings.

Key research questions to achieve the research aim were:

- How do parents with LD perceive communication with support service professionals?
- How do parents with LD report that they are supported to meet their children‘s needs?
- What are some of the barriers to parents with LD receiving support?
- In parents‘ views, how may these barriers to support be overcome?
- What positive experiences of support services do parents with LD describe?

In line with a CR framework, these questions aimed to identify the mechanisms by which positive change can be brought about in the experiences of parents with LD. ―Case studies are more suited to *how* questions" which can be exploratory in nature, because in line with CR, case study methodology asks questions which deal with ―operational links needing to be traced over time, rather than mere frequency or incidence" (Yin, 1989 p.18; Yin, 2003, p.6).

4.3 Epistemological stance

As noted in Sections 1.2, 1.4 and 1.5, this study was conducted from a CR research position (Bhaskar, 1998; Robson, 2002). CR's principal concern is with ontology or the ‗nature of reality' and starts with questions about what exists (Bergin et al., 2008). Bhaskar (1978) argues that ontology should be ―viewed as separate to, and necessary for, a theory of epistemology, or knowledge" (p.12).

CR proposes an ontology which presumes that a reality exists which is beyond the realm of observers, and that this reality is stratified and differentiated (Bhaskar, 1998). For example, Bhaskar suggests that reality can be split into three domains, as summarised in Table 4.3.

Domain	Description
The *real* domain	• Comprises everything that exists (Sayer, 2000) natural or social. • Is the realm of ―objects, their structures and powers" (Sayer, 2000, P. 11). • ―In this domain mechanisms (what makes something happen in the world) events and experiences exist" (Bergin et al, 2008, p. 174). • This real domain is beyond what we experience or observe and has powers that can be activated or not (Sayer, 2000)
The *actual* domain	• ―Refers to what happens in reality when the powers or mechanisms of the real are activated, and events and experiences are produced" (Collier, 1994 p. 3; Sayer, 2000; Danermark et al., 2002) • May not always be observable (Bergin et al., 2008).
The *Empirical* domain	• ―Is comprised only of what we experience (directly or indirectly); however, not all events are experienced" (Collier, 1994 p. 7). • ―The domain of the real is distinct and greater than the empirical domain. However, the empirical is in a ‗contingent relation' to the domains of the actual and the real" (Outhwaite, 1998 p. 175). • Provides a partial view of reality.

Table 4.3: Domains of reality according to CR

A feature of reality, according to CR is that ‗there is an ontological gap between what we experience and understand, what really happens, and – most important – the deep dimension where the mechanisms are [real domain] which produce the events" (Danermark et al., 2002, p. 39). Therefore, CR asserts that our knowledge of the world is imperfect and ―theory-laden" (Sayer, 2000 p. 21). Within these parameters CR encourages researchers to look beyond what is observable and to consider the constituent elements behind this (for example, the contingent inter-relationship between the domain of the *actual* and the domain of the *real*). We may gain experience and understanding of adults with LD; however, realist ontology provides researchers with the chance to independently explore the difficulties faced by adults with LD, within the domain of the real and to discover the mechanisms that may be producing parenting difficulties.

A feature of this approach is that the events or outcomes that a CR study investigates, are the exterior and observable behaviours of people and often rely on data that are reported, as opposed to directly observed. For example, this study explores descriptions of events that parents with LD have experienced or are currently experiencing, which I, as the researcher have not experienced first-hand. This is not necessarily a limitation as Madill notes, —…all accounts, whether those of participants or those of researchers, are understood to be imbued with subjectivity and therefore not prima facie invalidated by conflicting with alternative perspectives." (Madill et al., 2000, p. 9).

CR accepts that —the way we perceive facts, particularly in the social realm, depends partly upon our beliefs and expectations" (Bunge, 1993, p. 231), and hence acknowledges an intrinsic subjectivity in the construction of knowledge; this is highly compatible with constructionist positions (Watkins, 1994-95).

Working within a CR paradigm, within this present study, I do not intend to present an 'objective' account of the experiences of parents with LD; instead I aim to provide a contextual description of their experiences in the past and at the point the interviews were conducted.

The overarching methodology I adopted for this study was exploratory case study methodology, which is defined as: “an empirical enquiry that investigates a contemporary phenomenon in depth and within its real-life context” and which “copes with the technically distinctive situation in which there will be many more variables of interest than data points” and therefore “relies on multiple sources of evidence” (Yin, 2009, p. 18). Darke et al., (1998) suggest that “case studies are particularly useful where the experiences of individuals and the contexts of actions are critical” (p. 279).

4.4 Case study methodology

As indicated above, the over-arching methodology I adopted for this study was case study. The aim of this thesis is to examine a number of cases in order to gain insight into an issue; therefore I chose *exploratory* case study design (Yin, 1984).

Some authors, such as Stake (2005) and Harding (1987) argue that case study is not a methodology. Stake (2005) suggests that case study does not present a clear rationale of how research should be conducted. Similarly, Harding (1987) suggests that methodology is “a theory and analysis of how research should proceed” (p.3) and a case study approach does not achieve this because it has poorly defined parameters. Other authors argue that “the fact that the case study is fuzzy round the edge does not mean that it doesn't have distinctive characteristics” (Gerring, 2004 p.346). For example, Cohen et al., (2007) present certain elements which are characteristic of case study approaches, as outlined below:

Purpose: 1) To represent, analyse and illuminate the individuality of real participants and contexts through available accounts. 2) To grasp the intricacy and context of behaviour. 3) To contribute to practice, policy and intervention. 4) To present and represent reality, to give a sense of being there” (p. 67).

Foci: 1) Individual participants and local contexts. 2) Individual and distinct examples. 3) An individual case. 4) Phenomena and systems bounded to time and context such as individuals, organisations and communities.

Key terms: Distinctiveness, uniqueness, in-depth analysis, portrayal, interpretive, inferential, subjective, descriptive” (Cohen et al., 2007, p. 237), analytical, complex, particularity.

Characteristics: 1) In-depth, rich and detailed data. 2) Observations (participant and non-participant). 3) Non-interventionist. 4) Empathetic and holistic view of phenomena.

Case study, according to this description *would* be a methodology because in part, it is closely aligned with qualitative research methods such as observation and interviews that aim to elicit evidence from the individual about their experiences in relation to contextual and systemic factors. Case study provides a rationale for using qualitative research methods to generate new knowledge.

The main strengths of case study methodology are that it is *transparadigmatic* (VanWynsberghe & Khan, 2007); and that it is compatible with several different epistemological positions (Verschuren, 2003) including the CR approach of this study which focuses on context and mechanisms. The results are often understood by a wide audience as they are —immediately intelligible” (Cohen et al., 2007, p. 256), frequently written in non-professional language and —speak for themselves” (Cohen et al., 2007, p. 256). Case studies encapsulate unique features of the research context which may be lost in larger scale studies and which might be key to understanding a situation. They can embrace unanticipated events and uncontrolled variables. Finally, case studies can provide insight into other, similar cases.

The principal limitations of this approach are often cited by those who operate within positivist epistemologies (Flyvbjerg, 2004). As a result, a number of the criticisms directed at case study methodology may not be of significance to CR researchers. For example, such criticisms of case study methodology include the perceived failure to control for confounding variables, complications with completing objective data analysis and low statistical representativeness. As a CR researcher I would argue that these criticisms are not of significance to this research because I am committed to using —a naturalistic approach that seeks to understand phenomena in context-specific settings” (p. 178) or "real world setting [where] the researcher does not attempt to manipulate the phenomenon of interest" (Patton, 2001, p. 39).

Despite it being possible to research multiple cases, this is not typically done within CR research to increase the sample size in the traditional (positivist) sense (Flyvberg, 2004). The concept of generalisability is differently interpreted; this will be considered with in Section 4.7 *Generalisation and* utility. Other criticisms relate to case selection and contingent claims for reliability, validity and utility. These are addressed In Section 4.6 *Trustworthiness*.

4.5 Case selection

I judged that a small sample size would allow me to understand parents‘ experiences in sufficient detail. My review of previous case study research with parents with LD revealed that studies involved single cases (Germain, 2002), several cases (Simpson & Price, 2010) or some studies having up to 6 or 7 participants (Hoole & Morgan, 2011). I have chosen to use four cases to help me explore the particulars of each case in-depth but also to explore relationship between different parents‘ reported experiences. Inevitably also, choice of cases was constrained by a number of pragmatic factors.

Selecting –good cases for small samples is a challenging endeavour" (Gerring, 2007 p. 239). Gerring (2007) acknowledges that, as in the current study, most case studies aim to explicate characteristics of a wider population: –They are about something larger than the case itself, even if the resulting generalization is issued in a tentative fashion" (Gerring 2004, p.347).

The –case study calls for an intensive and in-depth focus on the specific unit of analysis and generally requires a much smaller sample size than survey research"

(Gomm et al., 2000 p. 31; Yin, 2004), which is why I used purposive sampling to select four cases ‗representative‘ of parents with LD within the Local Authority. Also, Gerring (2007) suggests that when case study findings are considered in relation to multiple-case evidence, the risk of sample bias is somewhat lessened.

Representative, rather than extreme cases were selected to ensure that the outcomes from the study might be more informative and applicable to other parents with mild to moderate LD across the Local Authority (LA) and possibly, through the process of theoretical generalisation, to other parents in other LAs. In contrast, if a purely random selection of cases had been chosen, the findings could become of limited relevance to anything beyond the parameters of each case itself, unless a considerably larger sample had been used, which might have compromised the depth and quality of research findings. Also, it is argued that a study based on a non-representative sample has limited external validity (Gerring, 2007). The purposive sampling criteria for participation in this study required participants who:

- resided in Newtown;
- were over the age of 18 years;
- were a parent;
- lived independently;
- were accessing a support service such as OfL (pseudonym for a voluntary sector organisation which supports adults with LD) or Social Services;

- described themselves as having mild learning difficulties, for example, they required support to live independently and face difficulties in numeracy and literacy and sustaining education or work (DoH, 2001:14);
- had attended a special school, special classes in a mainstream school or had extra support in mainstream classes when they were younger;
- were not affected by any known additional confounding variables such as on-going court proceedings; and
- met ethical criteria presented (see section 4.8.1); for example, there were no concerns regarding mental capacity to take part in the study.

I identified potential cases through discussions with colleagues at Newtown Inclusion Support Services and through discussion with a voluntary sector advocacy agency, OfL[3]. Potential participants were initially contacted by a worker who had a working relationship with the family. The worker was asked to explain the remit of the study using an accessible information sheet (see Appendix Three) 12 potential participants were identified as meeting criteria, 11 female, 1 male, all of whom agreed to take part in the study (see Appendix Four). Through discussion with workers who had identified participants and a review of file notes, it was considered that two cases were not representative of the wider LD population on the grounds that the parent may have recently faced some personal difficulty, such as a bereavement or redundancy or that they were known to have acted aggressively towards professionals in the past, and should therefore not be included in the research sample.

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[3] Pseudonym

I identified four ‗representative' cases for interview (see Table 4.4 for a schematic overview of the sample selected).

Pseudonym	**Background information**
Parent One (P1)	• Male • 49 years old • British • English as first language • Married (to parent Two) and living with partner • One son who is 9 years old • Lives independently • Attended a special school for moderate learning difficulties • Lived in Newtown for whole life
Parent Two (P2)	• Female • 47 years old • British • English as first language • Married (to Parent One) and living with partner • One son who is 9 years old • Lives independently • Attended a special school for moderate learning difficulties • Lived in Newtown for whole life
Parent Three (P3)	• Female • 27 years old • British • English as first language • Married and living with partner • Three daughters, aged 13, 7 and 3, 7 year old daughter has statement of special educational needs and attends an SEBD provision in Newtown • Lives independently • Attended a special school for moderate learning difficulties, she did not complete compulsory education and left school at 14 years old • Lived in Newtown for whole life
Parent Four (P4)	• Female • 31 years old • British • English as first language • Living with partner, not father of her child • One son who is 8 years old, natural father has passed away • Lives independently • Attended a special school for moderate learning difficulties. Did not complete compulsory education and left school at 13 years old • Lived in Newtown for whole life

Table 4.4: Overview of sample selected

I selected a married couple, one of whom was a male with LD, whose inclusion was considered particularly important because past research has focussed almost exclusively on mothers (Traustadóttir and Sigurjónsdóttir, 2010): this was a valuable opportunity to gain a father‘s perspective. Also, previous research had focussed largely on single parent families (Traustadóttir and Sigurjónsdóttir, 2010): thus, I considered that seeking the views of a married couple would address these limitations. The first couple who had been identified for involvement in this study, faced some personal difficulties and were, in the event, reluctant to be interviewed. After scheduling two interviews and being asked to come back for a third time, I took this as an indication of their desire to withdraw from the study, which was later confirmed by them. I also selected two of five unmarried mothers identified as meeting the criteria for interview. The first of these did not answer the door or her telephone when I arrived for interview on two occasions, which I took as an indication of her desire to withdraw from the study. I then selected a further mother from the three remaining potential participants. My final cases comprised one married couple (mother and father), and two single mothers.

When working within a CR framework and selecting cases for investigation, it is important to outline boundaries. –Case studies provide a detailed description of a specific temporal and spatial boundary. Attending to place and time brings context to the structures and relationships that are of interest” (Merriam, 1988, p. 45). This study is spatially bound within one LA with its established practices. This boundary enabled me to develop specific hypotheses by demarcating what is internal and external to the cases studied.

Finally, Yin (2009) proposed that case studies can be either holistic, providing a global, overarching view of a case, or embedded, describing two or more specific foci, in addition to a global view” (p. 34). An embedded design was chosen for this study, with the foci being the experiences of parents with LD of local support services and their views on how delivery of support may be facilitated. Figure 4.1, below illustrates the relationship between each case, the context and the foci.

Figure 4.1: Illustration of the case study, its context and embedded units

4.6 Trustworthiness

Robson (2002) describes case study as "…a strategy for doing research which involves an empirical investigation of a particular contemporary phenomenon…" (p. 178). The word 'empirical', which Robson uses, refers to a rigorous form of systematic, scientific enquiry” (p. 178). It is argued that whilst qualitative research ‗uses a naturalistic approach that seeks to understand phenomena in context-specific settings” (p. 178) or "real world setting [where] the researcher does not attempt to manipulate the phenomenon of interest" (Patton, 2001, p. 39). Case study still involves a degree of ‗rigour requires data collection and analysis procedures to be selected with care and the reasons for their use justified. By doing this, the case study researcher is able to address issues of reliability and validity, not in the positivist sense, which would require standardisation of procedure” (Patton, 2001, p. 39) and an objective or neutral stance on the part of the researcher, but in a realist sense, by making processes explicit and acknowledging the researcher‘s involvement in the research process.

Both qualitative and quantitative research must demonstrate credibility (Golafshani, 2003). However, the credibility of quantitative research usually depends on the design of the research and its instruments and tools, whilst the ‗credibility of qualitative research depends on the ability and effort of the researcher” (Patton, 2001 p. 43).

Reliability is usually a concept aligned with *testing* or *evaluating* quantitative data (Golafshani, 2003) and in the traditional positivist sense, reliability has often been aligned with replication and deduction. Working from a critical realist position, I was more interested in producing a defensible causal explanation as a basis for the reliability or trustworthiness of this present study. I would argue that the most valuable form of ‗testing‘ for qualitative research is *quality*, whereby, a good qualitative study can help us —understand a situation that would otherwise be enigmatic or confusing" (Eisner, 1991, p. 58). Patton (2001) agrees that in qualitative research, trustworthiness is determined by the researcher's ability and skill. I will now consider the validity or trustworthiness of this study.

—If the validity or trustworthiness can be maximized or tested, then more credible and defensible results may lead to generalisability" (Johnson, 1997, p. 283). This is one of the features suggested by Stenbacka (2001) as the framework for conducting and recording high quality qualitative research. Yin (2009) proposes that case study research is open to criticism due to difficulties with asserting validity, and advises case study researchers to give judicious thought to three measures of validity; *construct validity, internal validity* and *external validity*. I will now consider these in turn.

Construct validity refers to whether the theory presented by the study provides an extensive and precise description of reality (Yin, 2009). In order to address this type of validity, I shared findings with participants, requesting feedback relating to accuracy (see Appendix Nine). Lincoln and Guba (1985; 2000) describe this type of ‗member checking' as —the most crucial technique for establishing credibility" (p. 314); it is an approach used in a wealth of research to strengthen trustworthiness (Cho & Trent, 2006).

Internal validity —seeks to demonstrate that the explanation of a particular event, issue or set of data which a piece of research provides can actually be sustained by the data" (Cohen et al., 2007, p. 135). To address this type of validity, a reproducible and well-documented research procedure was used to guide the research process (see Sections 4.8.2 *Procedure* and 4.8.4 for *Interview procedure*). Also, the data analysis method chosen was systematic thematic analysis; data analysis was reviewed by a second researcher and discussed (see below for more details on triangulation).

External validity ~~r~~efers to the degree to which the results can be generalised to the wider population, cases or situations" (Cohen et al., 2007, p. 136). This type of validity refers to the issue of generalisation, which is discussed in detail in section 4.7.

Triangulation is an accepted means of improving the trustworthiness of research (Mathison, 1988). Triangulation in social science research ~~r~~efers to a process by which a researcher wants to verify a finding by showing that independent measures of it agree with or, at least, do not contradict it" (Miles and Huberman, 1994, p. 146).

Miles and Huberman (1994, p. 214) distinguished four kinds of triangulation in qualitative research:

- ~~tr~~iangulation by method (observation, interviews, documents, etc.);
- triangulation by data source (data collected from different persons, or at different times, or from different places);

- triangulation by researcher (comparable to inter-rater reliability in quantitative methods); and
- triangulation by data type (e.g., combining quantitative and qualitative data)."

The type of triangulation chosen depends on the purpose of a study. The purpose of the present study was to develop an understanding of the lived experiences of parents with LD and to consider their views and experiences of local support services.

To achieve this, triangulation by method and data type were not considered applicable, because interviews were considered to be the most appropriate method of data collection (see section 4.8.3). Triangulation by data source was not applicable to this study because the purpose was to understand the experiences of parents with LD from their unique perspective alone. Triangulation by researcher was considered and applied to the present study. This is an approach used in a number of studies which applied thematic analysis to their data (Baum et al., 2006; Campbell et al., 2007; Hesketh et al.,2005; Kegler et al., 2009). To conduct this type of triangulation, I coded the data and abstracted themes from the data corpus. A second researcher, my research supervisor, then independently reviewed the data and confirmed the themes, with discrepancies in coding resolved through discussion; as described in section 4.7).

4.7 Generalisation and utility

A frequently cited criticism of case study methodology is its dependence on a single case causes it to be incapable of yielding outcomes which can be satisfactorily generalised (Tellis, 2007). However, it can be argued that case study research does not intend to provide universally generalisable findings in the positivist sense (Donmoyer, 1990; Guba & Lincoln, 1981; Schofield, 1990). As a critical realist, I would defend Lincoln and Guba‘s (2002) position that —It's far easier, and more epistemologically sound, simply to give up on the idea of generalization. If the generalizations are accepted, they should be...indeterminate, relative and time and context-bound." Like predictions, generalizations should be recognized as context-specific; as a result, generalisations require continuous updating as contexts change (Cronbach, 1975).

However, it is possible to make two kinds of generalisation, -generalisation to populations and generalisation to theory" (Walsham, 1995 p. 384; Sharp, 1998). Generalisation to populations is rooted firmly in positivist epistemology and involves providing evidence that the case being referred to is representative of the population from which it is taken. Thus, case study methodology is often viewed as "microscopic" because it lacks an adequate number of cases (Yin, 1993). The aim of the study should be to determine the parameters within which its findings will be applicable; in this way, -even a single case could be considered acceptable, provided it met the established objectives of the study" (Yin, 1994 p. 31). Yin (1994) further suggests that -generalization of results, from either single or multiple designs, is made to theory and not to populations" (p. 31) because sample size, whether 2 or 200, does not transform a microscopic study into a macroscopic study.

Lincoln and Guba (2002) have proposed the notion of a *working hypothesis* to encapsulate the notion that, despite there being no —true" generalization; case study researchers can cautiously apply hypotheses within certain conditions and circumstances. Thus, hypotheses can be produced from either a single case or multiple cases. Based on this concept, this exploratory case study develops a tentative theory of practice in relation to the support received by parents with LD, and how such support might be facilitated within one local authority, and, based on this, provides knowledge for the consideration of services which support parents with LD in this Local Authority. The aim of the study is not to generate data that are generalisable to a much larger population, but rather to enrich understanding of local issues in order to inform local solutions. As a result, the benefits of a qualitative case study approach were judged to exceed the benefits of the experimental method or survey. In addition, the multiple case study method, as described by Yin (2009) allows enough flexibility for emerging themes from each participant to be further explored within each interview and as well as between cases.

The current case study design has similarities with the design described by Wikeley et al., (2007), whereby, some theoretical comparisons were made in analysis through a comparison of the three studies' results.

Discovering similarities across case studies or translatability is ―the degree to which one case study‘s findings can fit other cases” (Goetz & LeCompte, 1984, p. 2). Thus, through the use of precise descriptions of cases, if findings are consistent across studies, their findings may be translated across case contexts to generate and test hypotheses, so contributing to the legitimate theoretical generalisation of findings. Hence, although to generalise findings and their applicability to other contexts was not a primary objective of the current study, it is argued that, through the process of theoretical generalisation, it is legitimate to consider their applicability within other, similar settings.

4.8 Method

4.8.1 Ethical considerations

The primary ethical considerations addressed here relate to the interview procedure. A full account of ethical considerations is provided in the University of Birmingham Application for Ethical Review (AER) form (see excerpts in Appendix Five). The most salient considerations and the steps taken to address these are summarised below.

The Economic and Social Research Council framework (2010) suggests that in cases where research involves potentially ―vulnerable groups such as children, older persons or adults with LD, every effort should be made to secure actively and freely given, informed consent from individual participants” (p. 4). The importance of ensuring individuals with LD are supported in developing a full and accurate understanding of their participation in research has been highlighted by many researchers (Arscott et al., 1998; Porter & Lacey, 2005; Lacey, 2010).

In order to achieve this, guidance was sought from experienced researchers in this area within the university. Through such discussion and reference to approaches used in previous studies (Lacey, 2009; OfL[4], 2011) I was able to develop an accessible information sheet for participants and an accessible consent form (see Appendices Three and Six). Short sentences with simple language were used, with accompanying pictures where appropriate, as suggested by Lacey (2009). The content of these forms is closely aligned with the specification for ‗fully informed consent‘ given by the British Educational Research Association (BERA) (2004) and the British Psychological Society (BPS) (2011).

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[4] pseudonym for a voluntary sector organisation which supports adults with LD.

4.8.2 Procedure

To manage the complexities inherent in planning and conducting qualitative research, a four-stage model devised by Cohen et al., (2007) was applied. Table 4.5 presents the process as applied to this research.

Stage	**Timescale and Outcomes**
1: identify the purposes of the research	**Late September 2010:** • Purpose identified: To explore the views of parents with LD, to inform practice of local support services. **October 2010:** • Research questions refined. **November 2010:** • Research proposal produced by Trainee Educational Psychologist (TEP) and shared with Principal Educational Psychologist (PEP) and supervising tutor.
2: identify and give priority to the constraints under which the research will take place.	**December 2010:** • Telephone discussion with OfL, Newtown adult support services and social services to introduce research idea. **January 2011:** • identifying key stakeholders in the research; the PEP and OfL **February 2011:** • meeting with PEP and OfL to discuss research brief. **March 2011:** • Meeting with an experienced researcher and acknowledged expert within the field of learning disabilities and related research to contribute to Application for Ethical Review (AER). • AER submitted. **May 2011:** •AER • Proposed timeline for research agreed with supervising tutor.
3: plan the possibilities for the research within the constraints	**June-July 2011:** • Literature review undertaken. • Critical policy review undertaken. **August – September** • Meeting with PEP and tutor, semi-structured individual interviews were selected as the method of data gathering

4: Design	**October 2011:** •Development of research method and tools • Meeting with researchers at university to develop accessibility of interview questions, consent forms and information sheets. • Consultation with OfL to pilot and obtain feedback on its accessibility and suitability (see Appendix Seven). **November 2011:** • Participants identified with OfL. Selection based on selection criteria outlined in Section 4.5. •Participants contacted by key workers; consent gained. **December 2011:** • Data collection completed.

Table 4.5: Research sequence

4.8.3 Data collection: semi-structured interview

This study aimed to explore the experiences of being a parent with LD. Semi-structured interviews were used to gather information. The reason for using qualitative interviews in this study was that this method was considered ‗fit for purpose‘, in the sense that it afforded a flexible interpersonal framework within which to support participants in sharing with me the complexity and context of the real world setting within which each parent with LD lived and her/his experience as a parent, whilst addressing the research questions.

Although focus groups were considered, I believed that this approach might disadvantage quieter, less confident adults and compromise the confidentiality of information provided by parents. Also, because focus groups are reliant upon the language skills of the participants involved, I considered the approach unsuitable for my target sample. The option for a structured interview was rejected on the grounds that it would be inherently rigid and inflexible (Cohen et al., 2007); semi-structured interviews offered me, the researcher, the possibility of differentiating the wording of questions, using visual aids and changing the order of questions in response to the needs, feelings, responses and cognitive and communicative capacity of individual respondents.

The themes for exploration during the semi-structured interview and subsequent questions and prompts were developed, building upon the critical literature and policy review. A pilot procedure was conducted; the interview questions (see Appendix Seven) were shared with staff from OfL, who offered feedback on their accessibility and suitability so that questions would be compatible with parent‘s projected range of understanding and skills.

Table 4.6 describes the semi-structured interview schedule; it demonstrated how the questions link to the research questions and presents the associated rationale for question choice, aligned with the concluding synthesis presented in Section 3.7 of the Literature Review. Appendix Eight provides photographs of the resources used during interview.

Research questions and interview questions	**Supporting rationale behind question and theme selection:**
Research Question One: How do parents with LD perceive communication with support service professionals? 1. Did anyone give you information about becoming a parent? 2. Did you know what to expect? 3. Do you go to many meetings at school? What are they like? 4. Do you know why services are involved with your family? 5. Do you understand everything they tell you? 6. Do you feel like people listen to you? 7. Are you in charge of what happens to you and your family?	*The Lamb Inquiry* (DCSF, 2009)*:* a key finding of this report was that parents feel that ‗good, honest and open communication‘ is one of the most important components of building confidence and good relationships. In light of this, I aimed to explore the views of parents with LD and their experiences of the current support systems currently in place, particularly how good, open and honest they are from their perspective. My second aim was to explore the extent to which parents with LD feel their rights are met and how accessible information and support is for them. I was interested in how parents considered their relationship with support service professionals, for example, whether they believed they were listened to. *Good Practice Guidance on Working with Parents with a Learning Disability (2007)* highlights five key features of good practice when working with parents with LD: accessible information and communication; clear and co-ordinated referral and assessment procedures and processes; support designed to meet the needs of parents and children based on assessments of their needs and strengths; long-term support where necessary; and access to independent advocacy. Local authorities have a responsibility to ―let families know how to contact them and what they might expect by way of help, advice and services" (HM Government, 2005, p.79). I was interested to explore whether parents with LD were aware of the support available to them and what types of support they were accessing, along with the factors which facilitated or hindered their access.

Research Question Two: How do Parents with LD report that they are supported to meet their children’s needs? 1. When you found out you were having a child, how did you feel? Who supported you? 2. Were there any support groups you went to? Or were asked to go to? 3. What is good about being a parent? 4. What is hard about being a parent? 5. Who helps you? Or Who do you ask for help? 6. Are there things you would like more help with right now for your children? 7. Are you happy with the support you get for your child? 8. When you need help for your child, where do you go?	The research indicates that parents with LD are less likely to receive appropriate support with parenting before and after child protection authorities intervene but are at higher risk of having their children taken into care (Booth et al., 2005; McConnell et al., 2006). Within the current study, I aimed to ask parents about their own experiences of support when becoming a parent and during early stages of parenting, where parenting programmes are thought to have the most impact, (Coren et al., 2011). I wanted to explore whether they were able to access such support and factors which facilitated or hindered their engagement with such support. In their *Seventh Report* in 2008, The Joint Select Committee on Human Rights highlighted the assertion that children of parents with LD have the right to live in a safe and supportive environment. In relation to the developmental stages described, ~~c~~hildren‘s chances of achieving optimal outcomes will depend on their parents‘ capacities to respond appropriately to their needs at different stages of their lives” (DoH, 2009, p. 128). In this current study, I was interested to explore the extent which parents with LD considered the needs of their children to be met through the support they were receiving. Whether they could identify stages in their children‘s lives or developmental tasks where they perceived they needed help and whether they were able to access this successfully.
Research Questions Three and Four: What are some of the barriers to parents with LD receiving support? How may these barriers be overcome? 1. Which Support Services do you use? How long for?	Parent and child intervention studies from as early as the 1980s have shown that the risk of poor outcomes for children of parents with LD can be reduced with appropriate support and services (McConnell et al., 2008). Experimental and quasi-experimental trials have demonstrated the efficacy of parenting programs when designed specifically for parents with intellectual disabilities. Studies have demonstrated positive gains across an array of parenting skills (e.g., Tymchuk, 1990; Tymchuk et al., 1992; Tymchuk et al., 1990).

2. Has anything ever stopped you from asking for help? 3. Do you have a key worker for your family? 4. Do you know why services are involved with your family? 5. How would you rate the support you have had? 6. What do they help you with? 7. Do you trust them? 8. Can you challenge them? 9. How would you describe them? 10. How can they be made better?	The quality of support often makes the difference between whether children remain in the family home or are taken into care (Booth & Booth, 1996). I aimed to explore what parents considered to be the quality of support they had received from professionals and what factors influenced their views. International research shows that many parents with LD are hesitant to ask for help and afraid to receive services, while others refuse to engage with support offered (Traustadóttir and Sigurjónsdóttir, 2010). Parents with LD often receive services from a variety of agencies, and parents do not always agree with the advice they are given. As part of the present study, I hoped to explore the extent to which parents with LD have engaged with services and whether their engagement has been facilitated or hindered by the way they consider professionals to perceive them for example, or they have refused to engage due to a difference of opinion from service professionals and how this has impacted their access to support.
Research Question Five: What positive experiences of support services do parents with LD describe? 1. Did anyone help you find your home? 2. Did anyone help you find a job? 3. Are you in charge of what happens to you and your family? 4. Do you feel like people listen to you? 5. Are you able to live a normal life?	*Valuing People* (2001) and *Valuing People Now* (2009) aim to ensure that all people with LD are provided with the support they need to lead their lives as fully as possible, to engage in the same opportunities and take on the same responsibilities as everyone else, have their rights met and be treated with dignity and respect. In order to achieve this, *Valuing People Now* recommends person centred planning, advocacy and support to give people more choice, independence and control in their lives. However, *The Joint Committee on Human Rights* published their *Seventh Report* in 2008 conducted an inquiry into the rights of parents with LD. The committee suggested there was a significant gap between the aims of *Valuing People* and the experience of adults with LD.

Table 4.6: Interview Schedule and supporting rationale

4.8.4 Interview procedure

Interviews were held at participants‘ homes. I began by reviewing the information sheet (see Appendix Three) with them (which had been discussed with them previously by a key worker). I then discussed the consent form with them (see Appendix Six). After gaining their consent I began the interview. By drawing on previous research conducted by OfL (2007) in Newtown, I put in place the following practical and procedural arrangements to facilitate the success of interview:

- All written information was presented in accessible formats (see Appendices Three, Six and Eight for information sheet, consent form and interview questions); Suitable simple language without jargon was used.
- Prior to interview, participants were telephoned to remind them of timings.
- As noted above, interviews were held at parents homes; although had they so wished, alternative arrangements would have been made.
- Each session began with background questions to build rapport, such as ‗how long have you lived in Newtown for?‘ and ‗what school did you go to?‘
- The pace was appropriate, and through a pilot procedure, the interview questions were pitched to fall within parents‘ projected range of understanding.
- Careful facilitation and questioning were used to overcome any tendency for interviewees to respond compliantly.

- Acknowledgment and praise were given to those who participated, by thanking them, and they were told they would be given a readable version of the final report (see Appendix Nine for this report).

Three interviews (involving four participants) were completed, each lasting between 30 and 45 minutes. A married couple (mother and father) were interviewed together, at their request. An option was provided to be interviewed separately; however, both parents stated a preference to be interviewed together. Steps were taken to ensure that parents had an independent voice, for example, they were prompted to answer each question individually and their responses were coded separately.

Each interview was recorded using a Dictaphone. Questions and prompts sheets for the interviews are included in Appendix Eight.

4.8.5 Minimising threats to trustworthiness

Having elected to explore parents' views through a qualitative interview study, I was aware of the limitations associated with this approach (Silverman, 1993; Cohen et al, 2000; Robson, 2002; Kvale, 2007) and the contingent need to control for threats to trustworthiness at all stages of the interview study (Kvale, 2007) within a critical realist paradigm. Below, I have outlined four of the key potential sources of bias that have been highlighted in the literature (Oppenheim, 1992; Scheurich, 1995; Cohen et al., 2000), including issues which are particularly pertinent when interviewing parents with LD (Porter & Lacey, 2005; Lewis, 2002), and give information about how these factors were addressed within the interviews.

1. **"Misperceptions on the part of the interviewer of what the respondent is saying." (Cohen et al., 2000. p.150)**

   To minimise risk of this type of bias, as part of the interviews, I attempted to clarify and confirm the meaning of interviewees' statements and verify any interpretations and inferences with the interviewees themselves. Silverman (1993) terms this practice ‗respondent validation'.

2. **"A tendency for the interviewer to seek answers that support their preconceived notions." (Cohen et al., 2000. p.150)**

This was minimised through approaching each interview with genuine curiosity as opposed to aiming to test out particular hypotheses or theories; using active listening techniques within the interviews; being conscious of her or his verbal and non-verbal responses; and attempting to remain neutral at all times.

3. **"Misconceptions on the part of the respondent of what is being asked." (Cohen et al., 2000. p.150)**

Prior to the interviews I had sought guidance from experienced researchers with parents with LD and a caseworker from an advocacy agency who works with parents with LD on a daily basis. This resulted in simplifying language used and devising visual prompts (see Appendix Eight) to make questions as accessible as possible to interviewees.

4. **“Poor rapport between interviewer and interviewee.” (Oppenheim, 1992. p. 96-97)**

To minimise risk in this area, I introduced myself to the parents prior to the interviews and shared the research information sheet. I began each interview with a general -chat” about the area and the respondent/family. Also the verification of inferences during interviews (respondent validation) helped to demonstrate to the interviewees that I was attending to, and interested in their views.

A further potential threat is raised by Porter and Lacey (2005) who highlight the potential power imbalance in interview situations involving parents with LD. I took steps to minimise this imbalance by:

- informing parents of their right to refuse or withdraw their participation;
- explaining that I did not work for the any agency which could affect their access to funding or support;
- inviting parents to address me using my first name;
- informing parents that their views were highly valued; and
- thanking them for their contribution to the study.

