Being a Parent with a Learning Disability:
A Qualitative Study

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ACKNOWLEDGMENTS

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1.0 OVERVIEW

1.1 Background

Due to philosophical and political changes, such as normalisation and disability rights movements, people with a learning disability are now increasingly acknowledged as full citizens of society (Brown & Smith, 1993). This importantly includes the right to have sexual relationships and to become a parent (Department of Health, 2001; The Scottish Executive, 2001). As a result, the number of parents with a learning disability in the United Kingdom (UK) is steadily increasing (Tarleton *et al*., 2006; Woodhouse *et al.,* 2002).

A Learning Disability is defined as "significantly sub-average mental functioning shown by an IQ of approximately 70 or below, concurrent deficits or impairments in adaptive functioning and onset before 18 years of age" (American Psychiatric Association, 2000). Research has identified that parents with a learning disability often have difficulties in making appropriate and well informed decisions, meeting their children's health and safety needs and providing a stimulating environment that encourages social and emotional development of the child (Feldman, 1994). Despite this, it is important to acknowledge that there is no systematic correlation between parental learning disability and ability to be a parent (International Association for the Scientific Study of Intellectual Disabilities [IASSID], 2008). However, research evidence by Dowdney and Skuse (1993) suggests that a parental IQ below 60 is a predictor of inadequate parental competence.

Published research on parents with a learning disability now spans across five decades (Llewellyn *et al.,* 2010; Wade *et al.,* 2008). Such research has highlighted a number of issues (aside from cognitive impairment) that people with a learning disability face when they become a parents. These include increased rates of anxiety and depression (Feldman, 2002), poor housing, poverty and restricted vocational opportunities (McGaw & Newman, 2005) social isolation and limited social support networks (Llewellyn, 1999). All of which are recognised risk factors to both lowered parental psychological well–being and poor child rearing environments (Cleaver & Nicholson, 2007). In addition parents with a learning disability are over-represented within child protection systems with a high proportion of parents losing custody of their children (Booth *et al.*, 2005).

1.2 The research portfolio

This research portfolio aims to further explore the issues faced by parents with a learning disability.

Firstly, a systematic review of qualitative research into the social support of parents with a learning disability is presented. This not only indicated that a range of social support is provided to parents with a learning disability and received with different perceptions, but also highlighted the need for further qualitative research in the area, to gain a better insight into the lived experiences of this group of parents.

Secondly, and further to the findings of the systematic review, is the empirical research study. Adopting a qualitative design (Interpretative Phenomenological

Analysis- IPA) (Smith, 1996; Smith *et al.,* 2009), the study aimed to explore what parents with a learning disability understood about their learning disability and how they perceived it to impact on them in their parenting role. Analysis revealed five themes which reflect the perceptions and experiences of a sample of eight parents with a learning disability.

Finally, to enable efficient and effective dissemination of the findings to the wider audience a journal article is presented. The journal article, as well as attempting to summarise the methodology used, focused on the most salient theme of the findings, which was how participants viewed themselves in relation to having a learning disability and being a parent.

1.3 Terminology and formatting- a note of caution

Despite there being broad agreement about the diagnostic criteria for a learning disability, there is still some variety in the terminology used to describe this group of people (Eayrs *et al*., 1993). The different terms that are most commonly used are intellectual impairment, intellectual disability (both of which are predominantly used in the United States), cognitive impairment, mental retardation and mental handicap (the latter of which may feature more in older literature).

Throughout this research portfolio both 'learning disability' (which is the preferred term within the UK) and 'intellectual disability' are used interchangeably. Most commonly, the use of 'intellectual disability' reflects either the context in which

original or previous research has been carried out or the adopted terminology of the journal in which the research features or is intended to be published.

Similarly, it is worth noting that chapters of the portfolio adopt different formatting and referencing styles, depending on the author guidelines of the journal it is intended for publication in. Where chapters have adopted a specific journal style this has been indicated and the author guidelines for each journal have been provided in the appendices (Appendix 12a and 12b).

Title.

Social support of parents with intellectual disabilities: A systematic review of qualitative studies.

Written in accordance with author guidelines for:
Journal of Applied Research in Intellectual Disability.

Abbreviated title for running head:
Social support for parents: A review

2.1 Abstract

Background: Social support is thought to help promote the competence of parents with an intellectual disability[1]. A number of qualitative studies have reported on the views of parents about their support networks in relation to their parenting role. The aim of this paper is to systematically review such studies to further understand how social support is viewed by parents with an intellectual disability.

Materials and Methods: Five electronic databases were used to search the relevant literature. Nine studies were reviewed and the main findings synthesised.

Results: Family members are central to social support networks, with friendships distinctly lacking. A range of types of support are provided, yet these are not always perceived as helpful. Current findings are limited by methodological weaknesses in the literature.

Conclusions: A consideration of parents' social support networks, with an understanding of how these are perceived is needed before support interventions are provided in clinical practice.

Keywords: parents, intellectual disability, social support, review, perceptions, qualitative research.

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[1] In line with the scope of the selected journal, the term intellectual disability is used throughout.

2.2 Introduction

Published research on parents with an intellectual disability now spans five decades, with three distinct waves of research being identified (Llewellyn *et al*. 2010).

The first wave of research, which began in the 1950's, was conducted at a time when people with an intellectual disability did not have equal rights, with some women being subject to involuntary sterilisation whilst living in large institutions (Aunos & Feldman, 2002). Research of this nature focussed on the heritability of an intellectual disability and supported the professional belief that people with an intellectual disability were unfit to reproduce, because of the high risk that they would pass on their intellectual disability to future generations.

The second wave of research, which was carried out post the 'normalisation' and disability rights movements, during the 1990's, no longer questioned whether or not people with an intellectual disability should be allowed to parent, but instead asked questions about how adequate and able people with an intellectual disability were to be parents. As a result, parenting training, which in most cases provided the mother only with basic child care skills, was offered and evaluated as part of the research. Feldman (1994) conducted the first comprehensive review of parenting intervention studies and concluded that parents with an intellectual disability could demonstrate improved skills in a range of parenting tasks (e.g. positive interactions with their children, providing stimulating environments and behaviour management). More recently, Wade *et al*. (2008) attempted to update this, with a review of studies that were published since 1994. Consistent with the initial review, Wade *et al's*. findings

suggested that with the appropriate level of support, parents with an intellectual disability could care for their children. In addition, a Cochrane Review was completed in 2010. This highlighted the lack of good quality studies in the area, and also indicated the competence of parents with an intellectual disability could be improved with appropriate support and interventions (Coren *et al*. 2010).

Criticisms of waves one and two of the research include the over emphasis on 'internal' factors associated with having an intellectual disability and becoming a parent, such as reduced cognitive functioning and difficulties in areas of adaptive functioning. The potential impact of any contextual factors on parental competency, such as social support or living arrangements are often unrecognised or fail to be addressed (Wade *et al*. 2008). In addition, this research is primarily based on the opinions and perspectives of professionals only. These criticisms of early research led to the development of a third wave of research, in which the views and perceptions of parents with an intellectual disability was the principle focus (Booth & Booth, 1995). Furthermore, this research has started to investigate the likely impact of the social and/or environmental circumstances of parents with an intellectual disability and the impact this has on ability to parent and child outcomes (Llewellyn *et al*. 2010).

Although still a relatively new and emerging wave of research, the factor that has perhaps been most researched in terms of impact on parental competence is social support. There is a body of evidence that indicates that parents with an intellectual disability are more likely to experience poor social circumstances, including poverty,

restricted vocational opportunities, poor housing, and limited social networks (McGaw & Newman, 2005), all of which are recognised risk factors to both lowered parental psychological well–being and poor child rearing environments (Cleaver & Nicholson, 2007). Social support has been identified as a positive factor which is considered to improve parental competency and child outcomes. Social support is defined as the benefits obtained by individuals from their relationships with others, such as material gains or emotional support (Koeske & Koeske, 1990). A number of research studies have reported on the various aspects of social support of parents with an intellectual disability. Research has found some parents report receiving minimal or no social support, whilst others have extensive support networks from both formal and informal sources (Llewellyn *et al*. 2010). Quantitative studies of parents with an intellectual disability indicate that family members are most likely to provide social support, followed by service providers, with limited identified support being provided by friends or neighbours (McConnell *et al*. 2009). With regards to the relationship between social support and outcomes for parents with an intellectual disability and their children, a study by Aunos *et al*. (2008) reported no significant correlation between size of social support or parental satisfaction with this and parenting style. However, a significant correlation between parenting style, levels of parenting stress and perceived child problem behaviours was found (Aunos *et al*. 2008).

Although such research has provided a better understanding of the amount and sources of social support that exist for parents with an intellectual disability, it is acknowledged that an understanding about how this support is perceived by the

parents themselves or how it contributes to their parenting role remains relatively unknown. Although early research by Tucker and Johnston (1989) proposed that social support for parents with an intellectual disability tends to be either 'competence promoting' (support which reinforces and encourages the development of skills within the parenting role) or 'competence inhibiting' (which de-skills parents and leads to feelings of being de-valued and undermined), further research conducted from an 'insider perspective' is needed to understand how parents with an intellectual disability view their social support needs. In order for parental support to be effective, the level and nature of it must match the needs of the parent (Llewellyn *et al*. 2010).

2.2.1 The current review.

The current paper aims to review the existing qualitative research on the views and perceptions of parents with an intellectual disability about their social support. This will develop a better understanding of their experiences and perceived support needs In addition, both the clinical and future research implications will be considered.

2.3 Materials and methods

2.3.1 Search Strategy

Studies were identified using established guidelines for conducting systematic reviews (NHS Centre for Research Dissemination CRD, 2001) and followed a four stage process.

In stage 1 the following online databases were used to identify appropriate studies: PsychINFO, CINAHL, MEDLINE, EMBASE and ASSIA. The search was conducted using the following key words in combination as search terms; 'parents' (including 'mothers' and 'fathers'), 'intellectual disabilities' (which included related diagnostic terms such as 'learning disability', 'mental retardation', 'intellectual disability', 'intellectual difficulties' and 'cognitive impairment'), 'social support' and 'experiences'.

Stage 2 of the search process involved screening the abstracts of the identified studies for relevance to the current review topic area and study design. It also involved locating additional studies through a manual search of the selected studies' reference lists and hand searching of key intellectual disability journals. In addition, principle authors of identified published papers in the topic area were also contacted to request information about any unpublished work.

At stage 3 of the search process, full articles of the selected studies were further examined and the review criteria below were applied. The search was carried out in March 2011.

2.3.2 Review criteria

The review inclusion criteria were English language studies, published in peer reviewed journals, which had a qualitative or mixed methods design, and which reported primary data about the experiences of parents with an intellectual disability and their social support. Review articles and studies which did not have the experiences of parents with an intellectual disability and their social support as the main focus were excluded.

2.3.3 Data Extraction and Quality Assessment

Stage 4 of the systematic review involved data extraction and appraising studies for quality. Relevant information from the selected studies, such as the research context, sample size, sample characteristics, and data collection and analysis methods was gained during the initial reading of the selected studies.

The current review used a quality appraisal checklist incorporating ten evaluative criteria from existing models (Critical Appraisal Skills Programme, 2002, Mays & Pope, 2000). The ten evaluative criteria included: 1) presence of clear aims and objectives; 2) clear description of the research setting or context; 3) appropriateness of the use of a qualitative design; 4) clear definition of sample characteristics and evidence of appropriate recruitment strategies; 5) systematic account of data

collection, 6) systematic account of data analysis; 7) appropriateness of findings including how they relate to the research question; 8) evidence of reflexivity within the research process; 9) consideration of ethical issues and 10) level of contribution to the existing knowledge. The quality assessment form used to aid this process can be seen in Appendix 1.

Each criterion was assessed adopting outcome ratings as used by Cesario *et al.* (2001) and incorporating the quality grading system as used in the Scottish Intercollegiate Guidelines Network (SIGN 50, 2008). This outcome rating system allocates 3 points if each criterion was 'well addressed', 2 points if 'adequately addressed', 1 point if 'poorly addressed' and 0 points if 'not reported' or non-applicable (Cesario *et al.* 2001). A total quality score for each study was then developed by summing the scores of each criterion, therefore creating a possible score out of 30. Studies given a total score of 22.5-30 were given a grade of ++, which indicated that between 75% and 100% of the criterion had been met and indicated few flaws and a low risk of bias. Studies gaining a total score between 15-22.4 were given a grade of +, suggesting that 50% to 74% of the criterion had been met with some flaws and a moderate risk of bias. When studies gained a total score of 15 or below they were assigned a – grade, which indicated that less then 50% of the criterion had been met with significant flaws and a high risk of bias.

2.3.4 Synthesis of findings

Although there are multiple methods available, there remains considerable debate about the synthesis of findings from qualitative research (Barnett- Page & Thomas,

2009; *Mays et al.* 2005; Thomas & Harden, 2008). In particular, it remains unclear whether frameworks such as meta-synthesis (Light & Pillemar, 1984) and meta-ethnography (Noblit & Hare, 1988) are able to synthesise all relevant qualitative studies or only the ones that have employed the same or similar methods (e.g. grounded theory, phenomenology). The basis for this is that even though qualitative studies may address the same issues, different methods of investigation will provide its own perspective (Lloyd-Jones, 2004). Sandelowski and Banoso (2003) suggest that choice of synthesis method is dependent on the purpose of the review and nature of the research findings across the relevant studies.

The current review included studies that used different qualitative methods and different level of interpretation (e.g. content analysis, phenomenology). As such, it was felt that studies were too disparate to allow for the use of established methods such as meta-synthesis or meta-ethnography. Therefore the findings of relevant studies were synthesised using a narrative summary approach.

2.4 Results

2.4.1 Included studies

At stage 1 of the search process a total of 257 studies were identified. Screening for relevance plus hand searching of reference lists and key Intellectual Disability journals (stage 2) located 39 studies. Finally, nine were reviewed.

Figure 2.1 outlines the systematic review process and the number of studies identified at each stage.