In interviews where there is a perceived power differential by the interviewee, there is often a heightened risk of ‗acquiescence‘ (Breakwell, 2000. p. 54) or tendency for respondents to confirm what is put to them regardless of what they feel or think. I used judicious repetition and rewording of questions at different points during each interview as a way of checking for consistency and authenticity within each parent‘s unfolding narrative.

In order to defend this work against the 'anything goes' criticism often invoked in relation to qualitative research (Antaki et al., 2002), Attride-Stirling (2001) states that qualitative researchers should include an account of the all-too-often omitted account of how they conducted their analysis of data within their reports. To demonstrate how I moved from the raw interview data to the themes and findings presented in Chapter 5, Section 4.8.6 aims to illustrate the analytical approach taken.

4.8.6 The thematic analysis process

For this study Thematic Analysis (TA) was chosen as it offers an approach to data analysis that is flexible and congruent with critical realism and the use of semi-structured interview data (Boyatzis, 1998; Braun & Clarke 2006). The term is sometimes criticised as ―lacking specificity and as being used by researchers as a label for an unsystematic and informal analysis of data" (Boyatzis, 1998; Braun & Clarke 2006 p. 92). To overcome this criticism an inductive form of TA was undertaken using the procedure described by Braun and Clarke (2006). Inductive analysis is described by Patton (1990) as a ‗data-driven,‘ process of coding data without the use of pre-existing coding frames.

Braun and Clarke (2006) summarise thematic analysis as ‗searching across a data set… to find repeated patterns of meaning‘ (p.86). Whilst they are careful to emphasise that decisions about what constitutes a theme are ultimately a result of researcher judgement, they do provide guidelines for conducting a rigorous thematic analysis, structured around a six phase process. The six stages of this process are outlined below in Table 4.7.

Phase	Description
i. Familiarising myself with the data	Lapadat and Lindsay (1999) suggest using transcription as an active, as opposed to passive process. I used this as the first step in transforming the raw data into useable information. Data were transcribed for content only. All verbal utterances were recorded verbatim, including non-word sounds, such as ‗um‘ and ‗er‘ and coughing and laughing. Pauses were recorded as ‗...‘, regardless of length. Words that were unclear were recorded as ‗xxx‘. Also, interruptions or changes to conversation mid-word were recorded as ‗-‗. Transcriptions of the interviews were made to word-processed electronic documents and were both preceded and followed by listening to the audio transcript, to check for accuracy and to increase familiarity with the data (transcribed interviews, are included in Appendix Ten).
ii. Generating initial codes	Once transcribed, the interview transcripts were then coded. Codes were applied to interview extracts and related solely to verbal content. At this stage, codes were applied to each individual interview; no attempt was made at this stage to identify themes recurring across the data. All extracts within the data sets relating to support services were coded, see Appendix Ten.
iii. Searching for themes	Once the three interviews were coded, I began to search for themes within individual interviews by identifying patterns and similarities across coded extracts in transcripts using coloured highlighters (see Appendix Ten, column two where initial codes are coloured in each interview). After three cycles of this process, the coded extracts from all three interviews were brought together and organised into theme-areas that occurred across all three data sets. I built a tentative list of themes in the form of a visual thematic map (see Appendix Eleven) for each interview.

iv. Reviewing themes	This phase was conducted in two parts. Part one, involved reviewing all coded extracts and initial codes. New codes were identified and linked to themes identified in phase three and codes which were not previously linked to themes in phase three were linked to a theme, or discarded. Any new coded extracts were added to the initial thematic map to form a second thematic map (see Appendix Twelve). Part two of this phase involved a process of revision, during which the number, names and breadth of each theme was refined and a third thematic map was created (see Appendix Thirteen). The aim of this phase was to achieve a collection of themes and subthemes that represented the data.
v. Defining and naming themes	After refining themes, I referred back to the data extracts for each theme and collated these under each theme heading, along with a narrative account (see Appendix Fourteen). Collating thematically-linked data extracts allowed me to gain a better ‗feel‘ for essence of each theme and to therefore define it more clearly. The data extracts were then organised into subthemes, which were also defined and labelled more clearly. It was at this stage that I decided upon the final name for each identified theme and finalised my thematic maps (Appendix Fifteen).
vi. Producing the report	This stage involved the final analysis and write-up of the report, presented in the Chapter Five of this paper.

Table 4.7: Braun and Clarke‘s (2006) phases of thematic analysis and steps undertaken by the researcher

The key questions that I considered throughout the analytic process to promote trustworthiness, as I moved systematically through each stage of data analysis, are outlined below:

What is considered a theme?

A theme is described as —capturing something important about the data in relation to the research question and represents some type of patterned response or meaning within the data set" (Braun and Clarke, 2006, p. 82). There is no clear agreement about what constitutes a theme; however, the process tends to be based upon two concepts: recurrence and importance (Buetow, 2010). Braun and Clarke (2006) highlight the role of researcher judgement in defining themes and emphasise the need to be flexible and consistent throughout analysis.

I adopted a critically reflective process of preliminary data analysis. I coded the data and developed themes, and a second researcher independently reviewed the data and confirmed the themes, with discussion and agreement reached in the small number of cases, the second researcher suggested alternatives. For example, she suggested the following:

- combining sub-themes which had significant similarity or over-lap in relation to supporting extracts;

- omitting themes which had limited or tentative supporting evidence from the data; and
- providing more contextual information to render quotations meaningful to readers.

Inductive or deductive data analysis?

-An inductive approach means the themes identified are strongly linked to the data themselves and not driven by the researcher‘s theoretical interest in the area or topic” (Patton, 1990, p. 95). Therefore, inductive analysis is a way of coding data without attempting to reduce them into pre-existing coding frames. A deductive approach is more theory-driven. A deductive approach to analysis -tends to provide a less rich description of the data overall and more a detailed analysis of some aspect of the data” (Braun & Clarke, 2006, p. 82).

A combination of inductive and deductive approaches was applied to this study. The initial inductive approach meant that that data were collected and then analysed to see what themes emerged through a process of reading and re-reading the interview transcripts, taking a _bottom up‘ approach towards the analysis. In a second phase of analysis I looked at my data again deductively, reflecting on previous research findings on the topic. The interview questions were based on previous research findings, so bringing a deductive/a priori frame to the data that would be collected.

Semantic or latent analysis?

Thematic analysis can focus on a ~~se~~mantic or explicit level or at a latent or interpretative level” (Boyatzis, 1998. p. 45). A semantic approach is where themes are detected at the surface level of the data and the researcher does not try to abstract information from beyond what the participant has said.

This study involved a progression from description, where the data were organised and summarised to show semantic content, to analytic interpretation, where I began to develop theories as to the significance of relationships within the data and their wider interpretations and implications in relation to previous literature: an approach suggested by Patton (1990).

Braun and Clarke (2006, p.96) generated a 15 –point checklist of criteria for good thematic analysis, which was used to guide the analytic process. The checklist is presented in Table 4.8.

Process	**No**	**Criteria**	**Criteria met through**
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for ‗accuracy‘.	I transcribed interviews and checked transcriptions against the recordings.
Initial coding	2	Each data item has been given equal attention in the coding process.	Each interview was coded on a different day, allowing for assimilation and reflection between each stage of analysis.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.	During Phase 5., every coded extract was reviewed and examples which captured the essence of codes were included. Often, more than one example for each code was included.
	4	All relevant extracts for all each theme have been collated.	See Appendix Fourteen, in Phase 5 all extracts were collated.
	5	Themes have been checked against each other and back to the original data set.	Several cycles of my data analysis involved re-checking themes against the original data set.
	6	Themes are internally coherent, consistent, and distinctive.	Through checking themes against the original data set, consistency was ensured.
Analysis	7	Data have been analysed – interpreted, made sense of – rather than just paraphrased or described.	Phase 5 involved several cycles to help move beyond the semantic level. See Appendix Fourteen, for reflections on the data.
	8	Analysis and data match each other- the extracts illustrate the analytic claims.	This involved a process of moving back and forth between themes, coded extracts and the original data set.
	9	Analysis tells a convincing and well-organized story about the data and topic.	See Chapter 5.

	10	A good balance between analytic narrative and illustrative extracts is provided.	See Chapter 5.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.	I planned my study time so that analysis took place in small blocks over a period of time to allow enough time to immerse myself in the data. This also allowed me to reflect over a period of time.
	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.	As recommended by Braun & Clarke (2006) I looked at examples of thematic analysis conducted by other researchers for ideas on questions to ask throughout the process (see Table 4.7) and to ensure I had a clear understanding of the process overall. My approach is described in detail in this table
	13	There is a good fit between what you claim you do and what you show you have done- i.e., described method and reported analysis are consistent.	I wrote my method section, particularly Table 4.7, whilst I was conducting my analysis to provide a clear account or log of what I was doing.
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis.	My aim was to ensure there is evidence of this throughout this research report
	15	The researcher is positioned as active in the research process; themes do not just ‗emerge‘.	I was aware of the way in which a researcher can become passive during the analysis of interview data and I strove to overcome this by a continual process of reflection (see Appendix Fourteen) throughout data analysis.

Table 4.8: 15 –point checklist of criteria for good thematic analysis (Braun & Clarke, 2006, p.96)

4.9 Interpretation and reporting of findings

As suggested by Braun and Clarke (2006) the interpretation of the findings takes place once a thematic map is finalised. In order to guide the analysis, Braun and Clarke (2006) encourage the researcher to go beyond the semantic or surface level of the data and ask questions such as —what does this theme mean?”, “What are the assumptions underpinning it?”, “What are the implications of this theme?”, –What conditions are likely to have given rise to it?”, –Why do people talk about this thing in this particular way (as opposed to other ways)?” or –What is the overall story the different themes reveal about the topic?”. By asking these questions a story emerged that related to my initial research questions, as well as to my integrated conceptual framework.

In the next chapter I report and discuss my findings. Evidence for each theme is presented in the form of data extracts from individual interview transcripts in order to strengthen the transparency and validity of the report. After the themes have been presented, I consider the findings in relation to my integrated conceptual framework. In Chapter 5 and the concluding chapter (Chapter 6) I aim to move beyond description to provide an analytic narrative that links the research themes with the research questions, explores themes, drawing on the literature outlined in Chapters 2 and 3, and develop arguments in relation to the research questions. I also consider how the findings of this study may contribute to conceptual and theoretical generalisation and make an original contribution to knowledge.

Chapter Five

Results and Discussion

5.1 Introduction

Braun and Clarke (2006) suggest that Phase 6 of data analysis begins when a researcher has abstracted a set of fully worked-out themes, and involves the final analysis and write-up of the report. The aim of Phase 6 and of this chapter is to tell the complicated story of my data in a way which ensures that an authentic account of parental perspectives is presented which convinces the reader of the merit and validity of my analysis. In order to do this, I discuss the findings analytically, highlighting the most pertinent findings in relation to my research questions, by moving beyond a description of the data and making links to the literature presented in Chapters 2 and 3.

Results are presented using thematic diagrams, with reference to a thematic map produced during the thematic analysis process discussed in Section 4.8.6. The final thematic map (see Figure 5.1), presents an integrated overview of the main themes and subthemes abstracted from my analysis and the interactions between these and the research aim. Data extracts from the interviews are presented in this chapter to support each theme. The purpose of using this approach is to provide a concise and coherent account of the story that the data tell, both within and across themes.

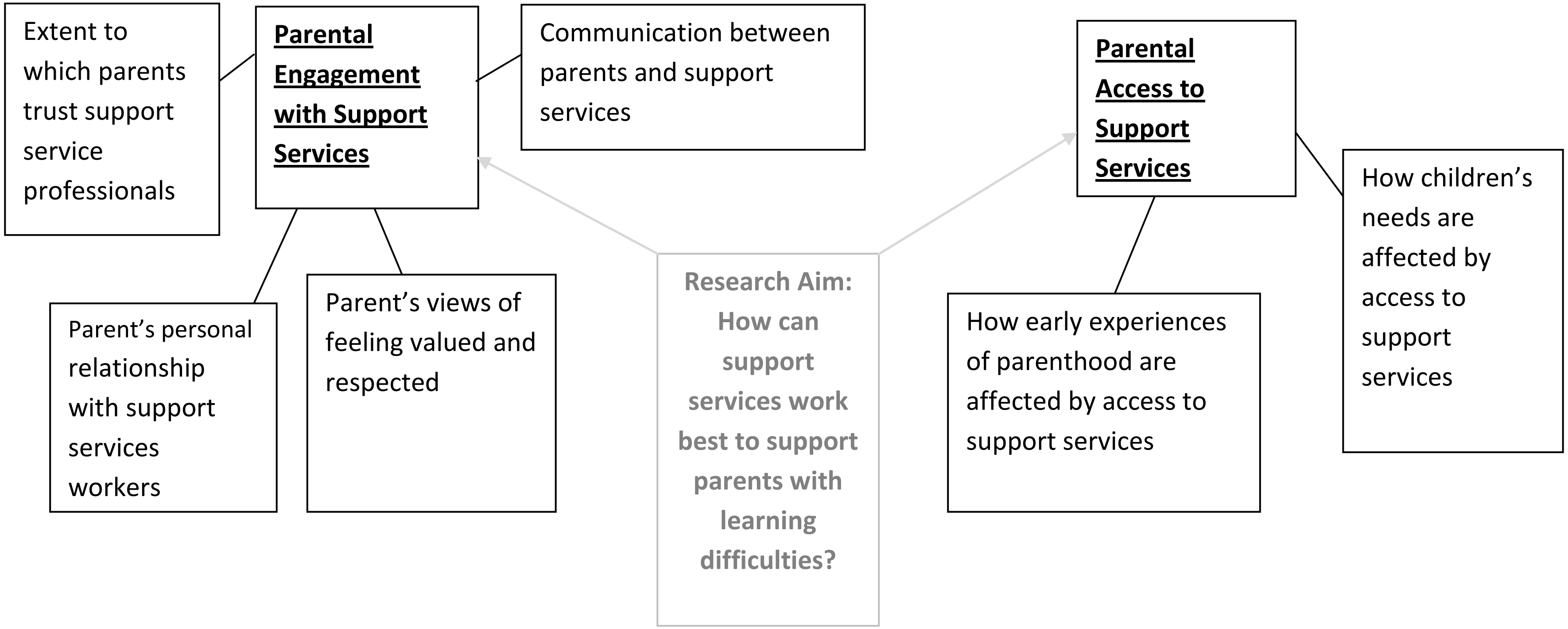

Figure 5.1: Final Thematic Map

In relation to Figure 5.1, the superordinate themes and main themes are displayed as being distinct from one another, however it is important to note that they are not wholly independent, but are inter-related in ways which will be described in more detail throughout this chapter. As a result, there will be instances where one quote from a parent may be used to illustrate several themes. The choice as to which extract to use for each theme was made in relation to its perceived saliency, or the extent to which they were deemed to offer knowledge relating to the theme. Braun and Clarke‘s (2006) approach to thematic analysis advocates a level of ambivalence on the part of the researcher when selecting extracts to support themes, which should appropriately exist in abstracting deeper meaning and determining what wider significance particular context-embedded utterances may hold, thus, this has also led to the multiple usage of some extracts.

The themes presented, address the research questions which are again presented below for ease of reference:

1. How do parents with LD perceive communication with support service professionals?
2. How do parents with LD report that they are supported to meet their children‘s needs?
3. What are some of the barriers to parents with LD receiving support?
4. In parents‘ views, how may these barriers to support be overcome?
5. What positive experiences of support services do parents with LD describe?

The findings of this report are divided into several parts. First, I provide an overview of the two superordinate themes abstracted from the data corpus. Then, the six subthemes are introduced individually, supported by data. After the superordinate theme and subthemes have been presented, I discuss the findings, highlighting the most salient points and making links with themes explicated within Chapters 2 and 3.

5.2 Superordinate theme: parental engagement with support services

5.2.1 Subtheme 1: parents' views of feeling valued and respected

The data suggested that when interacting with support service professionals, parents' experiences varied greatly. All parents largely felt supported, respected and their opinions valued by school staff, such as teachers. Also, where parents had a positive relationship, based on mutual respect with a professional, they would engage with them and ask them for support. However, parents could identify contexts in which they though their opinions were not valued, such as in multi-agency meetings at their child's school. Instead of feeling valued and respected, parents suggested that they felt blamed for the difficulties their families faced in these meetings.

All of the parents interviewed described relationships with professionals where there was little mutual respect leading to parents feeling as though professionals look down on them, they feeling ignored and as though professionals did not have time for them. Also, all parents described not being consulted in relation to decisions made about their children, in a way that was accessible to them.

Box 5.1

Illustrative examples of parents' feedback within the „Parents' views of feeling valued and respected' subtheme

Three parents described how professionals visit their home but do not follow-up with them after visits, offer them support, advice or guidance:

Below, P1 and P2 are referring to an initial visit from social services:

P2: *We haven't heard nothing from them since after that* (initial visit)

P1: *He played up the one the one day we bought him home, we take him back to school and he did play up. But...but...We ain't heard nothing since*

Below, P3 is being asked about input from social services:

SA (interviewer): Would you say they've been quite helpful?

P3: *The one has a bit, yeah, but not really...I dunno*

Three parents describe how professionals have limited time for them:

Below, P1 is referring to an appointment with child and adolescent mental health services:

P1: *We only go half hour at a time. You can't do a lot in half hour*

Below, P2 is discussing an appointment with child and adolescent mental health services:

SA: Do you think they could've offered you more help?

P2: *A bit more help I think, yeah*

SA: With what things?

P2: *Talking to M* (child)*, supporting...things like that*

P2 suggested that support was limited because the CAMHS appointment was too short.

Below, P2 is referring to multi-agency meetings held at her child‘s school:

P2: *Not that long, half an hour. So, it’s not easy*

P2: *They just shut the book, conversa.....finished now, it’s time*

This parent felt that she was unable to raise her own concerns during meetings because she was not given the time to do so.

Below, P1 is referring to multi-agency meetings held at his child‘s school:

SA (interviewer): Do you ever say can we talk about his reading and writing?

P1: *We don’t have that long*

This parent felt that he was unable to raise his concerns during meetings because he was not given the time to do so.

One parent does not ask for help as a result of previous experiences:

Below, P3 described some examples of how she needed help but states she is reluctant to ask for help because she feels that support professional do not listen to her. She describes below, how in previous meetings she had become very angry and frustrated because she felt ignored by support professionals and she wanted to avoid this happening again:

SA: What about at the meetings in school? Do you understand what they‘re all talking about?

P3: *No, no-..no, not really*

SA: Do you ask them when you don‘t understand?

P3: *Nah, I just let „em carry on...they don’t listen to me yeah, they just talking too much sometimes*

SA: They don‘t listen?

P3: *Not really, so I let „em carry on...quicker for me to get out the office or something*

SA: Why do you want to get out the office quickly?

P3: *Because I get angry, I get frustrated...and then I feel like I wanna kick off to tell you the truth*

SA: Are there any things that you would like more help with?

P3: *At the minute...to put H on the right way I think*

SA: Right...Erm...sometimes you have meetings at school about H; what are they like?

P3: *I get frustrated, angry...One time, I got up and slammed the doors...coz, I, you know, I...when I talk yeah, I have to keep repeating myself yeah to make „em understand ... if they don't reply back to me or anything yeah, I get angry*

SA: OK, you get angry because they'e not listening.

P3: *They ain't... they ain't*

Below, P3 explains further why she does not ask for help from professionals:

P3: *Coz when...you know what, to tell you the truth, when like H's been really bad, when...before she started school, no one really bothered to help me, do you understand? So really yeah, to me yeah, I think, I can do it man*

P3: *If it were up to me, I wouldn't ask for help...carry on the way I am.*

One parent feels blamed for the difficulties their child faces:

P2: *If you get it wrong in their book, the teacher will think won't they*

When asked about support for her child in school:

P2: *I'm glad this is happening. I really am, coz I was worried. He can't read and write, what'll happen? Where can he go? Nobody'll have him. Kids'll take the mick if he can't read and write when he's 12. What's gone wrong? They blame the parents. Don't they? I'm glad the teacher realised he can't read and write. I'm glad some people are helping now. He's 9 now still the same.*

P2 appeared to be very anxious about professionals blaming her for her child‘s difficulties. She mentioned it a few times throughout interview.

All parents report feeling valued and respected enough to ask for help from school staff and professionals they have a positive relationship with:

Below, P3 talks about her family worker with whom she has a positive relationship:

SA: Has anything ever stopped you for asking them for help?

P3: *No, because I just tell „em if I need help*

P3: *I do challenge her (key worker)*

When asked what she does when school staff say things she does not understand:

P3: *No, I ask „em and ask „em til I understand*

SA: Are you happy with the support you get from school?

P4: *Yeah, they...alright, yeah*

SA: OK. And do you feel like you can challenge what school say to you? Could you say ‗no‘ I don‘t want to do that?

P1: *Yeah, yeah. Them supportive*

P2: *Yeah, I'm glad they supportive. I was worried about that*

Three parents report not feeling valued in multi-agency meetings:

Below, P3 is asked about whether she contributes to multi-agency meetings:

SA: What about at the meetings in school? Do you understand what they‘re all talking about?

P3: *No, no-..no, not really*

SA: Do you ask them when you don‘t understand?

P3: *Nah, I just let „em carry on...they don’t listen to me yeah, they just talking too much sometimes*

P3: *I think people don’t listen to me...they look down on me yeah*

P3: *I get frustrated, angry...One time, I got up and slammed the doors...coz, I, you know, I...when I talk yeah, I have to keep repeating myself yeah to make „em understand ... if they don’t reply back to me or anything yeah, I get angry*

Below, are P4‘s responses when asked about her experiences of multi-agency meetings:

P4: *No-one listens to me, I’m always saying...they don’t listen*

SA: At the meetings at school, when everyone comes to talk to you, do you understand what they are saying?

P4: *No, how can I? I take D (partner)... he* (referring to her husband) *don’t get it either you know*

P4: *Yeah, they keep talking and don’t ask me how I am, coz of my surgery and that, it’s bad...*

When asked about whether she feels able to contribute to multi-agency meetings:

P2: *Not that long, half an hour. So, it’s not easy* (to ask for help with reading).

Two parents report a lack of mutual respect between parents and professionals:

Below, P3 describes a particularly difficult relationship with social services. There appears to be a clear lack of respect for the social worker and their input:

(when asked to rate input from the social worker)

SA: What about social services? What would you give them?

P3: *0 man.*

SA: 0? Why?

P3: *I don't like „em (laughs)*

SA: You don‘t like ‗em? Ok. What don‘t you like about them?

P3: *Them just too nosy man*

SA: Too nosy...what about the person, what are they like?

P3: *C, the social worker what I got now, she's alright. The one I got first, M, he told a lot of lies...a lot of lies... the other one was alright too.*

P3 describes her view of social services below:

P3: *They say they try to keep families ap...together, but they don't they keep „em apart*

When asked to describe her social worker, P3 is very negative. This could be linked to the frustration of not understanding their requirements or expectations:

P3: *It ain't on there* (the resources sheet with describing words) , *words don't come for him (laughs)*

SA: Positively or negatively?

P3: *Negative, they ain't good*

SA: And do you understand what they‘re saying?

P3: *No, not really*

P4: *if the dog's done one on the carpet and that. Oh, she gets half angry and starts telling me this and that...I can't be bothered, she don't listen and I'm angry.*

P4: *I say no, I do what I gotta, to get them off my back don't I?*

SA: OK. Do you feel like people listen to you?

P4: No one listens to me, I'm always saying...they don't listen

The level of consensus between parents was high in relation to feeling that professionals did not spend enough time with them, for example, P1, P2 and P3 reported having little information provided from social services after visits had taken place. There was unanimity amongst parents in relation to viewing school staff as particularly supportive. There were strong feelings of anger expressed by P3 and P4 in relation to feeling ignored in multi-agency meetings. The overall strength of evidence suggests that feeling ignored by professionals is the most important dimension within this theme area. For example, the lack of follow-up after visits reported by P1, P2 and P3, the perception that professionals do not have enough time for them and feeling that they are not listened to in meetings, contributes to the strength of this subtheme.

5.2.2 Subtheme 2: communication between parents and support services

Parents described how the majority of communication with professionals was inaccessible to them and reported how this had led to a lack of awareness and understanding of the roles of professionals. Often a lack of understanding of why services were involved led to anger and frustration on the part of the parent.

On the other hand, some key workers were perceived as being very effective, by spending time with the family and communicating with them in a way they could understand, so that parents felt professionals were available for support and they had a trusting relationship with them.

Box 5.2

Illustrative examples of parents' feedback within the „Communication between parents and support services' subtheme

Three parents describe poor communication with professionals which leads to a lack of understanding regarding support:

Below, P1 and P2 are asked about their experience of social services:

SA: So, you‘re involved with social services as well, aren‘t you?

P1: *Yeah*

SA (interviewer): And are they giving you any support at all?

P2: *We ain't heard…We haven't heard nothing from them since after that (referring to the initial visit by social services)*

P1: *We ain't heard......do they do work at the school now P?*

P2: *I don't know what's happened*

SA: And you haven‘t heard anything since (initial home visit)?

P1: *No*

P2: *No*

Both P1 and P2 seemed confused as to why social services were involved with their family. When asked later, they were not sure where the phone number for social services could be found and suggested that they would not call them. Below, P1 was asked why social services were involved with the family:

P1: *He (son) played up the one the one day we bought him home, we take him back to school and he did play up. But...but...We ain't heard nothing since.*

SA: Did they give you any advice on how to deal with that, if it happens again?

P1: *They just give us a number didn't they P?*

P3 also did not appear to know how to contact social services:

(when asked how P3 contacts social services)

P3: *When I see „em, if she comes to my house and that*

SA: Do you ring them (social services)?

P3: *Not really...I don't got the number*

SA: And do you understand what they're (social services) saying?

P3: *No, not really*

One parent has a particularly positive relationship with her key worker, and describes how her key worker ensures she understand why that services is involved with the family are through her effective communication:

SA: Do you know why they (social services) are involved with your family?

P3: *Yeah, coz of H* (her daughter)

SA: How much do you understand on a scale of 1-10?

P3: *10*

SA: OK. What do you like about them (family support worker)?

P3: *I dunno, I can talk to „em*

SA: OK. How would you rate the support you‘ve had? What would you give N (family support worker)

P3: *I say 10*

SA: OK. Why a 10?

P3: *Coz, I can get on with N and N...if I need help yeah, she helps me*

Reading is a particularly difficult form of communication to access for all four parents interviewed:

Below, when P3 is asked about what is hard about being a parent, reading is mentioned:

SA: Yeah. Anything else you find hard?

P3: *When the kids like...you know when them got letters and read a book and that*

SA: Yeah

P3: *I can’t read too good*

SA: You‘re doing really well N, thank you. Who helps you with reading letters?

P3: *Well...when I got time, I do it, I do try myself*

P3 is able to identify where she can get help with reading letters:

P3: *If I can’t read „em, yeah, I take „em to my mum or someone, who’s like around*

SA: Are there any professionals you can ring for help?

P3: *Yeah..erm..N, my family support worker*

P3: *Anything yeah...if anything needs to be read quick, I go to N.*

Below, P2 describes how she finds it difficult to read letters sent to her by professionals. P1 and P2 both report a lack of support available with this:

SA*:* What‘s the main way CAMHS and social services communicate with you? Do they call you, have a meeting or send letters...

P1: *They probably send a letter to us, something like that. Well, they send the letters do they P?*

SA: Are the letters easy to read?

P2: *It's hard int it... it's hard*

SA: To read the letters?

P2: *Yeah, it's hard*

SA: Does anyone help you?

P2: *They...no*

SA: Who could you ask?

P1: *We don't ask, do we P?*

P2: *No, don't ask*

Below, P4 also describes reading as a difficulty she faces as a parent; however, she seems to lack support to be able to access reading material and expresses a strong resistance to access help from professionals:

SA: Do you try and help him (her son)?

P4: *With what?*

SA: Reading

P4: *Yeah...I ...can't, y'know read and that but he tells me and then ...he just does it*

SA: Right. Yeah, so, who do you ask for help... with reading or other things you need help with?

P4: *Well...I got D*

SA: OK, so D, your partner, helps you?

P4: (laughs) *He's a lazy „un... can't read though but he plays with M like...sometimes*

SA: Do you ask any professionals to help you?

P4: *Erm...I ain't got time for „em you know...if...if...just ain't got time for „em...I gotta help my mum everyday and that ...they just have a go, telling me what to do and they gonna tek him if I don't do it*

Overall, the strength of evidence suggests that poor communication is the most important dimension in this theme. The level of consensus is high between parents regarding letters from support services being difficult to understand due to their limited reading ability. Also, there is a high level of consensus regarding not asking for help with reading difficulties.

5.2.3 Subtheme 3: parents' personal relationship with support services workers

The evidence suggested that the way parents viewed support service professionals was affected by the duration of their working relationship. It also appeared that the perceived personal characteristics of the support workers also affected whether parents engaged with services. Parents generally described school staff in terms of positive characteristics.

Box 5.3
Illustrative examples of parents' feedback within the „Parents' personal relationship with support services workers' subtheme
A positive working relationship with professionals is important to all of the parents interviewed: Below, P3 describes her relationship with her family support worker: SA: Are there any professionals you can ring for help? P3: *Yeah..erm..N, my family support worker* P3: *Anything yeah...if anything needs to be read quick, I go to N*

When asked why she can approach N (her family support worker):

P3: *Coz, I can get on with N and N...if I need help yeah, she helps me*

Whereas, previous social workers were perceived negatively, the present social worker is described positively. This suggests that a positive working relationship is very important and possibly influenced by perceived personal characteristics:

P3: *I don't like „em* (referring to social workers) *(laughs)*

SA: You don‗t like ‗em? OK. What don‗t you like about them?

P3: *Them just too nosy man*

SA: Too nosy...what about the person, what are they like?

P3: *C, the social worker what I got now, she's alright. The one I got first, M, he told a lot of lies...a lot of lies... the other one was alright too.*

P3: *I dunno man...and then...I dunno...but my family support worker, she's alright...no, my new social worker, she's alright too*.

SA: Would you say they‗ve (social services) been quite helpful?

P3: *The one has a bit, yeah, but not really...I dunno...I get on with her yeah*

When asked to describe support from support service professionals, both P1 and P2 referred to personal characteristics below:

SA: OK. So, how would you describe staff at school?

P1: *Them always happy, ain't they P?*

P2: *Them always happy, yeah.*

SA: What about CAMHS?

P1: *Them (CAMHS) just all...them, them, helpful, cheerful*

SA: And what about social services?

P1: *About the same*

P2: *Yeah, same*

Below, P4 reports a particularly negative view of one support worker:

P4: *Sometimes ... I don't like her sometimes. She comes round and I pretend I ain't in to keep her off me back. I hid behind the sofa I did...dogs kept barking*

P4: *Her's always telling me you know ... I just can't be-...I ain't bothered with her*

P4: *Erm...I ain't got time for „em you know...if...if...just ain't got time for „em...I gotta help my mum everyday and that ...they just have a go, telling me what to do and they gonna tek him if I don't do it*

P4: *Angry all the time... telling me what to do and that...I get angry*

Overall, the strength of evidence suggests that developing a positive relationship with a support worker is important to all of the parents interviewed. The strength of feeling towards support workers varied amongst parents, for example, P3 expressed strong feelings about professionals she had worked with in the past, whilst P1 and P2's views were less intense. Two hypotheses are raised in relation to strength of feeling towards professionals 1.) strength of feeling is due to professionals' personal characteristics or 2.) strength of feeling is due to the unwelcome professional role requirements personalised by the parents interviewed because of their defensive and ill-informed orientation to these workers.

5.2.4 Subtheme 4: extent to which parents trust support service professionals

The evidence suggested that being able to trust support service professionals was very important to parents. Trust appeared to be linked to experiences; for example, if parents felt they had been let down, they would be reluctant to engage with that specific worker. There seemed to be a high level of fear or mistrust around social services' involvement, and as a result, the parents seemed reluctant to engage with services or ask for help when needed, expressing instead a desire to be left alone. A central fear was having their children taken away into care.

Box 5.4

Illustrative examples of parents' feedback within the „Extent to which parents trust support service professionals' subtheme

The extent to which all parents trust support services to help them, is affected by how they are perceived. This is sometimes based on previous experiences and sometimes on the personal characteristics of professionals:

Below, P3 is asked to describe her social worker:

P3: *C, the social worker what I got now, she's alright. The one I got first, M, he told a lot of lies...a lot of lies... the other one was alright too.*

Below, P3 describes her view of social services:

P3: *They (social services) say, try to keep families apart which they don't*

SA: Keep families apart?

P3: *They say they try to keep families ap...together, but they don't they keep „em apart.*

SA: So, you think they're trying to keep your family apart?

P3: *Yeah yeah yeah..until like...so many months down the line, do you know what I'm on about?*

P3: *Them (Social services) trying to take us apart...they lie...they ain't nice man. Every little thing, they pick on it*

P3 has a strong belief that the remit of social services is to divide families, based on her experiences.

Below, P3 reports feeling unhappy about her child‘s school reporting her to social services:

(I asked how long she had been involved with social services)

P3: *Since the very first time what... you know when the school phoned „em about H, what they shouldn't have done yeah, none of their business*

P3 seemed quite agitated by this, and goes on to discuss how she has little trust for anyone.

Below, P4 is asked about the extent to which she trusts a support professional from an advocacy group for parents with LD.

SA: Do you trust S?

P4: *No...no*

SA*:* why not?

P4: I just don't like her

SA: You don‘t like h-

P4: *- telling me what to do and that*

SA: OK. Do you trust Social services?

P4: ...No

SA: Why not?

P4: *They wanna take M don't they*

P4 does not appear to trust any professional she is currently involved with, and seems afraid of what might happen.

P4: *If we had a drink right, she (advocate) reports us, or if the dogs done one on the carpet and that.*

P4: *She (advocate) said that, she said about reporting me to the social; it ain't fair, they can't tell me though, I do what I want...*

P4: *I dunno...her (advocate) report me and that, you know what „em like, but I take no notice*

Below, P1 and P2 describe having lower trust for social services in comparison to CAMHS and school based on their limited contact with them:

SA: Erm...but you trust school?

P1: *Yeah*

SA: And what about social services? Do you trust them?

P2: *Yeah, alright*

SA: On a scale of 1-10 how much do you trust social services? School and CAMHS were 9 or 10.

P1: *We only seen them once ain't we P?*

P2: *I say 6.*

Below, P3 describes how she is most trusting of her key worker. In comparison, her social worker is not trusted, based on her previous experiences with him:

SA: Do you trust N?

P3: *Yeah*

SA: What about social services, do you trust them?

P3: *I dunno man...not really*

SA: Why not?

P3: *Them trying to take us apart...they lie...they ain't nice man. Every little thing, they pick on it*

The strength of evidence suggests that previous experiences of support services shaped a parent‘s view of them. Therefore, there is little consensus between parents in relation to how much they trust a support service professional (such as a social worker) because their views are shaped by their prior experiences. For example, P3 and P4 have had a negative experience with social services in the past, which has led to the development of a very negative view of them. Whilst P1 and P2 had a more positive experience of social services and describe them as being ‗alright‘.

There appears to be a high level of consensus between parents that limited contact leads to less trust. For example, P1, P2 and P3 rate support services they have most contact with higher than those they have had less contact with.