Stage 1.	→	Identify relevant studies, search electronic databases using search terms	→	n= 257
Stage 2	→	Screen abstracts of 257 identified studies for relevance to topic/ study design using review criteria.	→	n=39
Stage 3	→	Read full articles of 39 selected studies. Further apply review criteria	→	n= 9
Stage 4.	→	Extract data and critically assess the 9 selected studies.		
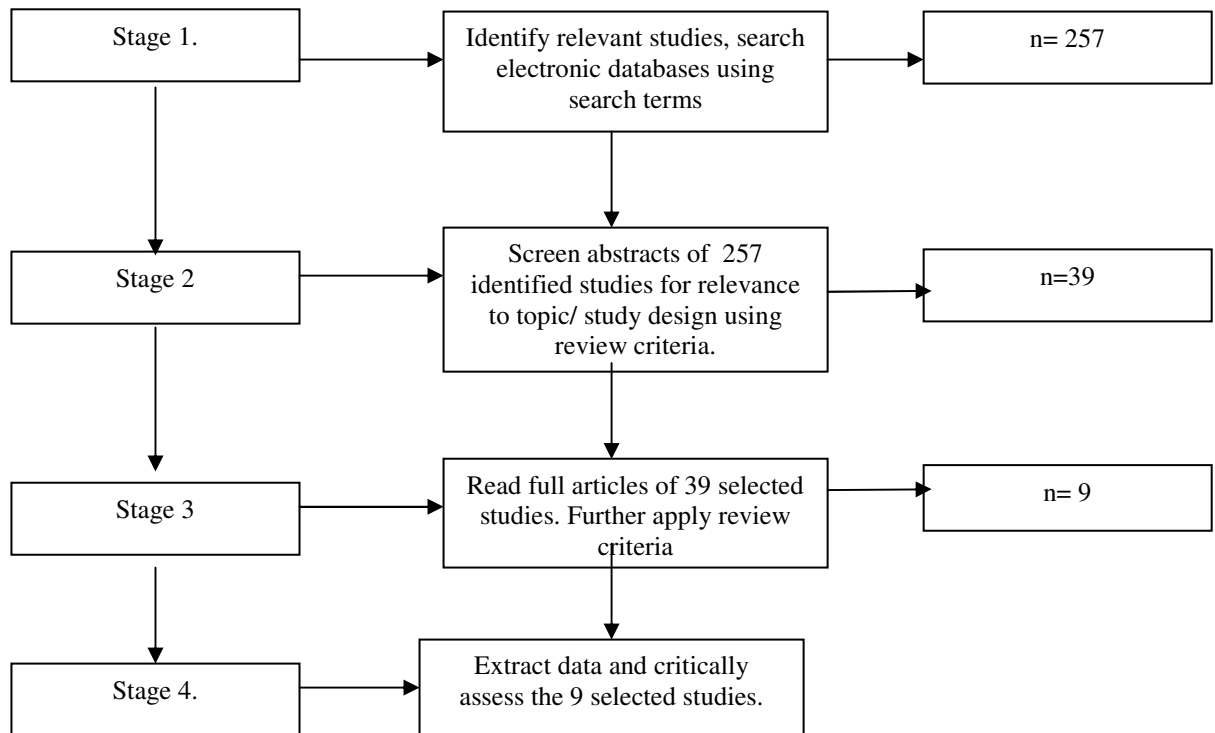
Figure 2.1: A summary of the review process.

2.4.2 Study characteristics

A summary of the studies included in the review is presented in Table 2.1.

2.4.3 Quality ratings

The quality ratings for the nine reviewed studies are shown in Table 2. 2

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Out of a possible score of 30, ratings ranged from 12 to 22. Two studies met 75% or more of the quality criteria, suggesting good quality. Over half of the studies (five out of nine) met 50% or more of the quality criteria and were therefore felt to be of average quality. The remaining two studies bias met less than 50% of the quality criteria, suggesting significant methodological flaws.

A sample (one third) of papers were independently, second rated by an experienced qualitative researcher. The quality rating scores differed by one point on two of the reviewed papers and by three points on the other. There was a high overall agreement rate (83%).

Table 2.1: Summary of reviewed studies.

Study	Aims	Sample size	Participant characteristics	Context	Study design	Qualitative data analysis method	Main findings/ themes	Conclusions/ clinical implications
1. Ehlers-Flint (2002)	Explore perceptions and experiences of mothers with ID [2] with a focus on relationships between social vulnerabilities and perceived social support.	20 (mothers only)	Mild-moderate ID (IQ- 60-85), age range 21-43, mothers who both did and did not have custody of their children.	California, USA, recruitment via voluntary agency for parents and children.	Mixed-quantitative and qualitative, questionnaires (PAQs, ISC[3]) and open ended survey about parenting experience.	Descriptive, frequency analysis.	• Parenting viewed as a rewarding experience • social supports provided mainly by family members • highlighted that social support received can be helpful yet critical.	Appropriate support from services can be helpful towards attitudes of parents.
2. Llewellyn (1995)	Investigation of how parents with ID view their relationships and support provided	12 (6 mothers and 6 fathers as couples)	Age range 28-39 all but 2 had a diagnosis of ID, all had children living with them	Not mentioned, recruited through statutory and advocacy services.	Qualitative only, In depth interviews and observations over a 2 year period	Themes emerged using constant comparative approach, reference to principles of Grounded Theory.	• Support viewed as a restraint as well as a resource • parents follow a preferred pattern in help seeking • limited friendships in social networks	Service concepts of 'parenting' and 'family' should be challenged to incorporate the importance and involvement of social support and relationships.

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[2] ID- Intellectual Disability.
[3] PAQs= Parenting Attitudes Q-Sort (Block, 1965), ISC= Inventory of Social Contacts (Richardson, 1984)

3. Llewellyn *et al.* (1998)	Extend on previous research by Walton-Allen & Feldman (1991), include the views of significant others and add qualitative findings	47 parents (40 mothers and 7 fathers), 32 significant others (family) and 38 service workers.	Mild-upper moderate ID, variety of living arrangements, majority had children living with them, some had at least one child removed in past	Australia, recruitment via social service agencies, significant others nominated by participants.	Mixed-quantitative and qualitative, Questionnaires (based on service need[4]) and development of open ended surveys to look at views of parental need from parents, their significant others and their service workers	Emergence of common themes, reference to constant comparative approach. Views of parents and significant others compared.	• Significant difference in the perceived service needs of parents and their significant others and service workers. • Support needs of parents tend to be centred around help with child care • parents would like to feel more involved in their communities	Consideration of parental support needs prior to providing any services, encouragement or facilitation of community involvement in support from services.
4. Llewellyn *et al.* (1999)	Examine the composition and characteristics of the support networks of mothers with an ID.	25 (mothers only)	Age range 24-43, mild-upper moderate level of ID, all had children living with them	Australia. Recruitment through statutory and non-statutory social service agencies.	Qualitative , semi-structured interviews	Reference to grounded theory, constant comparative approach in the generation of themes.	• Social support networks seen as dependent on living circumstances • 3 support networks identified.	Need to consider maternal social support networks and views on this prior to determining service involvement

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[4] Service Use and Needs Survey (adapted from Walton-Allen & Feldman, 1991)

5. Mayes *et al.* (2008)	Explore the experience of becoming a mother with ID and how social support networks are negotiated.	17 (mothers only)	Age range 18-37, pregnant women who were already parents and first time mothers.	Australia. Recruitment through ante-natal clinics, formal support organisations and word of mouth.	Qualitative, semi-structured interviews	Phenonmenological approach.	• During pregnancy and after child birth mothers do negotiate who they seek support from • support seeking tends to be practical, • importance of availability in support networks • mothering as a set of social tasks.	Social support networks of mothers need to be considered in the assessment of parenting ability.
6. Pixa-Kettner, (1998)	Explore parenthood experiences and perceptions of parents with ID and their children, focus on their views about support received	30 (12 mothers, 4 fathers, 10 couples, 4 grown up children of parents with ID)	Variety of living circumstances, parents who had custody of their children and those who didn't.	Germany, method of recruitment not stated.	Mixed-quantitative and qualitative, demographic based questionnaire and interviews	Generation of themes through compare and contrast method.	• 6 themes identified, examples of these themes included influences of social background, support at the time of pregnancy and birth, relationship with the child and a feeling of judgement in the support offered to them	Individual parenthood experiences are impacted on by both internal and external factors, professional support services to provide be more accepting and provide positive support.

7. Sternfert-Kroese *et al.* (2002)	Explore issues of psychological well-being and social support in mothers with ID focus on parental attitudes	17 (mothers only)	Mild-moderate ID, age range, 25-49, mothers with custody of their children and those who didn't.	UK (West Midlands), recruitment through social services and voluntary support services for parents with ID	Mixed-quantitative and qualitative, Questionnaires (ABS, self esteem measure, assertiveness measure [5]), semi structured interviews	Data categorised into emergent themes, reference to Grounded Theory.	• Mothers reported benefits to being a parent • not all social support received was seen as helpful • most helpful social support was help with child care	Supportive social networks are important to psychological well-being, professional support services should be responsive to the already existing supports of parents.
8. Tarleton & Ward (2007)	Describe examples of positive support for parents with ID	30 (25 mothers, 5 fathers)	Age range 20-50, majority receiving formal support from statutory services, some receiving informal support though voluntary organisation only	UK (Britain, Scotland, Wales). Recruited via formal support services and voluntary groups.	Qualitative, interviews with parents (individual, couples and group)	Use of constant comparative approach, made reference to the use of established qualitative analysis procedures.	• With appropriate level of support parents are able to feel "good enough" in their parenting role • parents value support from other parents • importance of support to 'get their voices heard'	Emerging concept of 'parenting with support' which services should adopt., Services to provide positive support which empowers parents with ID.

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[5] ABS= Affect Balance Scale (adapted from Bradburn, 1969), Self Esteem Questionnaire (adapted from Rosenberg, 1965), Assertiveness questionnaire (adapted from Gambill & Richey, 1975)

| 9. Traustadóttir & Sigurjónsdóttir (2008). | Longitudinal study to examine the role of extended family in supporting mothers with ID | 18 (mothers only) | Age range 25-83, from 3 generations of mothers with ID, those with children living with them and those who had children removed. | Iceland, recruitment through self advocacy groups and personal contacts | Qualitative, interviews (individuals and group), participant observations over 2 years | Constant comparative approach, reference to principles of grounded theory | • Importance of support from extended female family members
 • family seen as advocates for mothers with ID | Service providers need to acknowledge the importance of support provided from extended family members. |

Table 2.2: Quality assessment ratings.

	Quality Criteria										Total Score	Overall Rating
	(1)	**(2)**	**(3)**	**(4)**	**(5)**	**(6)**	**(7)**	**(8)**	**(9)**	**(10)**		
Studies												
1. Ehlers-Flint (2002)	2	2	3	3	3	1	2	0	0	2	**18/30**	+
2. Llewellyn (1995)	2	1	3	3	3	3	3	1	0	3	**22/30**	++
3. Llewellyn *et al.* (1998)	3	3	2	3	2	2	1	0	0	2	**18/30**	+
4. Llewellyn *et al.* (1999)	1	1	2	3	3	2	3	0	1	3	**19/30**	+
5. Mayes *et al.* (2008)	2	1	2	2	2	3	2	2	2	3	**21/30**	+
6. Pixa-Kettner (1998)	2	2	2	2	1	1	2	0	0	2	**14/30**	-
7. Sternfert- Krose *et al.* (2002)	3	3	2	3	2	1	2	0	2	3	**21/30**	+
8. Tarleton & Ward (2007)	2	3	1	2	2	3	3	3	0	3	**22/30**	++
9. Traustadóttir & Sigurjónsdóttir (2008).	1	1	2	2	1	1	2	1	0	1	**12/30**	-

1) Presence of clear aims and objectives.
2) Clear description of the research setting or context.
3) Appropriateness of the use of a qualitative design.
4) Clear definition of sample characteristics and evidence of appropriate recruitment strategies.
5) Systematic account of data collection.
6) Systematic account of data analysis.
7) Appropriateness of findings including how they relate to the research question.
8) Evidence of reflexivity within the research process.
9) Consideration of ethical issues.
10) Level of contribution to the existing knowledge.

3=Well addressed,   2= Adequately addressed,   1=Poorly addressed,   0= Not reported/not applicable.

2.4.4 Synthesis of findings

The findings from the reviewed studies were grouped into the following areas; creation and characteristics of social support networks, types of social support, perceived helpfulness of social support and perceived social support needs.

2.4.4.1 Creation and characteristics of social support networks

Parents with an intellectual disability are regarded as a socially isolated group (Aunos *et al*. 2008). Several of the reviewed studies supported this, with the average number of social contacts of parents with an intellectual disability being considerably less than for parents without an intellectual disability (Sternfert-Kroese *et al*. 2002). Two studies reported that the creation and characteristics of social support networks of parents with an intellectual disability are influenced heavily by living arrangements, with Llewellyn (1999) identifying three types of social support networks. Mothers living alone had overall less contact with others and more reliance on 'formal supports' (i.e. support from professionals in services). Findings from a long term project by Traustadóttir and Sigurjónsdóttir (2008) also suggested that the level of support a mother could expect to receive in her parenting role was partly determined by her living circumstances. Additionally, Ehlers-Flint (2002) highlighted that the personal histories of mothers with intellectual disabilities (e.g. their own experiences of childhood and being parented) can influence the subsequent creation of social support networks.

The above reviewed studies would suggest that parents with an intellectual disability have limited influence over their support networks and that they are passive receivers of support as opposed to being assertively involved in who they receive support from. However, Mayes *et al.* (2008) concluded that in preparation for parenthood mothers "strategically negotiated support networks" (p.21). This active negotiation involved mothers making decisions about what they need for themselves as a mother and for their child, resulting in some of the participants deliberately changing their living circumstances in order to maximise the support they gained. Mayes *et al.* (2008) acknowledge that this is a 'rare' finding amongst the literature and in the absence of any follow up, it is unclear whether such active negotiation continues into child rearing. Furthermore, Llewellyn *et al.*'s (1994) study suggests that parents with an intellectual disability actively follow and show a preferred pattern of seeking support in times of difficulty, beginning with partners, then family and finally followed by professionals. This finding supports the idea that parents with an intellectual disability are not passive members of their social support systems, but they do, in fact, regulate this and choose who they receive support from.

With regards to characteristics of social support networks, the majority of studies emphasised the importance of informal support from partners, family or extended family members. Specifically Traustadóttir & Sigurjónsdóttir (2008) recognised the importance of support from a female family member, who in a sense provided 'mothering' to the mother with an intellectual disability in many aspects of her parenting role. Studies also highlighted the lack of non-family members in social support networks (e.g. friendships), with Sternfert-Kroese *et al.* (2002) noting that of

the 129 social contacts identified across 17 participants, only 29 were from non-family members. Some of the studies noted that participants had mentioned friends and acquaintances, but it was reported that these were not people who were perceived to provide social support (Llewellyn, 1998). The feature of formal support (i.e. from professionals within statutory and non-statutory organisations) was seen as dependent on the level of informal support. For instance, Llewellyn (1998) suggested that formal support is required less when there is a larger and more available informal social support network.

2.4.4.2 Types of social support received

Six of the reviewed studies reported on the types of support received, which suggested that a variety of support can be provided to parents. For instance a number of studies (Llewellyn *et al.* 1999, Mayes *et al.* 2002, Tarleton & Ward, 2007, Traustadóttir & Sigurjónsdóttir, 2008) reported on the importance of 'practical' support which ranged from help with different aspects of child care, to transportation to and from medical appointments. Additional types of support were also commonly identified throughout the reviewed studies and included information/ advice giving (Llewellyn, 1995), material/ financial support (Sternfert-Kroese *et al.* 2002) and emotional support (Mayes *et al.* 2008). However the perceived level of helpfulness of these types of support varied across the studies (see below). Within the type of support received, findings from Sternfert- Kroese *et al.* (2002) and Llewellyn (1995) suggest that there is a difference between the types of support provided by formal and informal support sources. For instance, formal support in both of these studies tended to be help with filling out forms, dealing with matters regarding housing and

benefits or dealing with school or respite issues. These findings are further supported by Tarleton and Ward (2007) who report that support from formal sources is not only related to parenting issues but also deals with wider issues that can influence a parental role, such as debt, school and housing.

Although some studies reported an apparent difference between the types of support received from formal and informal sources, Traustadóttir & Sigurjónsdóttir (2008) suggest that the two should not be viewed as separate sources, rather they are reliant on each other for maximisation across the support network. For instance, their findings from a longitudinal study of three generations of mothers with an intellectual disability highlight the value of having informal members of support networks available when a parent is receiving support from a formal source, such as the indirect role of an informal support member as an advocate.

2.4.4.3 Views about and experiences of social support received

Despite a range of types of support having been identified, the reviewed studies reported mixed findings on how this support was perceived by parents. The majority of studies (Llewellyn, 1995; Pixa-Kettner, 2002; Sternfert-Kroese, 2002; Traustadóttir & Sigurjónsdóttir, 2008) reported that support provided by those in a social support network (both formal and informal support sources) was not always helpful or welcomed. This is in line with early research by Tucker and Johnson (1989) in which support can be either 'competence inhibiting' or 'competence promoting'. Studies highlighted that support can be viewed as controlling, interfering and judgemental of mothers and fathers in their parenting role. Examples of

unhelpful support reflected fear of 'surveillance' from others, reporting to social services and ultimately removal of a child (Traustadóttir & Sigurjónsdóttir, 2008). In addition, criticism of parenting from family members and professionals, conflicting advice from multiple perspectives and support that was provided solely based on the opinions of others and which ignored parental wishes were also seen as unhelpful. Support was viewed as helpful when it was based on a good and shared understanding of the parent's difficulties and needs, was non-judgemental and was based on trust and respect (Llewellyn, 1995; Llewellyn *et al.* 1999; Tarleton & Ward, 2007). Furthermore, support that provided a sense of reciprocity (e.g. shared tasks where individuals each have a role to play) was highly valued by parents, not only in practical tasks but also for the emotional support provided in their parenting role (Tarleton & Ward, 2007).

By contrast, Mayes *et al.* (2008) imply that, because of the active role that mothers in their study had in seeking and gaining support, they viewed the support in only a positive and helpful way. Similarly, Ehlers-Flint's (2002) study found that higher levels of support were reported than interference. However, this overall finding conflicts with data from the study's open ended survey in which over half of the mothers that were interviewed reported that they were criticised by family members.

2.4.4.4 Perceived social support needs

One third of the reviewed studies reported on the perceived support needs of parents with an intellectual disability (Ehlers-Flint, 2002; Llewellyn *et al.* 1998; Tarleton & Ward, 2007) and help with childcare was frequently highlighted. In their mixed

methods study, Llewellyn *et al.* (1998) found that support with childcare, including child development, child discipline and child safety was perceived to be needed more than other aspects of support such as domestic or community needs. This study also revealed a significant difference in the perceived support needs of parents with an intellectual disability and their significant others, including workers from formal support agencies. However, it is unclear if this difference is due to an overestimation of support needs by service workers (and therefore an underestimation of actual parental ability) or vice versa, in that parents themselves overestimate their competency as a parent and then underestimate their support needs. Based on their findings, Tarleton and Ward (2007) coined the term 'parenting with support'. This encapsulates the perceived support needs of parents, which includes support to feel empowered and valued in their role as a mother or father, support to overcome previous negative experiences (such as removal of a child from their care) and support that is founded on a fair and shared opinion of the parents difficulties, strengths and most importantly wishes.

When parents in Llewellyn *et al.'s* (1998) and Ehlers-Flint's (2002) studies were asked what additional support they would value, both reported that they would like to increase their social support networks to include friendships and to be become more involved in the communities they were living in. Specifically, Llewellyn *et al.* (1998) suggested that parents would like to meet with, and receive support from, other parents with an intellectual disability, but that this was rarely available to them. In addition, fathers in this study reported that they would value specific support to them, which reflects the overall unrecognised needs and opinions of fathers with an

intellectual disability. Mothers in Ehler-Flint's (2002) study reported a wish to expand their social support networks to include friends, as opposed to these being centred on family members. These findings complement and build on some of those found in other reviewed studies (e.g. Sternfert-Kroese *et al.* 2002; Llewellyn, 1995) that suggest a distinct lack of friendships in the social support networks of parents with an intellectual disability.

2.4.4.5 Limitations of existing literature

Despite the majority of the reviewed studies demonstrating average to good methodological quality, a number of methodological limitations were identified.

Firstly, over half of studies (five out of nine) included only mothers in their participant sample. Even when fathers were included, they were in the minority. This creates a potential bias towards mothers' views only. This limitation reflects a wider issue within the literature on parents with an intellectual disability, in that, in both clinical and research fields, the experiences of fathers with an intellectual disability are rarely reported on or are absent (Gosden & Kirkland, 2008; O'Hara & Martin, 2003).

Secondly, although the majority of papers used the terminology 'intellectual disability', a number of alternative terms were used to describe the participant sample such as 'mental retardation' (Llewellyn, 1995) and 'cognitive disability' (Ehlers-Flint, 2002). This is in part reflective of the time and context in which the research was conducted, but also reflects a wider issue within intellectual disability

research literature as a whole (Eayrs *et al*. 1993). Some studies (Mayes *et al*, 2008; Tarleton & Ward, 2007; Traustadóttir & Sigurjónsdóttir, 2008) did not explicitly report on the level of intellectual disability of the participant sample, nor made any reference to how intellectual disability was assessed. This creates the possibility that some participants may not have had a diagnosed intellectual disability, thus creating unrepresentative results.

Thirdly, only a small number of the reviewed studies explicitly mentioned issues of an ethical nature (Mayes *et al*, 2008; Sternfert-Kroese *et al*, 2002). The consideration and management of ethical issues when conducting research with people with an intellectual disability is important, especially issues of informed consent and withdrawal (Gilbert, 2004). As less than half of the reviewed studies made reference to issues such as confidentiality, gaining of informed consent and ethical approval from an external source, it is unclear how issues of increased social vulnerabilities and the research relationship (particularly when in many of the studies the participant sample were deemed to be socially isolated) were ethically managed.

Fourthly, some of the studies (Llewellyn, 1999, Mayes *et al.* 2008, Traustadóttir & Sigurjónsdóttir, 2008) did not provide clear descriptions of the research context, which left some questions unanswered, particularly about procedure of the study and participant recruitment.

Finally, the description of data collection procedures and analysis based on qualitative approaches were poorly defined in over one third of the reviewed studies

(Ehlers-Flint, 2002; Pixa-Kettner, 1998; Sternfert-Kroese *et al*, 2002; Traustadóttir & Sigurjónsdóttir, 2008), with some presenting descriptive results only or providing limited examples of the data to illustrate their process of analysis. The referencing of recognised qualitative approaches was felt to be limited, with only two of the reviewed studies describing established methods of analysis. Furthermore, the use of credibility methods for ensuring methodological rigor such as respondent validation , triangulation or more than one reviewer during data analysis was limited or absent. The role of the researcher in the analysis process was additionally missing from all of the reviewed studies. The acknowledging of the researchers' theoretical orientations, values and assumptions would have improved the quality of the findings by adding a consideration of possible alternative interpretations of the data.

2.5 Discussion

This systematic review identified nine papers which contained data on the views of parents with an intellectual disability about social support. Findings suggest that social support is primarily provided by family members with support from friends being limited. A range of types of support were identified which included practical help as well as emotional and financial support. A number of studies suggested that parents see a difference in the support provided by informal support sources (e.g. family) and support provided by formal support sources (e.g. professionals). Although the majority of findings suggested that parents with an intellectual disability are not actively involved in the creation of their social support, as this can be seen as dependent on living circumstances and personal history, a few studies suggested that in preparation for parenthood mothers do positively select who they

will receive support from in order to maximise support opportunities for themselves and their child. In addition, one study suggested that mothers demonstrate a preferred sequence in seeking help in times of difficulty. Findings also suggested that not all support received was perceived as helpful, with some participants feeling 'controlled' and 'put-down' by the support provided by both family and professionals. Examples of helpful support included help that is perceived as needed and wanted by the parents themselves, and support that is non-judgemental and creates a sense of reciprocity in parenting tasks. Parents with an intellectual disability perceived their social support needs as being: to increase supportive friendships within social networks and to improve community participation for themselves and their children. However, the extent to which the results can be generalised is limited by the methodological limitations of the reviewed studies.

2.5.1 Implications for practice

Findings from this review highlight the importance of considering the social support networks of parents with an intellectual disability prior to providing parenting support interventions. Additionally, information about the types of support provided within this network, together with an understanding of how this is viewed by the parents themselves (i.e. if the support is helpful or unhelpful) should be sought as part of the assessment process. An awareness of these issues may help professionals review current working practices and gain a better understanding of the experiences of parents with an intellectual disability which can be incorporated into the delivery of services.

The adoption of the 'parenting with support' approach (Tarleton & Ward, 2007) by services working with parents with intellectual disabilities is felt to be a positive way forward in acknowledging the rights of people with an intellectual disability to become parents and care for their children with the appropriate level of support. In addition, this approach safeguards the needs of the children involved.

In addition, the findings from the reviewed studies acknowledge the need for professional support services to challenge the traditional concept of 'parenting', in which the tasks of being a parent are relatively discrete and prerogative to the individuals involved (i.e. the mother and father). The reviewed studies collectively suggest that parenting is, in fact, not carried out in isolation by one or two key individuals but instead there are 'communal' aspects of parenting that are carried out across the social support networks of parents with intellectual disabilities. This relates to the notion of parental competence being 'distributed' within a social and community network and arsing from the interdependent social relationships of all those who contribute to the parenting tasks, rather than lying with the parents alone (Llewellyn *et al.* 2008).

Finally, the findings also highlighted the value of providing parents with an intellectual disability with the opportunity to speak about their experiences of being a parent. This is in line with other areas of research that emphasise the growing need to understand the lives of people with an intellectual disability from their own perspective and in their own context. As a result of this, the patient and public involvement movement is being routinely used to include people with an intellectual

disability, which will ultimately lead to the creation of user led services by people with an intellectual disability.

2.5.2 Future research

In the light of the findings of this review, there remains a need for further qualitative studies to explore the views and perceptions of parents with an intellectual disability in relation to their social support. Several issues remain unanswered or unclear by the reviewed literature including: 1) how active parents are in the creation and maintenance of their social support networks; 2) the relationship between social support and parental well being from a qualitative perspective and 3) if characteristics and types of support network remain the same throughout stages of parental role.

Future research should increase attempts to include fathers with an intellectual disability as well as specifically assess for the presence of an intellectual disability through participant eligibility criteria. Furthermore, data collection and analysis should be explicitly described with reference to accepted methods for ensuring the quality of the findings including reflexivity and peer review. These considerations will result in the development of a clearer understanding of the perceptions of parents with a intellectual disability, in terms of their views and support needs.

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3.0 EMPIRICAL STUDY

3.1 ABSTRACT

Background- When people with a learning disability become parents this is often viewed with concern and disapproval from others. Specifically, an individual's ability to manage the complexities of parenting is questioned and assumptions of incompetency are made. Little is known about the how parents themselves understand their learning disability, and how they perceive this to impact on them as a parent.

Method- Semi-structured interviews were conducted with eight parents (three mothers, five fathers) with a learning disability. Interviews were recorded and transcribed. Analysis was carried out using Interpretative Phenomenological Analysis (IPA).

Results- Five master themes were identified: *The self as different identities; The opinions of powerful others; Accepting the reality; The same but different and Learning to cope.*

Conclusions- Findings suggest that parents with a learning disability hold three separate identities: as a person with a learning disability; as a parent and as an individual with personal likes and strengths. However, in becoming a parent, identity as a person with a learning disability is emphasised. Parenting experiences appear to be shaped by the opinions of others, which often creates realities to accept and standards to be adhered to. Parents with a learning disability are all too aware and fearful of the consequences of not adhering to these set standards; the removal of their child.

3.2 INTRODUCTION

3.2.1 Summary of systematic review

The systematic review highlighted the need for further qualitative research to explore the views and experiences of parents with a learning disability in regard to their social support networks and perceived support needs. While the nine reviewed studies provided a range and depth of information regarding the characteristics and types of social support, as well as views on perceived helpfulness, the findings are limited by a number of methodological weaknesses.

Social support is only one area of investigation within the literature on parents with a learning disability. As highlighted in the overview section, people with a learning disability experience additional issues when they become a parent. Hence, there is a wider need to further explore these issues (importantly from their perspective) to increase awareness of the lived experiences of this group of parents.