5.2.5 Discussion of superordinate theme ***Parental Engagement with Support Services***

Overall, the views organised within the superordinate theme **Parental Engagement with Support Services** tell a story where parental engagement with services is affected by:

- the extent to which they feel valued and respected in their role as parents;
- the accessibility of communication with support services;
- personal relationships with professionals; and
- the extent to which parents trust support service professionals to act in their best interest.

As outlined in Chapter 3, a key recommendation from *The Lamb Inquiry* (DCSF, 2009) is that ―The system (for parents) needs to feel more like one where everyone is on the same side" (p. 6.). Thus, I aimed to explore the views of parents with LD and their experiences of the support systems currently in place, particularly how good, open and honest they are from their perspective. My second aim was to explore the extent to which parents with LD felt their rights were being met and how accessible information and support was for them.

The message from the current study is that all parents engaged most with school staff at their children‘s school and viewed them as a positive source of support, for example, when asked if they trust school, P1 and P2 reported that they did (see Box 5.4) . However, a conflict sometimes arose because school staff are responsible for reporting ‗concerns' to social services, for example, P4 in the present study reported feeling that school should not be reporting them to social services as it was ―*none of their business*" (see Box 5.4). Such actions have the potential to undermine the relationship that schools and parents have built, possibly leading to mistrust and disengagement from parents.

As outlined in Chapter 3, the aims of *Valuing People* (DoH, 2001) and *Valuing People Now* (DoH, 2009) were to ensure that all people with LD have their rights met and are treated with dignity and respect. In order to achieve this, *Valuing People Now* (DoH, 2009) recommends advocacy, person-centred planning, and support to give parents independence and control over their family‘s life. Therefore, in the current study I was interested in exploring the expressed views of parents with LD in relation to their experiences of becoming a parent. Specifically, I hoped to explore their experience of person-centred planning, accessing information and advocacy.

All parents in the present study reported attending multi-agency meetings at school settings (see Box 5.1). However, most parents reported that although these meetings were useful, they felt predominantly ignored and subsequently took on either a passive or aggressive role; for example, P3 reported –*they don't listen to me...I get frustrated, angry*" and P4 reported –*No one listens to me*" (see Box 5.1) . Similarly, Hoole and Morgan (2011) found that participants perceived a significant power imbalance between themselves and support staff, and felt that they were often not listened to, which led them to feel frustrated and angry.

In relation to these findings, Wade et al., (2008) suggests that parents with LD prefer family-centred support as opposed to professional-centred support. Family-centred support emphasises and builds on the views and needs of parents rather than being led by professionals and/or the needs of the children only. However, in line with my findings, Chambers (2000) suggests that meaningful consultation with parents, where their needs are considered at the forefront of planning, when devising support, is rarely achieved.

As outlined in Section 3.7, within the current study, I aimed to ask parents about their own experiences of support when becoming a parent and during early stages of parenting, where parenting support programmes are thought to have the most impact. I wanted to explore whether they were able to access such support and factors which facilitated or hindered their engagement with this support. Also, I was interested in how parents viewed their relationship with support service professionals, for example, whether they believed they were listened to. What I found was that, parents with LD often view themselves as being judged or accused during multi-agency meetings, for any failures their families face and as a result, this often lead to feelings of frustration and aggression. My findings were that two parents (P3 and P4) expressed great frustration and anger because they felt they were not being listened to, at times this frustration had given rise to aggression towards professionals.

As outlined in Chapter 3, *The Story So Far* (DoH, 2005) suggested that person-centred planning, when conducted well, was making a notable positive difference to the lives of adults with LD. However most parents in this study described a situation where they felt they were being blamed for the difficulties their families faced and that professionals looked down on them for not being able to meet their expectations. For example, P2 felt teachers blamed her for her child‘s difficulties (see Box 5.1); P3 stated -*they* (professionals in multi-agency meetings) *look down on me*...”; and P4 reported doing what she could to -*keep her* (social worker) *off me back*.” P1 in particular went on to express a degree of acceptance that, for example, if their child is unable to read when they finish school, that everyone will say it is their fault, stating -*they blame the parents, don’t they.*” (see Box 5.1). Research by Booth & Booth (2004; 2005a) and McConnell & Llewellyn (2000) found often parents with LD are blamed for parenting difficulties, rather than the appropriateness of support being questioned.

As outlined in Chapter 3, the importance of relationships between parents and professionals was highlighted in research by Tucker and Johnson (1989), whereby; professionals‘ ability to provide adequate support depends on their ability to build positive working relationships with parents. In the current study, I was interested in exploring whether parents with LD in Newtown felt they had received long-term support, when needed. I aimed to explore whether the extent to which the parents I interviewed considered their needs and the needs of their children were being fully met at a local level. I aimed to elicit examples of good practice, as well as perceived barriers and suggestions for improvement.

My findings suggest that where a parent did have a positive relationship with a key professional, this led to the parent feeling confident enough to ask for help when needed. For example, P3 reported being able to –*get on*” with her family support worker and feeling she could approach her for –*anything*” she needed (see Box 5.3). McConnell and Llewellyn, (2000) and McGaha, (2002) suggest that positive interactions between parents and professionals typically led to increased access to support and better outcomes for children of parents with LD. Also, my findings suggest that parental engagement with support services appeared to be limited by difficulties with communication between parents and services. For example, P1 and P2 described having contact with social services with no follow-up advice or information and did not appear to have a clear understanding regarding the basis for their involvement –*we haven’t heard nothing from them since*.” P3, when asked if she understood what social services told her last time she spoke to them, replied –*no, not really*” (see Box 5.2).

None of the parents in my study could read; however, both P1 and P2 reported having letters from support services as their main form of communication (see Box 5.2). P1 and P2 were also unclear about who to contact for support with certain issues. Starke (2010) found that parents with LD often criticise support services for not providing enough ‗comprehensible‘ information. Also, Ahuja and Williams (2010) found that access to appropriate support services was significantly lowered due to lack of accessible information available to parents about which agencies to contact, and how, in different situations.

Ahuja and Williams (2010) found that lack of continuity in care received by parents with LD resulted in high levels of distress, especially for children. A finding from my study was that several parents felt that not enough time was spent with families by professionals. For example, P1 and P2 felt that meetings were too short to allow them to contribute their opinions fully (see Box 5.1) and P3 felt that it was ―*annoying*” that her social worker kept changing. Changes in workers, such as social workers, often meant that a meaningful relationship could not be secured with professionals (Guinea, 2001).

Most of the parents interviewed admitted needing further help in order to support their family and daily lives; for example, P1, P2 and P3 wanted more support to help their child read (See Box 5.2). As outlined in Chapter 3, in relation to lifespan developmental stages, ―children‘s chances of achieving optimal outcomes will depend on their parents‘ capacities to respond appropriately to their needs at different stages of their lives” (DoH, 2009, p. 128). In this current study, I was interested to explore the extent which parents with LD considered the needs of their children to be met through the support they received, whether they could identify stages in their children‘s lives or developmental tasks where they perceived they needed help, and whether they were able to access this successfully. However, as a result of poor perceptions of support workers, parents often held a negative view of professionals which diminished help-seeking behaviour. For example, P4 felt that she was always being told what to do, but she was not listened to (see Box 5.3). P1 and P2 felt blamed for their child being unable to read (see Box 5.2). When asked if they would seek help, all parents reported that they would not. Starke (2010) also found very similar results, where parents were able to identify aspects of their lives where help was needed but displayed deep-rooted passivity, whereby they only engaged with services because of a dependency on the support offered, and often did not actively seek support beyond minimal requirements.

International research shows that many parents with LD are hesitant to ask for help and afraid to receive services, while others refuse to engage with support offered (Traustadóttir & Sigurjónsdóttir, 2010). Also, an apparent deterrent to engaging with support services may be that parents with LD fear they may lose care of their child and/or that they may not wish to be involved with learning disability services because of associated stigma (Cleaver & Nicholson, 2007). As part of the present study, I hoped to explore the extent to which parents with LD had engaged with services and whether their engagement had been facilitated or hindered by the way they considered professionals to perceive them for example, and/or they had refused to engage due to a difference of opinion with service professionals and how this had impacted their access to support.

My findings indicated that there was a high level of fear and mistrust surrounding involvement from professionals, particularly, social workers. P3 and P4 clearly reported that they did not trust social services, whilst P1 and P2 viewed social services more positively but trusted them less than other services, such as school and CAMHS (see Box 5.4). The evidence suggests that this mistrust was due to a number of factors, such as personal characteristics of workers and parents‘ previous involvement with social services. For example, P3 and P4 had been subject to a child protection plan and consequently believed that social services would ‑*pull families apart*" (P3). Baum and Burns (2007) found that mothers with LD who were at risk of child care proceedings made sense of this through external attributions, such as blaming professionals. The parents I interviewed identified areas where they felt they needed help, but did not feel that services would work in their best interest and were therefore reluctant to engage with professionals.

5.3 Superordinate theme: parental access to support services

5.3.1 Subtheme 1: how children's needs are affected by access to support services

The evidence suggested that all parents viewed the following needs as areas for concern regarding their children: physical health, behaviour and learning. Parents perceived support services to focus on the housing conditions as well as these. All parents reported/acknowledged that their children exhibited significant behavioural difficulties, and all parents openly reported needing help with this, however, none were accessing any type of support in this area.

All of the parents interviewed seemed aware of how their own difficulties affected their children; for example, they referred to their own difficulties with reading or health-related needs which affected their capacity to meet their children‘s needs. Accessing support to meet their needs appeared to be problematic.

Box 5.5

Illustrative examples of parents’ feedback within the „How children’s needs are affected by parents’ access to support services’ subtheme

Managing children’s behaviour is a concern for all of the parents interviewed and an area they identify as needing support in:

Below, P1 and P2 describe finding it difficult to manage their son‘s behaviour at times:

SA: ... what is hard about being a parent?

P1: *Probably some of his tempers sometimes*

SA: Right...erm...and you‘re finding it difficult to manage his behaviour sometimes?

P1: *Well...it’s...sometimes*

SA: Sometimes

P1: *We just leave him and he calms himself down then*

It seemed that P1 lacked techniques to manage his son‘s behaviour.

For P1 and P2, social services become involved due to the child‘s behaviour, or this is what parent‘s perceive to be the case:

(when asked if social services are involved)

P1: *Yeah, because he did play up at school, when we bought him up.*

SA: And do you know why they (social services) came to visit?

P2: *M plays up at school*

P1: *He played up the one the one day we bought him home, we take him back to school and he did play up. But...but...We ain't heard nothing since.*

SA: Did they give you any advice on how to deal with that, if it happens again?

P1: *They just give us a number didn't they P?*

P2: *Yeah, if there any more problems*

P1 and P2 may require support in this area.

Below, P3 describes difficulty managing her daughter‘s behaviour at home:

SA: What‘s hard about being a mum then?

P3: *When... (laughs)...H (daughter) is being naughty*

SA: H is being naughty?

P3: (laughs)*...yeah...I dunno then man...it's hard...coz, it's a big, erm, task for me...when things go...*

When P3 is asked why social services are involved with her family she reports that it is due to her daughter‘s behaviour at school.

When I asked P3 how support for her family could be improved she replied:

P3: *Coz when...you know what, to tell you the truth, when like H's been really bad, when...before she started school, no one really bothered to help me, do you understand? So really yeah, to me yeah, I think, I can do it man.*

SA: Are there any things that would like more help with?

P3: *At the minute...to put H (daughter) on the right way I think*

P4 describes having difficulty with getting her child to bed on time and describes strategies she uses to encourage this to happen. When asked about what was hard about being a parent P4 responded below:

P4: *Er...he (son) doesn't like going to bed, M doesn't, he won't go, he wants to be with me...*

SA: Erm...OK. How do you get him to go to bed?

P4*: Er...with the telly on, he's alright then, goes to bed like*

P4 describes having limited strategies for getting her son to go to sleep:

She goes on to describe having very little support and knowledge of how to access help with her son's sleeping.

Below, When asked what P4 needs help with at the moment, she mentions her son's behaviour as being difficult to manage.

SA: Do you need help with M?

P4: *Er...he's naughty sometimes ... but then he settles with D...I dunno*

Most parents describe health concerns for their children. In some cases, the professionals raise concerns that parents do not consider to be a priority:

Below, P3 discussed what her concerns as a parent were and how she has not accessed support for these

SA: Did you worry about them getting ill?

P3: *Yeah, being like a doctor...I dunno...I didn't know if they was ill like...to help them, do you get me?*

SA: Did you get any help from any professionals?

P3: *Nah*

Below, P1 and P2 describe how not being able to manage their son‘s behaviour has health implications for their child.

P2: *He needs an injection from Newtown Hospital, but he won’t have it done*

P1: *Oh, he plays up, he won’t have it done. We dunno what to do*

P2: *He won’t have injections coz we’re trying to find out if he has diabetes or not*

P1: *That’s when he kicks off, if he knows they’re gonna do injections, he’ll kick off then. He kicked off with his mum at the hospital*

Below, P1 and P2 explain that some professionals are involved with the family because their son‘s weight has become a cause for concern. P1 and P2 don‘t seem to consider this a priority themselves, and do not recognise why, and/or to what extent this is a concern for professionals:

P2: *Yeah...he just comes to help M, that’s all. Coz he’s put on a bit of weight. He’s lost a bit but that won’t do no good you see until they know what it is. They test his blood.*

P1: *They (school staff) try to make him lose a bit of weight*

P2: *And more exercise*

P2: *They don’t discuss that. The main target they discuss is-*

P1: *Weight*

P2: *-his weight. In my brain his reading and writing is most important and all, not just weight, his reading and writing.*

P1: *All they discuss at the meetings is weight*

P2: *I want him to be upper his reading and writing...to be proud of*

P1: *All they talk about is his weight. He lost a bit. They don’t really talk about nothing else*

Below, P4 explains that professionals raise housing conditions as a concern which she does not consider or recognise to be a priority:

P4: *Her's always telling me you know ... I just can't be-...I ain't bothered with her… About you know, doing that house ... and garden*

P4 describes hiding from a support service professional for the reason below:

P4: *If we had a drink right, she reports us, or if the dogs done one on the carpet and that. Oh, she gets half angry and starts telling me this and that...I can't be bothered, she don't listen and I'm angry.*

SA: What things have you got to do?

P4: *Er...the house and that, the garden...get rid of the dogs and... I dunno... loads yeah*

SA: What happens if you don‘t do it?

P4: *They'll take M off us, like with J* (previously taken into the care of the Local Authority)

SA: How would you rate the support from social services? 1 being really bad, 10 being amazing

P4: *I dunno...bad ain't it*

P4 seems to understand that there are consequences of her not improving housing conditions but doesn‘t seem clear on how to do this, she rates support as low.

Three parents refer to their own learning difficulties, specifically with reading, as affecting their child's learning progress:

P2 repeatedly mentioned how difficult it has been to support her son, ‗M' with school work, such as reading. She was very concerned about his progress:

P2: ... *He wants to learn, it's hard and I can't coz it's all change at school, I can't understand what they're doing at school. I don't know the new ru...it's changed when I was at school.*

P2: *I've been reading and that. He loves the pictures though. We done our best.*

P2: *Help him, it's easy now his homework, but when he gets older, it'll be hard for us to do, that's the problem*

P2: ... *I'm glad he's getting one-to-one teacher because I was worried because he's going down hill. He's two years behind work...he's told...his teacher told me last year. His teacher's been very poorly, so I don't know how he's got on this year*

P2: ... *I'm glad they're getting one-to-one coz I insisted that coz his reading and writing has gone down hill, he can't help it really, I'm glad they noticed that. The other teacher told me two years ago at school M will probably need a one- the teacher has left the school now – she says but probably M will need a one-to-one because erm...his writing's not that good and his reading's very poor.*

P2: *I'm glad this is happening. I really am, coz I was worried. He can't read and write, what'll happen? Where can he go? Nobody'll have him. Kids'll take the mick if he can't read and write when he's 12. What's gone wrong? They blame the parents, don't they. I'm glad the teacher realised he can't read and write. I'm glad some people are helping now. He's 9 now still the same.*

It appears that P2 is not clear on where to get support for her child's reading:

SA: Do you know where you could get more help for M's reading and writing?

P2: *No, the youth club is just for sports and playing. I ain't got a clue.*

Below, P3 and P4 also mention their own difficulties with reading as a barrier or difficulty when being a parent.

SA: what's hard about being a parent?

P3: *When the kids like...you know when them got letters and read a book and that*

P4: *I can't help him with school work, I told him that and...I can't read.*

Below, when asked what was hard about being a parent, P4 stated reading was a difficulty:

P4: *Er...or reading, he hates reading...but his teacher said he's got to or he's in trouble*

SA: Do you try and help him?

P4: *With what?*

SA: reading?

P4: *Yeah...I ...can't, y'know read and that but he tells me and then ...he just does it*

P3 expresses a desire to overcome her own difficulties with reading and learning.

P3: *I wanna work but erm...I wanna go back college really to tell you the truth but I have put my name down at school*

SA: Hmmm, that‘s good

P3: *Coz they got a Literacy course coming up*

SA: Anyone helping you with that?

P3: *No*

SA: No one‘s helping you, but you want to go back to school. Do you need help?

P3: *Yeah, coz I never...done nothing like that to tell you the truth*

There was a high level of consensus between parents that they required further support in meeting their child‘s behavioural, health and educational needs. There were particularly strong feelings relating to managing their child‘s behaviour, this appeared to be an area of significant difficulty for all parents interviewed and a dominant sub-theme in this area. For P2, a second priority was to meet her child‘s learning needs; she became quite upset when talking about not being able to help her child read, this was a particularly emotive area for her.

5.3.2 Subtheme 2: how early experiences of parenthood are affected by access to support services

The evidence suggested that family networks form an invaluable source of support throughout pregnancy and early parenthood for all of the parents interviewed. All parents seemed to perceive a lack of professional support during pregnancy and early parenthood and suggested that support services are largely reactive as opposed to preventative in their experience.

Three parents reported fear when their child was born and offered scenarios where they are too afraid to handle the child. Previous research (e.g. Booth & Booth, 2003) highlights the benefits of parental support groups pre/post-birth and how these can significantly improve the skill levels of parents with LD. Despite there being universal antenatal and postnatal support available in their local area through the hospital and local children‘s centre, none of the parents interviewed engaged with these services, and / or did not recall having done so.

Box 5.6
Illustrative examples of parents' feedback within the „How early experiences of parenthood are affected by access to support services' subtheme
Most parents do not recall having support offered to them pre-birth and report they did not know what to expect from parenthood: Below, P1 describes how he and his wife (P2) were not offered any support before the birth of their child. P1 also describes not knowing what to expect when becoming a father.

SA: Excellent. And when you found out you were going to be a dad, were you offered any support by anyone?

P1: *No, we didn't did we P?*

SA: OK. And did any professionals or anybody get in contact with you with information about being a dad? Like your Doctor or anyone?

P1: *No, none at all*

SA: You didn‘t get any leaflets or booklets?

P1: *Don't think so.*

SA: You don‘t think so. And then, with that in mind, did you know what to expect when you were going to become a dad?

P1: *Not really, no, coz it was my first time were it? It's something else, not really though, it's hard work though.*

P3 reports her experience of support before the birth of her child below:

SA: So, when you found out you were first pregnant with C, who did you get support from?

P3: *Erm...*

SA: Like, did you get any support from the doctor...

P3: *No, not really...I had appointments and that at the hospital. I had midwives and that. Apart from that, I was by myself really.*

Below, P4 describes having little support from professionals before her son was born. P4 also describes not knowing what to expect from parenthood.

SA: Ok, when you found out you were first pregnant, who did you get support from?

P4: *No, no one helps me, I always have to help myself...and my mum...Erm...*

SA: No one gave you any books, leaflets or videos on being a parent?

P4: *I don't think so*

SA: So, did you know what being a mum was going to be like?

P4: *No (laughs), no one told me anything, he was really little and that ... I was, you know, really what's the word*

When asked how she felt about becoming a mother, P4 answered below:

P4: *I was you know scared... to pick him up and that coz he was little*

Three parents describe a lack of perceived access to support networks and professional support post-birth, with most parents seeming to rely on family support:

P1 and P4, describe not being invited to attend support groups or being offered support post-birth from professionals.

SA: Were you invited to any support groups?

P1: *No*

SA: No? Not by your doctor or social worker or anybody?

P1: *No?*

SA: OK. Did you go to any support groups?

P4: *What like?*

SA: Where parents meet up to talk to each other

P4: *Nah...that sounds nice and that...I had a friend but she moved so...I did it by myself*

Below, when P3 is asked about whether she knew what to expect from being a parent, she refers to her family support network:

SA: So, you were 18, did you know what being a mum was going to be like?

P3: *Yeah, I...obviously, coz I saw my mum with my sisters*

Below, P3 highlights a lack of parenting skills when her child was born and how she relied on her family for support:

SA: Erm, on a scale of 1 to 10 how confident did you feel about being a mum?

P3: *I was confident weren't I... but...I couldn't bath her or nothing*

SA: Oh, why not?

P3: *Coz like...I was scared (laughs)*

SA: Right, who gave you help then?

P3: *My nan*

P4 reports feeling unsupported by professionals:

P4: *No, no one helps me, I always have to help myself...and my mum...Erm...*

SA: Who helped you?

P4: *No one helps me...but I just did it* (referring to early parenting role) *you know*

P3 and P4 both report some support from a health visitor after they had their children:

SA: Did you get any help from any professionals?

P4: *Nah, just the health visitor, she showed me sometimes but...nah, not really*

SA: What did she show you?

P4: *...holding him proper...feeding and that...and washing*

SA: The health visitor helped you?

P3: *Yeah...but I was scared...to bath her like*

The strength of evidence suggests that the parents interviewed did not engage with or access universal antenatal or postnatal support, which is a core entitlement for all parents. Parents expressed strong feelings about becoming a parent and lacking the skills and confidence to care for their child. A common trend appeared to be that parents accessed and engaged with support offered by family members during earlier stages of parenthood.

5.3.3 Discussion of superordinate theme: **parental access to support services**

As outlined in Chapter 3, the aims of *Valuing People* (DoH, 2001) and *Valuing People Now* (DoH, 2009) were to ensure that all people with LD were provided with the support they need to lead their lives as fully as possible. In relation to the findings outlined in this section, in the current study I was interested in exploring the expressed views of parents with LD in relation to their experiences of becoming parents. Specifically, I hoped to explore their experiences of person-centred planning, accessing information and advocacy.

My findings indicated that all parents who were interviewed wanted and needed support to manage some aspect of their children‘s lives. Areas of need which were highlighted by parents included health, behaviour and learning. Some parents felt that often their perception of what they needed support for, differed from the views of professionals and/or services provided. For example, P1 and P2 strongly felt that during multi-agency meetings, professionals often focussed on one aspect of a child‘s needs, such as weight (―*All they talk about is his weight*‖), and did not consider other aspects (see Box 5.5). Also, in P4‘s case, professionals considered housing an area of priority, however, P4 herself did not appear to understand or acknowledge the relevance of it. For example, when asked what is expected from her, she replies ―*Er...the house and that, the garden...get rid of the dogs and... I dunno... loads yeah*" (see Box 5.5). Studies (Llewellyn, et al., 1998; Booth & Booth, 1994; 2003; 2005; Guinea, 2001; Llewellyn & McConnell, 2005; Tarleton & Ward, 2007) have found similar results where parents with LD and their support workers differed in their views about areas of need and found that this often led to limited cooperation from parents. This appeared to be the case for P4, who expressed a strong resistance to engaging with services, for example, by hiding from professionals when they visit and not listening to advice given. In the interview she reported ―*I take no notice*" and ―*I can't be bothered*" (see Box 5.5).

Research into family-centred planning involving parents with LD advocates the use of multi-agency meetings as a way to develop collaborative relationships between parents and professionals (Espe-Sherwindt, 2008) and encourage parents to be more willing to access support when it is needed. However, here it must be noted that data discussed in Section 5.3.5 had indicated that the Newtown family sample had developed negative expectations of multi-agency meetings and that engaging their trust and commitment to a different (family-centred) approach at this juncture may prove challenging.

Three of the parents I interviewed openly discussed needing help to manage their child's behaviour and expressed significant difficulties in this area. In Box 5.5, P1, P2 and P3 describe how their child's behaviour has been difficult, but not knowing where or from whom to seek support. For example, P1 states ―*He* (referring to his son) *played up the one the one day we bought him home, we take him back to school and he did play up. But...but...we ain't heard nothing since*."

When studying parents with LD and their children‘s behaviour, Aunos et al., (2008), found that the high levels of maternal parenting stress, commonly found in single parent families where the mother has a LD, were associated with a lower frequency of positive and a high frequency of ‗hostile‘ and inconsistent or ineffective parenting styles, leading to more child behaviour problems. In the present study, although parents had highlighted managing their child‘s behaviour as an area in which they wanted help, they were not accessing any support for reasons such as:

a) the lack of accessible information about where and how to access support despite *The Lamb Inquiry* (DCSF, 2009) highlighting that parents felt that ‗good, honest and open communication‘ was most important for promoting confidence and building good relationships with professionals. For example, P1 stated ―*They* (social services) *just give us a number didn't they P*?"; and

b) feeling that support is not focussed on the parents‘ or families‘ needs where workers did not see a child‘s behaviour area as a priority, despite *The Good Practice Guidance* (DoH, 2007), *Valuing People* (DoH, 2001) and *Valuing People Now* (DoH, 2009) highlighting the fundamental importance of person-centred planning. For example, P1 and P2 reported ―*All they talk about* (professionals at multi-agency meetings) *is his weight*."

As referred to in Section 5.3.5, Starke (2010) found similar results when interviewing parents with LD about their experiences of support services, where parents described lack of accessible information and support as barriers to their accessing appropriate support. Baum and Burns (2007) propose that a number of parents with LD ―struggle to cope with their children‘s difficult behaviour because of the poor parenting role models they experienced in their own childhood" (p. 12). Also, the difficulties that some parents experienced, heightened during different developmental stages in a study conducted by Stenfert Kroese et al., (2002). A limited understanding of child development is suggested as being ―common among parents with LD, with some expressing a need for more support in this area" (Stenfert Kroese et al., 2002 p. 322).

As suggested in Chapter 3, *The Good Practice Guidance* (DoH, 2007) advocates early identification of needs, suggesting that procedures, criteria and pathways should be agreed between children‘s and adult social care and maternity services when pregnancy is confirmed. Also, *Valuing People,* DoH, 2001; and *Valuing People Now*, DoH, 2009) suggest that ―supporting parents during pregnancy is widely regarded as the most effective means of promoting health and well-being in the developing child" (p. 176). In the present study, all of the parents were asked about their experience of support during pregnancy in preparation for parenthood. All parents reported having no support from professionals during pregnancy and suggested that they did not know what to expect when their child was born. For example, P3 reported having *―appointments and that at the hospital. I had midwives and that. Apart from that, I was by myself really"* and when asked whether she knew what being a mum was going to be like, she said ―*No (laughs), no one told me anything; he was really little and that ... I was, you know, really what's the word…scared*" (see Box 5.6).

Booth and Booth (1994) highlight that parents with LD often fall *between* child and adult services. Despite, as outlined in Chapter 3, *The Good Practice Guidance* (DoH, 2007) providing suggestions that children‘s and adult social care and maternity services should be working together when pregnancy is confirmed, most of the parents in this study did not perceive collaboration between services.

As discussed in Chapter Three, there is evidence to suggest that parenting support groups and programmes can have a positive impact on a range of parenting factors for parents with LD (Wade et al., 2008; Coren et al., 2011). None of the parents interviewed in this study was reportedly invited to attend any parenting support groups; for example, when P4 was asked about this, she said she was not invited to any support groups but thought that they sounded ‗*nice*‘ (see Box 5.6). Wade et al., (2008) have suggested that services are not intervening early with parents with LD and that support tends to be crisis-driven, with the needs of families headed by a parent with LD typically recognised too late.

Traustadóttir and Sigurjónsdóttir (2010) in their study of mothers with LD and their support networks found that family networks were highlighted as an invaluable source of support throughout pregnancy and early parenthood. In the present study, one parent (P3) reported drawing on family support to help her during early parenthood. For example, P3 reports her grandmother and mother helped her to bathe her child (see Box 5.6).

5.4 Reflection on epistemological position

―There are many ways to study or carve the world up" (Williams, 2003, p. 43). Within my Critical Realist (CR) position, I acknowledge that each parent involved in the present study belongs to an individual context, or laminated system, that is, a system that refers to multiple layers of reality (Bhaskar & Danermark, 2006). As described in Chapter 4, three ontological domains are proposed within the CR framework: the empirical, the actual and the real. Each level has its own generative mechanisms, or mechanisms which produce events (Danermark, 2002) and phenomena are produced by mechanisms at different levels. Thus, one cannot explain phenomena in terms of the mechanisms working at just one level (Danermark, 2002). To illustrate, learning difficulties may be the result of mechanisms operating at a biological level, psychological level and social level. For example, there may be hereditary links; an individual experiences their learning difficulties through psychological mechanisms which are unique to themselves. Also, social mechanisms, such as stigma and social attitudes, strongly affect how learning difficulties are viewed. The implication of analysing phenomena from a CR perspective is that ‗truth' cannot be explained in terms of mechanisms working at just one level.

My task in the present study was to explore the mechanisms which led to parents‘ views of support services and to understand the interplay between them and how they shaped parents‘ experiences. What I have attempted to do, within the present study, is to consider the ‗whole‘ complex phenomena by not reducing parents‘ experiences to one single level, for example, I have tried to explore social mechanisms, psychological mechanisms and physical mechanisms through the use of interview techniques. Through this process, the consideration of generative mechanisms has highlighted the importance of context, in that different mechanisms apply to each case study.

Each parent‘s views and experiences of support services were different and the findings discussed in this chapter were subjective. Parents‘ expressed opinions have been filtered through their cognitive capabilities and are greatly affected by a range of mechanisms on a number of levels. It is important to note that the accounts of parents interviewed within the present study are only one stratum of the reality of service provision for parents with LD. The limitations of adopting a CR framework will be addressed in Section 6.3.

Chapter Six

Conclusions and Implications for Practice

6.1 Introduction

The central aim of this study was to explore parents' views and experiences of local support services, highlighting examples of good practice and positive experiences of parents with LD, as well as exploring some of the needs and the challenges faced by these parents, with the further aim of informing practice with the knowledge gained.

The methods used in collecting and analysing the data allowed me to address the research questions in relation to my area of enquiry. The process of thematic analysis that I applied to the data, revealed a story which highlighted a range of key issues in relation to support for parents with LD.

In Chapter 5 these findings were presented and discussed in relation to the literature presented in Chapters 2 and 3 and in relation to a Critical Realist (CR) approach to research. To conclude my research, a summary which presents the findings in relation to my initial research questions and existing research literature is outlined below.

6.2 Addressing research questions

The research questions, which are based on a review of the literature (see concluding synthesis in Section 3.7), are presented below for ease of reference:

1. How do parents with LD perceive communication with support service professionals?
2. How do parents with LD report that they are supported to meet their children‘s needs?
3. What are some of the barriers to parents with LD receiving support?
4. In parents‘ views, how may these barriers to support be overcome?
5. What positive experiences of support services do parents with LD describe?

6.2.1 Research question 1: How do parents with LD perceive communication with support service professionals?

As outlined in Section 3.7, I aimed to explore the views of parents with LD and their experiences of the support systems currently in place, particularly how good, open and honest they were from their perspective. My second aim was to explore the extent to which parents with LD felt their rights were met and how accessible information and support was for them.

In the current study all four parents reported attending multi-agency meetings in school settings. However, three parents reported not feeling valued in multi-agency meetings and subsequently they took on either a passive or aggressive role. For example, P3 reported –*they don’t listen to me...I get frustrated, angry.*” My findings were that two parents (P3 and P4, see Box 5.1) expressed great frustration and anger because they felt they were not listened to; at times this frustration gave rise to aggression towards professionals. P1, P2 and P4, (see Box 5.1) described a situation where they felt they were blamed for the difficulties their families faced and that professionals looked down on them for not being able to meet their expectations.

A key finding was that parents felt that not enough time was spent by professionals with their families and as a result, they felt unsupported. For example, three parents describe how professionals such as social workers had been to visit their home to complete assessments. Those three parents reported that there was no follow-up conversation with them after visits, no support or advice was offered to them, and no information provided (see Box 5.1).

Parents highlighted positive relationships with support workers and described how such relationships with professionals made them feel valued and respected as parents (see section 6.2.4). The strength of evidence suggests that such relationships were associated with long-term involvement from professionals.

6.2.2 Research question 2: How do parents with LD report that they are supported to meet their children's needs?

As outlined in Section 3.7, I aimed to ask parents about their own experiences of support when becoming a parent and during early stages of parenting, where parenting programmes are thought to have the most impact. I was interested to explore the extent which parents with LD considered the needs of their children to be met through the support they received, whether they could identify stages in their children's lives or developmental tasks where they perceived they needed help, and whether they were able to access this successfully. I aimed to explore what parents considered to be the quality of support they had received from professionals and which factors influenced their views.

The evidence suggests that parents held a predominantly negative view of services available to support them and their families. All parents reported having no support from professionals during pregnancy and suggested that they did not know what to expect when their child was born (see Box 5.6).

Most parents were content with the information and support provided by school staff; for example, P1 and P2 described school staff as being helpful with supporting their son's learning progress (see Box 5.6).

Managing children‘s behaviour was a concern for all of the parents interviewed and an area in which they identified a need for support. For example, P1, P2, P3 and P4 (see Box 5.5) described finding it difficult to manage their son‘s behaviour at times, but no parents reported receiving professional support.

Most parents were able to identify a practitioner or agency that they had found helpful since the birth of their children. P1 and P2 identified the CAMHS (Child and Adolescent Mental Health Service) as particularly helpful (see Box 5.4).

All parents referred to their family network as a particularly positive part of their lives (see Box 5.6). The interview evidence suggests that parents with LD relied on information, guidance and support from their own parents or sibling, in order to develop their parenting skills and to adequately meet their children‘s needs.

Most parents described areas of their child‘s development with which they would like support; however, they were reluctant to seek help as they felt that professionals did not value their needs above their own priorities. For example, P1 and P2 described wanting help with their child‘s reading but had not raised this in multi-agency meetings because these had a different focus concerning their son‘s weight (see Box 5.5).

6.2.3 Research question 3: What are some of the perceived barriers to parents with LD receiving support?

As outlined in Section 3.7, I wanted to explore whether parents with LD were able to access support when needed and factors which facilitated or hindered their engagement with such support. Also, I was interested in how parents viewed their relationship with support service professionals, for example, whether they believed they were listened to.

A key finding of *The Lamb Inquiry* (DCSF, 2009) was that parents felt that access to the information they needed, when they needed it and in a way that was accessible to them, was important for promoting confidence and building good relationships with professionals. My findings suggest that parental engagement with support services appeared to be limited by difficulties with communication between parents and services. For example, P1 and P2 described having contact with social services with no follow-up advice or information and did not appear to have a clear understanding regarding their involvement (see Box 5.2). None of the parents in my study had attained a level of functional literacy; however, both P1 and P2 reported having letters from support services as their main form of communication (see Box 5.2). P1 and P2 were also unclear about which agency to contact for support with certain issues, such as where to access support for helping their son lose weight, or where to gain support for managing their son‘s behaviour.