3.2.2 Background to the current study

As already discussed, the majority of what is known about parents with a learning disability has been conducted from the perspectives of professionals, with a focus on clinical and developmental outcomes (Booth & Booth, 1993). Implied within this is that professionals working with these parents in health and social care services adopt a common diagnostic framework in their understanding of what a learning disability is. Furthermore, they have a shared understanding about what difficulties this group of people may have when they become a parent (Tymchuk & Andron, 1992). Little is

known about what parents with a learning disability themselves understand about having a learning disability, nor how they see it to impact on them as a parent. However research by Walton-Allen and Feldman (1991), and later extended by Llewellyn *et al.* (1998), highlighted significant discrepancies between professional and parents views about their support needs.

Studies of parenthood in the general population highlight that is widely recognised as a desirable and highly valued role in today's society. Morahan-Martin (1991) suggests that becoming a parent confirms adult status and creates a positive self image, as well as providing the continuation and tradition associated with being part of a family. However, existing research suggests that when people with a learning disability become parents this is often viewed with concern and disapproval from others. Specifically, as a result of having a diagnosis of a learning disability, an individual's ability to manage the complexities of parenting is questioned and assumptions of incompetency are made (Murphy & Feldman, 2002).

A few studies have explored how people with a learning disability view parenthood. Both, Edmonds (2000) and Mayes *et al.* (2011) specifically investigated the mother identity in women with a learning disability. Results from both studies highlighted the central role that motherhood plays in the identities and life experiences of this group of people. Specifically, Edmonds (2000) concluded that having an identity as a mother is not only a significant indicator of gender identity and adult status, but also refutes the label of a learning disability.

Further research is needed to explore; firstly, how this group of parents (including fathers) understand their learning disability, and secondly, how they perceive their learning disability to impact on them in their role as a parent.

3.2.3 Aims of the current study

The current study seeks to build on the existing qualitative research base in this area. Specifically, the study aims to address the gap in the literature by exploring how parents with a learning disability understand their learning disability and how they perceive this to impact on them in their role as a parent. The current qualitative study is not hypothesis driven and instead adopts an exploratory approach. It is hoped that the results will offer further insight to professionals working with this group of parents and contribute towards the creation of shared understandings from which support can be provided.

3.3 METHODOLOGY

This chapter presents the research methodology and ethical issues considered in carrying out the study. The process of ensuring the quality of the current research is also outlined.

3.3.1 Design

The current study employed a qualitative research design using Interpretative Phenomenological Analysis (IPA) (Smith, 1996; Smith & Osbourne, 2003; Smith & Eatough, 2007; Smith *et al.*, 2009) to explore the understanding and perceptions of parents with a learning disability[6]. The main aims were to provide a detailed description of what parents with a learning disability understand about their learning disability and how they perceive this to impact on them in their parenting role.

3.3.1.1 *Using a qualitative approach with people with a learning disability*

Qualitative research relies on the generation and analysis of data in the form of words. There has historically been an assumption that because of difficulties in both understanding and expressing verbal language people with a learning disability are unable to take part in qualitative research (Edgerton, 1967). A number of researchers within the field of learning disabilities have acknowledged the challenges associated with this type of research, which include: inarticulateness; unresponsiveness; a

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[6] In line with UK preference, the term learning disability is used throughout the reporting of the empirical study.

concrete frame of reference and difficulties with the concept of time (Booth & Booth, 1996; Garbutt *et al.*, 2010; Gilbert, 2004; Munford *et al.,* 2008; Nind, 2008). However, Booth and Booth (1996) highlight that all too often the challenges of interviewing 'inarticulate' or 'unresponsive' participants are viewed in terms of the deficits of people with a learning disability rather than the limitations and inflexibility of the researcher's methods. This notion is further supported by Nind (2008) who emphasises that: "the challenges faced by qualitative researchers doing research with this group, like the challenges faced by the individuals themselves, are as much a product of the interaction between them and the wider context as of any inherent impairment" (p4).

Both of the above importantly suggest that with appropriate adaptation and modification of the researcher's approach, these challenges can be overcome. Ways of addressing these potential challenges include:

- Asking more questions and using more probes to fully illicit information;

- Focusing on the kind of language that is used by the participant;

- Taking into consideration the conduct of the interview. The researcher must identify a way to establish a level of communication that facilitates rapport;

- Starting each interview with no fixed assumption about the participant's ability to understand what is being asked of him/her. As the ability level of the informant is revealed, the interviewing methods can be refined; and

- If necessary, offering a number of different suggestions in order for the participants to think about the area in which their responses may lie.

(Booth & Booth, 1996).

There are a number of authors who strongly advocate the involvement of people with a learning disability in qualitative research. For instance, research by Munford *et al.* (2008),with parents with a learning disability highlighted that providing participants with an opportunity to tell their story and be respectfully listened to was a positive and liberating experience for the participants. Furthermore, there is a move towards user led services, in which the views and perceptions of service users are shaping the future delivery of services. This is especially important for people with a learning disability as they are most likely to have restricted choices and least likely to be given the opportunity to voice their opinions on the care they receive.

As a result of this recognition, qualitative research with people with a learning disability is increasingly valued and has been conducted within a range of topics including independent living (Bond & Hurst, 2010), sexual lives (Yacoub & Hall, 2008) physical restraint (Jones & Sternfert-Krose, 2007) and mental health issues (Taggart *et al.*, 2009).

3.3.1.2 *Interpretative Phenomenological Approach (IPA)*

Founded by Smith (1996), IPA is based on a number of theoretical underpinnings, some of which have a long intellectual history. Firstly, and perhaps most importantly is that IPA is founded on a phenomenological philosophy. Willig (2001) defines phenomenology as 'the ways in which human beings gain knowledge of the world around them' (p.50). Furthermore, Willig (2001) argues that a phenomenological approach does not make objective assumptions about an individual's experience of the world, but instead recognises that it is impossible to separate 'the person' from

'the world'. Therefore, based on this notion, the aim of IPA is to explore in detail, through accounts of lived experiences, how individuals perceive and make sense of this (Smith & Eatough, 2007).

In addition to being grounded within phenomenology, IPA is also interpretative. Smith (1996) acknowledges that whilst aiming to gain an account of an individual's world, it is not possible to gain complete access to a person's psychological world, thus IPA involves some interpretation on the part of the researcher (Smith *et al*., 2009). Within this, it is also recognised that it is impossible for the researcher to suspend his/her experiences and beliefs, which can create possible biases. These potential biases can be further complicated by any preconceptions that the researcher may have about the interpretative process. Therefore, the method of IPA emphasises the importance for the researcher to engage in on-going critical evaluation and reflect on his/ her level of connection with the data (Smith & Eatough, 2007). With regard to theoretical foundations of the interpretative aspect of IPA, it is influenced by hermeneutics (Palmer, 1969, as cited in Moran, 2000). Smith *et al*. (2009) highlight that IPA involves a double hermeneutic, whereby the individual is trying to make sense of, or find meaning in, their experiences, whilst the researcher is also attempting to make sense of how the individual is making sense of his/her experiences of the world. Furthermore, it is suggested that this dynamic research process involves both empathic hermeneutics (in that the researcher attempts to take on the viewpoint of the individual) and also critical hermeneutics (which allows the researcher to distance themselves from the data and ask critical questions about what has been said or trying to be conveyed).

The final theoretical underpinning within IPA is ideography. Unlike the nomothetic methods of inquiry that tend to dominate psychological research, IPA is regarded as an ideographic approach (Smith, 1995). Ideographic studies are based on intensive and detailed engagement with individual cases or a small group of individuals. Therefore, in IPA, the first stage of analysis requires in-depth connections with individual cases (e.g. individual transcripts). If analysis is with a small group, this level of analysis is repeated with every individual case within the group, and only at a later stage of the process does integration take place (Willig, 2001). Smith and Eatough (2007) argue that a good IPA study for group analysis should both identify generic themes from within the group, but also capture the lived experience of the particular individuals who have given their accounts.

Over the past decade, IPA has become increasingly recognised as a fully articulated qualitative psychological methodology which has proved to have particular benefit within Clinical and Health Psychology contexts (Biggerstaff & Thompson, 2008). This method has been applied across different research questions and with a variety of patient groups.

3.3.1.3 *Justification of IPA in the current study*

With the aim of exploring the understanding and perceptions of parents with a learning disability it is important to acknowledge that alternative qualitative methods could have been chosen, namely Grounded Theory (Strauss & Corbin, 1990) and Narrative Analysis (Labov & Waletzky, 1967). Whilst Grounded Theory has an

advantage in that it is regarded as a more established method (Willig, 2001), and narrative analysis has been specifically advocated in qualitative research with people with a learning disability (Booth & Booth, 1996), IPA was deemed more appropriate given the current research question. For instance, the principle aim of Grounded Theory is to understand why certain experiences occur, and then to develop an explanatory theory and narrative analysis (although recognised as similar in many ways to IPA) explores issues specifically relating to the self and identity (Crossley, 2007).

The method of IPA is more concerned with gaining a detailed description of lived experiences and perceptions based on a discovery-orientated and phenomenological approach (Smith & Eatough, 2007). As the aim of the current research was to explore in detail what parents with a learning disability understood about their learning disability and perceptions of how this impacted upon them in their parenting role, IPA was selected as the most appropriate qualitative methodology. Additionally, the application of IPA incorporates clear guidelines for the inexperienced qualitative researcher (Smith *et al*., 2009).

The availability of both academic and clinical supervisors experienced in the use of IPA and access to detailed accounts of the analytic procedure were also important considerations in the selection of this approach.

3.3.1.4 *The use of IPA in research involving people with a learning disability*

Within the increasing amount of qualitative research that is being carried out with people with a learning disability, IPA has become a valued method of analysis, specifically for the exploration of the lived experiences of this previously unheard group of people. As a result a number of studies, which have investigated topics that would traditionally have been regarded as 'off limits' to discuss with people with a learning disability have been completed. Examples include Baum and Burns (2007) who investigated the experiences and meanings of mothers with a learning disability who had lost custody of their children; Isherwood *et al.* (2007) who focussed on offending behaviours of men in forensic settings with a learning disability and more recently; Brown and Beail (2009) who explored self harming among people with a learning disability.

3.3.2 The research context

As qualitative research is considered to be the product of an interaction between the researcher and the participant, it is recommended that some information about the context in which the research was carried out is explicitly included (Yardley, 2000).

The research took place within an NHS Trust Learning Disability Service. The service is divided geographically into three regions, with each area having its own multi-disciplinary team. This team includes Community Learning Disability Nurses, Psychiatrists, Clinical Psychologists, Speech and Language Therapists, Occupational

Therapists and Social workers in a role as Care Managers. The research was carried out across all of the three areas.

With regards to referrals and service provision for parents with a learning disability in the local area, there is no specialised service. Assessment of and intervention for parents with a learning disability has become routine work of the professionals working within the multi-disciplinary teams. This supports the findings by Tarleton *et al*. (2006) who highlighted a significant lack of specialised and dedicated resources for parents with a learning disability. Recent service audits completed within the learning disability clinical psychology department highlighted that the number of referrals being made in relation to parenting issues had increased by over a third, in a three year period. This is in line with other published audits in the area, such as those by Woodhouse *et al.* (2001) and O'Hara and Martin (2002), both of which highlighted that the number of parenting related referrals to community learning disability teams is on the increase. In addition to this, a recent service audit conducted by the researcher also indicated that parenting related referrals tend to fall within two categories: those who are previously known to the service and have a formal diagnosis of a learning disability and those who are previously unknown, and who have only come to the attention of services because questions or concerns about their ability to parent have been raised. When the latter is the case, referrals are received from a range of sources including General Practitioners, Health Visitors, children services and social work. Furthermore, due to the fact that between 40-60 per cent of parents with a learning disability have their children removed from their

care (Booth *et al*., 2005) referrals to the service are also made by the sheriff courts and solicitors.

Most commonly, parents with a learning disability are seen by Community Learning Disability Nurses, Social Workers and Clinical Psychologists. In cases where the individual is previously unknown to the service, a full assessment by clinical psychology is undertaken to determine whether or not the individual has a learning disability. Alternatively, in cases where individuals are previously known to the service, advice, re-assessment, intervention or on going support from the above professionals is often requested.

In addition to acknowledging the research context, Yardley (2000) argues it is also fundamental in qualitative research to include some relevant background information about the researcher. By explicitly doing this, it is suggested that the reader is made aware of any potential factors which may influence the objectivity of the researcher.

In this study, the researcher worked in the learning disability clinical psychology department for her elective placement. Within this role, she worked across the three areas to provide a clinical psychology service to people with a learning disability, their families and carers. In this professional capacity, the researcher has been involved in assessing and diagnosing a learning disability on a number of occasions. However, none of these assessments had been in relation to parenting issues. Due to her research interest in parents with a learning disability and to avoid any conflicts of

interest no clinical work of a parenting nature was carried out during the completion of the study.

3.3.3 Ethical considerations

The main ethical issues arising from the study, along with steps taken to address them are outlined below.

3.3.3.1 *Informed consent*

Central to participation in research is the need for informed consent. Historically, people with learning disabilities have been considered unable to give informed consent or make decisions for themselves. However, this is no longer the case (Holland, 1998). A number of 'good practice' papers regarding the conduct of research with people with a learning disability and issues of informed consent have been produced, for example, Nind, (2008), Cameron & Murphy (2007) and Gilbert (2004).

To ensure informed consent the researcher consulted with the index worker (who was a member of the community learning disability team who had most contact with the participants and through whom recruitment into the study was facilitated) to gauge the individual's ability to provide informed consent. In addition, the participants were first given information about the study verbally by their index worker, following which a written participant information sheet (which was deemed appropriate for people with a learning disability by both academic and clinical

supervisors with extensive experience in working with people with a learning disability, as well as by speech and language therapists working in the local adult learning disability service) was given to the participants and gone through with them by the index worker. The participant information sheet explained why the study was being done, what it would involve, issues relating to confidentiality and how they could find out more information (See Appendix 2).

Additionally, a pre interview meeting with the researcher was arranged. The aim of this meeting was to introduce the researcher and participants and provide participants with more information about the study, covering all aspects contained on the participant information sheet. This pre-interview meeting also gave the participants the chance to ask the researcher any questions or raise concerns they may have had about the study. It was made clear that participation in the study was entirely voluntary and would in no way affect the care or support they were receiving from the community learning disability service. All participants were informed of their right to withdraw at any stage of the research, with no reasons given. Finally, all participants were required to sign a consent form for participation in the study. A consent form was developed, (which as above was also deemed as appropriate for people with a learning disability). The consent form required participants to indicate their agreement and understanding in different aspects of the research, the passing on of any information in the event of a disclosure and interviews being recorded. A copy of the consent form can be seen in Appendix 3. In line with recommendations by Nind (2008) on the conduct of qualitative research with people with a learning

disability, the consent form was also signed by a witness (who was the index worker) and the researcher.