Three parents reported feeling that professionals did not have enough time for them to discuss things in-depth and for them to seek help for areas with which they wanted guidance (see Box 5.1). Two parents reported a lack of mutual respect between themselves and professionals. P3 and P4 described how a lack of respect for certain professionals led to their resisting engagement with that service (see Box 5.1). One parent, P3 described some examples of how she needed help but was reluctant to seek assistance because she felt that support professional did not listen to her previously. She described, how in previous meetings she had become very angry and frustrated because she felt ignored by support professionals and she wanted to avoid this happening again (see Box 5.1).

No parent felt ‗in charge‘ of what happened to their families and described this as a crucial reason why they did not seek support or accept help from professionals.

6.2.4 Research question 4: How do parents with LD perceive that barriers to support can be overcome?

As outlined in Section 3.7, in the present study, I aimed to explore factors which facilitated involvement with support services, and present research whose findings could be used to improve the lives of parents with LD.

In response to this question, parents described an approach which would treat them with respect and value their opinions and choices. My findings suggest that where a parent had a positive relationship with a key professional, this led to the parent feeling confident enough to ask for help when needed. For example, P3 reported being able to “*get on*” with her family support worker and she felt she could approach her for “*anything*” she needed (see Box 5.3).

Reading was a particularly difficult form of communication for all four parents interviewed and can act as a barrier to accessing support. P2 described how she found it difficult to read letters sent to her by professionals. P1 and P2 both reported a lack of support available with this (see Box 5.2). P4 also described reading as a difficulty she faced as a parent; she also lacked support to be able to access written material, but expressed a strong resistance to access help from professionals. Findings suggest a key need for improved attention to communication media to ensure its accessibility to parents.

P3 spoke at length about not trusting social workers because she felt they told “*lies*” and tried to “*keep families apart*” (see Box 5.4). It would appear therefore that parents would benefit from an approach which is transparent, where information is readily available and accessible to them, and where professionals consulted them more fully before making or imposing changes which affect their families.

P4 talked about professionals who suggested she needed to make changes to the housing conditions in which she lived, but seemed unclear, when asked about what the changes were or how to implement them (see Box 5.6). P4 highlighted the need for professionals to outline their expectations and provide appropriate support in meeting agreed expectations. This approach could facilitate parental engagement with support services because the expectations agreed with them would be rendered more meaningful and less threatening.

Parents such as P1, P2 and P3 suggest that barriers to support could be overcome if professionals spent more time with them and there was longevity in the support relationship provided, as opposed to frequent changes in key worker, and services intervening when there is a ‗problem‘ and withdrawing when the situation improved.

6.2.5 Research question five: What positive experiences of support services do parents with LD describe?

As outlined in Section 3.7, in the present study, I was interested in exploring whether parents with LD in Newtown felt they had received long-term support, when needed. I aimed to elicit examples of good practice, as well as perceived barriers and suggestions for improvement.

One parent had a particularly positive relationship with her key worker; she described how this key worker ensured she understood why that service was involved with the family, through effective communication. In Box 5.2, P3 rated support from this particular worker as 10 out of 10.

Where a parent, like P3, was able to build a positive relationship with a support worker based on mutual trust and respect, this led to support being accessed more readily (see Box 5.1 and 5.3).

A conclusion from the current study is that all parents engaged most with school staff at their children‘s school and viewed them as a positive support service, for example, when asked if they trust school, P1 and P2 reported that they did (see Box 5.4). All parents reported feeling valued and respected enough to ask for help from school staff and professionals they had a positive relationship with. There was some conflict from the competing role of school regarding support for children‘s learning development, support for parents, safeguarding responsibilities and multi-agency working.

6.2.6 Summary

In summary, the main findings that emerged from this research were that parents held widely diverse views on the support they had received, and that their experiences were heavily influenced by an inter-dependent relationship between their expectations and expectations of practitioners, their feelings towards agencies and accessibility of information.

Within the present study a particularly salient theme was parents‘ perception that professionals did not spend enough time with them. This theme has been raised in previous studies (Mansell et al., 2004) and is discussed in Chapter 3. A second salient theme was parents‘ perception that professionals did not listen to them and that they were ignored in multi-agency meetings. This is a theme which may be worthy of further study as there was little exploration of it within extant research reviewed in Chapters 2 and 3. It appears that a further salient theme little explored in existing research is the significance of the role that the school setting and staff play in supporting parents with LD, this may also be an area which may be worthy of further study.

The extant literature outlined in Chapters 2 and 3, highlights the need to ensure that parents with LD are ‗good enough‘ (Budd, 2005; Sellars, 2011), or that parents are able to ensure that their children are: well fed; relatively clean; warm; dry; given chance to sleep regularly; given clear boundaries; cared for by adults who respond to their requests and needs; loved; and safe. Taylor et al., (2009) concluded that further targeted training and resources may be needed to ensure that parents with LD are able to be good enough parents. The present study contributes the finding that parents express significant difficulty with managing their children‘s behaviour, meeting health needs and facilitation their children‘s learning progress. This could be an area for further exploration when targeting training and resources for example.

As outlined in Chapter 2, previous research highlights the need for information and communication to be provided to parents in an accessible format. My findings indicate that where parents had a positive relationship with a key worker, based on mutual respect, who was accessible to them, they would seek support from them to understand information. My research contributes to existing literature by suggesting that in order to facilitate support, expectations between parents and professionals need to be aligned when planning takes place, so that support is rendered more meaningful and less threatening.

6.3 Methodological reflections

I will now reflect upon and consider the main limitations of this study.

The aim of this study was to explore the lived experiences of parents with LD, and essentially what I presented in this study were the positive experiences parents reported and perceived barriers to accessing support. What I did not explore was the question of how much parents valued or actually benefitted from the support they had received from services. By focussing on what they liked and disliked about services I did not explore the importance of that service to parents and what impact maintaining or withdrawing the support would have. Future studies could overcome this through their interview design.

An inclination of people with LD to give inconsistent and contradictory responses during interviews has frequently been cited as a criticism of the use of interviews with this population (McKenzie et al., 1999; McIver & Meredith, 1998) and it has been argued that interview data, should be treated with great caution. I have endeavoured to illustrate how the use of thematic analysis (which has previously been very little applied to learning disability research), can make it possible to explore contradictions through transparency of data analysis. I have done this by placing careful consideration on every statement uttered by parents and including contradictions within the results presented.

My influence, as the researcher, on the interview situation could limit the trustworthiness of the findings of the present study. For example, my responses to statements that parents made were embedded within my knowledge and understanding of parents' experiences and assumption generated from my review of previous literature in the area. In relation to this, previous research demonstrated that in situations where parents with LD perceive a power imbalance it is very likely that they may concede to the researcher's implicit assumptions and beliefs (McKenzie et al., 1999; Meredith, 1998; Porter & Lacey, 2005). I attempted to overcome these risks by considering my own position at the outset of each interview and throughout the research process and by being mindful of my responses to parents. For example, I listened carefully to their answers, smiling at (what I judged to be) appropriate times, nodding encouragingly to show my interest and I responded to their body language, such as facial expressions; if they were to frown, I would ask if they wanted me to repeat the question, restate the question in a more simplified way or explain things more clearly, for example.

During the data analysis process, it is possible that my own assumptions and beliefs may have led to certain conclusions being drawn, while alternative conclusions were over looked (Cohen et al., 2007). However, when conducting thematic analysis, the processes of inductive and deductive reasoning (described in Section *4.8.6)* are concerned with confirming and giving reasons for (justifying) events or phenomena (Frauley & Pearce, 2007); to achieve this, I committed myself to taking an active role in the research process. I attempted to address some of the associated limitations by considering my own position at the outset and by discussing alternative interpretations of data with a second researcher who reviewed my process of data analysis.

Reflexivity is —the process of critical self-reflections on one‘s biases, theoretical predispositions, preferences" (Schwandt, 2001, p. 224). In the practice of reflexive research, within the present study, I have sought to be aware of the context in which I operate, and parents with LD live, and appreciate how these affect our understanding and accounts of research stories (Christians, 2000; Edwards & Mauthner, 2002). In order to practice a reflexive approach to research within the present study, I began by taking into account ethical considerations through completion of an Application for Ethical Review from the University of Birmingham (see Appendix Five). Researchers such as Helgeland, (2005) suggest that ethical considerations should be at the forefront of reflexive research. Furthermore, I conducted a pilot study (see Appendix Seven) to explore biases, vulnerabilities and errors. In order to further improve my reflexivity, time-allowing, I could have written my pilot study in report form, to gain feedback from my research supervisor or academic tutor, in order to generate discussion and joint reflection.

I adopted a critically reflective process of preliminary data analysis. I coded the data and developed themes, and a second researcher independently reviewed the data and confirmed the themes, with discussion and agreement reached in the small number of cases, the second researcher suggested alternatives. For example, she suggested the following:

- combining sub-themes which had significant similarity or over-lap in relation to supporting extracts;
- omitting themes which had limited or tentative supporting evidence from the data; and
- providing more contextual information to render quotations meaningful to readers.

Upon reflection, in order to further improve the trustworthiness of my findings, I could have adopted a more reflexive approach through considering the effects of personal characteristics such as age, gender and professional status on the data collected and explored this in more detail, as suggested by Mays and Pope (2000).

As Whitely and Prince (2006) point out, findings from a study based on exploratory case study design may be translated to ‗answers‘ to research questions which are not definitive by their very nature. However, I would argue that the findings of the present study make a significant contribution to our knowledge in the area of learning disability and attest to the usefulness of case study design, interview methods and thematic analysis, which contribute a viable approach to researching the views and experiences of parents with LD.

In Chapter 4 the critical realist view that reality is stratified was introduced and in Chapter 5 this was discussed in relation to the findings presented. The limitations of adopting this view of reality will now be considered. One difficulty associated with viewing reality as multi-layered is the associated difficulty with making predictions (Danermark, 2002). As we move up the strata of reality from the empirical, to the actual, to the real, we move towards an increasingly complex interplay of mechanisms, where reality depends on so many factors that it becomes impossible to make predictions. What I have sought to do in the present study is not to give predictions but to provide knowledge about mechanisms and tendencies which affected the views and experiences of service provision for the parents interviewed in this study. Therefore, the central conclusion here is not to advise support services that if they want to achieve success, they have to do ‗x‘ but that my research is a base for knowledge.

From a critical realist perspective, a key finding from this study is that in order to inform practice in the area of support for parents with LD, there is a need for interdisciplinary research and theory development. In order to fully investigate the views and experiences of parents with LD, there is a need to explore and understand mechanisms operating at different levels which affect parents with LD, such as mechanisms operating at a:

- systemic level: resources and training for support service professionals to enable person-centred planning and enable services to support the increasing number of parents with LD;
- social level: developing parental access to support groups within the local community and facilitating community awareness to reduce stigma;
- psychological level: enabling parents with LD to feel valued and supported and supporting them to build relationships with support staff based on trust and respect; and.
- language level: communicating with parents in a way which is accessible to them.

Understanding which mechanisms affect this area of study highlights the importance of interdisciplinary work (Danermark, 2002). Danermark (2002) discusses the way in which a CR framework may lay the foundations of interdisciplinary research, an approach which was adopted by Bhaskar and Danermark (2006) in a study of interdisciplinarity and disability.

Although considered an adequate size for case study research for reasons discussed in Section *4.5,* there is the possibility of bias inherent in this small sample. For example, it could be suggested that parents who agreed to take part in this study held particularly strong beliefs about their experiences of support, or had strong views regarding practitioners with whom they had been involved. Such a selection bias may have contributed to the largely negative view of support received to-date by this sub-set of the LD parent population in Newtown.

In relation to the rational for using a small sample, provided in Chapter Four of the present study, I will now comment on the generalisation and utility of the findings. The findings of this study add to the existing theory base through the contribution of a number of functional findings. The findings can be used to initiate further study as indicated above in Section 6.2. A review of the existing literature on parents with LD has highlighted that only a limited theoretical knowledge exists concerning the views and experiences of parents with LD. Thus, the inductive research strategy adopted in the present study and the immersion in rich case data has enabled theory development from the data; providing a valuable starting point for theory generation and the refinement of existing theory by highlighting current gaps in knowledge.

6.4 Implications for practice

During the planning of this study, the professional roles of services involved in supporting families affected by LD were considered within the policy context set by the 2010 Coalition Government‘s Green Paper "Support and Aspiration: A New Approach to Special Education and Disability" (DfE, 2011). The vision of The

Green Paper is ~~to~~ provide the best quality of life possible to the most vulnerable children and young people in our society… identify and meet children‘s needs early by ensuring that health services and early education and childcare are accessible to all children; work in partnership with parents to give each child support to fulfil their potential; and join up education, health and social care to provide families with a package of support that reflects all of their needs” (section 5). This message builds on key points raised previously in policies such as *Valuing People* (DoH, 2001) and *Valuing People Now* (DoH, 2009) and suggests that support for vulnerable children is best achieved through:

- better coordination of services;
- more transparency in the provision of services; and
- parents having real choice over their child‘s education and the opportunity for direct control over support for their family.

During the design, implementation and writing of this research, Newtown was subject to a comprehensive spending review, resulting in significant cuts within the public and voluntary sector. These changes raise questions about how support services for parents with LD will be affected and how guidance outlined in the SEN Green Paper (DfE, 2011) to support vulnerable children and young people will be implemented successfully. Within this political and economic context, it is my view that the findings of this study provide potentially useful information for the development of support for families headed by parent/parents with LD.

For example, to increase parental confidence and give parents with LD ‗real choice‘ over support for their family, consideration of the training needs and professional supervision of practitioners has been highlighted as an important factor (Cambridge & Carnaby, 2007; Taylor et al., 2009). Training for practitioners who support parents with LD and their families could be modified to address ways to develop positive working relationships with parents more comprehensively and to overcome barriers faced by parents with LD accessing appropriate support (Melville et al., 2006).

Sharing research findings, alongside the lived experiences and life stories of service users with practitioners, may help to raise practitioner awareness of the values, thoughts, beliefs and experiences of the people with whom they work. Providing practitioners with knowledge of the historical and current political and local contexts in which parents with LD have lived or do live, may also raise practitioner awareness of some of the assumptions and expectations that parents may have (Traustadóttir & Sigurjónsdóttir, 2010). Such training should aim to prepare practitioners to plan and deliver better support for parents with LD.

The training needs of practitioners supporting parents with LD must be considered within the economic climate described previously. As a result of economic pressures, support services often lack the time and resources to support vulnerable families, due to insufficient numbers of staff in the field, whilst the numbers of parents with LD known to services is continuing to increase. For example, in their recent study, Jingree and Finlay (2011) explored how the phasing out of services for these adults has served to disempower adults with LD, limiting their choices and access to support.

In Newtown specifically, support services have been affected by the economic decline which has led to increased demands on reduced services. For example, P4 in the current study had received support for eight years from a voluntary organisation which supports families headed by parents with LD in Newtown. During a discussion with the family‘s key worker from the voluntary organisation, she explained that due to the reduction of staff numbers (due to budget reduction); she was no longer able to support P4‘s family, even though she strongly felt ‗they still needed it.‘ Shortly after the withdrawal of this support and after the completion of this study, the family became subject to child care proceedings; subsequently, P4‘s son has been removed from her care. Although this may not have been directly linked to withdrawal of support from the family, it may have been a contributing factor.

A research project by Scope has identified an approximate 11% cut to social care services for adults and children in Newtown in 2011 (Wood et al., 2011). The increasing demands placed on services and the associated stress caused calls for a closer examination of the training needs and support of practitioners.

In consideration of the increasing pressures placed on support services, there is no clear-cut answer to how these pressures can be mediated whilst improving service delivery to parents with LD. Newtown support services could refer to research such as Wood et al., (2011) who provide several case examples of local authorities who use increasingly innovative approaches to supporting vulnerable families. For example, they identified common elements such as:

- **Coproduction**: involving service users in designing and planning their services, and in some cases delivering them. Interestingly, this approach to service design and delivery is one that all parents in the present study highlighted as an essential element of effective support. For example, P3 talks favourably about her family support worker because *“she helps me the way I want her to help me.”*
- **A capabilities approach to disability**: looking at people‘s strengths and promoting what they can do, rather than a deficit model, which focuses on what people cannot do for themselves. All parents in the present study suggested that support they received focussed on their deficits as a parent. For example, P2 mentioned feeling blamed for not being able to help her child read (see Box 5.1) and P4 reported a list of things which support service professionals had given her to improve, such as housing conditions.
- **A strategy of progression or „just enough support’**: a model in which people gradually rely on less formal services and more community-based support.
- **A move towards more integrated services**: bringing in care, health and often housing and leisure. *Valuing People* (DoH, 2001) highlighted the need for a move towards integrated services over a decade ago. All of the parents

in the present study highlighted a lack of coordinated supported between health, child and adult support services. For example, they all reported having no support before the birth of their child.

- **A commitment to personalisation**: not as a cost-cutting measure, but as a foundation on which these other strategies can be built. The importance of person-centred planning was highlighted in a review of policy in Chapter Two of the present study. All parents interviewed placed importance on being listened to, being treated with respect and having their opinions valued by professionals (see Box 5.1).

6.4.1 Implications for the practice of educational psychologists

The British Psychological Society (2006) comprehensively defines the core functions of the EP role as —consultation, assessment, intervention, research and training, and identified these functions at the levels of the individual child/young person, the group (for example, class group, family), and the organisation (for example, the school, the local authority)" (p. 72). A potential advantage of the breadth of EP work is the contingent ability to facilitate the responsiveness of support services across health, education and social care to the needs of those who are most vulnerable.

A key finding of the current study is that the parents interviewed wanted their opinions to be valued, wanted to feel respected and to feel in charge of what happens to themselves and their families. As outlined in Chapter Two of this study, policy such as *Valuing People* (DoH, 2001), *Valuing People Now* (DoH, 2009) and *The Good Practice Guidance* (DoH, 2007) suggests that this is achievable through person-centred planning. Recent research conducted by Espiner and Hartnett (2012) suggests that person-centred planning involves deep, active listening techniques and an in-depth understanding of group dynamics. Their research concluded that more attention should be given to the facilitation of the person-centred planning process. Espiner and Hartnett (2012) suggest the need for skilled independent facilitators to enable the viewpoints of parents with LD and support service professionals to be heard. With consultation skills being specifically taught in EP training and further developed in EPs' professional practice (Kennedy et al., 2009), it can be argued that they have many of the skills required to facilitate person-centred planning by providing training for support service professionals, as described by Espiner and Hartnett (2012). EPs should be seeking ways to apply psychological frameworks such as consultative models of service delivery, to promote understanding and an awareness of the needs of families headed by a parent with LD.

In relation to facilitating support for parents with LD and their families, EPs will have to ensure that they continue to provide:

- a clear understanding of the particular context in which they are being requested to provide input and its relation to the broader context of the community and national setting, which could be achieved through data collection methods;

● skills in working with multi-agency professionals across both child and adult services, whilst capitalising on the skills and knowledge of other staff from a range of different professional backgrounds such as health, education and social care; and

● mechanisms for evaluating the work in which they are engaged so as to make most effective use of their professional expertise.

Newtown is still in the midst of developing responses to cuts to public sector funding following the 2010 election of the Conservative- Liberal Democrat Coalition Government and embedding new strategies to support parents with LD and their families. A first step to which EPs may be able to contribute may be to harness their research skills in developing more effective ways of gathering local data to identify Newtown‘s local population of parents with LD, and the impact service adjustments are having on this group. Local impact assessments must be based on a robust understanding of what is happening and a recognition that cuts spread across several service areas can create a much larger cumulative effect on individual families than service managers might have predicted or be aware. Without this level of assessment, further cuts and contingent reductions to levels of service provision will be made with an incomplete understanding of their effect, leaving already vulnerable families at increased risk.

6.5 Final comment

The findings of this study have addressed the research questions, highlighting the experiences and views of a small number of parents with LD in Newtown through the use of exploratory case study methodology. Within a critical realist framework, the present study has explored the interaction between a number of mechanisms which contribute to effective outcomes for parents with LD, their children and their families, whilst considering the implications of the local context and socio-political landscape.

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Appendix One

Public Domain Briefing

BEING A PARENT WITH LEARNING DIFFICULTIES: AN EXPLORATORY STUDY OF PARENT'S VIEWS AND EXPERIENCES OF LOCAL SUPPORT SERVICES

Context

This research was conducted within the supervised professional practice component of the curriculum of my programme of postgraduate professional training in Applied Educational and Child Psychology at the University of Birmingham. The study was completed with the support and agreement of Newtown Inclusion Support Service.

Introduction

The Department of Health (2001) defines learning difficulty (LD) as the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), all of which started before adulthood, with a lasting effect on development" (DoH, 2001, p.14). The New Labour Government White Paper, *Valuing People* (DoH, 2001) groups people with LD into those with mild or moderate learning disabilities" and those with severe and profound learning disabilities" (DoH, 2001 p.14). Individuals identified as having severe LD are those who require a significant amount of support with day-to-day life, whilst those with mild or moderate LD are able to live independently with support.

The number of parents with LD within the UK is currently unknown; Hatton and Emerson (2008) in their work for the Department of Health estimated that there were 828,000 adults with a LD in England. Despite not knowing the number of parents with LD in the UK, it is believed that this population is steadily rising (Ward & Tarleton, 2007). Both child and adult support services may find it challenging to appreciate and consider the needs of parents with LD and ensure the human rights of adults with LD and their children are being upheld.

Research Aims

The study aimed to explore parents' views and experiences of local support services, highlighting examples of good practice and positive experiences of parents with LD as well as exploring some of the needs and the challenges which they faced, with the further aim of informing practice with the research findings.

Key research questions were formulated within a critical realist epistemological framework and with reference to existing literature. The key research questions are:

- How do parents with LD consider that they have been supported so that they are secure in their parenting role?
- How do parents with LD report that they are supported to meet their children's needs?
- What are some of the barriers to parents with LD receiving support?
- In parents' views, how may these barriers to support be overcome?
- What positive experiences of support services do parents with LD describe?

Methodology

The study employs a case study methodology to gather qualitative data from multiple cases. Here, the ‗cases' comprises a sample of four parents (1 father and 3 mothers) with learning difficulties from Newtown Local Authority. I chose to use semi-structured interviews as a means to explore how parents with LD view their experiences and the world around them.

This research was given full ethical approval from the Ethics Committee at the University of Birmingham with particular attention given to gaining informed consent and ensuring anonymity and confidentiality.

The method used to analyse the data collected in this study is known as thematic analysis (Braun et al, 2006). This involved transcribing the interviews and subjecting them to qualitative analysis were I looked for themes within each person's transcript and across the four parents' responses.

Key Findings

Facilitators to support	*Barriers to support*
positive relationships with support workers	Three parents report not feeling valued in multi-agency meetings and subsequently they took on either a passive role or an aggressive role.
Positive relationships with professionals made them feel valued and respected as parents	Not enough time was spent by professionals with families.
Most parents were content with the information and support provided by school staff	No support from professionals during pregnancy
All four parents reported attending multi-agency meetings	Managing children's behaviour, health and learning is a concern for all of the parents
Most parents were able to identify a particular practitioner or agency that they had found helpful since the birth of their children	Parental engagement with support services appears to be limited by difficulties with communication between parents and services.
All parents referred to their family network as being a particularly positive part of their lives	Respect and value parents opinions and choices

Areas for development

Support for families of parents with LD should be person-centred, better coordinated, with parents having more control and choice over support for their family. Within the current political and economic landscape, this might be achieved through consideration of the following:

- **Coproduction**: involving service users in designing and planning their services, and in some cases delivering them.
- **A capabilities approach to disability**: looking at people‘s strengths and promoting what they can do, rather than a deficit model, which focuses on what people cannot do for themselves.
- **A strategy of progression or „just enough support’**: where people gradually rely on less formal services and more community-based support.
- **A move towards more integrated services**: bringing in care, health and often housing and leisure.
- **A commitment to personalisation**: not as a cost-cutting measure, but as a foundation on which these other strategies can be built around.

Questions.

Appendix Two

Developmental Tasks

Some examples of developmental tasks to be achieved at different stages are summarised by Masten et al., (2009).

Stage	Description
In early childhood	Forming attachment bonds with caregivers. Talking and learning the native language of the family; and complying with and following simple adult commands
In middle childhood	Learning to count, read, and do basic mathematics; Getting along with peers at school and making friends; and Engaging in rule-abiding behaviour at home and school.
In adolescence	Achieving academic success in more advanced topics; Graduating from high school; Making and maintaining close friends; and Learning and following the rules and laws that govern conduct in society
In early adulthood	Achieving higher education or vocational training; Gaining employment or other kinds of work; Forming a romantic or marital partnership; Engaging in responsible sexual behaviour; and Parenting effectively when one becomes a parent.

Appendix Three[5]

Accessible Information Sheet

(Adapted from Lacey, 2009)

- I am conducting a research project.
- I want to find out about more about parents and families with learning difficulties and the support they get.
- I would like to do an interview with you that will last about 30 minutes. **30:00**
- I can meet you at home or at your child's school.

- I would like to record the interview.
- I will meet with you a second time to share my findings when the project is finished.
- I hope you can help with the research.
- I will ask you what you think about the support you get from different people.
- Taking part in this project will not affect help you get from any services.
- You can contact me at any time if you do not want to be part of the project anymore. My contact details are at the bottom of this page.
- The information you give me will be private.
- If you tell me something that could harm you or someone else, I will need to tell someone to get some help.
- If you would like to take part in the research, please sign the consent form or ask someone to sign it for you.

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[5] Formatting has changed due to thesis presentation requirements

- You can ask me about the project at any time. My contact details are at the bottom of this page.

- You can ask the person who told you about the project questions about it.

- I am a research student so I have a supervisor at work. You can talk to my supervisor at any time. Here are her contact details: ___________________.

Sabreen Athwal

(Contact Details)

Thank You

Appendix Four

Details of participants considered for inclusion in research

	Participants			
	1	**2**	**3**	**4**
Gender	Female	Female	female	Male
in Newtown;	Yes	Yes	Yes	Yes
are over the age of 18 years	Yes	Yes	Yes	Yes
are a parent	Yes	Yes	Yes	Yes
live independently	Yes	Yes	Yes	Yes
are accessing a support service	Yes	Yes	Yes	Yes
describe themselves as having mild learning difficulties	Yes	Yes	Yes	Yes
had attended a special school, special classes in a mainstream school or had extra support in mainstream classes when they were younger	Yes	Yes	Yes	Yes
no known additional confounding variables such as on-going court proceedings	No - Undergoing court proceedings	Yes	Yes	Yes
met ethical criteria presented	Yes	Yes	Yes	Yes
Representative	Undergoing court proceedings for second time	Yes	Yes	Had displayed violence/aggression towards support staff in the past
Included in study	No	Yes	Yes	No

	Participants			
	5	**6**	**7**	**8**
Gender	Female	Female	Female	Female
in Newtown;	Yes	Yes	Yes	Yes
are over the age of 18 years	Yes	Yes	Yes	Yes
are a parent	Yes	Yes	Yes	Yes
live independently	Yes	Yes	Yes	Yes
are accessing a support service	Yes	Yes	Yes	Yes
describe themselves as having mild learning difficulties	Yes	Yes	Yes	Yes
had attended a special school, special classes in a mainstream school or had extra support in mainstream classes when they were younger	Yes	Yes	Yes	Yes
no known additional confounding variables such as on-going court proceedings	Yes	Yes	No – mental capacity. Seeking help for depression.	No – undergoing court proceedings
met ethical criteria presented	Yes	Yes	Yes	Yes
Representative	Yes	Yes	Yes	Yes
Included in study	Yes, but faced some personal difficulty so were not included in the final sample. They withdrew at interview stage.		No	Yes

	Participants			
	9	**10**	**11**	**12**
Gender	Female	Male	Female	Female
in Newtown;	Yes	Yes	Yes	Yes
are over the age of 18 years	Yes	Yes	Yes	Yes
are a parent	Yes	Yes	Yes	Yes
live independently	Yes	Yes	Yes	Yes
are accessing a support service	Yes	Yes	Yes	Yes
describe themselves as having mild learning difficulties	Yes	Yes	Yes	Yes
had attended a special school, special classes in a mainstream school or had extra support in mainstream classes when they were younger	Yes	Yes	Yes	Yes
no known additional confounding variables such as on-going court proceedings	Yes	Yes	Yes	Yes
met ethical criteria presented	Yes	Yes	Yes	Yes
Representative	Yes	Yes	Yes	Had English as an additional language
Included in study	Yes – but withdrew at interview stage	Yes – recruited after others withdrew	Yes - recruited after others withdrew	No

Appendix Five

Application for Ethical Review form

Relevant extracts from my application for ethical review have been included below. A full copy can be made available upon request. Appendices have not been included but are also available upon request.

1. **RECRUITMENT**
   Please state clearly how the participants will be identified, approached and recruited. Include any relationship between the investigator(s) and participant(s) (e.g. instructor-student).

Potential participants will be identified through professionals working with parents with learning difficulties such as fellow educational psychologists, and adult support services such as [redacted] or [redacted], who will be asked to identify potential participants within one local authority.

Professionals will be informed about the aims of this research and shown the research information sheet (see Appendix Three) and asked to approach individuals whom they judge will be suitable for this study.

Therefore, firstly parents will be informed about the research by professionals who are currently or used previously to be involved in their care, an approach advocated by Fry (2007) and Booth and Booth (1994). The information sheet will then be given to the individuals who meet inclusion criteria by their key professional who will discuss this with them in detail to ensure a clear understanding of the key aims. They will be asked if they would be willing for a researcher to contact them to arrange a meeting to discuss the research in more detail.

I will accept parents in the order in which I receive notification of their provisional agreement to participate in this research.

If more than six parents signal agreement, I will provide the key worker with a short letter expressing thanks to the parent, explaining that the response rate has been excellent, exceeding my initial expectations, and asking the next four parents if they are willing for me to keep their names on a waiting list, so that, should other parents drop out, I can contact them again to take up their generous offer of participating in the study.

2. **CONSENT**
   a) Describe the process that the investigator(s) will be using to obtain valid consent. If consent is not to be obtained explain why**.** If the participants are minors or for other reasons are not competent to consent, describe the proposed alternate source of consent, including any permission / information letter to be provided to the person(s) providing the consent

The importance of ensuring individuals with learning difficulties are supported in developing a full and accurate understanding of their participation in research has been highlighted (Arscott et al., 1998). The ESRC framework (2010) suggests that in cases where research involves potentially vulnerable groups such as children, older persons or adults with learning difficulties, every effort should be made to secure actively and freely given, informed consent from individual participants. In order to help me achieve this, I sought guidance from experienced researchers within the university. Through discussion I was able to gain a deeper understanding of how to communicate with this group in an accessible way.

I have taken into consideration suggestions and comments made about conducting research with parents with learning difficulties and incorporated this into my planning.

In relation to the ESRC guidelines, for this study firstly parents will be informed about the research by professionals who are currently, or who, in the recent past, have been involved in their care: an approach recommended by Booth and Booth (1994).

An accessible information sheet and consent form (see Appendices Three and Four) will be given to the individuals, who will be asked if they would be willing for a researcher to contact them to arrange a meeting to discuss the research in more detail. If parents are still interested in participating in the research, an appointment will be arranged for them to meet with me to review the information sheet about the research project and to address any questions or concerns they may have.

In order further to ensure that the parents understand what they are consenting to, the topic areas which the interview will probe will be shared with them, discussed and they will be asked if they are happy to talk about these things in detail with me, and for me to record their answers so that they can be included in the findings of this research project, shared with other professionals anonymously and published within the public domain.

Booth and Booth (1994) advocate an approach to working with adults who have learning difficulties which is self-developing, in that it is important to begin without fixed assumptions about the person‘s ability to understand what is being asked of them. Instead, we need to build rapport and adapt our style or language as we go on to suit the needs of the participant. This dynamic and responsive approach to conversation with both adults and children is a core skill that I have developed under supervision, within my current role as a trainee educational psychologist, and where I consider my skills secure.

Many parents with learning difficulties are at risk of or lose custody of their children. Therefore, discussing experiences of parenthood can be an emotionally arousing and sensitive topic. In line with BERA ethical guidelines (2004) interviews will be conducted with this in mind and I aim continually to observe the emotional responses of participants, and to adjust my questioning in order to minimise risks of evoking fear or distress.

If any emotional distress is communicated, the interview will be terminated, and I will ensure that appropriate support is provided thereafter by the key worker, myself, or other workers (such as a designated member of school staff) with whom the parent has a good working relationship, to ensure full debriefing and after-care to address any residual distress.

As suggested in the BPS Code of Ethics and Conduct (2009), I will receive supervision from an Educational Psychologist and University Tutor throughout the research to guide any decision-making, along with continuing access to support and guidance from university staff

Parents will be debriefed at the end of the interview by reviewing the information and consent forms. The participants will be reassured that all information used in the study will be anonymous. Participants will also be informed of their right to withdraw at any time up to the point of publication, and to request that their interview responses and other information relating to them be deleted from the data corpus.

3. PARTICIPANT FEEDBACK

Explain what feedback/ information will be provided to the participants after participation in the research. (For example, a more complete description of the purpose of the research, or access to the results of the research).

Provision of feedback is integral to the research process (Fry 2007). Parents will be provided with feedback in a one-to-one setting with me.

Where possible, visual methods, such as force field analysis, will be used to feed back a summary of the findings. Force field analysis looks at forces that are either driving movement toward a goal (helping forces) or blocking movement toward a goal (hindering forces) and can be presented pictorially on one sheet of A4 paper (see Appendix Five). Short sentences with simple language will be used to feedback findings and accompanying pictures will be added where appropriate, as suggested by Lacey (2009).

The approach to feedback for parents will be one of –here‘s what I think/found...what do you think?” This will check reliability of findings, and aims to encourage each parent to volunteer further feedback. This feedback will involve a general summary of the findings; data from individual parents will not be shared.

Findings will be presented to *Options for Life* and *Parent Partnership* representatives who will be invited to attend a presentation about the research. This will involve a general summary of the findings and will not discuss data from individual parents.

4. PARTICIPANT WITHDRAWAL

a) Describe how the participants will be informed of their right to withdraw from the project.

The information sheet/consent form (see Appendices Three and Four) outline parents‘ right to withdraw at any point during the research.

This will also be explained to them by me at the first point of contact and prior to interview.

The right to withdraw will be explained to any referring agency involved in the study, which may be approached by participants wishing to terminate their involvement. It will be explained that participants do not need to give a reason for their withdrawal and can do so at any point up to publication.

b) Explain any consequences for the participant of withdrawing from the study and indicate what will be done with the participant‘s data if they withdraw.

There will be no consequences for participants withdrawing from the study. Any responses given will not be included in the final study and will be deleted.

Data it will be stored in a safe and secure manner, in line with the requirements of the Data Protection Act (1998). No personal data will be stored against tape recordings.

Once the research has been published and passed, written notes and tape recordings will be stored for 10 years per University of Birmingham requirements on the university network and deleted thereafter.

5. CONFIDENTIALITY

Information will be kept confidentially. Participants will be assigned an identity code which their interview data will be stored against. Participants will be referred to by their ID code only, during feedback and in the final written report.

The only record of names will be on consent forms but these will be stored separately from data and in a secure place.

It will be made clear that individual views will be presented collectively in a research paper (BPS Code of Ethics and Conduct, 2009). It will not be possible to identify individual views from the research paper.

It will be explained both through the information sheet and consent form (see Appendices Three and Four) and in person that data will be treated confidentially. However, if information is shared that suggests that a respondent or others are at risk of harm, confidentiality will be broken and the appropriate authority informed. This is made clear in the information and consent forms and participants are encouraged to contact myself or the person who told them about the project, if they have questions regarding this.

6. STORAGE, ACCESS AND DISPOSAL OF DATA

Describe what research data will be stored, where, for what period of time, the measures that will be put in place to ensure security of the data, who will have access to the data, and the method and timing of disposal of the data.

Data will be stored in a safe and secure manner, in line with Data Protection Act (1998). No personal data will be stored against tape recordings or written notes.

Whilst the data are being used they will be stored in a locked cabinet. Only I will have access to the raw data. If data are to be shared with any other person, such as, my supervisor, they will be shared anonymously.

Once the research has been published and passed, written notes and tape recordings will be stored for 10 years per University of Birmingham requirements on the university network and deleted thereafter.

7. RISKS

a) Outline any potential risks to **INDIVIDUALS**, including research staff, research participants, other individuals not involved in the research and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap

Many parents with learning difficulties are at risk of losing custody of their children (Fry, 2007). Therefore, discussing experiences of parenthood can be an emotionally arousing and sensitive topic. Interviews will be conducted with this in mind and terminated if a participant finds the process emotionally distressing.

I will receive supervision from a senior educational psychologist and university tutor throughout. Supervision will be used for reflection on the position of research participants and their emotional responses to minimise potential feelings of incompetence, powerlessness, threat or distress.

All participants will be debriefed ensuring they received appropriate support, if required. The participants will be reassured that all information used in the study will be anonymous.

Participants will be informed of their right to withdraw at any time up to the point of publication.

All research can develop in ways that raise unforeseen ethical challenges; this will always be discussed through supervision and further advice or guidance will be sought, if required, through The University of Birmingham‘s Ethics Committee, in the first instance.

Once risks have been identified, I would ensure that these are discussed with research participants in order to secure valid consent (ESRC framework, 2010).

The above risks will be discussed with participants prior to interviews being conducted so they are able to use reasoned judgement to decide whether or not they wish to participate.

Appendix Six

Consent Form

(Adapted from Lacey, 2009)

My Name is:____________________

Please circle your answer to each question

1. I would like to be in the research project	Yes	No
2. I understand I can say I do **not** want to be part of the project at any time	Yes	No
3. I am happy to answer questions about myself and my family	Yes	No
4. I am happy to have my answers recorded	Yes	No
5. I am happy for my answers to be put in a report and shared with other people	Yes	No
6. I understand my answers may be used in the report but my name will not be used	Yes	No
7. If I have a question, I know who to ask	Yes	No
8. I understand that if I say something that could harm someone, you will need to tell someone to get some help.	Yes	No

If you are signing for someone else, please write your name here:

Appendix Seven

Pilot feedback on interview schedule

Draft One Interview Schedule

Themes for the semi-structured interview

Research aim: to gain insight into the experiences of parents with learning difficulties and their views of the support they have received from local services.

Rapport Building

Theme One: Being a parent

Areas for exploration:

- How do parents frame their responsibilities and needs?
- How do parents conceptualise their competencies?
- How to parents choose the approaches they use?
- What are parents; sense of self-efficacy?

Example Questions: What is hard about being a parent? Prompts: What is good about being a parent? What are you in charge of? What do you try to make sure your child has?

Theme Two: Experience of Support Services:

Areas for exploration:

- What local support services do parents access?
- How did parents get involved with them?
- How have these services supported the family so far?
- Do families think agencies share information with each other?
- How would parents describe the services? (sensitive, respectful, clear to understand?)
- What are some barriers to accessing services?
- Is communication good, honest and open?

Example Questions: Which services do you use? How did you find out at about them? What do they help you with? Where do you meet them? How often do you speak to them? Do you trust them? Do you understand the things they tell you?

Theme Three: Equal Opportunities:

Areas for exploration:

- Ask parents to describe their experience of becoming and being a parent.
- Do parents feel treated the same or differently from other members of the community?
- Are they independent in their own view?

- Do parents have choice over things like housing, deciding to be a parent etc?
- Are parents given the option to work, learn, get about, meet people etc, if they are capable of doing so? What support do parents get for this?
- What are some of the parent‘s strengths as a parent?
- Do parents feel empowered?

Example Questions: How did you feel when you found out you were going to be a mum/dad? Did anyone offer you help when you found out you were going to be a mum/dad? Who do you live with now? Who helped you get this house/home? Do you work? Would you like to work? What do you like to do for fun? Are you part of any groups where you can meet new people? Do you drive? How do you travel around?

<u>Theme Four: Addressing children’s needs:</u>

Areas for exploration:

- Parents tell me about what areas they feel they need help in at the moment
- What are parents‘/families‘ individual needs?
- What are the children‘s needs? Do parents feel they understand their children‘s needs?
- Who has helped parents get support for their children‘s needs?
- What are some of the barriers to parents getting the support they need for their children?
- Have parent ever sought help for something? what happened? How do parents find access information/help?
- Are schools informed on the family‘s needs and do they respond supportively?
- Do families have a close partnership with the schools their children attend?
- Is person-centred planning taking place?

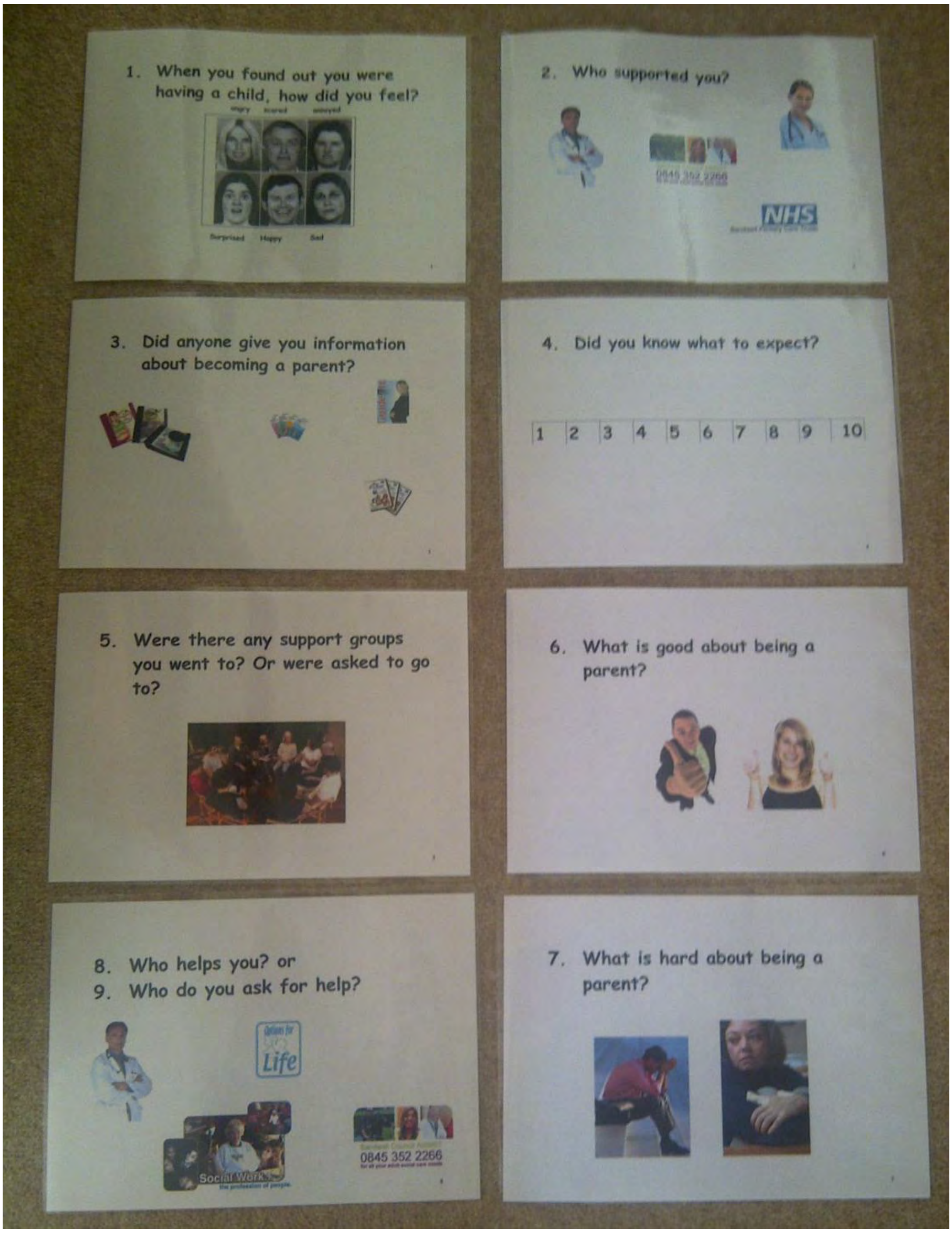
Example Questions: Are there things you would like more help with right now? What things does (child‘s name) need help with? Who helps you/him/her with that? How often do you talk to (child‘s name)‘s teacher? Do you go to many meetings at school? Who else goes to the meetings? What do you talk about at these meetings? How happy are you with the support school gives you? Do you think you should get more help? How come you don‘t? When you need help, where do you go?

Pilot Feedback

Feedback from MH and SN (OfL caseworkers)	**Changes made to draft one of interview schedule to create final draft**
1. Visual prompts might be helpful to augment the questions being asked verbally. They suggested having the question written down for parents to see and refer to and also that pictures are used to aid understanding 2. Questions need to be broken down e.g. which services do you use? Could become ‗who helped you?‘ with images of professionals or professional logos that parents might be familiar with 3. Fewer questions should be used, no more than 30 to avoid overwhelming the parents 4. Questions need to be focussed and concrete so that parents understand what is being asked of them and they are able to answer as fully as possible 5. Start with an easy question to get parents talking, what is hard about being a parent is too ‗loaded‘ and too much too early 6. Help with ordering questions and refining wording of questions was given	1. Each question will be presented on A4 paper, landscape, with a clear and easy to read font available for parents to read. I will look for pictures, photos where possible to aid understanding. 2. I think scaling could be used for some questions as a way for parents to describe their feelings. 3. I will spend more time working on developing short sentences with simple language to use. 4. I will refine my questions so that my research questions are addressed appropriately and the interview schedule is more focussed and shorter 5. I‘ll start with asking parents how they felt when they found out they were having a child to build rapport after initial background conversation

Appendix Eight

Photographs of cue cards used in the semi-structured interview with parents



1. When you found out you were having a child, how did you feel?

2. Who supported you?

3. Did anyone give you information about becoming a parent?

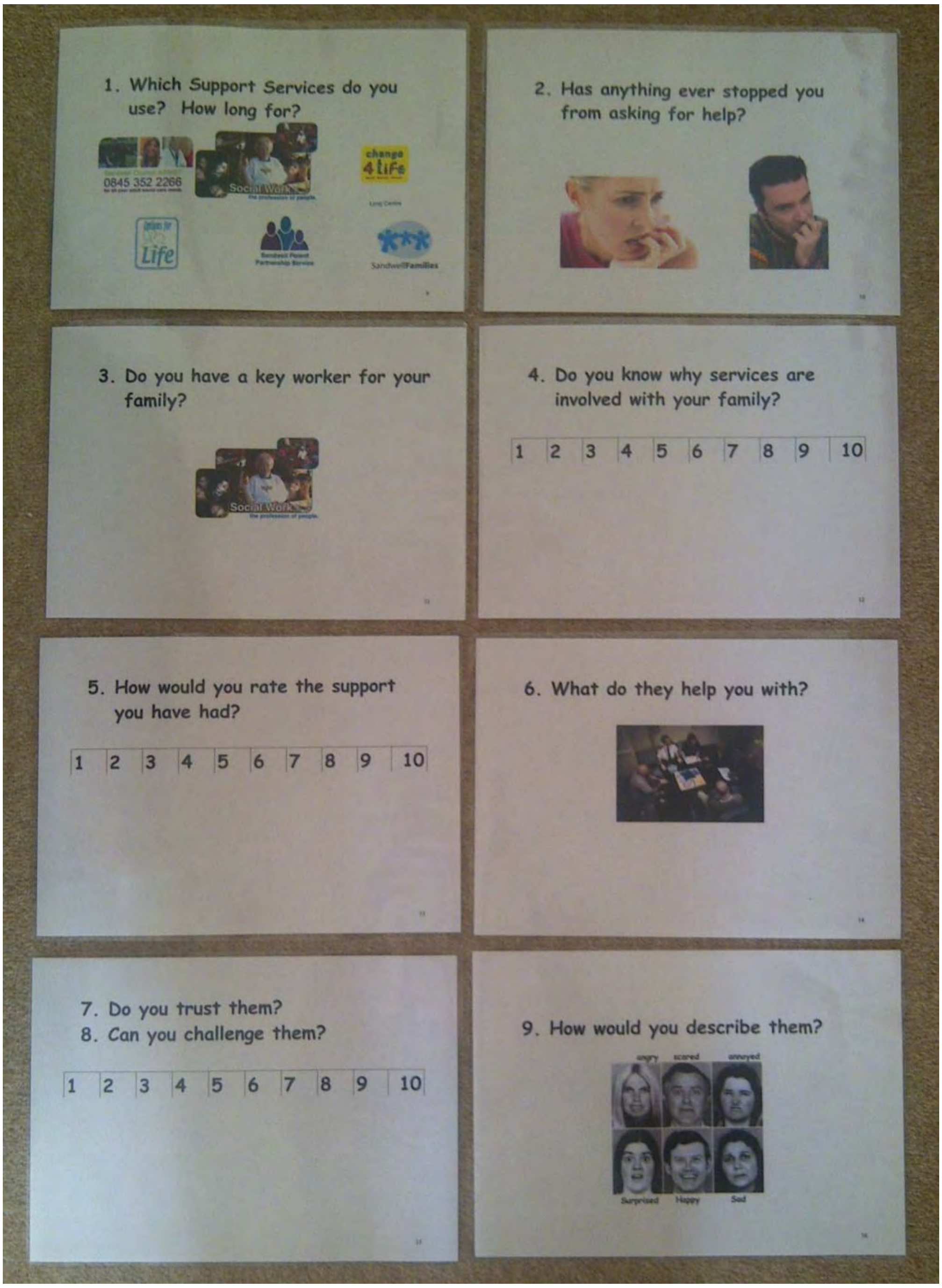
4. Did you know what to expect?

5. Were there any support groups you went to? Or were asked to go to?

6. What is good about being a parent?

8. Who helps you? or
9. Who do you ask for help?

7. What is hard about being a parent?



1. Which Support Services do you use? How long for?

2. Has anything ever stopped you from asking for help?

3. Do you have a key worker for your family?

4. Do you know why services are involved with your family?

1	2	3	4	5	6	7	8	9	10

5. How would you rate the support you have had?

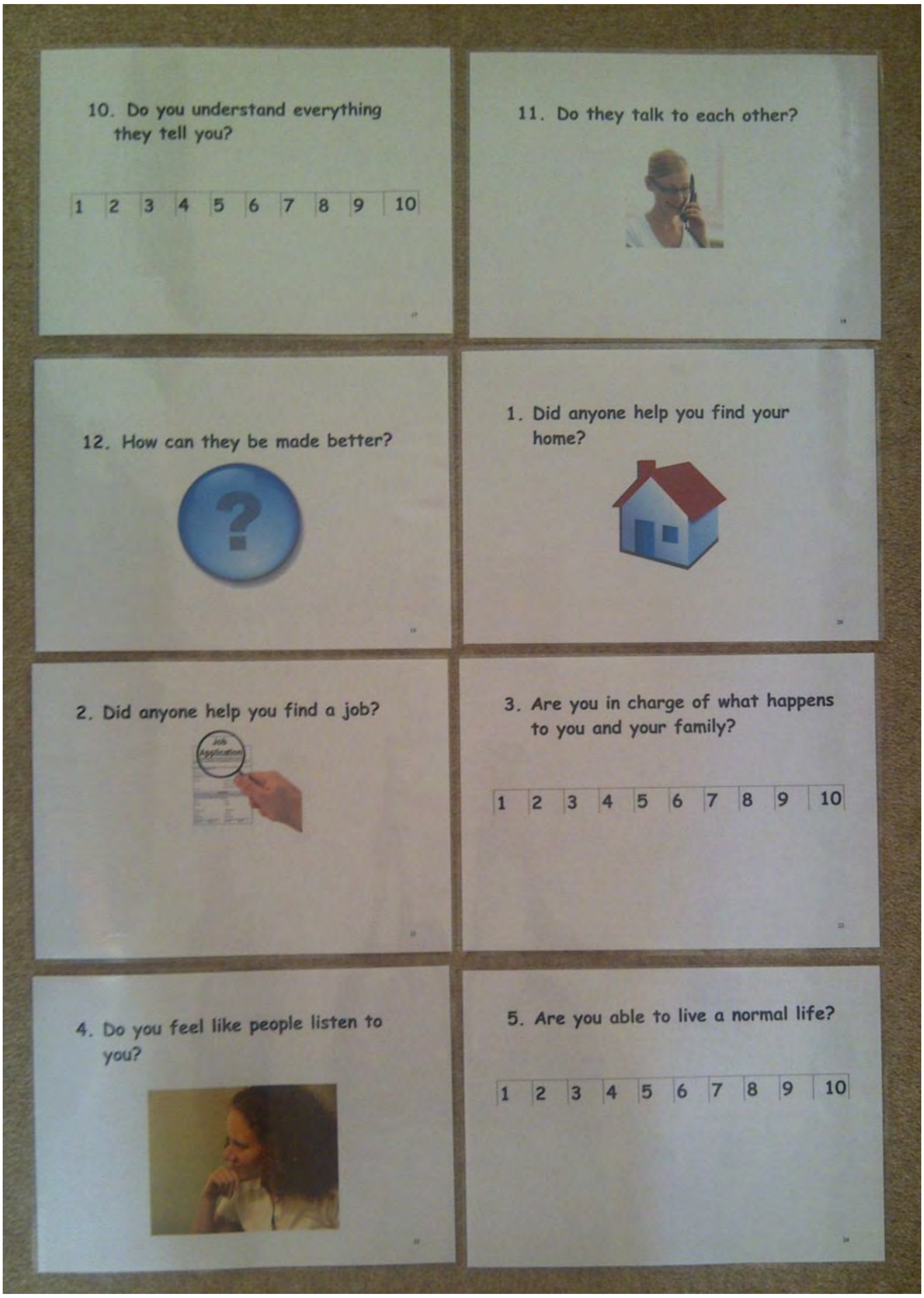
1	2	3	4	5	6	7	8	9	10

6. What do they help you with?

7. Do you trust them?
8. Can you challenge them?

1	2	3	4	5	6	7	8	9	10

9. How would you describe them?



10. Do you understand everything they tell you?

1 2 3 4 5 6 7 8 9 10

11. Do they talk to each other?

12. How can they be made better?

1. Did anyone help you find your home?

2. Did anyone help you find a job?

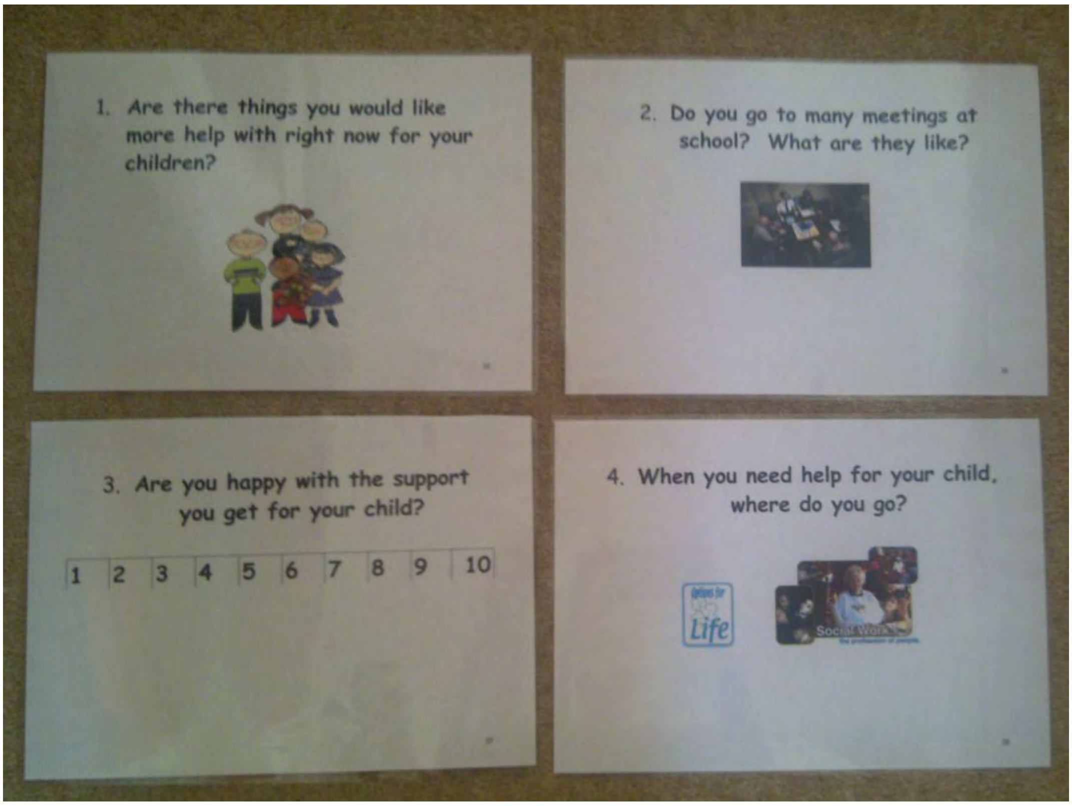
3. Are you in charge of what happens to you and your family?

1 2 3 4 5 6 7 8 9 10

4. Do you feel like people listen to you?

5. Are you able to live a normal life?

1 2 3 4 5 6 7 8 9 10



1. Are there things you would like more help with right now for your children?

2. Do you go to many meetings at school? What are they like?

3. Are you happy with the support you get for your child?

1	2	3	4	5	6	7	8	9	10

4. When you need help for your child, where do you go?

Appendix Nine

Feedback to parents

We had an interview on ________ (date)

I wanted to find out about more about parents with learning difficulties and the support they get.

I have written a report on what I found out.

Good things parents said about the support they get were:

Parents told me that good relationships with support workers is very important

Parents told me that good relationships make them feel respected

Parents told me that they are happy with the help they get from school staff.

Parents told me that sometimes they go to meetings with lots of different people there who try to help them.

Parents told me that they have one worker who has been very helpful since having a child

Parents told me that their family gives them help when you need it.

Things which need to be better are:

Parents told me that support workers did not spend enough time with them

Parents told me that sometimes they feel like no one listens to them in meetings

Parents told me that when people don‘t listen to them, they get angry

Parents told me that they didn‘t have any help before the baby came

Parents told me that they find it hard to stop their child from being naughty

Parents told me that they find it hard to understand things support workers say

Parents told me that they find it hard to read letters

Thank you for helping me get this information

I will be sharing my report with professionals to try and make things better

Appendix Ten

Extracts coded with highlighters to identify themes

Interview One

		Cycle 1 initial codes	Initial themes	Cycle 2 codes and themes
SA	So when you found out you were going to be a parent, how did you feel?			
P1	Happy	Happy when expecting	Happy when expecting	Happy when expecting
SA	Happy?			
P1	Yeah			
SA	How old were you when you had M?			
P1	Oh, about 40 weren‘t I? Coz he‘s 9			
SA	And you were really happy about that?	Happy when expecting	Happy when expecting	Happy when expecting
P1	Yeah			

SA	Excellent. And when you found out you were going to be parents, were you offered any support by anyone? Any professionals?			
P1	No, we didn‘t did we P?	No support from professionals during pregnancy	No support from professionals during pregnancy	No support from professionals during pregnancy
SA	OK. And did any professionals or anybody get in contact with you with information about being a dad? Like your Doctor or anyone?			
P1	No, none at all	No information received about parenting prior to birth	No information received about parenting prior to birth	No information received about parenting prior to birth
SA	You didn‘t get any leaflets or booklets?			
P1	Don‘t think so. I can‘t remember, can you P?	No accessible materials or information prior to birth	No accessible materials or information prior to birth	No accessible materials or information prior to birth
SA	You don‘t think so. And then, with that in mind, did you know what to expect when you were			

	going to become a dad?			
P1	Not really, no, coz it was my first time were it? It‘s something else, not really though, it‘s hard work though.	Not knowing what to expect	Not knowing what to expect	Not knowing what to expect Uncertainty/fear
SA	Yeah, I bet it is!			
P1	He was getting up early, he still gets up early now.			
SA	Yeah...			
P1	He‘s a good boy			
SA	Hmmm...so you have no problem getting him to school on time?			
P1	No, he‘s up at 5 every morning, day he P? He‘s a good boy.			
P2	He goes to bed at 8 O‘clock			
SA	So, on a scale of 1-10, 1 being I didn‘t know anything about being a dad -			

P1	No, I didn‘t know anything. No, not really, no.	Not knowing what to expect pre-birth	Not knowing what to expect pre-birth	Not knowing what to expect pre-birth Uncertainty/fear
SA	Ok, erm...so were there any support groups you went to?			
P1	No	No support groups attended	No support groups attended	No support groups attended Alone
SA	Were you invited to any support groups?			
P1	No	Not invited to support groups	Not invited to support groups	Not invited to support groups Alone
SA	No? Not by your doctor or social worker or anybody?			

P1	No?			Alone
SA	So, in your view then, what‘s good about being a parent?			
P1	Just being with him and that			
SA	Yeah, spending time with him?			Spending time with child
P1	I spend a lot of time with him and that			
P2	Fishing, yeah?			
P1	Yeah, fishing, I spend a lot of time with him and that			Hobbies, meeting the child‘s needs
SA	Fishing?			
P2	You can‘t now coz of the dark nights			
P1	We can‘t now but we do in the summer, he‘s normally with me, he ain‘t with his mum, he‘s always with me, ain‘t he? I take him out and that or... oh, her does as well, don‘t get me wrong but...			

P2	Yeah, we went Blackpool together, didn‘t we? Last week didn‘t we?			meeting the child‘s needs
P1	Yeah, we went to Blackpool			
P2	See the lights			
P1	Yeah			
SA	So, you‘ve got a close relationship with him?			
P1	Yeah, oh he‘s all dad ain‘t he P?			Nurture/love
P2	Yeah, not all me (laughs)			
SA	Ah			
P1	Yeah, coz I was at work all the while you see, so, he day see much of me when I was coming up. Coz when I come at night he‘d be asleep, wouldn‘t he P?			
P2	So, now he‘s all you			
P1	Yeah, he is now			
SA	Right...and the next question I wanted to ask you was, what is hard about being a parent?			

P1	Probably some of his tempers sometimes	Managing children's behaviour is difficult	Managing children's behaviour is difficult	Managing children's behaviour is difficult
P2	Yeah, attention a lot now he's older	Providing child with attention is difficult	Providing child with attention is difficult	Providing child with attention is difficult nurture
P1	He likes to have attention day he P?			Providing child with attention is difficult nurture
P2	Coz he can't read write, main target and he wants to learn now he's 9. He wants to learn, it's hard and I can't coz it's all change at school, I can't understand what they're doing at school. I don't know the new ru...it's changed when I was at school.	Child is struggling to achieve academically Parents difficulty in understand learning needs	Child is struggling to achieve academically Parents difficulty in understand learning needs	Child is struggling to achieve academically Parents difficulty in understand learning needs

				Feeling unsupported Anxious/worried
SA	Yes...			
P2	It‘s all changed. That‘s what‘s hard for me and him, int it?	Parents difficulty in understand learning needs	Parents difficulty in understand learning needs	Parents difficulty in understand learning needs Feeling unsupported
SA	Yeah, so your finding it hard with the way things have changed with the learning?			
P2	Hmmmm			
SA	And supporting his learning?			
P2	Hmmm			
SA	Right...erm...and you‘re finding it difficult to manage his behaviour sometimes?			

P1	Well...it‘s...sometimes			
SA	Sometimes			
P1	We just leave him and he calms himself down then	Lacking techniques to manage child‘s behaviour	Lacking techniques to manage child‘s behaviour	Lacking techniques to manage child‘s behaviour
P2	Yep			
P1	What we do ain‘t it?			
SA	Any other things your finding difficult?			
P2	We wish‘d he could read and write, M says	Parents academic ability is a barrier	Parents academic ability is a barrier	Parents academic ability is a barrier Anxious/worried
SA	He does?			
P2	It hurt...it must hurt him, hadn‘t it really?	Child‘s emotional well-being affected by parents ability	Child‘s emotional well-being affected by parents ability	Child‘s emotional well-being affected by parents ability

				Worried
SA	And do you feel like you can help him with that?			
P2	I‘ve been reading and that. He loves the pictures though. We done our best.	Parents try their best	Parents try their best	Parents try their best/lacking skills Feeling unsupported
P1	We‘ve been reading. He‘s got reading books upstairs, he reads them don‘t he?			
P2	Oh, we do his homework with him.	Parents try to support academic progress	Parents try to support academic progress	Parents try to support academic progress
P1	Yeah			
P2	Help him, it‘s easy now his homework but when he gets older, it‘ll be hard for us to do, that‘s the problem	Parents aware that their ability is a potential barrier	Parents aware that their ability is a potential barrier	Parents aware that their ability is a potential barrier Anxious and worried about the future
SA	Yeah, I can understand that			

P2	It‘s all change at school	Parents concerned about supporting child‘s learning	Parents concerned about supporting child‘s learning	Parents concerned about supporting child‘s learning
SA	Definitely, and it changes all of the time. Erm...anything else you wanted to say that you find difficult?			
P1	No...			
SA	Ok. And at the moment, who helps you when you need support? So, when you said about helping with his homework, or his behaviour, is there anybody you know you can go to?			
P1	Yeah, he goes to CAMHS and that don‘t...	Not aware of CAMHS role	Not aware of CAMHS role	Not aware of CAMHS role View CAMHS as supportive
P2	He goes to CAMHS now.			
SA	He goes to CAMHS...			

P2	He needs an injection from Newtown Hospital, but he won‘t have it done	Parents concerned about child‘s health	Parents concerned about child‘s health	Parents concerned about child‘s health
P1	Oh, he plays up, he won‘t have it done. We dunno what to do	Managing child‘s behaviour is affecting the child‘s health	Managing child‘s behaviour is affecting the child‘s health	Managing child‘s behaviour is affecting the child‘s health Anxious and worried, feeling helpless
P2	He won‘t have injections coz we‘re trying to find out if he has diabetes or not	Parents concerned about child‘s health	Parents concerned about child‘s health	Parents concerned about child‘s health
P1	That‘s when he kicks off, if he knows they‘re gonna do injections, he‘ll kick off then. He kicked off with his mum at the hospital	Managing child‘s behaviour is affecting the child‘s health, parents find it difficult to manage behaviour	Managing child‘s behaviour is affecting the child‘s health, parents find it difficult to manage behaviour	Managing child‘s behaviour is affecting the child‘s health, parents find it difficult to manage behaviour
SA	He‘s afraid of needles isn‘t he?			
P1	Yeah, he‘s having some help now.			
SA	So, what support does CAMHS give you?			

P2	He‘s going with his dad from now on...			
P1	I‘m going with him next time coz I stop with him now you see. Yeah, yeah. I have counselling anyway for mine. Coz that could help me as well, you see.	Unable to clearly explain the role of CAMHS	Unable to clearly explain the role of CAMHS	Unable to clearly explain the role of CAMHS Own mental health is a concern
SA	Do they give you help as well then?			
P1	How many times we gone?			
P2	Twice			
P1	Twice			
SA	Twice. Ok. So, you‘re involved with social services as well, aren‘t you?			
P2	They do...they came here once, didn‘t they?			
P1	Yeah			
SA	And are they giving you any support at all?			

P2	We haven‘t heard nothing from them since after that	Lack of on-going communication	Lack of on-going communication	Lack of on-going communication Feeling unsupported by SS
P1	We ain‘t heard...do they do work at the school now P?	Un-sure of role	Un-sure of role	Un-sure of role of social services
P2	I don‘t know what‘s happened			Un-sure of role of social services Feeling unsupported
SA	OK. So, if you found you were struggling with anything, do you know who you would go to for help?			
P1	Yeah			
P2	Teacher in it?	Positive relationship with teacher	Positive relationship with teacher	Positive relationship with teacher
P1	School, yeah.	Parents view school	Parents view school	Parents view school

		as approachable for help and support when needed	as approachable for help and support when needed	as approachable for help and support when needed
SA	School			
P1	School, yeah			
SA	That‘s a good idea. The next questions are about are support that you‘ve had from services like CAMHS and Social Services and anybody else you‘ve been involved with. How long have you had support from CAMHS for?			
P2	Three weeks int it?			
P1	We‘ve been twice now			
P2	Three weeks	Short-term involvement	Short-term involvement	Short-term involvement
P1	It took ‗em that long to get the paperwork done and that, day it P?			Feel they have been waiting a long time
P2	Hmmmm			
SA	And what about social services?			