3.3.3.2 *Vulnerability of the participant sample*

Individuals with a learning disability are regarded as a vulnerable participant sample for various reasons including impaired cognitive functioning and social isolation (Dagnan, 2008). It is also acknowledged that people with a learning disability may be more socially acquiescent than other groups, and therefore may feel under more pressure to consent to the research study (Cameron & Murphy, 2007). Within the current research, possible factors that increase vulnerability, such as mental health difficulties and legal proceedings arising from child protection issues may have also been present.

Close working with an index worker from the community learning disability service allowed for monitoring of potential vulnerability issues, and it was agreed that if the participants' level of vulnerability changed during participation, the researcher would inform the index worker (or vice versa) and if indicated, participation into the study would be terminated. In addition, the eligibility criteria for the study outlined that individuals were not appropriate for the study if they were actively involved in legal proceedings relating to child protection (e.g. attending court), their child/ children had been removed from their care as a result of child protection proceedings in the last 18 months, were experiencing mental health difficulties that significantly affected their functioning or were misusing substances (alcohol or drugs) that again significantly impacted on their functioning.

3.3.3.3 *The research relationship*

Research with vulnerable groups requires consideration of the relationship developed with the participant during the research process. Specifically, within the learning disability population, individuals often lack social networks and often professionals feature within this more than friends (Pockney, 2006). Entering into a research relationship can potentially extend an individual's social network, especially when research is carried out within their own homes.

Before interviews with participants began, the role of the researcher was explicitly discussed, in that her contact with them would be short term and for a set number of times only. In addition it was explained to the participants that, although the researcher worked part time in the community learning disability psychology service, the research was separate from the care that they were receiving from the service.

3.3.3.4 *Minimising distress*

Due to the nature of the research it was possible that participants may have become upset or distressed by some of the issues that arose during the interviews.

During recruitment into the study, participants were made aware that issues may arise which they may find upsetting. Prior to the interviews commencing, participants were advised that they can take a break at anytime or discontinue with the interview if they wished. The researcher also allowed a short period of time at the end of the interview to discuss the participant's experience of this and any impact it

may have had on him/ her, additionally, participants were informed that if they continued to experience long term upset or distress that they should contact their index worker.

3.3.3.5 *Confidentiality- management of disclosures*

At the beginning of the study participants were informed of the limits of confidentiality. Specifically, participants were advised that if they provided any information which caused the researcher concern regarding the safety of themselves or others, their index worker (and other agencies if necessary) would be informed. If a disclosure of sensitive information was made or if any of the information given by the participant caused concern for the researcher it was intended that the interview would be stopped and that the index worker would be informed. An explicit pathway for the management of disclosures was developed in consultation with supervisors and incorporated local child and vulnerable adult protection policies (see Appendix 4).

3.3.3.6 *Confidentiality- protection of participant anonymity*

For a number of reasons, including that participants were drawn from a discrete population, protection of participant anonymity was important to consider. At the point of data collection, all participants were assigned with an anonymous code which only the researcher knew and used. Furthermore, all personal identifiable information was removed or replaced during transcription and direct quotes used in the final report were anonymous. The recordings and subsequent transcriptions were

stored on an encrypted memory stick (which was supplied and approved by the local NHS Trust). The interview recordings were listened to by the researcher only.

3.3.3.7 *Ethical approval*

The research proposal for the study was initially reviewed and approved by the University of Edinburgh DClinPsychol Ethics Committee in July 2010. Additionally, ethical approval was sought from the local area NHS Medical Research Ethics Committee (via the Integrated Research Application System- IRAS) in November 2010. A favourable opinion was granted in January 2011 (See Appendix 5a). The study was also submitted for registration and approval with the local Research and Development Department. This was granted in January 2011 (See Appendix 5b).

The study was informed by guidelines set out in the British Psychological Society's Good Practice Guidelines for the Conduct of Psychological Research within the NHS (British Psychological Society, 2005).

3.3.4 Participants

3.3.4.1 *Method of sampling*

As the aim of qualitative research is to explore the experiences of a specific or clearly defined group, it is suggested that purposeful sampling is most appropriate (Smith & Eatough, 2007). The aim of the current research was to investigate participant's understanding of having a learning disability and the perceived impact that this had on their role as a parent. Whilst it is recognised that there may be some

commonalities in perceptions of parents with undiagnosed learning disabilities or even specific learning difficulties, a key focus of the current research required participants to be aware of having a learning disability. Therefore, a diagnosed learning disability was part of the inclusion criteria (see below). It was also importantly acknowledged that participants' accounts of being a parent are likely to be influenced by whether or not they have custody of their children or they currently care for their child with them at home. Despite this, as the specified group of interest for the research was parents with a learning disability and given that the focus of the research study was on participants' understanding of having a learning disability and the impact on them as a parent, participants who did not have custody of their child/ children or did not care for their child on a day to basis were not excluded in the sample. However, to protect the ethical rights and vulnerability of parents who no longer cared for their child, specific eligibility criteria regarding this were explicitly set out. Furthermore, the fact that an unrepresentative proportion (40-60 per cent) of parents with a learning disability have their children removed (McConnell *et al.,* 2004), exclusion of participants who fell within this group would have created a biased sample of the group of interest and caused potential recruitment difficulties.

With regards to homogeneity, the current sample was homogeneous on two factors; having a learning disability (and been seen by adult learning disability services) and being a parent. Due to participant recruitment and access difficulties, other factors that could have impacted on the results, such as marital status, number of children, ages of children, were not controlled for. However, in relation to the research aims, the current sample met the requirements in order to answer them. Additionally, and

as acknowledged by Smith *et al*., (2009) the variation in the current sample allowed for divergence to arise and be explored (e.g. differences between mothers and fathers).

3.3.4.2 *Eligibility criteria*

Participants were required to have a diagnosed learning disability, be an open case, and have current involvement with the learning disability service. Participants had to be parents (i.e. a mother or a father), although it was not necessary that their children lived with them. They also had to be able to provide informed consent to take part in the study.

Participants were excluded if there were increased vulnerability issues, such as severe mental health difficulties or substance abuse (to such an extent that functioning was significantly impacted). Additionally, participants who were actively involved in legal proceedings resulting from child protection issues or those who had lost the primary care of their child/ children in the last 18 months as a result of child protection issues were also excluded.

3.3.4.3 *Sample size*

Unlike quantitative methodologies the concept of statistical power does not apply in qualitative research. Factors to consider within the sample sizes for qualitative research include the nature and aims of the study, the level of homogeneity of the sample and the allocated time for analysis and reporting (Smith & Osbourne, 2008). According to Smith and Eatough (2007) IPA studies are usually conducted with

relatively small samples which are guided by striking a balance between allowing an in-depth analysis with individual cases, whilst exploring a full range of issues across the sample. Turpin *et al.* (1997) argue that six to eight participants is sufficient for clinical and health psychology post-graduate programs. More recently, Smith *et al.* (2009) suggest that numbers of 4-10 interviews for professional doctorates may be adopted.

The current study aimed to recruit up to 10 participants, with the aim of allowing for an in-depth exploration of emerging themes yet still manageable within the time constraints of the study.

3.3.4.4 *Participant characteristics*

Eight participants took part in the current study (three mothers, five fathers). Ages ranged from 23-46. A summary table of participant characteristics are presented in Table 3.1.

All participants had a diagnosed learning disability within the mild range. This was confirmed at the point of entry into the study by their index worker who had worked with them for a significant amount of time and had access to their case notes. Participants' social circumstances varied, with some living in their own homes with their partners and/ or children, some living with their children and partner in their parents' home and some living alone or with their partner only (and not their child or children). None of the participants were in employment, yet a small number were actively seeking employment opportunities at the time of interview. As well as being involved with the learning disability service, a number of additional services and

agencies were involved with the participants which included social work (from both adult and child and family services, in the form of care managers, support workers), health visitors and statutory and voluntary organisations providing parenting and child care support

Table 3.1: Summary of participant characteristics

Participant	Age	Gender	Level of LD	Number of children	Ages of children **	Number of children living with them	Previous child removal
P01	31	M	Mild	3	13y, 3y, 4 m	1	Yes
P02	23	M	Mild	1	4y	1	No
P03	38	F	Mild	1	9y	1	No
P04 *	36	M	Mild	3	11y, 6y, 5m	3	No
P05*	35	F	Mild	3	11y, 6y, 5m	3	No
P06	46	F	Mild	4	20y, 18y, 12y, 10y	2	No
P07	43	M	Mild	1	15y	0	No
P08	44	M	Mild	2	30y, 25y,1 due.	0	No

*- P04 and P05 were a married couple, however were interviewed separately.
**- y= years old, m= months old

3.3.4.5 *Recruitment*

Participant recruitment began in January 2011. However, prior to this, the researcher met with the learning disability teams across the local health board to present her study and gauge an initial idea of potential participant numbers. During this initial scoping meeting, members of the learning disability teams, which included Community Learning Disability Nurses, Occupational Therapists, Clinical Psychologists and Social Workers (in the role of Care Managers), were informed of their role as 'index workers' within the research. This meant that they would initially

approach the potential participants about the study, provide a witness signature on the participant consent form and be a link between participants and the researcher if any information needed to be passed on.

Following this, members of the learning disability teams were asked to identify individuals who were on their current case load who may be appropriate for the study. To aid this, members of the team were provided with a copy of the participant eligibility criteria along with copies of the participant information sheet. Potential participants who met the eligibility criteria were then verbally informed about the study by their index worker and given a participant information sheet. Although the participant information was developed in conjunction with supervision from experienced clinicians and researchers in the area of learning disabilities, and was deemed accessible for people with a learning disability, the index workers initially went through the participant information sheet with all potential participants. At the end of the participant information sheet there was a tear off slip which required potential participants to indicate that they agreed to be contacted by the researcher to arrange an introductory meeting. Contact details of the potential participants were also provided on the tear off slip, which was then returned to the researcher by the index worker.

Once potential participants had agreed to be contacted by the researcher, recruitment followed two explicit stages;

Stage 1- Initial contact and introductory meeting

Using the contact details provided, the researcher telephoned the potential participants to introduce herself and arrange a convenient time for an introductory meeting.

The introductory meeting was an opportunity for the researcher and potential participants to meet to discuss the study. Specifically at this meeting participant involvement was discussed and any questions or concerns that the participants had were clarified. This introductory meeting lasted approximately 30 minutes and was carried out in either the potential participant's home or at the learning disability clinic base that they were most familiar with. Following this, potential participants were given a period of one week to consider whether or not they wanted to take part. They were then phoned by the researcher to ascertain their decision.

Stage 2- Gaining informed consent and conduct of interview

If potential participants indicated that they did not want to take part in the study, they were thanked for showing an initial interest and their name and contact details were destroyed.

If potential participants had indicated they did want to take part, a further meeting with them was arranged. Again, this meeting was carried out in either the participant's home or at the learning disability clinic base that was most familiar to them. The consent form was required to be signed in the presence of a witness. The

witness for all participants was the index worker through which recruitment was facilitated.

Following the gaining of consent the interview took place.

The recruitment process, along with the numbers of participants recruited to each stage is presented in Figure 3.1.

3.3.5 Procedure

3.3.5.1 *Interviews*

Semi-structured interviews were conducted. According to Willig (2001), semi structured interviews enable specific questions to be asked, while allowing for greater flexibility in following up responses to examine areas in depth. This method of interviewing was selected for a number of reasons, including that it is the most commonly used tool of data collection in qualitative research (Barker *et al*., 2002). Furthermore, Smith and Osbourne (2003) consider semi-structure interviews to the best method for collecting data for analysis using IPA.

3.3.5.1.1 *Interview schedule*

Semi-structured interviews are guided by an interview schedule, which provides an overall framework for the interview and provides focus for the research questions. In constructing an interview schedule, Willig (2001) suggests that questions should be open ended, neutral rather than leading and avoid the use of jargon. Smith (2005)

also advises that questions should not be too explicit, in that questions should not be too closed that they lead the participant in a particular direction, which then potentially prevents novel or unexpected areas of discussion by the participant.

```
                    ┌─────────────────────────────┐
                    │      Initial approach-       │
                    │ Total number of participants │
                    │  approached by index workers │
                    │  and given information        │
                    │         sheet= 18            │
                    └─────────────────────────────┘
              ┌──────────────┐          ┌────────────────────────┐
              │ Participants │          │ Declined participation │
              │ excluded = 2 │          │         = 4            │
              └──────────────┘          └────────────────────────┘
                    ┌─────────────────────────────┐
                    │          Stage 1-            │
                    │  Total participants met for  │
                    │ introductory meeting (met    │
                    │ inclusion criteria) =  12    │
                    └─────────────────────────────┘
         ┌──────────────────────┐     ┌─────────────────────────┐
         │ Declined to          │     │        Stage 2-         │
         │ participate = 4      │     │ Gaining of consent and  │
         │                      │     │ conduct of interview = 8│
         └──────────────────────┘     └─────────────────────────┘
```
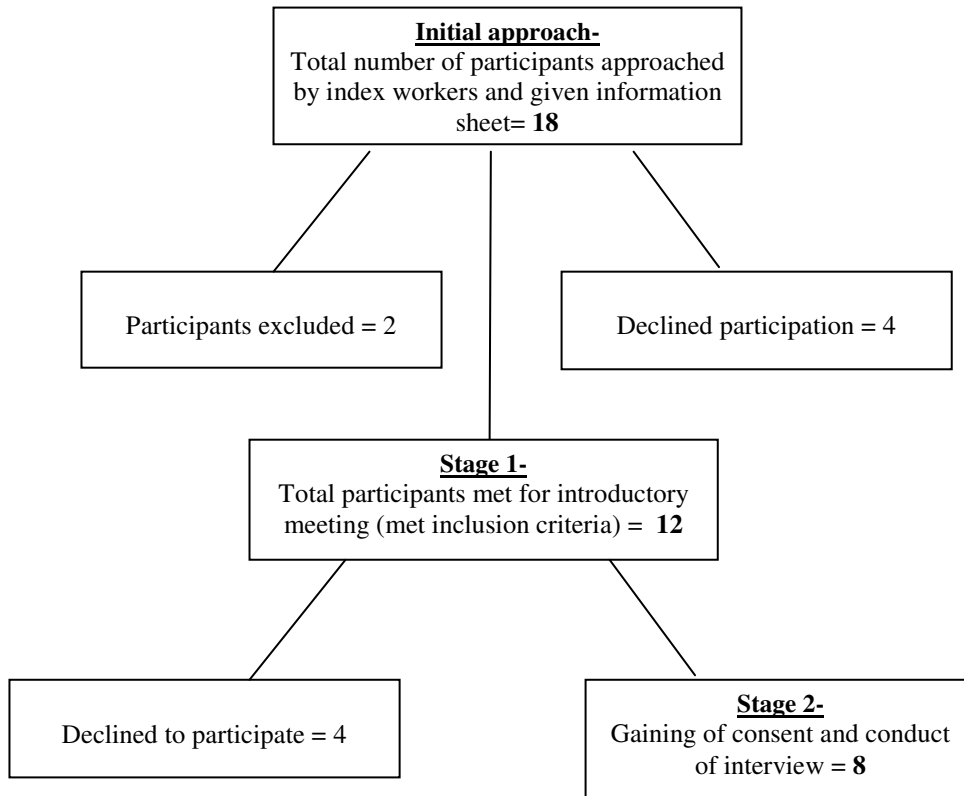
Figure 3.1: Recruitment process flow-chart.