P1	That‘s going back a while, ain‘t it P?			No on-going communication since initial visit
P2	About three or four months?			
P1	Yeah, Something like that			
P2	Something like that			
SA	In relation to M was that?			
P1	Yeah, because he did play up at school, when we bought him up	Aware of why services intervened Services reactive not preventative Managing behaviour remains an issue	Aware of why services intervened Services reactive not preventative Managing behaviour remains an issue	Aware of why services intervened Services reactive not preventative Managing behaviour remains an issue
SA	And you haven‘t heard anything since?			
P1	No	Lack of on-going support and communication	Lack of on-going support and communication	Lack of on-going support and communication

P2	No			Lack of on-going support and communication
SA	And do you know why they came to visit?			
P1	Yeah...coz, coz...Yeah			
P2	M plays up at school			
P1	He played up the one the one day we bought him home, we take him back to school and he did play up. But...but...We ain't heard nothing since.	Parents view the support service as reactive, only intervene if there is a problem Managing behaviour remains an issue	Parents view the support service as reactive, only intervene if there is a problem Managing behaviour remains an issue	Parents view the support service as reactive, only intervene if there is a problem Managing behaviour remains an issue Lack of on-going support and communication

SA	Did they give you any advice on how to deal with that, if it happens again?			
P1	They just give us a number didn‘t they P?	No advice or strategies offered to support the family‘s needs	No advice or strategies offered to support the family‘s needs	No advice or strategies offered to support the family‘s needs
P2	Yeah, if there any more problems...not good is it?			Feeling unsupported, alone
P1	Yeah, not good	Contact details provided by SS	Contact details provided by SS	Contact details provided by SS
SA	So they gave you a phone number if you had any more problems?			
P1	Yeah			
SA	Have you ever asked them for help?			
P1	No	Help never sought from SS	Help never sought from SS	Help never sought from SS
P2	No			
P1	No			

SA	Erm...Has anything every stopped you from asking for help?			
P1	No	No perceived barrier to asking for help	No perceived barrier to asking for help	No perceived barrier to asking for help Finding services unapproachable
SA	Ok, as far as you know, do you have a key worker for your family? Either with Social services or CAMHS or School? Someone who you can contact if you need help.			
P1	We‘ve only got the phone number	Parents have one contact detail	Parents have one contact detail	Parents have one contact detail Not able to identify a key worker
P2	There is a man we saw recently, ain‘t there?			
P1	He‘s something to do with the school coz M‘s put	Not sure of the role of the ‗man‘ – his	Not sure of the role of the ‗man‘ – his	Not sure of the role of the ‗man‘ – his name

	a bit of weight.	name not know etc. Health difficulties are a concern for parents	name not know etc. Health difficulties are a concern for parents	not know etc. Health difficulties are a concern for parents
P2	He helps			
P1	Yeah, he helps, yeah yeah. I don‘t know his name. He‘s erm...	Not a close relationship with the _man who helps‘ Role ambiguity	Not a close relationship with the _man who helps‘ Role ambiguity	Not a close relationship with the _man who helps‘ Role ambiguity
P2	He‘s Ca.....what‘s he called? He‘s a main int he?			Not a close relationship with the _man who helps‘ Role ambiguity
P1	Yeah. coz M‘s put a bit of weight.	Health remains a concern	Health remains a concern	Health remains a concern

P2	He‘s very concerned about M‘s.... He‘s a younger one...			Anxious /worried about child‘s health
P1	Very young			
SA	Do you know what his job is?			
P1	Yeah...he just comes to help M, that‘s all. Coz he‘s put on a bit of weight. He‘s lost a bit but that won‘t do no good you see until they know what it is. They test his blood.	Role ambiguity	Role ambiguity	Role ambiguity
JM	And the teachers...and the children shouldn‘t take the mick out of my son because M doesn‘t like it.	Child faces teasing from peers	Child faces teasing from peers	Child faces teasing from peers Parents concerned about child‘s emotional wellbeing
SA	He‘s sensitive?			
JM	He‘s sensitive, you‘ll know that when you see him.			Parents concerned about child‘s emotional wellbeing

SA	That‘s something we need to work one, helping the other children accept him and understand the way he is.			
P2	Yeah. There‘s a few get picked on in his class.	Child is victim of teasing from peers	Child is victim of teasing from peers	Child is victim of teasing from peers Social difficulties faced by child
SA	So do you know why CAMHS are involved?			
P2	To help	View CAMHS support positively	View CAMHS support positively	View CAMHS support positively
P1	Yeah			
SA	Yeah...so you‘ve had one contact with social services and two with CAMHS?			
P1	Yeah			
SA	How would you rate them on a scale of 1 to 10? 1 being terrible and 10 being amazing, couldn‘t ask for more. Let‘s think about CAMHS first.			

P2	CAMHS we ...			
P1	Alright...we‘ve only been twice so far, he‘s got to carry on a bit longer with them you see			
SA	So, you think it‘s alright? How could it be better?			
P1	We only go half hour at a time. You can‘t do a lot in half hour.	Parents feel input from services is limited, affected by time	Parents feel input from services is limited, affected by time	Parents feel input from services is limited, affected by time
P2	It‘s just talking int it. Talking.			Uncertainty regarding CAMHS work with their son
P1	Yeah. He talks don‘t he? It‘s only about half hour a time (coughs)			Parents feel input from services is limited, affected by time
P2	Next week it‘s different int it? It‘s drawing			Uncertainty regarding CAMHS work with their son
P1	Yeah, he can draw next time			Uncertainty regarding CAMHS work with

				their son
P2	To help M find his targets, what he‘s heading for	Uncertainty regarding CAMHS work with their son	Uncertainty regarding CAMHS work with their son	Uncertainty regarding CAMHS work with their son
SA	What are you hoping CAMHS will be able to do?			
P2	To see if he can have a needle...injection			Uncertainty regarding CAMHS work with their son
P1	Yeah			
P2	To find out if he‘s got it or ain‘t. Even the teacher wants to know and head teacher.			
SA	Yeah. Hopefully they will be able to help with that. I know you‘ve only had one visit from social services. So, how would you rate their service?			
P2	6, I reckon			
SA	6? So you think they could be better? What would make them better for you?	Feel services could be improved	Feel services could be improved	Feel services could be improved

P2	Getting the job done. M does injections-	Feel unsupported by SS Needs not being met	Feel unsupported by SS Needs not being met	Feel unsupported by SS Needs not being met
P1	It takes time though don‘t it?			
P2	It takes time			
P1	You can‘t just rush into it	Aware of time limitations of services	Aware of time limitations of services	Aware of time limitations of services
P2	You can‘t rush it no...no.			
P1	It takes time			
SA	Do you think they could‘ve offered you more help?			
P2	A bit more help I think, yeah	Feel services could be improved by offering more help	Feel services could be improved by offering more help	Feel services could be improved by offering more help Feeling unsupported

SA	With what things?			
P2	Talking to M, supporting...things like that	Feel services could be improved through better communication	Feel services could be improved through better communication	Feel services could be improved through better communication
SA	And yourselves?			
P2	Talking to us, yeah, yeah.			Feeling unsupported as parents
SA	Ok. So this next question is do you trust CAMHS?			
P1	Yeah			
P2	Yeah			
SA	On a scale of 1-10, how much do you trust CAMHS?			
P1	I trust em a lot. They alright ain't it?	Trust professionals such as CAMHS	Trust professionals such as CAMHS	Trust professionals such as CAMHS
P2	I say 9			

P1	9, 10			
SA	School?			
P2	9,10. I‘m glad he‘s getting one-to-one teacher because I was worried because he‘s going down hill. He‘s two years behind work...he‘s told...his teacher told me last year. His teacher‘s been very poorly, so I don‘t know how he‘s got on this year	Trust school Education – anxiety around child‘s progress Clarity of communication	Trust school Education – anxiety around child‘s progress Clarity of communication	Trust school Education – anxiety around child‘s progress Clarity of communication
P1	No, no, no. They cancelled...			
SA	Yeah...			
P2	They cancelled it you see, we thought it was going on at school.			
SA	He is still getting the one-to-one support at school, I spoke to the school yesterday about that and will be giving them advice on how to support him.			

P2	That‘s good, I‘m really pleased with that			
P1	As long as he‘s getting on with his work and that. They didn‘t get back in touch to see about his work and that, coz it got cancelled.	Lack of communication between home and school causing parental anxiety	Lack of communication between home and school causing parental anxiety	Lack of communication between home and school causing parental anxiety Feeling unsupported
SA	Have you found it hard to the get the information you want from school sometimes			
P2	Yeah			
P1	Yeah (coughs)			
SA	Erm...but you trust school?			
P1	Yeah			
SA	And what about social services? Do you trust them?			
P2	Yeah, alright			

SA	On a scale of 1-10? School and CAMHS were 9 or 10.			
P1	We only seen them once ain‘t we P?			
P2	I say 5. Yeah, not sure on them are we?	Trust is lower for SS than services they‘ve had more contact with	Trust is lower for SS than services they‘ve had more contact with	Trust is lower for SS than services they‘ve had more contact with Uncertainty regarding SS‘s intentions
SA	OK. And do you feel like you can challenge what school say to you? Could you say ‗no‘ I don‘t want to do that?			
P1	Yeah, yeah. Them supportive.	Feel supported enough to challenge school	Feel supported enough to challenge school	Feel supported enough to challenge school
P2	Yeah, I‘m glad they supportive. I was worried about that.	Feel supported enough to challenge school	Feel supported enough to challenge school	Feel supported enough to challenge school
P2	He doesn‘t know what teacher he‘s going to			Anxious and uncertain

	have, M says yet. It‘s all different ones so...I don‘t know what them going, doing.			about child‘s learning
P1	Someone different come in today			
SA	Yes. He has supply teachers at the moment			
P1	Yeah, yeah			
SA	And what about CAMHS, can you challenge them?			
P1	Yeah, fine	Feel supported enough to challenge CAMHS	Feel supported enough to challenge CAMHS	Feel supported enough to challenge CAMHS
P2	Seem good don‘t they?	View CAMHS positively	View CAMHS positively	View CAMHS positively
SA	And Social services, can you challenge them? Like, say ‗no, I don‘t want to do that...”			
P2	no problem	Feel supported enough to challenge SS	Feel supported enough to challenge SS	Feel supported enough to challenge SS
SA	OK. So, how would you describe staff at school?			

P1	Them always happy, ain‘t they P?	View school as supportive	View school as supportive	View school as supportive
P2	Them always happy, yeah.			
SA	What about CAMHS?			
P1	Them just all...them, them, helpful, cheerful	View CAMHS as positive	View CAMHS as positive	View CAMHS as positive
P2	Helpful			
SA	And what about social services?			
P1	About the same			
P2	Yeah, same	View SS positively	View SS positively	View SS positively
SA	And do you understand everything they tell you?			
P1	Yeah			
SA	So school?			
P1	They try to make him lose a bit of weight	Aware that child‘s health needs attention	Aware that child‘s health needs attention	Aware that child‘s health needs attention

P2	And more exercise			
P1	He does all that			
P2	He does yeah			
P1	He never sits about really, he‘s always doing something, especially in summer...we can‘t do no more than that really	Lack awareness of what the child needs to lose weight, seriousness of the issue	Lack awareness of what the child needs to lose weight, seriousness of the issue	Lack awareness of what the child needs to lose weight, seriousness of the issue Feeling blamed – having to explain themselves
SA	So you never come out of the meeting thinking ―I didn‘t understand that”			
P2	They explain clearly and I‘m glad they‘re getting one-to-one coz I insisted that coz his reading and writing has gone down hill, he can‘t help it really, I‘m glad they noticed that. The other teacher told me two years ago at school M will probably need a one- the teacher has left the school now – she	Anxiety over academic progress Unsure what support	Anxiety over academic progress Unsure what support	Anxiety over academic progress Unsure what support

	says but probably M will need a one-to-one because erm...his writing‘s not that good and his reading‘s very poor.	child gets at school Reading is a main concern for parents	child gets at school Reading is a main concern for parents	child gets at school Reading is a main concern for parents
P1	You‘ve taken him over Tipton a few times ain‘t ya P to get him help with his speech and that?			
P2	Speech and language...they come to school now. He‘s got to learn the stuff coz he‘s year four now, that‘s why	Understand that speech and language is a concern and school are helping	Understand that speech and language is a concern and school are helping	Understand that speech and language is a concern and school are helping
P1	We took him about 5 times			
SA	Yeah...			
P2	They even don‘t do swimming now until year 5, do they?			Anxiety over child‘s health
SA	How has the support from speech and language services been?			
P2	They been good yeah			

SA	Do they share the targets with you			
P1	Yeah, they give us cards and we help M say the letters and that	Working relationship with school and speech and language sevrices	Working relationship with school and speech and language services	Working relationship with school and speech and language services
SA	And when CAMHS explain what they have been doing with M, do you understand?			
P1	Yeah, I‘m gonna be with him inside anyway so...			
SA	What‘s the main way CAMHS and social services communicate with you? Do they call you, have a meeting or send letters...			
P1	They probably send a letter to us, something like that. Well, they send the letters do they P?			
P2	Yeah			
SA	Are the letters easy to read?			
P1	Yeah...			
P2	It‘s hard int it... it‘s hard			Not accessible form of communication

SA	To read the letters			
P2	Yeah, it‘s hard			
SA	Does anyone help you?			
P2	They...no	Difficulty reading letters sent by services	Difficulty reading letters sent by services	Difficulty reading letters sent by services No support for reading letters
SA	Who could you ask?			
P1	We don‘t ask, do we P?			
P2	No, don‘t ask...just do our best really.	Reluctant to ask for help	Reluctant to ask for help	Reluctant to ask for help Feeling unable to ask for help/alone
SA	Do you think CAMHS, speech and language,			

	social services and school all talk to each other?			
P2	CAMHS...er...they talk don‘t they to each other, don‘t they?			
P1	Yeah			
SA	How can the support be made better for you?			
P2	Improve his reading and writing you think?	Reading and writing is a main concern	Reading and writing is a main concern	Reading and writing is a main concern
P1	Sp...yeah			
P2	Homework, yeah. Coz it will be hard at big school won‘t it, the homework, won‘t it. The work will be different from what we do. Won‘t be able to help him then, will ya? Be stuck? That‘s gonna be hard at big school, ya think?	Parents concerned they can‘t help their child progress	Parents concerned they can‘t help their child progress	Parents concerned they can‘t help their child progress Fear and anxiety
SA	Yeah, it will be. So you need help with that?			
P2	Be a good idea really, to help in case he says mum..and I says, I can‘t do it M, I don‘t know myself, I leave it to you, don‘t I?	Feel unable to support child‘s learning	Feel unable to support child‘s learning	Feel unable to support child‘s learning

				Fear and anxiety
P1	Yeah you say I don‘t know what to do			
P2	If you get it wrong in their book, the teacher will think won‘t they. Most the time you get it right don‘t ya?	Concerned about how professionals perceive them	Concerned about how professionals perceive them	Concerned about how professionals perceive them Feeling blamed for child‘s lack of academic progress
P1	Hmmmm			
SA	Are there other things you‘d like help with at home?			
P1	Not really			
P2	Nope, the council‘s gonna get the decorating, aren‘t they? Landing, aren‘t they	Help from housing – waiting not sure of when- communication could be improved	Help from housing – waiting not sure of when- communication could be improved	Help from housing – waiting not sure of when- communication could be improved

P1	We‘re just waiting to see we day got asbestos that‘s all really			
SA	What about help with work?			
P2	About work			
P1	I ain‘t at work, am I			
P2	Can‘t work can ya?			
P1	I‘m in the box, ain‘t I? I dunno when I gonna go back yet			
SA	Is that something you want more help with?			
P1	I see my thingy don‘t I, my counselling	Has support for mental health issues	Has support for mental health issues	Has support for own mental health issues
P2	Doctor says, trying to get back to work but work‘s shutting down after Christmas int it?			
P1	Yeah			
P2	We don‘t know yet	Job uncertainty	Job uncertainty	Job uncertainty
SA	OK, Did anyone help you find your home?			

P1	Pat had already got her house, don‘t she? when I moved in with her (coughs)			
SA	OK			
P2	I was single mum, weren‘t I? Children grown up, one left 15 year old, I was working. Then my job...got made redundant, a few years later, diabetes type one, that was a shock for me, type 1, diabetes, he told me. I have to cope with it now, that‘s hard	Job uncertainty – redundancy Parent has own health issues	Job uncertainty – redundancy Parent has own health issues	Job uncertainty – redundancy Parent has own health issues Parents emotional well-being affected by own health issues
P1	That does get her down sometimes	Emotional well-being is affected	Emotional well-being is affected	Emotional well-being is affected
SA	Who helps you with that?			
P2	I have district nurses in to help me	Medical assistance	Medical assistance	Medical assistance
P1	They can come anytime, just turns up don‘t her	Not aware of when appointments should	Not aware of when appointments should	Not aware of when appointments should

		be	be	be
SA	Do you find that helpful?			
P2	Yeah, I just worry about M, he got bigger	Concerns about child's health	Concerns about child's health	Concerns about child's health
SA	Did anyone help you find your jobs?			
P1	My cousins all worked there, they got me a job. Been there straight from school like.	Has some access to family support network	Has some access to family support network	Has some access to family support network
SA	Do you feel in charge of what happens to you and your family?			
P1	Yeah			
P2	Hmmm			
SA	On a scale of 1-10			
P1	10			
P2	10	Feel in charge of family	Feel in charge of family	Feel in charge of family
SA	So, totally in charge of your family?			

P1	Yeah			
SA	Do you feel like people really listen to you?			
P1	They do at school and that			
SA	So, school are good at listening?			
P1	Yeah	Identify school as good listeners	Identify school as good listeners	Identify school as good listeners
SA	Do you think you live a totally normal life?			
P1	Yeah, normal as can be			
P2	Yeah. I worry about the reading and writing at school. They only have 10 minutes a day don‘t they?	Concerns about child‘s reading and writing	Concerns about child‘s reading and writing	Concerns about child‘s reading and writing Anxiety
SA	Do you bring these things up at meetings in school?			
P2	They don‘t discuss that. The main target they discuss is-			

P1	Weight	Don‘t feel listened to Their concerns not a priority	Don‘t feel listened to Their concerns not a priority	Don‘t feel listened to Their concerns not a priority
P2	-his weight. In my brain his reading and writing is most important and all, not just weight, his reading and writing.	Identify own concerns, feel school does not agree	Identify own concerns, feel school does not agree	Identify own concerns, feel school does not agree
P1	All they discuss at the meetings is weight			
P2	I want him to be upper his reading and writing...to be proud of			
SA	Of course.			
P1	All they talk about is his weight. He lost a bit. They don‘t really talk about nothing else			Ignored in multi-agency meetings. Feeling frustrated
P2	No and erm...his weight..what about school? class?			

SA	Do you ever say can we talk about his reading and writing?			
P2	They just shut the book, conversa.....finished now, it‘s time	Feel not listened to by school	Feel not listened to by school	Feel not listened to by school Ignored in multi-agency meetings
P1	We don‘t have that long			
P2	Not that long, half an hour. So, it‘s not easy. He‘s got Asthma, that‘s what they worry about his weight for...heart attacks, strokes, that‘s they worry for. I understand...	Feel that time pressures mean that they have limited time to voice concerns	Feel that time pressures mean that they have limited time to voice concerns	Feel that time pressures mean that they have limited time to voice concerns
P1	He has lost a little bit			
SA	He goes to Wellfit, doesn‘t he?	Parents take on board suggestions made by school	Parents take on board suggestions made by school	Parents take on board suggestions made by school
P1	Yeah, at school. I used to go up West Bromwich one first. The school one‘s every Friday, I used to	Gender issues make dad reluctant to	Gender issues make dad reluctant to	Gender issues make dad reluctant to

	go but I‘m the only man there so now I let P...I do	engage	engage	engage
P2	You liked the other one, didn‘t ya? Feel embarrassed (laughs)			
P1	I don‘t bother			
SA	So are you happy with the support you have?			
P2	I‘m glad this is happening. I really am, coz I was worried. He can‘t read and write, what‘ll happen? Where can he go? Nobody‘ll have him. Kids‘ll take the mick if he can‘t read and write when he‘s 12. What‘s gone wrong? They blame the parents. Don‘t they? I‘m glad the teacher realised he can‘t read and write. I‘m glad some people are helping now. He‘s 9 now still the same.	Reading and writing is a concern Children teasing their son Feel blamed for son‘s difficulties Feeling unsupported	Reading and writing is a concern Children teasing their son Feel blamed for son‘s difficulties Feeling unsupported	Reading and writing is a concern Children teasing their son Feel blamed for son‘s difficulties Feeling unsupported

				Anxious and worried
P1	I dunno P			
SA	Do you know where you could get more help for M‘s reading and writing?			
P2	No, the youth club is just for sports and playing. I ain‘t got a clue.	Not sure where to go for support	Not sure where to go for support	Not sure where to go for support
SA	That‘s all of the questions I wanted to ask, did you want to say anything else?			
P2	No that‘s it then			
P1	Yeah			

Interview two

SA	When you found out you were having a child, erm, how did you feel?	Initial Codes	Initial themes	Cycle 2 codes and themes
P3	Let‘s have a look			
SA	So, were you excited or scared?			
P3	Nah, I was alright about it	Positive about pregnancy	Positive about pregnancy	Positive about pregnancy
SA	You were alright about it?			
P3	Coz mum...her was alright	Identified family support network – emotional support	Identified family support network – emotional support	Identified family support network – emotional support
SA	Yeah...that‘s good			
P3	So...			
SA	How old were you when you had your oldest?			
P3	Er...when I just turned 18 when I had C			
SA	And you‘ve got three children altogether?			

P3	Yeah, yeah			
SA	So, when you found out you were first pregnant with C, who did you get support from?			
P3	Erm...			
SA	Like, did you get any support from the doctor...			
P3	No, not really...I had appointments and that at the hospital. I had midwives and that. Apart from that, I was by myself really.	No additional support during pregnancy	No additional support during pregnancy	No additional support during pregnancy Feeling alone
SA	Ok, that‘s fine. Er, did anyone give you information about becoming a parent?			
P3	Er...			
SA	So, did you get any DVD‘s, books or leaflets?			
P3	Yeah, fr...them packs, from them packs. Yeah, the Bounty packs .			
SA	Bounty packs?			

P3	Say, you have to go to Boots and ..they give yer a voucher and you have to go to Boots and pick them up. They got free stuff don‘t they.	No professional support given in the form of accessible materials	No professional support given in the form of accessible materials	No professional support given in the form of accessible materials
SA	Yeah...Who gave you the voucher?			
P3	It was in the book			
SA	Ok...I didn‘t know about that. So, when you found out you were having C, did you know what to expect?			
P3	In what way?			
SA	So, you were 18, did you know what being a mum was going to be like?			
P3	Yeah, I...obviously, coz I saw my mum with my sisters	Family support network important for preparation during pregnancy	Family support network important for preparation during pregnancy	Family support network important for preparation during pregnancy
SA	Yeah			
P3	Yeah			

SA	Erm, on a scale of 1 to 10 how confident did you feel about being a mum?			
P3	I was confident weren‘t I... but...I couldn‘t bath her or nothing			Uncertainty and fear with newborn child
SA	Oh, why not?			
P3	Coz like...I was scared (laughs)	Identified being afraid, under-prepared for baby	Identified being afraid, under-prepared for baby	Identified being afraid, under-prepared for baby Fear
SA	Right, who gave you help then?			
P3	My nan	Family support network provided knowledge to support mum in caring for baby	Family support network provided knowledge to support mum in caring for baby	Family support network provided knowledge to support mum in caring for baby
SA	Your nan?			
P3	Yeah			

SA	Did you get any help from any professionals?			
P3	Nah			Alone feeling unsupported by professionals
SA	No help?			
P3	Get only...erm...the health visitor...she was alright			
SA	The health visitor helped you?	Identified professional who offered support after birth	Identified professional who offered support after birth	Identified professional who offered support after birth
P3	Yeah...but I was scared...to bath her like	Feeling underprepared and afraid	Feeling underprepared and afraid	Feeling underprepared and afraid Fear
SA	Erm, Ok. Were there any support groups you went to?			
P3	Er...I went to Sure Start	Identified community support and accessed	Identified community support and accessed	Identified community support and accessed

		this independently	this independently	this independently
SA	Sure start?			
P3	Yeah...it was in the Dudley Borough			
SA	Yeah. How old was C when you went there?			
P3	Quite young, yeah, about...erm...I dunno (laughs)			
SA	That‘s OK. How did you know about Sure Start?			
P3	...we used to live next door to it	Identified community support and accessed this independently	Identified community support and accessed this independently	Identified community support and accessed this independently Lack of professional support pre-birth
SA	And did you find it helpful going there?			
P3	I just went for play and stays really			
SA	You didn‘t go to any other groups?			

P3	No	No access to parent support group. None offered.	No access to parent support group. None offered.	No access to parent support group. None offered. Alone
SA	OK. So, what‘s good about being a parent?			
P3	(laughs) ...I dunno...erm...you have to bring the small baby into the world innit? ... I dunno (laughs)			
SA	So-			
P3	You have to look after ‗em, love ‗em...you have to be like a doctor and nurse and that...if they get ill			Identifies responsibilities as a parent Love/nurture
SA	Did you worry about them getting ill?			
P3	Yeah, being like a doctor...I dunno...I didn‘t know if they was ill like...to help them, do you	Concerns about child‘s health needs	Concerns about child‘s health needs	Concerns about child‘s health needs

	get me?	and meeting them	and meeting them	and meeting them Anxiety and fear
SA	Yeah			
P3	There‘s lots of things			
SA	What‘s hard about being a mum then?			
P3	When... (laughs)...H is being naughty	Managing child‘s behaviour is a concern	Managing child‘s behaviour is a concern	Managing child‘s behaviour is a concern
SA	H is being naughty?			
P3	(laughs)...yeah...I dunno then man...it‘s hard...coz, it‘s a big, erm, task for me...when things go...	Challenging behaviour	Challenging behaviour	Challenging behaviour
SA	Yeah. Anything else you find hard?			
P3	Erm...what with?			
SA	Being a mum			

P3	When the kids like...you know when them got letters and read a book and that	Concerns about reading letters and books	Concerns about reading letters and books	Concerns about reading letters and books
SA	Yeah			
P3	I can‘t read too good	Admits not being able to access text/read	Admits not being able to access text/read	Admits not being able to access text/read unsupported
SA	Yeah			
P3	Yeah			
SA	OK. Anything else?			
P3	(shrugs)			
SA	You‘re doing really well N, thank you. Who helps you with reading books?			
P3	Well...when I got time, I do it, I do try myself	Tries to do things independently	Tries to do things independently	Tries to do things independently
SA	Yeah			

P3	Yeah			
SA	And what about the letters?			
P3	If I can‘t read ‗em, yeah, I take ‗em to my mum or someone, who‘s like around	Family is drawn on for support	Family is drawn on for support	Family is drawn on for support
SA	Are there any professionals you can ring for help?			
P3	Yeah..erm..N, my family support worker	Identifies key worker for family	Identifies key worker for family	Identifies key worker for family as a person to trust for help
SA	Your family support worker?			
P3	Yeah			
SA	Ok. So if you need help you go to her?			
P3	Anything yeah...if anything needs to be read quick, I go to N.	Identifies a worker that helps her read	Identifies a worker that helps her read	Identifies a worker that helps her read
SA	That‘s good. The nest questions are about support services. Which support services do			

	you use?			
P3	Erm...			
SA	So, you‘ve got a family support worker?...			
P3	A social worker...then the health centre send me leaflets...			
SA	Any help from OfL? Or P3? (anonimised)			
P3	No			
SA	How long have you had a family support worker for?			
P3	Since the very first time what... you know when the school phoned ‗em about H, what they shouldn‘t have done yeah, none of their business			Feeling blamed/ betrayed by school
SA	About H?			
P3	Yeah, sometime maybe that year yeah you know. But it weren‘t my fault yeah.	Long-term involvement from key worker	Long-term involvement from key worker	Long-term involvement from key worker

				Feeling blamed/ betrayed by school
SA	How long have you been involved with social services?	Long-term involvement from SS	Long-term involvement from SS	Long-term involvement from SS
P3	Er...a year			
SA	OK. Has anything ever stopped you for asking them for help?			
P3	No, because I just tell ‗em if I need help	Confident in asking for help	Confident in asking for help	Confident in asking for help
SA	That‘s good. How do you contact them?			
P3	When I see ‗em, if she comes to my house and that	Does not initiate contact	Does not initiate contact	Does not initiate contact
SA	If there was something urgent, how would you contact them?			
P3	I would talk to N when I see her	Does not initiate contact	Does not initiate contact	Does not initiate contact

SA	Do you ring them?			
P3	Not really...I don‘t got the number	No communication pathway identified	No communication pathway identified	No communication pathway identified
SA	I was going to ask if you have a key worker for your family but you have-			
P3	Yeah, we got N			Can identify a key worker
SA	Good. Where is she based?			
P3	Who N?...B (anonymised)	Knows where key worker is based	Knows where key worker is based	Knows where key worker is based
SA	B~~?			
P3	Yep			
SA	Do you know why they are involved with your family?			
P3	Who?			
SA	N?			
P3	Yeah, coz of H	Knows why key	Knows why key	Knows why key

		worker is involved with family	worker is involved with family	worker is involved with family
SA	And Social Services?			
P3	Yeah, coz of what school said to ‗em	Knows why SS is involved with family	Knows why SS is involved with family	Knows why SS is involved with family Feeling animosity that school contacted SS
SA	How much do you understand on a scale of 1-10-			
P3	10	Perceives herself to have good understanding	Perceives herself to have good understanding	Perceives herself to have good understanding
SA	10?			
P3	Maybe...yeah			
SA	OK. How would you rate the support you‘ve had? What would you give N?			
P3	I say 10	Values support given	Values support given	Values support given

		by key worker	by key worker	by key worker
SA	OK. Why a 10?			
P3	Coz, I can get on with N and N...if I need help yeah, she helps me	Values personal characteristics of key worker Importance of key workers personality	Values personal characteristics of key worker Importance of key workers personality	Values personal characteristics of key worker Importance of key workers personality Trust
SA	Yeah.			
P3	Her tries to help me yeah			
SA	What about social services? What would you give them?			
P3	0 man.			
SA	0? Why?			

P3	I don‘t like ‗em (laughs)	Importance of social workers personality identified	Importance of social workers personality identified	Importance of social workers personality identified
SA	You don‘t like ‗em? Ok. What don‘t you like about them?			
P3	Them just too nosy man	Not trusting of social worker Does not value their input	Not trusting of social worker Does not value their input	Not trusting of social worker Does not value their input
SA	Too nosy...what about the person, what are they like?			
P3	C, the social worker what I got now, she‘s alright. The one I got first, M, he told a lot of lies...a lot of lies... the other one was alright too.	Distrust Changes of social workers 3 times over a short period of time	Distrust Changes of social workers 3 times over a short period of time	Distrust Changes of social workers 3 times over a short period of time
SA	Right, told them to who?			

P3	All on my report			
SA	Do you know why the social worker kept changing?			
P3	Dunno...they do it all the time yeah			
SA	How do you feel about that?			
P3	It‘s annoying yeah	Changes of social worker leading to emotional response, annoyance, frustration	Changes of social worker leading to emotional response, annoyance, frustration	Changes of social worker leading to emotional response, annoyance, frustration
SA	Ok. How could they be made better?			
P3	They say, try to keep families apart which they don‘t			
SA	Keep families apart?			
P3	They say they try to keep families ap...together, but they don‘t they keep ‗em apart.	View of SS is negative, perceives their role as threatening to family unit	View of SS is negative, perceives their role as threatening to family unit	View of SS is negative, perceives their role as threatening to family unit

				Fear, feeling threatened by SS
SA	So, you think they‘re trying to keep your family apart?			
P3	Yeah yeah yeah..until like...so many months down the line, do you know what I‘m on about?	Perceives SS role as a threat	Perceives SS role as a threat	Perceives SS role as a threat
SA	I think so			
P3	I dunno man...and then...I dunno...bu my family support worker, she‘s alright...no, my new social worker, she‘s alright too.			Personality of worker is very important
SA	Ok. What do you like about them?			
P3	I dunno, I can talk to ‗em	Importance of being able to communicate with professionals	Importance of being able to communicate with professionals	Importance of being able to communicate with professionals Trust is important
SA	Yeah. And-			

P3	N helps me the way I want her to help me			
SA	OK. What is that with?			
P3	Letters...filling letters in...everything really	Reading highlighted as a need	Reading highlighted as a need	Reading highlighted as a need Professional support there to help read letters
SA	What do social services help you with?			
P3	Erm...they moved away now...a bit more than...because I'm...erm, in child in need now	Demonstrates an understanding of SS processes	Demonstrates an understanding of SS processes	Demonstrates an understanding of SS processes
SA	Yeah.			
P3	So, I don't really see no more, that much really...I'm glad			Fear of SS
SA	Would you say they've been quite helpful?			
P3	The one has a bit, yeah, but not really...I dunno...I get one with her yeah	Mixed views on SS	Mixed views on SS	Mixed views on SS

SA	Do you trust them?			
P3	What ya mean?			
SA	Do you trust N?			
P3	Yeah	Trusting of key worker	Trusting of key worker	Trusting of key worker
SA	A 10 out of 10?			
P3	I dunno, just trust...I don't trust people	Generally mistrusting of people	Generally mistrusting of people	Generally mistrusting of people
SA	Why not?			
P3	I dunno...it's just the way I am			
SA	What about social services, do you trust them?			
P3	I dunno man...not really	Not trusting of social services	Not trusting of social services	Not trusting of social services
SA	Why not			
P3	Them trying to take us apart...they lie...they ain't nice man. Every little thing, they pick on it	Perceive SS as a threat to family unit	Perceive SS as a threat to family unit	Perceive SS as a threat to family unit

				Fear and anxiety over SS
SA	Do you trust school?			
P3	They trying to help...I dunno...I think it‘s funny when H does stuff, I know it ain‘t, but that‘s just the way I am (laughs)	See school as helpful	See school as helpful	See school as helpful Trust is questionable with school
SA	Yeah. If N says something you don‘t agree with, do you feel like you can challenge her?			
P3	I do challenge her (laughs)	Feels able to challenge key worker	Feels able to challenge key worker	Feels able to challenge key worker
SA	What about social services			
P3	I tell ‗em no way but I do do it in my time... coz otherwise they tell lies and that	Referring to lies by SS - distrusting	Referring to lies by SS - distrusting	Referring to lies by SS - distrusting
SA	Ca-			
P3	You know, sometimes, I don‘t think, it comes before my brains engaged yeah			

SA	Yeah, I understand what you mean. How would you describe N?			
P3	Er...happy			
SA	What about C?			
P3	Happy			
SA	What about the other two social workers you had?			
P3	It ain‘t on there, words don‘t come for him (laughs)	Male SS viewed negatively	Male SS viewed negatively	Male SS viewed negatively
SA	Positively or negatively?			
P3	Negative, they ain‘t good	Male SS viewed negatively	Male SS viewed negatively	Male SS viewed negatively
SA	Do you understand everything they tell you?			
P3	No, I ask ‗em and ask ‗em til I understand	Feels confident to ask questions	Feels confident to ask questions	Feels confident to ask questions Not able to

				understand everything professionals tell her
SA	So you ask them until you understand?			
P3	Yeah			
SA	How do they contact you?			
P3	Phone ...or letters and that			
SA	And do you understand what they‘re saying?			
P3	No, not really	Lacks understanding of what she is being told – form of communication used is inaccessible	Lacks understanding of what she is being told – form of communication used is inaccessible	Lacks understanding of what she is being told – form of communication used is inaccessible
SA	What about at the meetings in school? Do you understand what they‘re all talking about?	Lacks understanding of what she is being told –	Lacks understanding of what she is being told –	Lacks understanding of what she is being told –

		form of communication used is inaccessible	form of communication used is inaccessible	form of communication used is inaccessible
P3	No, no-..no, not really			
SA	Do you ask them when you don‘t understand?			
P3	Nah, I just let ‗em carry on...they don‘t listen to me yeah, they just talking too much sometimes	Feels like a passive recipient of information Lacks understanding of what she is being told – form of communication used is inaccessible	Feels like a passive recipient of information Lacks understanding of what she is being told – form of communication used is inaccessible	Feels like a passive recipient of information Lacks understanding of what she is being told – form of communication used is inaccessible Ignored in multi-agency meetings

SA	They don‗t listen?			
P3	Not really, so I let ‗em carry on...quicker for me to get out the office or something	Does not feel opinion is valued or listened to	Does not feel opinion is valued or listened to	Does not feel opinion is valued or listened to
SA	Why do you want to get out the office quickly?			
P3	Because I get angry, I get frustrated...and then I feel like I wanna kick off to tell you the truth	Emotional instability Emotional wellbeing of parent Anger management Frustration	Emotional instability Emotional wellbeing of parent Anger management Frustration	Emotional instability Emotional wellbeing of parent due to lack of communication Anger management due to lack of communication Frustration due to lack of communication
SA	What makes you angry			

P3	I don‘t understand...myself I guess...my brain just switches	Anger management Frustration	Anger management Frustration	Anger management due to lack of communication Frustration due to lack of communication
SA	You‘ve always been great when I‘ve spoken to you			
P3	It depends...if I don‘t understand it yeah, then I get angry and frustrated	Anger and Frustration stem from lack of understanding	Anger and Frustration stem from lack of understanding	Anger and Frustration stem from lack of understanding
SA	Do you understand everything N tells you?			
P3	Er...yeah, coz she goes...she goes into it with me...the others don‘t	Time spent by key worker to ensure information is accessed and understood	Time spent by key worker to ensure information is accessed and understood	Time spent by key worker to ensure information is accessed and understood
SA	Who doesn‘t?			
P3	School, social services sometimes yeah, they			Volatile relationship

	don‘t get me			with SS and school at times
SA	Do you think that they all talk to each other?			
P3	Obvious, yeah			
SA	So you don‘t have to keep repeating yourself?			
P3	Probably have to repeat it sometimes but...yeah	Some repetition	Some repetition	Some repetition
SA	How do you think the support services can be made better?			
P3	Tell me			
SA	Like social services, your family support worker and school, how could they be better?			
P3	I don‘t know...I don‘t need nothing from them really, coz I can cope, do you understand me?	Wanting to be left alone Independence	Wanting to be left alone Independence	Wanting to be left alone Independence

		Reluctance to engage with services	Reluctance to engage with services	Reluctance to engage with services Fear
SA	Yeah			
P3	Coz when...you know what, to tell you the truth, when like H's been really bad, when...before she started school, no one really bothered to help me, do you understand? So really yeah, to me yeah, I think, I can do it man.	Reluctance to engage with services Previous negative experiences affect current views	Reluctance to engage with services Previous negative experiences affect current views	Reluctance to engage with services Previous negative experiences affect current views
SA	Yeah			
P3	I just get on with it really	Try to be independent	Try to be independent	Try to be independent Feeling let down by services in the past
SA	Anything they can do to help you more?			

P3	If it were up to me, I wouldn‘t ask for help...carry on the way I am	Wanting to be left alone Independence Reluctance to engage with services	Wanting to be left alone Independence Reluctance to engage with services	Wanting to be left alone Independence Reluctance to engage with services
SA	Erm, did anyone help you when you were moving house?			
P3	No			
SA	OK. You did it all on your own?			
P3	Yeah			
SA	Do you work N?			
P3	No			
SA	Do you want to?			
P3	I wanna work but erm...I wanna go back college really to tell you the truth but I have put	Wants to go back to	Wants to go back to	Wants to go back to

	my name down at school	school Accessing education to improve life	school Accessing education to improve life	school Accessing education to improve life
SA	Hmmm, that's good			
P3	Coz they got a Literacy course coming up	Want to access education to improve literacy skills	Want to access education to improve literacy skills	Want to access education to improve literacy skills
SA	Anyone helping you with that?			
P3	No	Lack of support to reach goals	Lack of support to reach goals	Lack of support to reach goals
SA	No one's helping you, but you want to go back to school. Do you need help?			
P3	Yeah, coz I never...done nothing like that to tell you the truth	Afraid to try alone	Afraid to try alone	Afraid to try alone
SA	OK... Are you in charge of what happens to you and your family?			
P3	I know I'm the mum, so I have to be in	Angry when control	Angry when control	Angry when control

	charge...but if like someone says you gotta do this, I get really angry (laughs)	over family is questioned Feels in control	over family is questioned Feels in control	over family is questioned Feels in control
SA	What about with professionals?			
P3	They here to help...but I don‘t think I need ‗em	Wants independence Does not feel she needs support	Wants independence Does not feel she needs support	Wants independence Does not feel she needs support
SA	Yeah...Do you feel like people really listen to you?			
P3	N does, yeah ... they all probably listen to me but in my way yeah, I think people don‘t listen to me...they look down on me yeah	Feels other perceive her negatively	Feels other perceive her negatively	Feels other perceive her negatively Feeling ignored
SA	Who looks down on you?			

P3	The teachers...social workers and that. N's been good...I can't put her down.	Feels other perceive her negatively School judge her	Feels other perceive her negatively School judge her	Feels other perceive her negatively School judge her
SA	I'm glad to hear that...Do you live a normal life?			
P3	Yeah...apart from H's behaviour...it's the way she is	Difficulty managing children's behaviour Lead normal life	Difficulty managing children's behaviour Lead normal life	Difficulty managing children's behaviour Lead normal life
SA	Is that something you need help with			
P3	No, because it's just H ain't it			
SA	Are there any things that would like more help with?			
P3	At the minute...to put H on the right way I think	Difficulty managing children's behaviour – wants help	Difficulty managing children's behaviour – wants help	Difficulty managing children's behaviour – wants help

SA	Right...Erm...sometimes you have meetings at school about H, what are they like?			
P3	I get frustrated, angry...One time, I got up and slammed the doors...coz, I, you know, I...when I talk yeah, I have to keep repeating myself yeah to make ‗em understand ... if they don‘t reply back to me or anything yeah, I get angry	Anger and Frustration stem from lack of understanding by professionals	Anger and Frustration stem from lack of understanding by professionals	Anger and Frustration stem from lack of understanding by professionals Feeling ignored
SA	OK, you get angry because they‘re not listening			
P3	They ain‘t... they ain‘t	Feels other‘s don‘t listen to her views	Feels other‘s don‘t listen to her views	Feels other‘s don‘t listen to her views
SA	OK...Are you happy with the support you get?			
P3	Yes, I suppose so...I got no choice but yeah	Feels doesn‘t have a choice/control over services being involved with the family	Feels doesn‘t have a choice/control over services being involved with the family	Feels doesn‘t have a choice/control over services being involved with the family
SA	You don‘t feel like you have a choice?			

P3	I dunno (laughs)...yeah, it‘s here so...obviously I gotta take the support	Passively accepts support	Passively accepts support	Passively accepts support
SA	So, do you know where you could go if you needed more help?			
P3	Yeah			
SA	Who would you go to for help with the kids?			
P3	N	Identifies key worker as reliable for help	Identifies key worker as reliable for help	Identifies key worker as reliable for help
SA	Would you ask social services?			
P3	No, coz I...my heart don‘t go to ‗em man			Negative relationship with social worker
SA	Do you think they would help?			
P3	They probably would yeah...but to me yeah, I‘d rather phone N before phoning social services	Positive relationship with key worker	Positive relationship with key worker	Positive relationship with key worker
SA	Is that because you‘ve got a good relationship with her?			
P3	Yeah, I suppose	Positive relationship	Positive relationship	Positive relationship

		with key worker	with key worker	with key worker

Interview Three

SA	So, the first question I'd like to ask you J, is how did you feel when you found out you were having a child?	Initial Codes	Initial themes	Cycle 2 codes and themes
P4	Happy	Positive about pregnancy	Positive about pregnancy	Positive about pregnancy
SA	Happy?			
P4	Happy (coughs) yeah... erm...I wanted another but her said I can't			Frustration Feeling ignored
SA	Oh right?...Who did?			
P4	Her, S, said it ent alright (coughs)			
SA	S, from OfL?			
P4	Yeah			
SA	Any idea why?			

P4	Not really... I daren't take no notice of her, I told her, I did	A turbulent relationship with staff	A turbulent relationship with staff	A turbulent relationship with staff Feeling controlled, angry and frustrated
SA	Ok...so you were happy when you found out you were having a baby and you would like another one but S said not to?			
P4	Yeah, I take no notice	Reluctant to engage with professionals	Reluctant to engage with professionals	Reluctant to engage with professionals
SA	Erm...why did she say that to you?			
P4	I dunno...her report me and that, you know what _emlike, but I take no notice	Reluctant to engage with professionals	Reluctant to engage with professionals	Reluctant to engage with professionals Fear of being _eported'
SA	Hmmmm...do-			
P4	She said that, she said about reporting me to the social, it ain't fair, they can't tell me	Not accepting advice	Not accepting advice	Not accepting advice

	though, I do what I want...			Fear of SS. Feeling unfairly treated.
SA	Yeah, you can. Why don't you want to listen to her?			
P4	She's just always poking her nose about...She don't like me ya know	Feels as though professionals are interfering Feels unliked by professionals	Feels as though professionals are interfering Feels unliked by professionals	Feels as though professionals are interfering Feels unliked by professionals Feeling treated unfairly
SA	Doesn't like you?			
P4	Sometimes ... I don't like her sometimes. She comes round and I pretend I ain't in to keep her off me back. I hid behind the sofa I did...dogs kept barking	Relationship with professional is based on personal characteristics	Relationship with professional is based on personal characteristics	Relationship with professional is based on personal characteristics

				Fear. Reluctant to engage. Avoiding professionals.
SA	Why did you hide from her?			
P4	If we had a drink right, she reports us, or if the dogs done one on the carpet and that. Oh, she gets half angry and starts telling me this and that...I can‘t be bothered, she don‘t listen and I‘m angry.			Fear Lacking knowledge of importance of keeping the house clean Feeling blamed/victimised Relationship with worker is turbulent Reluctant to engage.

				Avoiding professionals.
SA	Ok, so will you have more kids?			
P4	Yeah...but not coz of my health, y'know coz of my eggs and that, I got to have the surgery soon so ...yeah	Concerns about own health issues	Concerns about own health issues	Concerns about own health issues anxiety
SA	So...not yet then because of your health?			
P4	Yeah...and my back is bust up too	Concerns about own health issues	Concerns about own health issues	Concerns about own health issues
SA	Ok, when you found out you were first pregnant, who did you get support from?			
P4	Erm...well, my mum ain't too well, so I has to do her injections...erm...I dunno	Wider family issues affecting the family	Wider family issues affecting the family	Wider family issues affecting the family Feeling alone
SA	Did anyone help you get ready for when M came?			

P4	No, no one helps me, I always have to help myself...and my mum...Erm...	No support network available	No support network available	No support network available Feeling unsupported/alone
SA	Right...did anyone give you information about being a parent?			
P4	...I can‘t remember that			
SA	No one gave you any books, leaflets or videos on being a parent?	Lack of access to information, resources about pregnancy and parenting	Lack of access to information, resources about pregnancy and parenting	Lack of access to information, resources about pregnancy and parenting
P4	I don‘t think so			
SA	So, did you know what being a mum was going to be like?			
P4	No (laughs), no one told me anything, he was really little and that ... I was, you know, really what‘s the word	Not prepared for parenting, no professional support	Not prepared for parenting, no professional support	Not prepared for parenting, no professional support

		Uncertainty and fear	Uncertainty and fear	Uncertainty and fear
SA	Worried? scared? Happy? Excited?			
P4	I was you know scared... to pick him up and that coz he was little	Fear of hurting baby Un prepared	Fear of hurting baby Un prepared	Fear of hurting baby Un prepared
SA	Who helped you?			
P4	No one helps me...but I just did it you know	Feeling unsupported	Feeling unsupported	Feeling unsupported
SA	Did you get any help from any professionals?			
P4	Like from...who?			
SA	Social services, health visitor, OfL?			
P4	Nah, just the health visitor, she showed me sometimes but...nah, not really	Lack of co-ordinated support	Lack of co-ordinated support	Lack of co-ordinated support Feeling alone

SA	What did she show you?			
P4	...holding him proper...feeding and that...and washing	Health visitor provided needed guidance after birth	Health visitor provided needed guidance after birth	Health visitor provided needed guidance after birth
SA	OK. Did you go to any support groups?			
P4	What like?			
SA	Where parents meet up to talk to each other			
P4	Nah...that sounds nice and that...I had a friend but she moved so...I did it by myself	No access to support groups	No access to support groups	No access to support groups Feeling alone
SA	Right. Did anyone mention going to a group?			
P4	Nah, not to me...nah	Support groups not offered	Support groups not offered	Support groups not offered

SA	OK. So what‘s good about being a parent J?			
P4	Everything really...playing, he likes playing washing up...and...he‘s always watching telly and that			
SA	What do you like doing with him?			
P4	I give him food and ...wash him and that, he‘s got lots of toys...oh yeah, he likes toys, he does (laughs)	Focus on basic needs of child	Focus on basic needs of child	Focus on basic needs of child - lacking knowledge of need for nurture
SA	Yeah, I can imagine. So, what‘s hard about being a mum?			
P4	Hard?			
SA	Yeah, difficult?			
P4	Er...he doesn‘t like going to bed, M doesn‘t, he won‘t go, he wants to be with me...or reading, he hates reading...but his teacher said he‘s got to or he‘s in trouble	Managing challenging behaviour is difficult Supporting child‘s academic progress is	Managing challenging behaviour is difficult Supporting child‘s academic progress is	Managing challenging behaviour is difficult Supporting child‘s academic progress is

		difficult	difficult	difficult Giving child attention – lacking knowledge of need for nurture
SA	Do you try and help him?			
P4	With what?			
SA	Reading?			
P4	Yeah...I ...can‘t, y‘know read and that but he tells me and then ...he just does it	Parent can‘t read	Parent can‘t read	Parent can‘t read
SA	Erm...Ok. How do you get him to go to bed?			
P4	Er...with the telly on, he‘s alright then, goes to bed like	Need guidance to manage behaviour effectively	Need guidance to manage behaviour effectively	Need guidance to manage behaviour effectively
SA	Right. Yeah, so, who do you ask for help?			
P4	Help?			
SA	Yeah...with reading or other things you need			

	help with?			
P4	Well...I got D	Partner is her main support	Partner is her main support	Partner is her main support
SA	OK, so D, your partner, helps you?			
P4	(laughs) He‘s a lazy ‗un... can‘t read though but he plays with M like...sometimes	Partner also can‘t read	Partner also can‘t read	Partner also can‘t read
SA	Do you ask any professionals to help you?			
P4	Professionals?			
SA	Yeah, social services, health visitor, OfL, school?			
P4	Erm...I ain‘t asking the social... or her, S	Reluctant to ask for help	Reluctant to ask for help	Reluctant to ask for help Negative view of SS/fear/anxiety
SA	Why not ask social services?			
P4	Erm...I ain‘t got time for ‗emyou	Previous experiences	Previous experiences	Previous experiences

	know...if...if...just ain‘t got time for ‗em...I gotta help my mum everyday and that ...they just have a go, telling me what to do and they gonna tek him if I don‘t do it	with services make them reluctant to engage Fear of threat to family unit	with services make them reluctant to engage Fear of threat to family unit	with services make them reluctant to engage Fear of threat to family unit
SA	Right...do you know the name of your social worker?			
P4	Yeah...but I forgot her name	No close relationship with SS	No close relationship with SS	No close relationship with SS
SA	What about asking S?			
P4	Her‘s always telling me you know ... I just can‘t be-...I ain‘t bothered with her	Negative relationships not based on respect or trust	Negative relationships not based on respect or trust	Negative relationships not based on respect or trust
SA	What about school? Do they help you?			
P4	Erm...They help M and that don‘t they?	View school as helping child	View school as helping child	View school as helping child
SA	Yeah, do they help you as well?			

P4	Yeah...	View school as helping her	View school as helping her	View school as helping her
SA	How do they help you			
P4	Erm... dunno really, just tellin me and that			
SA	Telling you what?			
P4	About you know, doing that house ... and garden	Not clear on what school is advising	Not clear on what school is advising	Not clear on what school is advising
SA	So, which support services do you use?			
P4	Erm...			
SA	Social services?			
P4	Yeah			
SA	How long for?			
P4	A while back...a year I think	Support from SS over some time	Support from SS over some time	Support from SS over some time
SA	OfL, how long have you used them for?			
P4	Since M was little, 8 years or	Long-term support	Long-term support	Long-term support from

	something...yeah...8 I think	from advocacy group	from advocacy group	advocacy group
SA	Anything ever stop you from asking for help?			
P4	I don't need help and that...I'm fine, I am	Reluctant to engage with services	Reluctant to engage with services	Reluctant to engage with services Wanting to be independent
SA	That's good, you never get stuck?			
P4	...'spose I do, no one helps me anyway though	Doesn't feel supported	Doesn't feel supported	Doesn't feel supported alone
SA	Do you have a key worker for your family?			
P4	Yeah, we got S and the social one...erm...yeah	Can identify key worker	Can identify key worker	Can identify key worker
SA	You can't remember the social workers name?			

P4	It‘s that woman...she‘s got long hair...I forgot, it changes like 4 times	Key worker changes from SS cause confusion	Key worker changes from SS cause confusion	Key worker changes from SS cause confusion Frustration at social worker changes
SA	Do you know what she does?			
P4	Yeah			
SA	Why is she involved with your family?			
P4	Right, the school was complaining so now...they said that I got to do everything or ...or...that‘s it	Do not value the referral, see it as a negative Feeling threatened	Do not value the referral, see it as a negative Feeling threatened	Do not value the referral, see it as a negative Feeling threatened Blamed/betrayed by school
SA	So school referred you to social services. How did you feel about that?			

P4	Angry, they might take M off me now...it‘s their fault though ain‘t it			Feeling betrayed by school Blame school for referral to SS
SA	What things have you got to do?			
P4	Er...the house and that, the garden...get rid of the dogs and... I dunno... loads yeah	Has some understanding of why services are involved	Has some understanding of why services are involved	Has some understanding of why services are involved
SA	What happens if you don‘t do it?			
P4	They‘ll take M off us, like with J	Feeling threatened Might lose child Previous child in care	Feeling threatened Might lose child Previous child in care	Feeling threatened Might lose child Previous child in care Fear based on previous

				experience of SS Distrust SS
SA	J?			
P4	My first bab, lives in West Brom			
SA	With who?			
P4	Carers	Child in care	Child in care	Child in care
SA	Right, so J is in care and M is living with you but you have to make changes?			
P4	I dunno...yeah			Confused about expectations from SS
SA	How would you rate the support from social services? 1 being really bad, 10 being amazing			
P4	I dunno...bad ain‘t it	Negative view of SS	Negative view of SS	Negative view of SS

				Distrust SS
SA	So you‘d say they were not good?			
P4	Not good is it?	Negative view of SS	Negative view of SS	Negative view of SS
SA	What does S help you with?			
P4	S...I dunno...M‘s stuff really			
SA	How does she help him?			
P4	She..er...gets him like a computer, which he broke it and takes him on trips and that...I can‘t go coz of my mum	Accessing resources and support for child Referring to wider family health issue impacting life	Accessing resources and support for child Referring to wider family health issue impacting life	Accessing resources and support for child Referring to wider family health issue impacting life Feeling unsupported in own needs
SA	How would you rate S‘s support?			

P4	I dunno			
SA	If 1 is bad and 10 is amazing			
P4	She‘s ... I dunno, I ain‘t bothered with her	Reluctant to discuss key worker from advocacy group	Reluctant to discuss key worker from advocacy group	Reluctant to discuss key worker from advocacy group Negative view of key worker
SA	Do you trust S?			
P4	No...no	Not trusting of key worker from advocacy group	Not trusting of key worker from advocacy group	Not trusting of key worker from advocacy group
SA	Why not			
P4	I just don‘t like her	Personal dislike of key worker from advocacy group	Personal dislike of key worker from advocacy group	Personal dislike of key worker from advocacy group
SA	You don‘t like h-			
P4	-telling me what to do and that	Feeling pressured into	Feeling pressured into	Feeling pressured into

		doing things Lack of consultation/discussion	doing things Lack of consultation/discussion	doing things Lack of consultation/discussion
SA	OK. Do you trust Social services?			
P4	...No	Not trusting of SS	Not trusting of SS	Not trusting of SS
SA	Why not?			
P4	They wanna take M don‘t they	Feeling threatened by SS	Feeling threatened by SS	Feeling threatened by SS Fear/anxiety based on previous negative experiences of SS
SA	Right. Do you feel like you can challenge them? Like if they tell you to do something, can you say no?			
P4	I say no, I do what I gotta, to get them off my back don‘t I?	Do not value input from SS	Do not value input from SS	Do not value input from SS

				Fearful
SA	Yeah, Ok. How would you describe them?			
P4	Angry all the time... telling me what to do and that...I get angry	Feeling angry and frustrated by SS	Feeling angry and frustrated by SS	Feeling angry and frustrated by SS
SA	Do you understand everything they tell you?			
P4	I don‘t listen to ‗em do I... they keep going on	Passive recipient of support	Passive recipient of support	Passive recipient of support
SA	At the meetings at school, when everyone comes to talk to you, do you understand what they are saying?			
P4	No, how can I? I take D... he don‘t get it either you know	Lack of understanding of advice given	Lack of understanding of advice given	Lack of understanding of advice given Feeling ignored in multi-agency meetings
SA	Right, do you say you don‘t understand?			

P4	Er...no, they just keep talking			
SA	Right, do they talk to each other?			
P4	Yeah, they keep talking and don‘t ask me how I am, coz of my surgery and that, it‘s bad...	Feeling ignored	Feeling ignored	Feeling ignored Feeling unsupported
SA	How can they be better?			
P4	Better?			
SA	Yeah			
P4	They can‘t get better can they?	Lack of optimism in services improving	Lack of optimism in services improving	Lack of optimism in services improving
SA	What would you tell them to do, to get better?			
P4	I‘d say I don‘t need ya or anything...No one helps me anyway do they?	Feeling unsupported	Feeling unsupported	Feeling unsupported Feeling ignored
SA	Ok. Is there anything that you need help			

	with?			
P4	My mum has her injections, I help with that...	Family health implications	Family health implications	Family health implications
SA	Do you need help with the house			
P4	Yeah...I‘m doing the house... D‘s doing the house where he can but he can‘t paint with his chest and that...and I got my bust back	Own health implications affecting their ability to act on guidance from SS	Own health implications affecting their ability to act on guidance from SS	Own health implications affecting their ability to act on guidance from SS
SA	Right and with the garden			
P4	I ain‘t doing the garden coz of my back and that	Own health implications affecting their ability to act on guidance from SS	Own health implications affecting their ability to act on guidance from SS	Own health implications affecting their ability to act on guidance from SS
SA	Do you need help with those things?			
P4	Yeah...but I just do it don‘t I?	Identifies that help is needed	Identifies that help is needed	Identifies that help is needed
SA	Do you need help with M?			
P4	Er...he‘s naughty sometimes ... but then he			

	settles with D...I dunno			
SA	Last few questions J, you‘ve done really well so far. Did anyone help you find this house?			
P4	Yeah			
SA	Who was that?			
P4	Er...her... I forgot			
SA	Do you work?			
P4	Nah... I got my surgery soon	Own health affecting family life	Own health affecting family life	Own health affecting family life Anxious about own health
SA	OK, would you want to work			
P4	Yeah...D goes to the job centre but ain‘t nothing for him yet			
SA	OK. Can I ask, do you feel like you are in charge of what happens to you and your			

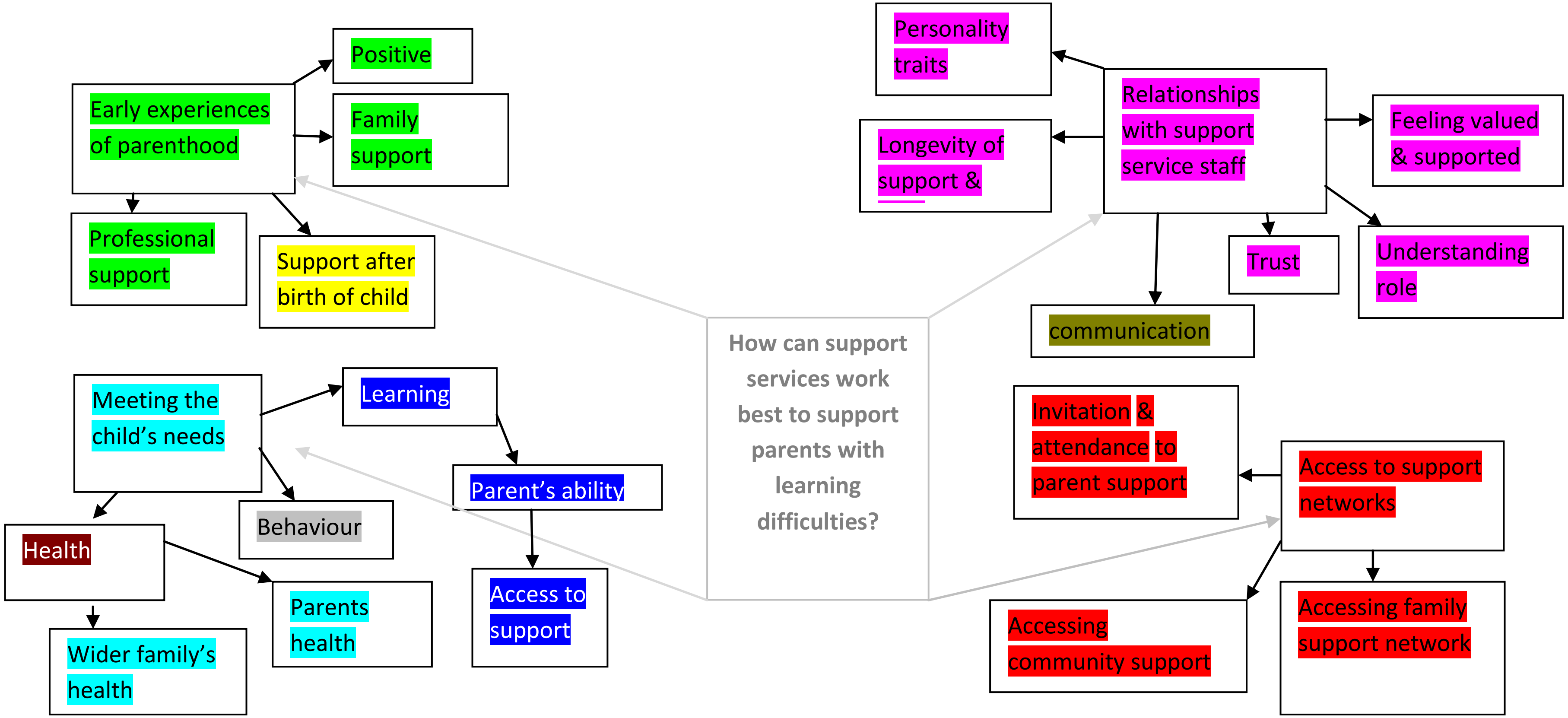
	family?			
P4	Erm...In charge?			
SA	Yeah			
P4	Yeah...I help my mum with her injections and ...I got M as well	Feeling responsible for child and mum	Feeling responsible for child and mum	Feeling responsible for child and mum
SA	OK. Do you feel like people listen to you?			
P4	No one listens to me, I‘m always saying...they don‘t listen	Feeling like no one listens	Feeling like no one listens	Feeling like no one listens Feeling ignored/frustrated/angry
SA	Who doesn‘t listen?			
P4	Everyone			
SA	Like who?			
P4	S, Social, ...M ...or D			
SA	Right. Do you live a normal life?			

P4	(laughs)...yeah, it's normal			
SA	Are there things you'd like help with for M?			
P4	Like what?			
SA	Like with his school work, looking after him at home...			
P4	I can't help him with school work, I told him that and...I can't read. He's always got mess on his top and that too...he eats his dinner	Own ability is a barrier to helping g child progress	Own ability is a barrier to helping g child progress	Own ability is a barrier to helping g child progress
SA	OK. So maybe some help with his school work?			
P4	Yeah, he needs that...erm, yeah			
SA	Are you happy with the support you get from school?			
P4	Yeah, they...alright, yeah	Getting some support from school	Getting some support from school	Getting some support from school
SA	And when you need help with school work,			

	do you ask school			
P4	I dunno...erm...M asks his teacher			
SA	OK.			

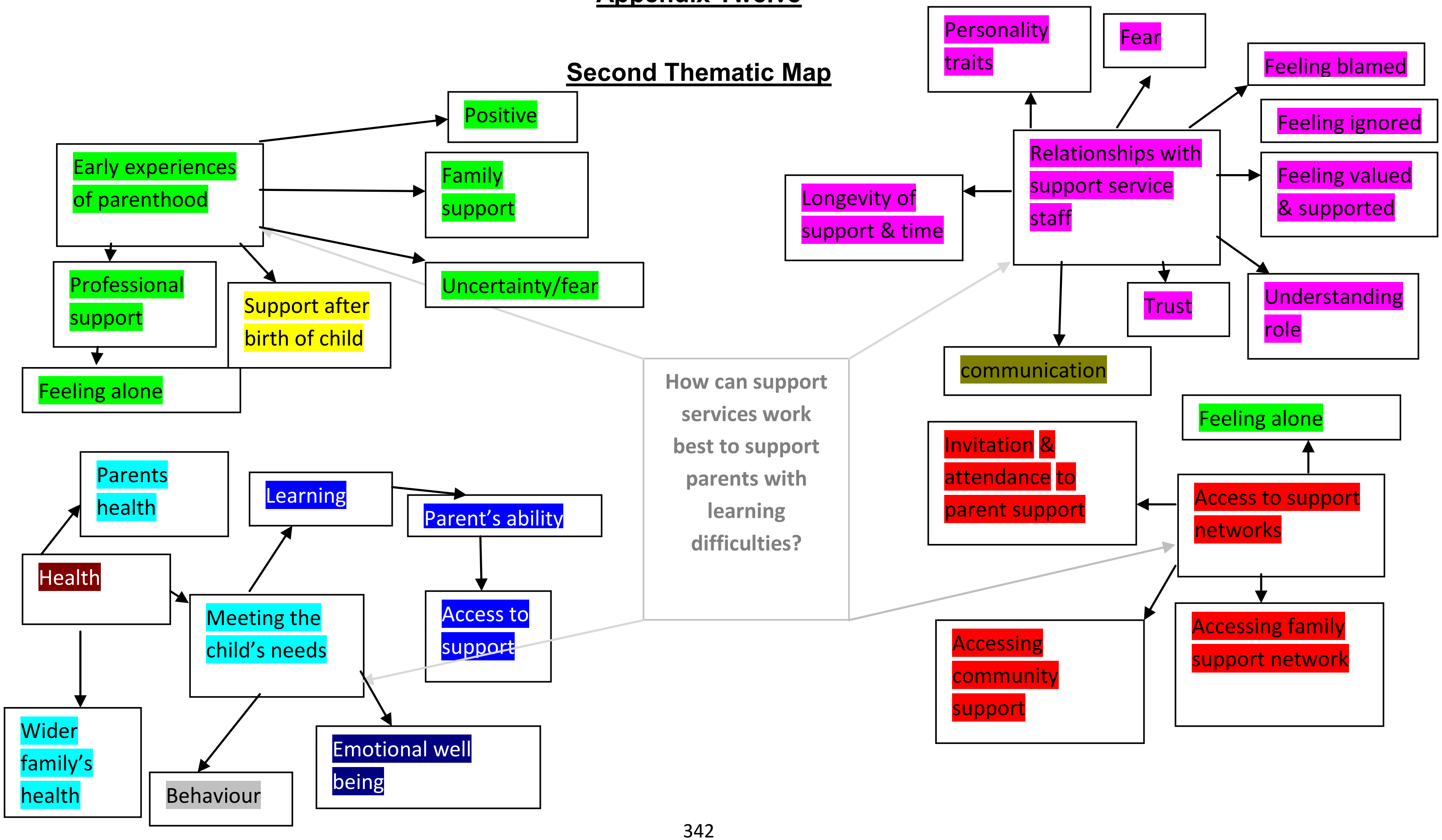
Appendix Eleven

Initial Thematic Map



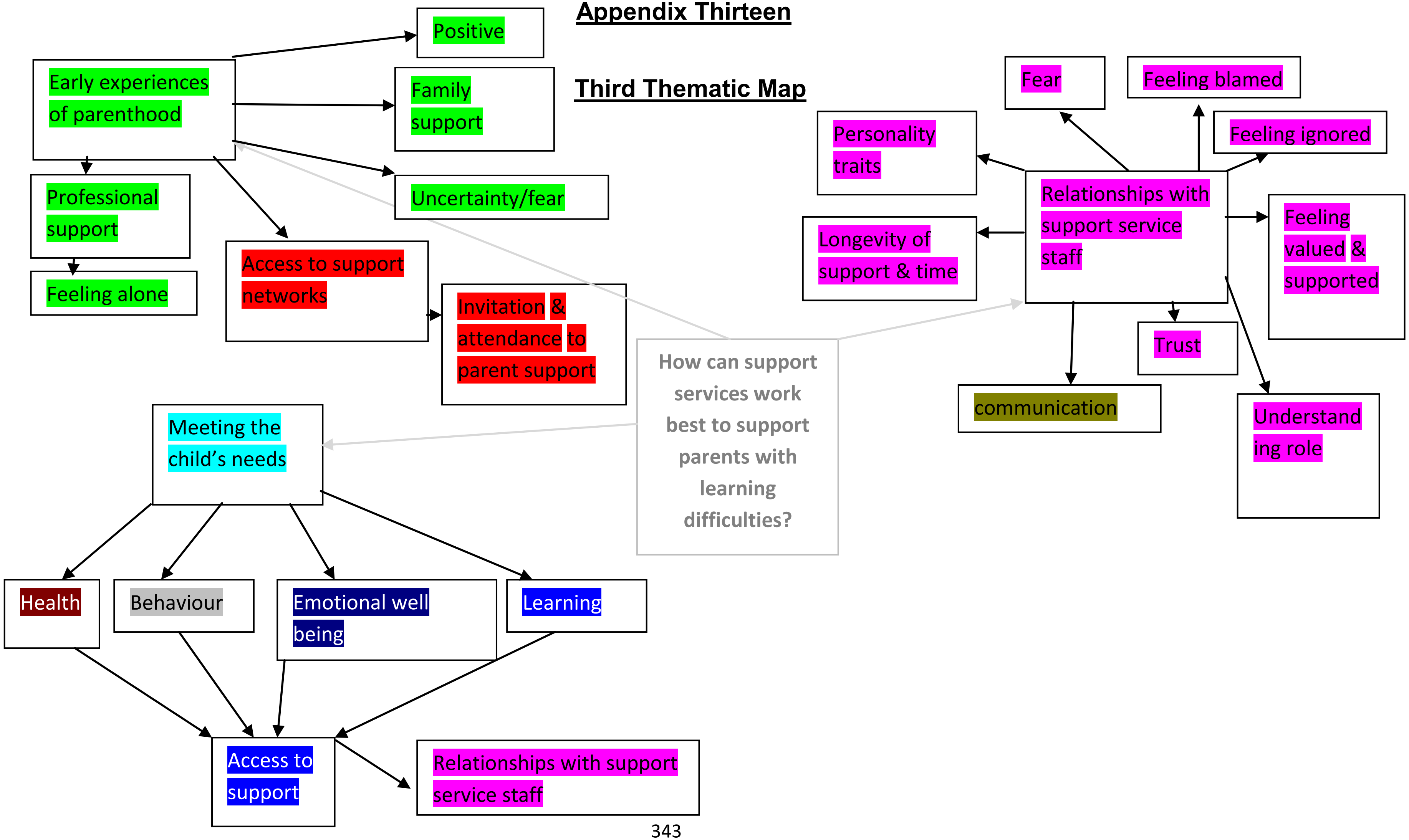
Appendix Twelve

Second Thematic Map



Appendix Thirteen

Third Thematic Map



Appendix Fourteen

Phase 5 of thematic analysis: defining and naming themes

Theme 1. Parental Engagement with Support Services

Subtheme: parent's views of feeling valued and respected		
Initial Codes	**Example Extracts**	**Narrative/initial reflections**
–View CAMHS as supportive –Feeling unsupported by SS –Parents view school as approachable for help and support when needed –Positive relationship with teacher – Parents view the support service as reactive, only intervene if there is a problem –View CAMHS support positively – Parents feel input from services is limited, affected by time – Feel unsupported by SS – Needs not being met – Feel services could be improved by offering more help – Feeling unsupported by	P2: We haven‘t heard nothing from them since after that P1: He played up the one the one day we bought him home, we take him back to school and he did play up. But...but...We ain‘t heard nothing since. P1: We only go half hour at a time. You can‘t do a lot in half hour.	A common element here is that school are often the agencies to first report ‗problems‘ to social services. Parents view support services as being reactive, they tend to intervene when things escalate. There appears to be little support provided prior to this point. Also, if there doesn‘t appear to have escalated to crisis point, it appears that some services withdraw, not offering any support. Overall, parents seem to feel ignored

SS – Feeling unsupported as parents – Feel supported enough to challenge CAMHS – Feel supported enough to challenge CAMHS school –Feel supported enough to challenge SS –View school as supportive – Feeling unable to ask for help/alone Concerned about how professionals perceive them –Identify school as good listeners – Don‘t feel listened to –Their concerns not a priority	P1: Yeah, yeah. Them (school) supportive. P2: No, don‘t ask...just do our best really. P2: If you get it wrong in their book, the teacher will think won‘t they. P2: They just shut the book, conversa.....finished now, it‘s time	and not listened to in multi-agency meetings. Some then take on a passive role, they accept that they will not be listened to and do not try to challenge this. On the other hand, some parents express anger and frustration which can lead to outbursts towards professionals. It appears that parents feel blamed for the difficulties their families face. It appears that they feel other‘s look down on them – there is an overall lack of

–Identify own concerns, feel school does not agree – Ignored in multi-agency meetings. –Feeling frustrated – Feel not listened to by school –Ignored in multi-agency meetings –Feeling blamed/ betrayed by school –Feeling blamed/ betrayed by school –Confident in asking for help –Feeling animosity that school contacted SS –Changes of social worker leading to emotional response, annoyance, frustration –Feels able to challenge key worker –Feels confident to ask questions –Feels like a passive recipient of information –Ignored in multi-agency meetings –Does not feel opinion is valued or listened to –Angry when control over family is questioned –Feels in control –Feel ignored –Feels other perceive her negatively –School judge her	P3: Since the very first time what... you know when the school phoned ‗em about H, what they shouldn‘t have done yeah, none of their business SA: Has anything ever stopped you for asking them for help? P3: No, because I just tell ‗em if I need help P3: I do challenge her (key worker) P3: No, I ask ‗em and ask ‗em til I understand P3:Nah, I just let ‗em carry on...they don‘t listen to me yeah, they just talking too much sometimes	respect. One parents talks about she is unsupported in her desire to have another child. She feels as though her wants are ignored by the key worker. The most positive relationship appears to be with schools and school staff, which may be because parents have most contact with them. Parents appear to feel that CAMHS are helpful and supportive but do not seem to have a clear understanding of their role. The positive view may stem from viewing CAMHS in a ‗medical expert‘ role.