Smith and Eatough (2007) encourage that semi-structured interviews begin with general questions, which allow for rapport to be established and may be enough for participants to talk freely about the topic. These questions are then followed up with more specific prompts or probes to help clarify questions or encourage participants that may be more hesitant.

The interview schedule for the current research (Appendix 6) was developed in consultation with a clinical supervisor with experience in the field of learning disabilities and academic supervisors with extensive research experience in qualitative research and research with people with a learning disability. In addition, the relevant literature was considered which provided advice on the general construction of interview guides (Smith & Eatough; 2007; Smith *et al*., 2009; Willig, 2001), as well as specific literature on the conduct of qualitative research with individuals with learning disabilities (Munford *et al*., 2008; Nind, 2008). The interview schedule was also reviewed and approved by the local area NHS Medical Research Ethics Committee and the local Research and Development department.

The schedule consisted of a number of open-ended questions based on the over-arching research questions of the study. To prepare for the possibility that the initial questions would be insufficient to elicit satisfactory responses, each question contained a number of further probes. In line with guidance on the conduction of qualitative research with people with a learning disability (Booth & Booth, 1996), these probe questions/ prompts encouraged participants to expand on their answers and ground their responses within examples.

The interview schedule addressed the following areas:

1. Participants understanding of their learning disability

2. How participants perceived their learning disability to impact on them in their role as a parent.

3. Participant's experiences of support to them in their parenting role.

3.3.5.1.2 *Pilot interview*

In order to test the feasibility of the interview schedule, a pilot interview was carried out with a participant. Feedback was sought following this (i.e. their views on the questions asked and the interview process). The transcript of the pilot interview was also examined by a clinical supervisor who worked in the area of learning disabilities. The feedback from both of these sources did not indicate that revision of the interview schedule was required.

3.3.5.1.3 *Interview format*

Interviews were conducted on an individual basis and took place in either the participant's home or at the learning disability clinic base that was most convenient to them. As some of the participants lived in rural areas and none of them drove nor had access to their own transport, the offer to conduct the interview within the participant's own home allowed for greater convenience and therefore more equal and greater access to participate in the study. Smith *et al*. (1995) argue that carrying out the interview in a familiar environment such as their own home may make participants feel more comfortable and therefore be advantageous to the interview process. However, it was also recognised that for some, the home environment may not be appropriate to conduct interviews in, due to other family members being present. Therefore, all participants were offered the choice of locations for the conduct of the interview.

Prior to the interview commencing, participants were reminded of the limits of confidentiality. Participants were also advised of their rights to stop the interview at any point or to take a break from the interview for comfort purposes.

Demographic information (e.g. age, gender, number of children, ages of children, living circumstances) was gathered at the start of each interview. A demographic data collection sheet was developed and used for the purposes of this (see Appendix 7).

The length of the interviews ranged from 22 minutes to 67 minutes, with an average interview duration of 42 minutes.

The interview schedule was used flexibly throughout the interview to allow exploration of issues that were raised by participants. Within this, the researcher used her experience as a Trainee Clinical Psychologist to guide the interviewing process and skills such as rapport building, active listening and reflective techniques were used. The researcher frequently summarised information to check its accuracy and to ensure that the participants felt that they had been heard. At the end of the interview, participants were given the opportunity to express their views on the interview process and ask the researcher any questions they may have had.

3.3.5.2 *Data management*

All interviews were recorded using a digital voice recorder. The recordings were then transferred to computerised audio files and stored on an NHS supplied, encrypted

memory stick and erased from the voice recorder. Interview recordings were then transcribed verbatim by the researcher. At the point of transcription a code was assigned to each interview and all personal and potentially identifiable information was removed.

A computerised qualitative data analysis package (N-Vivo 9) was used to store, organise and refine data.

3.3.5.3 *Data analysis*

Within IPA, emphasis is placed on the process of moving from individual accounts to shared themes. As previously highlighted, the identification of themes requires an interaction between the researcher and the interview data. Therefore, throughout the analysis process the researcher attempted to remain close to what the participants said (i.e. their actual words) whilst always acknowledging that the emergence of themes draws heavily on the researchers own interpretative resources. To encourage the acknowledgement of this, plus note any other comments, thoughts or points of significance the researcher kept a reflective diary throughout the data analysis process.

The data was analysed in accordance with IPA procedure as set out by Smith *et al.* (2009). This provides a six step guide to conducting analysis and is recommended for use by inexperienced qualitative researchers (Smith *et al.*, 2009). These steps are summarised below.

Step 1- Reading and re-reading

Audio recordings of the interviews were transcribed by the researcher verbatim, following which she became actively engaged with the data through repeated reading of individual transcripts. Comments, thoughts and reflections were noted in the researcher's reflective diary to aid later interpretation.

Step 2- Initial noting

The researcher used exploratory coding to analyse each transcript. This included the use of descriptive comments (to describe the content of the account), linguistic comments (to highlight the use of any specific language within the account) and conceptual comments (to raise interpretative questions) of the account. Initial noting comments were made by hand on a line by line basis, noted in the left hand margin and used a colour coding system.

Step 3- Developing emergent themes

Through an exploration of patterns within the initial notes, the researcher began to identify themes. The themes attempt to capture both a reflection of the participants' experiences as well as the researcher's reflections on the interpretation of this (Smith *et al*., 2009). According to Smith and Osbourne (2003), themes consist of phrases that begin to move the researcher's initial and perhaps more content level based notes of the text to a more abstract and conceptual level. Smith & Eatough (2007) suggest that developing emergent themes may also include the introduction of psychological concepts to capture the meaning of the text. Emerging themes were documented in

the right hand margin of the transcript. An example of a coded transcript can be seen in Appendix 8.

Step 4- Connections across emergent themes

The researcher explored connections between the themes to produce a higher level, super-ordinate theme to describe or label similar themes. Initially, to facilitate this, the researcher produced by hand a mind map, which presented all of the emergent themes as well as the relationships between them. A typed version of this can be seen in Appendix 9. This stage of analysis was further facilitated by the use a qualitative data analysis package (N- Vivo 9), which allowed the researcher to further organise and store themes. A summary table presenting the development of super-ordinate themes and sub-themes within this was then produced for each transcript (see Appendix 10 for an example).

Step 5- Moving on the next case

In line with the ideographic principles that underpin IPA, steps 1 to 4 were repeated for each transcript, allowing for the identification and emergence of new themes from each account.

Step 6- Looking for patterns across cases

Summary tables for each individual transcript were compared to identify recurrent super-ordinate themes, and examples of isolated themes. Smith *et al.* (2009) emphasise that there is no rule for what counts as recurrence, but rather it is influenced by a number of factors including level of commenting and purpose of the

research project. Using the summary tables of super-ordinate themes, the researcher manually integrated them into a table of master themes and sub-ordinate themes which represented the participant group as a whole. As with step 3, the development of master themes was facilitated with the use of a mind map to demonstrate the relationship between the emerging themes.

3.3.6 Ensuring quality

In quantitative research, the quality or scientific value of a study is measured against criteria of reliability, validity and generaliasability. However, such established criteria are not consistent in the evaluation of methodological quality and rigour within qualitative research (Meyrick, 2006). In an attempt to overcome this, a number of qualitative researchers (Elliott *et al*., 1999; Yardley, 2000, 2008) have developed criteria to evaluate methodological and analytic rigour in qualitative research which include sensitivity to context, commitment and rigour, coherence and transparency and impact and importance.

3.3.6.1 *Sensitivity to context*

Smith *et al*. (2009) suggest that relevant literature is used to direct the study to demonstrate sensitivity to context. The researcher was therefore sensitive to the existing qualitative literature concerning the experiences and issues faced by parents with a learning disability.

Within sensitivity to context, Smith *et al.* (2009) also highlight the need to consider any power imbalances that may be present in the relationship between the researcher and participants. The researcher was mindful of the possible impact that her role as a Trainee Clinical Psychologist working within the learning disability clinical psychology service could have on participants, in particular with regard to speaking about any aspects of the service provided by the learning disability teams. The researcher was also aware that participants were likely to have had some involvement with a Psychologist in the past (e.g. for assessment of their learning disability) and that they may have had pre-conceived ideas about the researcher's clinical role. In an attempt to overcome these issues, the role of the researcher was fully explained (i.e. as a researcher only as opposed to a clinician) and that involvement in the study was separate from and would in no way affect the care and support they were receiving from the learning disability service. In addition, participants were aware that the research was being carried out as part of a doctoral level thesis, hence it is possible that this could have contributed towards the power imbalance with the researcher being viewed in an expert role and increasing the likelihood that participants felt they had to provide the right or most socially acceptable responses. Similarly, it was important to acknowledge that for some participants in the sample, the expressing of their own opinions or the recalling of accounts from their side without clinical evaluation or judgment from others may have been an unfamiliar experience to them. Therefore, to overcome issues of possible social acquiescence the researcher stressed at the start of each interview that she was interested to hear their experiences from their own perspectives and that there was no right or wrong answers.

3.3.6.2 *Commitment and rigour*

The principle of commitment and rigour refers to the extent to which a sufficient level of detailed analysis to ensure the validity of the results can be demonstrated (Yardley, 2000).

Commitment can be demonstrated in several ways including extensive engagement with the topic area and methodology used as well as 'immersion' with the data. The researcher has had an interest in the topic area since the start of her clinical training and as a result completed a local service evaluation project into the referral pathways of parents with a learning disability, which was both formally written up as an academic project and presented to the local learning disability psychology service. In addition, preparation for the current research required a comprehensive literature review into the topic area of parents with a learning disability. With regards to commitment to the methodological approach, the researcher engaged with extensive reading of the methods and principles of IPA, as well as attending a qualitative research seminar which was based on the use of IPA. To further enhance commitment to the data, the researcher transcribed all interview content to allow her to become fully immersed with the participants' accounts.

Rigour was enhanced in this study through a range of methods including sampling, multiple coders and repeated checking of themes. Firstly, the researcher interviewed individuals specifically with a diagnosed learning disability (and who were aware of this) in an attempt to keep the sample relatively homogenous, while including those with children who did and did not live with them to purposively sample a broad

range of perspectives. Secondly, multiple perspectives (also known as triangulation) were used. Barbour (2001) suggests that qualitative interpretations from multiple sources should be compared against each other to enhance the findings. Therefore, samples of analysed transcripts were reviewed by a clinical supervisor who had experience in both IPA and working clinically with people with a learning disability and an academic supervisor with extensive experience in qualitative research. This not only provided corroboration of identified themes but also offered differing perspectives in the refinement of themes. Respondent feedback (feeding back of emergent themes with participants) was also used in this study. Following completion of all data analysis, three participants were randomly selected and contacted by the researcher to provide feedback and discuss the findings. Finally, the researcher engaged in a process of cyclical checking of themes against individual transcripts to ensure that the themes were developed from the data. This is demonstrated through the use of supportive quotations from participant accounts and the use of a summary table to represent patterns of themes.

3.3.6.3 *Coherence and transparency*

Coherence refers to the presentation of findings that are consistent with the theoretical background and the research questions. To maintain this, the researcher's clinical and academic supervisors checked samples of transcripts with the analysis process and reviewed drafts of the write-up of the study.

Transparency within qualitative research is the extent to which all aspects of the research procedure are disclosed and clearly documented. The researcher provided a

clear description of the sampling, interview format and process of analysis of the current study. The use of summary tables and diagrams were used to further evidence the emergence of themes and the relationships between them. A qualitative data analysis package was also used to organise and refine the development of codes, hence allowing a clear data trail. Reflexivity of the researcher is considered to be an important aspect of transparency, particularly in IPA as the researcher must acknowledge and detail their position in the study. To maintain a reflexive stance, the researcher kept a reflective diary throughout the study.

3.3.6.4 *Impact and importance*

Impact and importance is the contribution of the current research findings to theoretical knowledge and its translation into practice. Yardley (2000) states this to be the 'decisive criterion' by which any research should be judged and references to this principle are included within several quality appraisal checklists for the evaluation of qualitative research (e.g. Critical Appraisal Skills Programme [CASP], 2002; Mays & Pope, 2000).

It is anticipated that this research, which highlights the understanding and perceptions of parents with a learning disability about their learning disability and parenting role may offer new insights to those clinicians who continue to support them. This may hopefully have implications for future support, possible by creating a shared understanding of the needs of this client group between the parents themselves and the professionals who work with them.

3.4 RESULTS

3.4.1 Emergence and distribution of themes

Seventeen super-ordinate themes emerged from the interviews and these were subsumed within five master themes: *The self as different identities; The opinions of powerful others; Accepting the reality; The same but different* and *Learning to cope.*

A summary of the master themes and related super-ordinate themes are presented in Table 3.2.

There were differences in the presence and depth of the super-ordinate themes across participants' interviews, with some more willing and able to reflect on their experiences than others. This was reflected in the distribution of themes across the participant sample (see Appendix 11).

The next section will provide a detailed description of each master theme and its super-ordinate themes (indicated using italics) along with illustrative verbatim quotations from each participant's transcripts. The extracts were selected to provide the most coherent expression of themes, whilst representing the views across the sample. All extracts are from fully anonymised transcripts, with the source of each extract indicated by the participant's assigned participant number.

Table 3.2: Summary of master themes and super-ordinate themes.

Master Themes	Super-ordinate themes.
The self as different identities	Being a person with a learning disability Becoming a parent Self Identity Separate identities
The opinion of powerful others	Others as experts Presumptions of incompetence Self evaluation as a parent What I think makes no difference
Accepting the reality	Involvement with services Threat of child removal The 'Bottom-line"
The same but different	Acknowledgement of common parenting experiences Hopes and expectations for their children Unsaid social comparisons
Learning to cope	Learning parenting tasks Coping within their means Value of parenting in partnership.

3.4.2 The self as different identities

The first master theme describes participant's views of themself. These identities, or expressions of the self, were conveyed in three different ways. Firstly, as a person with a learning disability, secondly, as a parent, and finally, as a person with individual beliefs, likes and strengths (i.e. outside both having a learning disability and being a parent). This led to the compartmentalisation of the self into three identities, with participants talking about them as distinctly separate. This master theme contains four sub-themes to represent the above.

3.4.2.1 *Being a person with a learning disability*

All participants acknowledged having a learning disability, however the way in which they identified with this varied. Some participant accounts suggested that having a learning disability was an integral part of them, as the difficulties that they associated with having a learning disability had been present since they were children.

> " *I canna mind about really ever been told, but going back when I was younger I've always been like that*" (P06, page 1, lines 35-36*).*

Other participants however, did not relate to having a learning disability in the same way. Instead their perceptions were embedded in other difficulties, suggesting that for them, their learning disability was a bi-product of other difficulties.

> *" I- So do you see yourself as having a learning disability?*
> *P03- Well yeah, 'cause I've got epilepsy"* (P03, page 2/3, lines 38/1).

> *" I feel like people no understand me because of my learning difficulty,*
> *'cause I got a speech impairment"* (P07, page 1, line 18).

Although different in the way that they identified with being a person with a learning disability, all participants provided examples of their difficulties. For the majority of participants their difficulties were perceived as specifically related to cognitive tasks and often linked back to the problems they had experienced at school.

> *"Yeah erm and difficulties with my sums (..) and that"* (P08, page 1, line 34).

> *"I can't do spellings work either"* (P06, page 3, line 33).

> *" I feel it hard reading long er, long letters"* (P05, page 1, line 11).

A number of participants also described how such difficulties continue to impact upon them in their day to day lives, including within their role as being a parent.

> *" It effects me 'cause I canna read anything that comes up (..) Like if it*
> *was left to me we'd have a whole heap a mail unopened 'cause I would*
> *na be able to read it"* (P04, page 1, lines 26-28).

> *" It is difficult see 'cause I can't really help with my girls homework*
> *'cause I can't read that well"* (P06, page 3, lines 24-25).

The above extracts reflect the perception of participants that difficulties are experienced, and impact on life, in very specific ways.

When speaking about having a learning disability, most participants made reference to their childhoods and experiences at school. Within this, participants recalled situations that were suggestive of hardship and distress.

> *"School was a nightmare eh (..), I was in and out of school, I was like a yo yo eh. I was always bottom of the class and would get thrown out of school quite a lot....."*(P01, page 1, line 27).

> *" It took me hard, it took me hard because erm there were a lot of things going on for me at school"* (P03, page 1, lines 33-34).

Furthermore, some participant accounts created a sense of feeling singled out, which was perceived to be directly associated with having a learning disability

> *"…but that is what the teachers did, you know pick on the simple ones (..) well that is very difficult, it's very difficult being at school for a long time and being picked on."* (P08, page 3, lines 14-16).

Perceptions of difficulties, experience of hardship and feeling singled out cumulatively created a sense that having a learning disability was negatively viewed and an un-welcomed identity by most participants. The following quote from participant 3 demonstrates this.

> *"yeah when I was at school I did (..) I really wished I did na have it"* (P03, Page 1, line 23).

3.4.2.2 *Becoming a parent*

In contrast to the negative associations of being a person with a learning disability, most participant narratives were characterised by a welcomed and positive identity to becoming a parent. This was particularly evident in the interviews with mothers, as they conveyed their strong identities with motherhood.

> *" I've always wanted to be a mum and then when it happened I kept thinking to my sel I'm gonna be a mum, I'm gonna be a mum!"* (P03, page 5, lines 15-16).

> *"It's great being a mum, you know just taking care of the kids and being there"* (P05, page 4 , line 15).

When her first baby was born, participant 6 suggested that for the first time in her life she felt a sense of positive ownership in her identity.

> *"I was over the moon, you know being a first mum, having a first child of my own (…) It was a lovely time"*. (P06, page 5, lines 13-14).

Although the theme of becoming a parent was evident in all of the interviews with fathers, it was not as strong or expressed in the same way as for mothers. When asked about their reactions to finding out that they were going to become a father, some reported mixed feelings.

> *" I was excited, really excited eh (…) till I realised that stuff, everything was gonna change in my life"* (P02, page 2, lines 15-16).

> *" Finding out **(name of wife) was a shock to the system! I just wanted to run (..) but being there at the birth was good, the birth was better….."* (P04, page 2, lines 6-7).

The apparent differences between mothers and fathers may be as a result of gender role beliefs within parenting, but may also be related to proximity of the child, as three out of the five fathers interviewed did not have the daily involvement and contact with their children in comparison to all the mothers that were interviewed.

As a result of a positive and welcomed identity with parenthood, participants' narratives conveyed feelings of joy, happiness and pride in becoming a parent and embarking on the journey of raising their children.

> *" It's great being a dad, you know knowing that somebody needs you to look out, look after them. It's kinda like we got this dad instinct. It's*

like a bond between us, between me and her that means she has to be wi me. I can't imagine not having that now" (P02, page 5, lines 30-34).

" It feels great [laughs] (…) erm you know seeing her from a wee baby crawling about to look at her now, she's almost a lady now. She is growing up just so fast" (P06, page 10, lines 1-3).

"Ken[7] (….) Can't explain (…) makes you feel, erm makes me feel happy. Happy inside to watch them from a wee baby into a big girl" (P07, page 5, lines 24-25).

Despite most participants welcoming the identity of parenthood, the same cannot be said about the reactions of others. Some participants spoke of their fear about telling other people, including members of their family and professionals about becoming a parent, because they were uncertain about how they might react.

*" P02- Well my mum did na ken ** (name of girlfriend) was even pregnant (..) I was a wee bitty scared to tell her.*
I- Can I ask why you were scared to tell your mum?
P02- 'cause I could na speak to my mum, 'cause I was kind a scared eh (..) scared what she would say" (P02, page 3, lines 8-12).

In telling other people about becoming a parent, participant 8 conveyed a sense of judgement and disapproval from the responses of others.

" She was rowing with me and saying like 'you should have told me your girlfriend was pregnant', ken, you know I thought, I thought I don't need to tell you nothing again with what happens in my life. If I want to have a baby to her it's up to me and she can't give me a row for it". (P08, page 4, lines 19-22).

3.4.2.3 *Self identity*

In addition to describing an identity as a person with a learning disability and as a parent, participants also described a self identity. This sense of self identity was

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[7] In the local dialect, "ken" is colloquial for 'you know' or 'know'.

conveyed through the expression of their beliefs about themselves, their individual

likes and perceived strengths.

> *"I mean it's not as if I'm a bad person eh, I've just had my problems, but I'm getting there."* (P01, page 10, line 29).

> *" I'm crazy on country and western, I've just ordered a John Wayne clock for my wall. I mean it was a bit expensive (…) it's to go on my lounge wall. But I love country and western so I really wanted it".* (P06, page 10, lines 22-24).

> *"I'm good at cooking and all that (..) I like to cook for other people. See ** (name of partner) reads the recipe out to me and then I do the ingredients. Well I went to college for 3 years and did cooking and then I got a certificate at the end".* (P08, page 2, lines 20-23).

Within the extracts above, no reference is made to either having a learning disability

or being a parent, thus creating a sense of self which was separate to the other

identities.

3.4.2.4 *Separate identities*

As implied by the distinction of the three previous super-ordinate themes, most

participants conveyed that their identity as a person with a learning disability and

identity as a parent were separate. The extracts below represent how participants

compartmentalised their identities, and clearly separate them out.

> *" Well I've always blamed that for getting made a fool of (..) I've always blamed myself, well not myself but the difficulties for getting made a fool of at school"* (P03, page 1, lines 24-25).

This demonstrates how participant 3 distinguishes between having a learning

disability and her self identity. In the process of doing so, she externalises her

identity with learning disability in that she refers to it as 'that' and 'the difficulties', yet speaks of her self identity as being integral to her as she uses the word 'myself'.

Having a learning disability was also separated from being a parent.

> *"I just care about being a dad and put my difficulties to the back of my mind and get on with it"* (P04, page 3, lines 16-19).

Finally, all three identities were perceived as being distinct from one another.

> *"It wasn't about me or my difficulties it was mainly my girls. The girls were more important than that"* (P06, page 8, lines 28-31).

Here the language creates separation of the three identities with the words 'me' used to reflect identity with the self, 'difficulties' to refer to her identity as being a person with a learning disability, 'my girls' to represent her identity as a parent.

Not all participant accounts conveyed such clear compartmentalisations. Some participants made reference to how the different identities influence one another, creating relationships between them. This was most evident in the relationship between the self identity and becoming a parent, and was present in the accounts of fathers.

> *"Erm, it was just like that my life was gonna change, it was gonna be less fun if you know what I mean? I used to like playing on the computer a lot and go out on my own but I canna suit myself, do that anymore".* (P02, page 2, lines 18-20).

> *"I'm settled, I've no moved on. Like when I was younger and growing up I would move from place to place, like never stay anywhere too long, a bit of a tear away really, but now I've stayed put".* (P04, page 5, lines 2-4).

These extracts demonstrate how self identity was modified as the result of becoming a parent, suggesting that although the three identities are held, they do impact on each other.

3.4.3 The opinion of powerful others

The second master theme encapsulates the ways in which participants perceived and related to the opinions of others, both as a parent, and also as a person with a learning disability.

3.4.3.1 *Others as experts*

Most participants perceived the 'other' in opinions of others to be in an advantageous position to them. This meant that they were either viewed to be in a position of power (e.g. a health or social care professional) or were family member that were viewed to have more experience at being a parent.

The following extract from participant 6 demonstrates how she turned to her health visitor for advice about a personal dilemma she encountered in relation to being a parent.

> *"When I found out I was pregnant with ** (name of oldest daughter) I went to my health visitor at ** (name of clinic) 'cause at that time I didn't know whether to keep her or not, or what was the right thing to do like, so I went to see her 'cause she knew me from before and I just wanted to see what she said about it"* (P06, page 5, lines 29-33).

In this, participant 6 implies that based on her knowledge and perceived position of power, the health visitor would be able to provide her with the 'right' answer to her

dilemma, which ultimately could have influenced the path that her imminent future took.

Participants 2 and 8, who were both fathers made reference to family members who were regarded as 'experts' in parenting and child care.

> *"My mum could actually tell you right away what to do er with your wee one, 'cause my mum has got a wee one just now and had four of us so she has lots of experience and would be able to tell you what to do right away. Erm (..) and I'm just trying to learn what to do still and my mum tells me right away 'cause she's got more experience"* (P02, page 2, lines 6-10).

> *" Yeah lots of advice from my sister and my carer, 'cause they know, you know, they have had children so they know what to do"* (P08, page 10, lines 12-13).

The above extracts convey that because of their previous inexperience at being a parent and rearing children, the opinions of others are of more value than their own. In addition, they both make reference to female 'others' only (i.e. mothers, sisters), suggesting that within their role as a parent, fathers value and rely on maternal influences.

3.4.3.2 *Presumptions of incompetence*

Some participant accounts conveyed that others formed their opinions of them on assumptions based on their difficulties only, with no acknowledgement of their strengths. The following quotes from participants 1 and 4 demonstrate how this related to them as a parent.

> *"…well it's no so much my mum, its more my dad. He was basically like you'll never never do it. Ken you'll never be able to look after a bairn on your own and stuff like that"* (P01, page 11, lines 19-21).

> *"….probably 'cause she thought I was na ready (…) I was a wee bitty young like and wi my difficulties and stuff I think she just thought that I was na ready and would na be able to cope wi having a kid"* (P02, page 3, lines 17-19).

Specifically, participant 2 highlights that within the opinion of others his role as a parent was overshadowed by the difficulties associated with him having a learning disability.

Few participants made reference to how others acknowledged their strengths; instead emphasis was placed on their deficits only. The extract below from participant 6 demonstrates this as she makes reference to the opinions of professionals.

> *" I mean looking at my past, there are some good bits and some bad bits and yes I've had some difficulties, but I did my best to change that, but they just keep bringing the past up, like the bad bits"* (P06, page 7, lines 32-34).

Not only was the presumption of incompetence evident in participants experiences of being a parent, but some participants also suggested that such negative assumptions had been encountered previously. The following quote from participant 3, who is recalling her experiences at school are evidence to this.

> *" …well I went to high school but then 'cause of my difficulties I got moved into a special class there 'cause the education er the education thing did'na think it was any use me being in the other class like, so I went there"* (P03, page 2, lines 22-24).

In this extract, participant 3 conveys how the opinions of others in an authoritative position not only made judgements about her based on her difficulties but also

dictated the experiences she had at school. As a result, a lack of control and limited choices was created.

3.4.3.3 *Self evaluation as a parent*

In evaluating themselves as parents, most participants' accounts were characterised by a reliance on what others thought about them. For some, the opinions of others were a significant indicator of their competency as a parent.

> *" Basically she ** (name of social worker), this is what she says is I'm doing well and I'm slowly getting there, so if she says that then I must be okay eh"* (P01, page 7, line 30).

In the above quote, participant 1 implies that the opinions of others have become the only meaningful way that he can evaluate himself as a father.

However, as a contrast participant 5 does not appear to view the opinions of others with such a level of importance. She acknowledges that others will have an opinion about her, but also clearly states her own beliefs about herself as a mother.

> *"I'd say I was a good mum, but other people might not think that, you know, so (…)"* (P05, page 5, lines 9-10).

The differences between these accounts may be the result of involvement with services, as participant 1 had significantly more contact with professionals in health and social care services than participant 5. Therefore, he placed greater emphasis on how others evaluated him.