–Feel frustrated –Feeling blamed –Feeling controlled, angry and frustrated –Feels as though professionals are interfering –Feeling treated unfairly –Feeling blamed/victimised –Negative relationships not based on respect or trust –Frustration at social worker changes –Blamed/betrayed by school –Feeling betrayed by school –Feeling threatened –Blame school for referral to SS –Feeling pressured into doing things –Passive recipient of support –Do not value input from SS –Lack of consultation/discussion –Feeling like no one listens –Feeling ignored/frustrated/angry –Feeling unsupported –Feeling unsupported –No advice or strategies offered to support the family‘s needs – Feeling unsupported, alone –Feel supported enough	P3:I think people don‘t listen to me...they look down on me yeah P3: I get frustrated, angry...One time, I got up and slammed the doors...coz, I, you know, I...when I talk yeah, I have to keep repeating myself yeah to make ‗em understand ... if they don‘t reply back to me or anything yeah, I get angry P3: I know I‘m the mum, so I have to be in charge...but if like someone says you gotta do this, I get really angry (laughs) P4: Happy (coughs) yeah... erm...I wanted another (child) but her said I can‘t P4: She‘s just always poking her nose	Parents sometimes feel blamed for not being able to support their child fully with aspects of their development e.g. school work, health, behaviour, they require more support to do this. Or, are they not engaging with the support offered? Parents don‘t appears to be consulted in relation to decisions made about their children in an accessible way – where does this lead to in terms of equal opportunities and anti-oppressive practice? Time is not spent my some support workers to build relationships with parents, to encourage mutual respect, trust and understanding. Some parents do not have an identifiable key worker, or do not know the names of professionals working with their families.

–Feel supported enough –Values support given by key worker –Feeling unsupported/alone	about...She don‘t like me ya know P4: if the dogs done one on the carpet and that. Oh, she gets half angry and starts telling me this and that...I can‘t be bothered, she don‘t listen and I‘m angry. SA: You can‘t remember the social workers name? P4: It‘s that woman...she‘s got long hair...I forgot, it changes like 4 times P4: Right, the school was complaining so now...they said that I got to do everything or ...or...that‘s it P4: They‘ll take M off us, like with J	

	P4: I say no, I do what I gotta, to get them off my back don‘t I? P4: Yeah, they keep talking and don‘t ask me how I am, coz of my surgery and that, it‘s bad... P4: No one listens to me, I‘m always saying...they don‘t listen SA: Do you ever say can we talk about his reading and writing? P1: We don‘t have that long P2: Not that long, half an hour. So, it‘s not easy.	

Subtheme: Communication between parents and support services		
Initial Codes	**Example Extracts**	**Narrative/initial reflections**
– Unable to clearly explain the role of CAMHS – Parents have one contact detail – Lack of on-going communication – Un-sure of role of social services – Un-sure of role of social services –Feel they have been waiting a long time –No on-going communication since initial visit –Lack of on-going support and communication –Lack of on-going support and communication –Lack of on-going support and communication –Contact details provided by SS –Feel services could be improved through better communication –Clarity of communication –Lack of communication between home and school causing parental anxiety	SA: And are they giving you any support at all? P1: We ain‘t heard...do they do work at the school now P? P2: I don‘t know what‘s happened SA: And you haven‘t heard anything since (initial home visit)? P1: No P2: No P1: He (son) played up the one the one day we bought him home, we take him back to school and he did	It appears that some lack of communication between parents and support services lead to a lack of awareness and understanding of the roles of professionals. The main ways in which support services seem to communicate with parents is through the use of written correspondence, such as letters. The parents interviewed in this study could not read. Some could not identify a person who could help them read letters. Accessible forms of communication should be used with parents with LD.

–Not aware of CAMHS role –Not sure of the role of the ‗man‘ – his name not know etc. –Not a close relationship with the ‗man who helps‘ –Role ambiguity –Not a close relationship with the ‗man who helps‘ –Role ambiguity –Role ambiguity –Uncertainty regarding CAMHS work with their son –Uncertainty regarding CAMHS work with their son –Uncertainty regarding CAMHS work with their son –Uncertainty regarding CAMHS work with their son Uncertainty regarding CAMHS work with their son –Not accessible form of communication –Difficulty reading letters sent by services –No support for reading letters –Help from housing – waiting not sure of when- communication could be improved –Not aware of when appointments should be –Knows why key worker is involved with family	play up. But...but...We ain‘t heard nothing since. SA: Did they give you any advice on how to deal with that, if it happens again? P1: They just give us a number didn‘t they P? P2: There is a man we saw recently, ain‘t there? P1: He‘s something to do with the school coz M‘s put a bit of weight. SA: Do you know why they (social services) are involved with your family? P3: Yeah, coz of H	Often a lack of understanding of why services are involved leads to anger and frustration on the part of the parent. This could also affect their willingness to engage with services. Lack of inaccessible forms of communication in multi-agency meetings also seems to be a source of anger and frustration for parents. It appears that support services lack the long-term involvement with parents that is suggested by policy as being vital for supporting parents with LD. This may be an issue with resources and funding. There appears to be very

–Knows why SS is involved with family –Perceives herself to have good understanding –No communication pathway identified –Knows where key worker is based –Importance of being able to communicate with professionals –Demonstrates an understanding of SS processes –Not able to understand everything professionals tell her –Lacks understanding of what she is being told –form of communication used is inaccessible –Lacks understanding of what she is being told –form of communication used is inaccessible –Lacks understanding of what she is being told –form of communication used is inaccessible –Lacks understanding of what she is being told –form of communication used is inaccessible –Emotional instability due to lack of communication –Emotional wellbeing of parent due to lack of communication	SA: How much do you understand on a scale of 1-10 P3: 10 SA: Do you ring them? P3: Not really...I don‗t got the number SA: Ok. What do you like about them (family support worker)? P3: I dunno, I can talk to ‗em SA: And do you understand what they‗re (social services) saying? P3: No, not really SA: What about at the meetings in	understanding on the part of parents re: professional‗s roles and involvement with their children. Clearer consultation needs to be had with accessible information shared with parents. Parents express some disengagement in multi-agency meetings, they appear to be a source of some frustration. Parents seem to becoming entrenched with the idea that no one listens to them and there is no point in contributing ideas, asking questions or getting involved in multi-agency meetings. There appear to be few steps, if any, taken to ensure that parents understand what is being asked of them, or what they are being told by professionals. This involves time

–Anger management due to lack of communication –Frustration due to lack of communication –Anger management due to lack of communication –Frustration due to lack of communication –Anger and Frustration stem from lack of understanding –Time spent by key worker to ensure information is accessed and understood –Anger and Frustration stem from lack of understanding by professionals –Feels other‘s don‘t listen to her views –Feels doesn‘t have a choice/control over services being involved with the family –Passively accepts support –Has some understanding of why services are involved –Accessing resources and support for child –Lack of understanding of advice given –Not clear on what school is advising –Tries to do things independently –Confused about expectations from SS –Feel that time pressures mean that they have limited time to voice concerns –Parents feel input from services is limited, affected by time	school? Do you understand what they‘re all talking about? P3: No, no-..no, not really P4: Er...the house and that, the garden...get rid of the dogs and... I dunno... loads yeah P4: She..er...gets him like a computer, which he broke it and takes him on trips and that...I can‘t go coz of my mum SA: At the meetings at school, when everyone comes to talk to you, do you understand what they are saying? P4: No, how can I? I take D (partner)... he don‘t get it either you know	being spent with the family and information presented in a variety of ways not just verbally. Some key workers appear to be very effective – they spend time with family, parents feel they are available for support and they have achieved a trusting relationship with parents, however, this is not a consistent finding. Time appears to be a significant barrier to parental engagement with services.

–Some repetition	SA: You‘re doing really well N, thank you. Who helps you with reading books? P3: Well...when I got time, I do it, I do try myself P1: Yeah. He talks don‘t he? It‘s (CAMHS appointments) only about half hour a time (coughs) P1: It took ‗em (CAMHS) that long to get the paperwork SA: So you don‘t have to keep repeating yourself? P3: Probably have to repeat it sometimes but...yeah	

Subtheme: Parent’s personal relationship with support services workers		
Initial Codes –Finding services unapproachable –View CAMHS as positive –View SS positively –Values personal characteristics of key worker –Importance of key workers personality –Importance of social workers personality identified Personality of worker is very important –Male SS viewed negatively –Male SS viewed negatively –Volatile relationship with SS and school at times Identifies key worker as reliable for help –Negative relationship with social worker –Positive relationship with key worker –Positive relationship with key worker –A turbulent relationship with staff –Reluctant to engage with professionals –Reluctant to engage with professionals –Relationship with professional is based on personal characteristics –Reluctant to engage. Avoiding	**Example Extracts** P1: Them (CAMHS) just all...them, them, helpful, cheerful P1: We‘ve only got the phone number SA: He goes to Wellfit, doesn‘t he? P1: Yeah, at school. I used to go up West Bromwich one first. The school one‘s every Friday, I used to go but I‘m the only man there so now I let P...I do P3: Coz, I can get on with N and N...if I need help yeah, she helps me	**Narrative/initial reflections** The way parents view the support workers may be affected by the amount of time that they work together. For example, P3 values N‘s (family support worker) input more so than the social worker‘s input. This may be because there is a lot more involvement from N, over a longer period of time. Also, N may not be perceived as a threat to the family unit. It also appears that the personal characteristics of the support workers also affect whether parents engage with services e.g. parent might pretend to be out because they don‘t

professionals. –Reluctant to engage. Avoiding professionals. Relationship with worker is turbulent –No close relationship with SS –View school as helping child –View school as helping her –Previous experiences with services make them reluctant to engage –Reluctant to discuss key worker from advocacy group –Personal dislike of key worker from advocacy group –Feeling angry and frustrated by SS –Not able to identify a key worker –Reluctant to ask for help –Gender issues make dad reluctant to engage –Mixed views on SS –Getting some support from school –Aware of time limitations of services	SA: You don‘t like ‗em (social services)? Ok. What don‘t you like about them? P3: Them just too nosy man P3: I dunno man...and then...I dunno...bu my family support worker, she‘s alright...no, my new social worker, she‘s alright too. SA: What about the other two social workers you had? P3: It ain‘t on there, words don‘t come for him (laughs) SA: Would you ask social services (for help)?	like the worker. Parents respond negatively to the thought of being ‗told‘ what to do by support workers. The experiences of parents seems to vary vastly e.g. some have a positive relationship with SS and other‘s do not, this appears to be dependent on their relationship with the individual. Overall, there appears to be some reluctance to engage with support services, there appears to be a significant degree of fear, this stems from previous experiences with services and also depends on the like/dislike of the professional.

	P3: No, coz I...my heart don't go to ‗emman P3: I'd rather phone N (family support worker) before phoning social services SA: Would you say they've been quite helpful? P3: The one has a bit, yeah, but not really...I dunno...I get one with her yeah P4: Sometimes ... I don't like her sometimes. She comes round and I pretend I ain't in to keep her off me back. I hid behind the sofa I did...dogs kept barking P4: Oh, she gets half angry and starts telling me this and that...I can't be	It is interesting that gender issues made dad reluctant to engage with some services.

	bothered, she don‘t listen and I‘m angry. P4: Her‘s always telling me you know ... I just can‘t be-...I ain‘t bothered with her P4: Erm...I ain‘t got time for _em you know...if...if...just ain‘t got time for _em...I gotta help my mum everyday and that ...they just have a go, telling me what to do and they gonna tek him if I don‘t do it P4: I just don‘t like her - telling me what to do and that P4: Angry all the time... telling me what to do and that...I get angry	

Subtheme: Extent to which parents trust support service professionals		
Initial Codes	**Example Extracts**	**Narrative/initial reflections**
– Help never sought from SS –Feel services could be improved –Trust professionals such as CAMHS –Trust school –Trust is lower for SS than services they've had more contact with –Uncertainty regarding SS's intentions –View CAMHS positively – Parents take on board suggestions made by school –Identifies key worker for family, trusts to help –Does not initiate contact –Does not initiate contact	P1: I trust em (CAMHS) a lot. They alright ain't it? SA: And what about CAMHS, can you challenge them? P1: Yeah, fine SA: Are there any professionals you can ring for help?	Trust of support service professionals seems to be linked to previous experiences e.g. if parents feel they have been let down in the past, they are reluctant to engage. There seems to be a high level of fear/mistrust around social services involvement – some of this is due to previous experiences e.g. other children taken into care, could some

–Can identify a key worker –Trust –Not trusting of social worker, does not value their input –Distrust –View of SS is negative, perceives their role as threatening to family unit –Fear, feeling threatened by SS –Perceives SS role as a threat –Trust is important –Fear of SS –Trusting of key worker –Generally mistrusting of people –Not trusting of social services –Perceive SS as a threat to family unit –Fear and anxiety over SS –See school as helpful –Trust is questionable with school –Referring to lies by SS - distrusting –Wanting to be left alone –Independence –Reluctance to engage with services –Fear –Reluctance to engage with services –Previous negative experiences affect current views –Try to be independent	P3: Yeah..erm..N, my family support worker SA: That‘s good. How do you contact them? P3: When I see ‗em, if she comes to my house and that SA: If there was something urgent, how would you contact them? NFI would talk to N when I see her P3: C, the social worker what I got now, she‘s alright. The one I got first, M, he told a lot of lies...a lot of lies... the other one was alright too. P3: They (social services) say, try to	of this be due to ‗reputation‘ social services have? E.g. media representation and the suggestion they are a reactive service which only get involved if there is a ‗problem.‘ The knowledge that social services are involved in care proceedings and have the power to take children into care etc., leads to them being perceived as a threat. As a result, these parents seem reluctant to engage with services. Parents express a wish to be left alone, this may be because they do not trust support services to work in their best interest. As a result, parents do not often initiate contact with support workers. What is interesting is that parents express a desire to want help and support with different aspects of their lives e.g. supporting

–Feeling let down by services in the past –Wanting to be left alone –Independence –Reluctance to engage with services –Wants independence –Does not feel she needs support –Fear of being ‗reported‘ –Not accepting advice –Fear of SS. Feeling unfairly treated. –Feels unliked by professionals –Fear –Fear –Negative view of SS/fear/anxiety –Fear of threat to family unit –Reluctant to engage with services –Wanting to be independent –Can identify key worker –Might lose child –Previous child in care –Fear based on previous experience of SS –Distrust SS –Child in care – Negative view of SS –Distrust SS –Negative view of SS –Negative view of key worker –Not trusting of key worker from advocacy	keep families apart which they don‘t SA: Keep families apart? P3: They say they try to keep families ap...together, but they don‘t they keep ‗em apart. SA: So, you think they‘re trying to keep your family apart? P3: Yeah yeah yeah..until like...so many months down the line, do you know what I‘m on about? P3: I dunno, just trust...I don‘t trust people P3: Them (Social services) trying to take us apart...they lie...they ain‘t nice man. Every little thing, they pick on it	child‘s behaviour, however, their fear of being blamed, mistrust of services (perhaps deriving from stigma) prevents them from initiating contact. Parents expressed that they perceived no barrier to asking for help from services, but it remained that they still did not ask for help, even when they identified areas in which they felt they needed help e.g. P3 help managing H‘s behaviour. A central fear is having their children taken away into care. 2/3 parents had already had previous experience of this, all three parents displayed an understanding of this process, all three felt threatened by this possibility. This may have prevented parents from asking for help. The length of time a parents has been

group – Not trusting of SS –Feeling threatened by SS –Fear/anxiety based on previous negative experiences of SS –Fearful –Feeling unsupported –No perceived barrier to asking for help from school –Lack of optimism in services improving –Short-term involvement –Long-term involvement from key worker –Long-term involvement from SS –Key worker changes from SS cause confusion –Changes of social workers 3 times over a short period of time – Support from SS over some time –Long-term support from advocacy group	P3: Coz when...you know what, to tell you the truth, when like H‘s been really bad, when...before she started school, no one really bothered to help me, do you understand? So really yeah, to me yeah, I think, I can do it man. P3: They here to help...but I don‘t think I need ‗em P4: If we had a drink right, she (advocate) reports us, or if the dogs done one on the carpet and that. P4: She (advocate) said that, she said about reporting me to the social, it ain‘t fair, they can‘t tell me though, I do what I want...	involved with support services appears to vary between 8 years to just a few months. Length of time did not guarantee engagement with services. E.g. P4 had been working with OfL for 8 years but was reluctant to engage, she did not trust or like them. All parents had experiences changes of social workers, some did not know the name of their current social worker, the message this sends to parents is that they are not important/valued. Every time a new worker is assigned, a new relationship must be built but time pressures do not allow this to happen. Two parents could identify a key worker for their family, but only one (P3) appeared to have a positive

	P4: I dunno...her (advocate) report me and that, you know what ‗em like, but I take no notice P4: I don‘t need help and that...I‘m fine, I am P4: They‘ll (social services) take M off us, like with J SA: Do you trust S? P4: No...no P4: They wanna take M don‘t they SA: OfL, how long have you used them for?	relationship with them. Only one parent had long-term involvement with a professional (outside of school staff), their personal relationship was turbulent, leading to a reluctance to engage.

	P4: Since M was little, 8 years or something...yeah...8 I think	

Theme 2. Parental Access to Support Services

Subtheme: How children's needs are affected by access to support services		
Initial Codes	**Example Extracts**	**Narrative/initial reflections**
–Hobbies, meeting the child's needs –Spending time with child –meeting the child's needs –Nurture/love – Managing children's behaviour is difficult – Providing child with attention is difficult –nurture –Providing child with attention is difficult –Nurture –Child is struggling to achieve academically	P1: Yeah, fishing, I spend a lot of time with him and that P2: Yeah, we went Blackpool together, didn't we? Last week didn't we? P1: Yeah, oh he's all dad ain't he P?	Children's needs that are referred to by parents include: physical health, behaviour and learning. Services seem to focus on the housing conditions as well as these. Parents understanding of what a child needs to lead to become a well-

–Parents difficulty in understand learning needs –Feeling unsupported, anxious/worried –Parents difficulty in understand learning needs –Feeling unsupported –Lacking techniques to manage child‘s behaviour –Parents academic ability is a barrier –Anxious/worried –Child‘s emotional well-being affected by parents ability –Worried –Parents try their best/lacking skills –Feeling unsupported – Parents try to support academic progress - Parents aware that their ability is a potential barrier –Anxious and worried about the future –Parents concerned about supporting child‘s learning –Parents concerned about child‘s health –Managing child‘s behaviour is affecting the child‘s health –Anxious and worried, feeling helpless –Parents concerned about child‘s health	SA: ... what is hard about being a parent? P1: Probably some of his tempers sometimes P2: Yeah, attention a lot now he‘s older P2: ... He wants to learn, it‘s hard and I can‘t coz it‘s all change at school, I can‘t understand what they‘re doing at school. I don‘t know the new ru...it‘s changed when I was at school. P2: It (not being able to read) hurt...it must hurt him, hadn‘t it really? P2: I‘ve been reading and that. He loves the pictures though. We done	adjusted member of society may be limited. E.g. demonstrating a limited understanding for the need for nurture. More training/support in accessible forms are needed to raise awareness of a child‘s needs and how these can be met. All families had children which exhibited significant behavioural difficulties, all parents openly reported needing help with this, however, they were not accessing any type of support. The extent of the difficulties they face may be hard to uncover because of the fear they had of having their child taken into care – fear was a barrier to asking for help, fear may be a barrier to them reporting the full extent of their needs. Parents seem very aware of how their

–Managing child‘s behaviour is affecting the child‘s health, parents find it difficult to manage behaviour –Own mental health is a concern –Managing behaviour remains an issue –Managing behaviour remains an issue –Health difficulties are a concern for parents –Health remains a concern –Anxious /worried about child‘s health –Child faces teasing from peers –Parents concerned about child‘s emotional wellbeing –Parents concerned about child‘s emotional wellbeing –Child is victim of teasing from peers –Education – anxiety around child‘s progress –Social difficulties faced by child –Feel supported by school –Feel supported by school – Anxious and uncertain about child‘s learning –Aware that child‘s health needs attention –Lack awareness of what the child needs to lose weight, seriousness of the issue –Feeling blamed – having to explain themselves –Anxiety over academic progress	our best. P2: Help him, it‘s easy now his homework but when he gets older, it‘ll be hard for us to do, that‘s the problem P2: He needs an injection from Newtown Hospital, but he won‘t have it done P1: Oh, he plays up, he won‘t have it done. We dunno what to do P1: That‘s when he (child) kicks off, if he knows they‘re gonna do injections, he‘ll kick off then. He kicked off with his mum at the hospital P1: I‘m going with him next time coz I	own difficulties are affecting their children e.g. reading ability/health. Accessing support to meet their needs still remains problematic. Parents appeared to be very open with sharing this information with me, it may be because they do not see me as a threat to their family unit, however, if they are telling people/professionals that they need help, why are they not getting it? Is there a line of accountability to help these parents? School are heavily involved with aspects of the children‘s development, many school‘s host TAC meetings or core group meetings with multi-agency professionals. These regular meetings provide parents with a forum for discussion, parents don‘t appear confident enough to capitalise on this. They don‘t appear to be clear on the remit of these meetings either.

–Unsure what support child gets at school –Reading is a main concern for parents – Understand that speech and language is a concern and school are helping –Anxiety over child‘s health –Working relationship with school and speech and language services –Reading and writing is a main concern –Parents concerned they can‘t help their child progress –Fear and anxiety Feel unable to support child‘s learning –Fear and anxiety –Feeling blamed for child‘s lack of academic progress –Has support for own mental health issues –Job uncertainty Job uncertainty – redundancy –Parent has own health issues –Parents emotional well-being affected by own health issues –Emotional well-being is affected –Medical assistance – Concerns about child‘s health – Feel in charge of family –Concerns about child‘s reading and writing –Anxiety	stop with him now you see. Yeah, yeah. I have counselling anyway for mine. Coz that could help me as well, you see. P2:...and the children shouldn‘t take the mick out of my son because M doesn‘t like it. P2: ... I‘m glad he‘s getting one-to-one teacher because I was worried because he‘s going down hill. He‘s two years behind work...he‘s told...his teacher told me last year. His teacher‘s been very poorly, so I don‘t know how he‘s got on this year P1: He (child) never sits about really, he‘s always doing something, especially in summer...we can‘t do no	Children‘s health seems to be suffering as a result of parents lack of understanding re: healthy eating/healthy diets but also because of difficulties managing children‘s behaviour e.g. they give into the child‘s demands to avoid confrontation. Parents are told not to do that and they need to be assertive and consistent, however, no support is offered in order to achieve this. Parents may lack the skills to apply this advice independently. Children are being affected by their parents difficulties e.g. health implications, behaviour. One case describes how a child is being teased by peers because of his low reading ability, this child is 9 years old, it is interesting that prior to this time he was not even at SA phase of the SEN

–Reading and writing is a concern –Children teasing their son –Feel blamed for son‘s difficulties –Feeling unsupported –Anxious and worried –Not sure where to go for support –Identifies responsibilities as a parent –Love/nurture –Concerns about child‘s health needs and meeting them –Anxiety and fear –Managing child‘s behaviour is a concern –Challenging behaviour –Concerns about reading letters and books – Admits not being able to access text/read –Unsupported –Family is drawn on for support –Identifies a worker that helps her read –Reading highlighted as a need –Professional support there to help read letters –Wants to go back to school –Accessing education to improve life –Want to access education to improve literacy skills –Lack of support to reach goals –Afraid to try alone	more than that really P2: ... I‘m glad they‘re getting one-to-one coz I insisted that coz his reading and writing has gone down hill, he can‘t help it really, I‘m glad they noticed that. The other teacher told me two years ago at school M will probably need a one- the teacher has left the school now – she says but probably M will need a one-to-one because erm...his writing‘s not that good and his reading‘s very poor. P1: Yeah, they (Speech and Language services) give us cards and we help M say the letters and that P2: Be a good idea really, to help in case he (child) says mum..and I says, I can‘t do it M, I don‘t know myself, I	Code of practice. This child‘s needs were not identified previously even though CAF had been raised and multi-agency meetings held. Parents feel blamed for their children‘s difficulties, this may make them reluctant to ask for help but also if services are blaming parents, they may be overlooking their own responsibilities towards the child. Parents have highlighted the importance for them to remain ‗in charge‘ of their families, they are afraid of control being taken away from them. They wish to appear competent in the eyes of professionals. Parents feel criticised by professionals when they show weakness or ask for help.

–Difficulty managing children‘s behaviour –Lead normal life –Difficulty managing children‘s behaviour – wants help –Lacking knowledge of importance of keeping the house clean –Concerns about own health issues –Anxiety –Concerns about own health issues –Wider family issues affecting the family –Focus on basic needs of child - lacking knowledge of need for nurture –Managing challenging behaviour is difficult –Supporting child‘s academic progress is difficult –Giving child attention – lacking knowledge of need for nurture –Parent can‘t read –Need guidance to manage behaviour effectively –Partner is her main support –Partner also can‘t read –Reluctant to ask for help –Referring to wider family health issue impacting life –Feeling unsupported in own needs –Family health implications	leave it to you (husband P1), don‘t I? P2: I was single mum, weren‘t I? Children grown up, one left 15 year old, I was working. Then my job...got made redundant, a few years later, diabetes type one, that was a shock for me, type 1, diabetes, he told me. I have to cope with it now, that‘s hard P2: I‘m glad this is happening. I really am, coz I was worried. He can‘t read and write, what‘ll happen? Where can he go? Nobody‘ll have him. Kids‘ll take the mick if he can‘t read and write when he‘s 12. What‘s gone wrong? They blame the parents. Don‘t they? I‘m glad the teacher realised he can‘t read and write. I‘m glad some people are helping now. He‘s 9 now still the same.	Reading is a central area of concern for parents. None of the parents could read and were not sure how to help their child. One parent expressed a desire to return to college and learn to read but did not know how/where/who to get help from. If she has told me, has she told other professionals? If so, why has support not been offered? Parents reported having been told to make changes to their homes in order to provide a safe, clean home environment for their children, this appeared to be a priority area to target by support services. However, there did not appear to be support in place to help parents make the changes needed. Parents did not seem to see the importance of making changes in

–Own health implications affecting their ability to act on guidance from SS –Own health implications affecting their ability to act on guidance from SS –Identifies that help is needed –Own health affecting family life –Anxious about own health –Feeling responsible for child and mum –Own ability is a barrier to helping g child progress	SA: Do you know where you could get more help for M‘s reading and writing? P2: No, the youth club is just for sports and playing. I ain‘t got a clue. SA: Did you worry about them getting ill? P3: Yeah, being like a doctor...I dunno...I didn‘t know if they was ill like...to help them, do you get me? SA: What‘s hard about being a mum then? P3: When... (laughs)...H (daughter) is being naughty P3: When the kids like...you know when them got letters and read a book	the home, they were more concerned with behaviour and learning progress. The two had different agendas/areas of priority, neither are being met. Support services seem to be highlighting areas of deficit in parenting ability but do not seem to be putting support structures in place, offering accessible advice or explaining the reasons behind their recommendations so that parents value information given or realise the importance of it. Parents need opportunities to share their concerns, set action points for support staff to meet their needs – this needs to be a reciprocal relationship, based on mutual trust and respect.

	and that P3: I can‘t read too good P3: I wanna work but erm...I wanna go back college really to tell you the truth but I have put my name down at school SA: No one‘s helping you, but you want to go back to school. Do you need help? P3: Yeah, coz I never...done nothing like that to tell you the truth P4: I give him food and ...wash him and that, he‘s got lots of toys...oh yeah, he likes toys, he does (laughs)	

	P4: Yeah...I ...can‘t, y‘know read and that SA: Erm...Ok. How do you get him to go to bed? P4: Er...with the telly on, he‘s alright then, goes to bed like P4: My mum has her injections, I help with that... SA: Do you need help with those things (referring to actions from social service conference)? P4: Yeah...but I just do it don‘t I? P4: I can‘t help him with school work, I told him that and...I can‘t read. He‘s	

	always got mess on his top and that too...he eats his dinner	

Subtheme: How early experiences of parenthood are affected by access to support services		
Initial Codes –Happy when expecting –Happy when expecting –No support from professionals during pregnancy –No information received about parenting prior to birth –No accessible materials or information prior to birth Not knowing what to expect –Uncertainty/fear –Not knowing what to expect pre-birth –Uncertainty/fear	**Example Extracts** SA: OK. And did any professionals or anybody get in contact with you with information about being a dad? Like your Doctor or anyone? P1: No, none at all SA: ...did you know what to expect	**Narrative/initial reflections** Parents with LD should be offered additional support throughout their pregnancy, in relation to knowing what to expect from the birth of a child, this doesn‘t seem to be happening for these parents.

–No support groups attended –Alone –Not invited to support groups –Alone –Alone –Has some access to family support network –Positive about pregnancy –Identified family support network – emotional support –No additional support during pregnancy –Feeling alone –No professional support given in the form of accessible materials – Family support network important for preparation during pregnancy –Uncertainty and fear with newborn child –Identified being afraid, under-prepared for baby –Family support network provided knowledge to support mum in caring for baby –Alone feeling unsupported by professionals –Fear –Identified professional who offered support after birth –Feeling underprepared and afraid –Fear	when you were going to become a dad? MK: Not really, no, coz it was my first time were it? It‘s something else, not really though, it‘s hard work though. SA: Were you invited to any support groups? P1: No SA: Did anyone help you find your jobs? P1: My cousins all worked there, they got me a job. Been there straight from school like. SA: Like, did you get any support from the doctor...	Family networks seem to be an invaluable source of support throughout pregnancy and early parenthood. Lack of support during early parenthood suggests that support services are largely reactive as opposed to preventative in these cases. Policy highlights the importance of early intervention and support from pregnancy to birth for parents with LD. It is difficult to separate experiences of support not being offered to families versus parents choosing to engage with services. Although, if parents aren‘t engaging is because they are afraid? Or lack understanding about what is being offered to them.

–Identified community support and accessed this independently –Identified community support and accessed this independently –Lack of professional support pre-birth –No access to parent support group. None offered –Alone –Positive about pregnancy –No support network available –Lack of access to information, resources about pregnancy and parenting –Not prepared for parenting, no professional support –Uncertainty and fear –Fear of hurting baby –Un prepared –Feeling unsupported – Lack of co-ordinated support –Feeling alone –Health visitor provided –needed guidance after birth – No access to support groups –Feeling alone –Support groups not offered	P3: No, not really...I had appointments and that at the hospital. I had midwives and that. Apart from that, I was by myself really. SA: So, you were 18, did you know what being a mum was going to be like? P3: Yeah, I...obviously, coz I saw my mum with my sisters P3: I was confident weren‘t I... but...I couldn‘t bath her or nothing SA: Oh, why not? P3: Coz like...I was scared (laughs) SA: Right, who gave you help then? P3: My nan	Parents report fear when child is born and scenarios where they are too afraid to handle the child – previous research highlights the benefits of parental support groups pre/post-birth and how this significantly improves the skill levels of parents with LD – this is still not being offered despite the knowledge of the parents backgrounds etc.

	P4: No, no one helps me, I always have to help myself...and my mum...Erm... SA: So, did you know what being a mum was going to be like? P4: No (laughs), no one told me anything, he was really little and that ... I was, you know, really what‘s the word SA: Worried? scared? Happy? Excited? P4: I was you know scared... to pick him up and that coz he was little SA: Who helped you? P4: No one helps me...but I just did it you know	

	SA: OK. Did you go to any support groups? P4: What like? SA: Where parents meet up to talk to each other P4: Nah...that sounds nice and that...I had a friend but she moved so...I did it by myself	

Appendix Fifteen

Final Thematic Map: Refining Themes