Specifically, the opinions of others in the evaluation of themselves as a parent was highlighted by participant 3. She repeatedly made reference to the seeking of others

opinions in order to evaluate herself as a mother. She then played this out during the

interview as she sought my opinion about her as a mother;

> *"I've had to get help with that, you know stop thinking that 'cause she
> says 'no you're doing a good job', she says that I'm doing okay so (…)
> What do you think, am I a good mum?"* (P03, page 9, lines 33-36*).*

3.4.3.4 *What I think makes no difference*

Closely related to the above super-ordinate theme, some participants conveyed that

their own beliefs about themselves as a parent were powerless, therefore did not see

the point in discussing them with others. This theme was particularly evident in

participants who had either significant past or current involvement with health and

social services. The following extracts from participant 1 and 6 demonstrate this.

> *" I did'na see the point in me going through it anyway, 'cause I think
> they'd made their decision (..) their decision way before I even started
> it eh. They had probably made their mind up just like that [clicks
> fingers]"* (P01, page 5, lines 4-7).

> *"P06- I used to sit there and think, I wonder if they've got kids?, I
> wonder if, how they would like it goin into them meetings and everyone
> talking about you an your kids and bringing you down?*
> *I – Did you ever ask any of them that?*
> *P06 –Na, at the end of the day it's not worth it, it makes no difference
> what I think (..) or what I do (..)"*(P06, page 7, lines 7-11).

Although these accounts acknowledge the participants own thoughts and beliefs

about their situation, they also suggest that in comparison to the opinions of the

perceived 'powerful others', they were not worth outwardly expressing as they

would in no way be influential to the outcome.

3.4.4 Accepting the reality

This master theme represents the realities that participants faced in their experiences as a parent. Related to the previous master- theme, these realities were in part constructed as a result of the opinions of others and included involvement with services and threat of child removal. Three super-ordinate themes make up this master theme to reflect the above.

3.4.4.1 *Involvement with services*

Although varying in length and intensity, all participants had some involvement with professional services. However, the way in which they described their experiences suggested different perceptions of this.

Participants 1 and 6 spoke most in depth about their contact with professional services. Both of the extracts below suggest how there were some aspects of service involvement that were a 'process' that they had to go through in order for them to keep their children.

> *"I – What kind of things have you been asked to do?*
> *P01- Basically do, well jump through hoops basically"* (P01, page 7, line 2)

> *"You know I know what it's all about, like at them meetings and stuff, it's the same old story with them all, they bring up the past all the time. Like I'd go to another meeting and it would be here we go again, same old stuff ken"* (P06, page 7, lines 5-8).

When discussing their experiences of involvement with services, some participants adopted a submissive position, in which a sense of acceptance and acquiescence to the opinions of others was created.

> *"Basically we are doing everything we are told this time, well I'm doing everything I'm told this time. You know ** (name of worker from social services) has given us a chance and I don't want to let her down"* (P01, page 6, lines 30-33).

> *" She just comes in to make sure that the house is clean, that the house is tidy and that the bairns are clean. Makes sure that the washing is up to date and stuff like that. It's not for long, but we just let her in to do the checking and that's that and then she goes again, know what I mean"* (P04, page 4, 15-18).

The above extracts, from two fathers, demonstrate how in order to maintain their current role as a father they comply with the standards and requirements that have been set by others within professional services.

However, in contrast to the adoption of a submissive position, participant 6 conveyed a position of resistance in relation to her 12 year involvement that she had with services.

> *" If they'd taken my kids off me I'd be lost, you know I wouldn't be the same person (…) But at the end of the day I'm not gonna let that happen and I would fight for them but they're here with me and I'm not letting them no where"* (P06, pages 8/9, lines 39-2).

With the use of the word 'fight', participant 6 also creates a sense of hostility in her attitude towards services. The stark differences in the positions of participants in relation to their involvement with services may be related to wider differences in identity with motherhood and fatherhood but may also be influenced by the length and level of service involvement that each participant had.

3.4.4.2 *Threat of child removal*

Most participants made inference to the underlying threat of the removal of their children. Linked to the previous master theme, the source of the underlying threat often stemmed from *'The opinion of powerful others'*, most explicitly, professional services and agencies. This theme was strongly present in participants who had more involvement with professional services.

> *"All I was thinking about at the end of the day was that they were gonna go into care and be taken off me, that was all I worried about".* (P06, page 6, lines 22-25).

> *"…so like if you don't do what you should then they will take it off you [referring to a simulator doll he had been given as part of his assessment with social services], and then your real baby off you too, 'cause that happens you know, kids get taken into care right away by the social…"* (P08, page 7, lines 13-17).

However, even in the absence of significant involvement with professional services, participant 3 spoke of her fears and worry that her daughter would be taken from her.

> *"Well I've always kinda worried that she might be (..) you know social services might take her away, and I've asked ** (name of family support worker) is that is gonna happen an she says no she will na be taken"* (P03, page 9, lines 21-24).

In addition to a threat from professional services and agencies, some participants made reference to their own family members, who had at times been the source of threat to take their children away.

> *"Put it this way, ** (family member) wanted to take my bairns off me for no **(swear word) particular reason. Basically no reason and I can't stand to see her now after that"* (P04, page 6, lines 29-31).

3.4.4.3 *The 'bottom-line'*

In accepting the realities they face as a parent, most participant narratives were characterised by the use of 'bottom-line' language. This meant that they conveyed their experiences 'as they were', with no attempt to 'dress them up' in anyway. The use of this kind of language included the words "just" and "basically", and phrases such as "to be honest with you" and "at the end of the day". The extracts below demonstrate them in context.

> *"That is basically it eh"* (P02, page, line 13).
>
> *"Well I just get it done…."* (P03, page 6, line 34)
>
> *"At the end of the day my kids have always been wi me"* (P06, page 8, line 17).

The repeated use of such words and phrases reinforced the suggestion that participants had accepted the realities that they face as a parent with a learning disability.

3.4.5 The same but different

This master theme reflects the way in which participants felt the same as other parents in many aspects of their parenting experiences, but also different in other aspects. Feelings of sameness were conveyed through the acknowledgement of common parenting experiences. Alongside this, feelings of difference were apparent as participants made unsaid comparisons to other parents and also spoke of their

hopes for their children, in relation to having a learning disability. This master theme has been divided into three super-ordinate themes to capture this.

3.4.5.1 *Acknowledgement of common parenting experiences*

Most participants acknowledged that their experiences as a parent were not unique to them, but possibly experienced by all parents. These acknowledgements included the rewarding aspects of parenting as well as the challenges.

Although no direct acknowledgment is made, the following quotes from participants 5, 6 and 7 create a sense of sameness in the parenting experiences of others, in which watching children grow and reach memorable milestones is fondly recalled.

> *"It's great, it makes me feel happy to see him doing so well, he'll be walking before we know it (...) He looks the like the spitting image of his brother when he was a wee baby"* (P05, page 7, line 27)

> *"It's great, well it goes so quick, I don't know where the time has gone, like my youngest is going to high school this year (..) I can't believe it you know she is growing up into a little lady. It really doesn't seem that long ago that I was dropping her off at nursery with her little chubby face and her curly hair, but now she's about to go to high school"* (P06, page 9, lines 30-34).

> *" Just watching her grow up, like her starting to walk and stuff. Likes to watch her play, like with her dolls and wee prams…."* (P07, page 5, lines 19-20).

In discussing the challenges of being a parent, some participants directly acknowledged that their experiences were shared by other parents. The extracts below from participants 3 and 4, in discussing their children's behaviour demonstrate this;

> *" It's mainly the fighting that I've got a problem with, I just think that they're trying to wind each other up, but that's what kids do eh"* (P04, page 4, lines 27-28).

> *"Just now she does have her ups and downs but I'm coping. Well you know we all have our ups and downs, not just me and ** (name of daughter) so…."* (P03, page 10, lines 9-12).

In contrast to the above, participant 2 acknowledges the challenge of being a parent for the first time, and recognises that this may be difficult for others in the same situation, however he also reports a feeling of being different within this because of having a learning disability.

> *"Erm yeah, but then other people like that don't have any experience of looking after kids, that is kinda hard too with it being your first kid, but like I'm more behind than them, so it is sort a different, more difficult for me"* (P02, page 1, lines 33-36).

3.4.5.2 *Hopes and expectations for their children*

Although the expression of hopes and expectations for their children could be regarded as a further example of participant's acknowledging common parenting experiences, some accounts were characterised by a hope not to 'pass on' their difficulties to their child. This hope was seen to be unique to them, as opposed to a common parenting experience as it was directly associated with having a learning disability.

> *"P04-"My main objective is to make sure my kids don't be (..) that my kids don't be like me*
> *I – In what ways don't you want them to be like you?*
> *P04 –Well, I don't want them to be having spelling problems like me or that"* (P04, page 3, lines 19-21).

> *"I hope his does na turn out like his dad eh, I hope he comes out dead brainy and that"* (P08, page 9, line 9).

For some participants, their children had similar difficulties to them or had also been diagnosed as having a learning disability.

> " Well I suppose I didn't want my girls to have difficulties like me, you know be like me, but my daughter **(name of daughter) has got disabilities too, you know she can't read or that either" (P06, page 3, lines 15-17).

> " I wish she was na like me, but she has taken after me and she struggles with her words and that" (P07, page 4, lines 18-19).

Within these extracts, participants 6 and 7 convey a sense of regret, in which they did not want their children to have the same experiences as they have had.

3.4.5.3 *Unsaid social comparisons*

In addition to their hopes for their children conveying a sense of difference, some participant accounts suggested other aspects of their experience as a parent to be unlike those of others. Within this, participants made comparisons to other parents, often in relation to them having a learning disability and the associated difficulties.

> " Erm, well lots of people are in my situation, a lot of people can't fill forms in but I dunna ken what they are like at being a mum" (P06, page 10, lines 5-6).

> "Well erm I know people that have a disability and are in wheelchairs and they had a child and their child has got on okay and is alright so (…)" (P08, page 10, lines 16-19).

As well as making comparisons on the basis of her perceived difficulties in relation to having a learning disability, participant 6 inexplicitly compared her experiences to others based on her lived reality of being a parent with a learning disability (e.g. involvement with services and threat of child removal).

> *"I used to sit there and think, I wonder if they've got kids, I wonder if they would like to be in a panel and everyone talk about them and bring them down (…) It's not easy".* (P06, page 7, lines 6-8).

In this she implies that others have not had the experiences that she has, nor would they like to.

In addition, some participants used the word 'normal' to describe the parenting experiences of others as opposed to using the word to refer to their own experiences. Hence, a sense that there was some aspect of their experience that was 'not normal' was conveyed.

> *"I- So what kind of things did you have to do as part of your assessment?*
> *P01- Just the kinds of things normal parents would do eh, normal stuff like bath and change the baby"* (P01, page 10, line 1).
>
> *"Well because (…) because she's normal. I mean she's got epilepsy but she's normal.. She's getting on at school just like the other kids…"*
> (P03, page 9, lines 13-15).

The above extract from participant 3 conveys how she expected her parenting experiences to be different because of her learning disability. However the uses of the word 'normal' and 'other', in referring to her daughter suggest that as a child herself, she was seen as different to other children.

3.4.6 Learning to cope

The final master theme represents the ways in which participants learned to cope with their experiences of being a parent, which included the necessary learning of parenting tasks, having to cope within their means and the benefits of parenting in a

partnership. This theme is comprised of three super-ordinate themes to reflect the above.

3.4.6.1 *Learning of parenting tasks*

When speaking about the tasks associated with being a parent, the interviews with fathers suggested that an element of learning was required. For participant 8, this process of learning was needed because of the associated difficulties of having a learning disability.

> " I- So what kind of help do you think you will need when your new baby comes along?
> P08- Erm (…) I dunna ken, maybe just to get trained like, 'cause of my diffculties, so get trained like about how to use his buggy and learn things"(P08, page 8, lines 33-35).

However, for others, the required learning was more related to their limited experience at being a father.

> " Stuff is new too, like I've never done these things before (…). I'm just getting there feeding him and stuff, but I'm a bitty nervous when he's in the bath" (P01, page 12, lines 6-7).

> " Like this is my first kid, so I'm a sort a just learning to cope with things as they come" (P02, page 5, line 25).

In contrast, the accounts of mothers did not convey that such a process of learning was needed.

> " Oh it was fine, I know how to bath a bairn and with my youngest I would get into a routine of bathing, changing and feeding so that was no problem…." (P06, page 4, lines 10-11).

This difference in perception of the amount of required learning is possibly related to gender roles within parenthood, as the mothers interviewed may have perceived themselves to have a natural maternal instinct, therefore specific 'teaching' of parenting tasks was not seen as necessary.

However, the value of previous experience of being a parent was still acknowledged in relation to parenting tasks in one of the mother's accounts;

> *"With my second one, I knew more what to expect and what to do with like bathing him and stuff"* (P05, page 3, lines 11-12).

3.4.6.2 *Coping within their means*

Some participant narratives conveyed that they were coping 'within their means' as a parent. This was conveyed across a number of levels including cognitively (as a result of their learning disability), but also practically and financially.

The following extracts from participant 4 and 6 demonstrate this.

> *"I try and help them with their school work as much as I can and so far it's gone not too bad, I mean I sometimes struggle with ** (name of eldest daughters) work 'cause it can be quite difficult, especially the maths but we (..) we get by."* (P04, page 3, lines 32-34).

> *" No, I didn't have no help, I brought them up mostly on my own, there were a few times when they were away from me and that was hard. But when I went into hospital to have ** (name of second daughter), she had to go into care, 'cause I had no one to watch her so I had to do what I could"* (P06, page 4, lines 15-18*).*

When unable to cope within their means participant 2 conveyed feelings of inadequacy and guilt at not being able to provide for his child.

> *"But when my kid is needin something and I dunna have the money, it's hard and I feel bad. Erm I guess that is another down side of me*

*being a dad, like when your kids are asking for stuff that I can't give
her 'cause I've not got the money or whatever, you know I feel bad
about it, kinda guilty, basically a guilty conscience that I'm not giving
her what she wants".* (P02, page 7, lines 4-8).

3.4.6.3 *Value of parenting in partnership*

Most participants described the ways in which the responsibility and tasks of
parenting are shared with significant others. Shared tasks most commonly included
practical help with childcare. Significant others ranged from partners, parents and
friends.

> *"Well, mum and dad, well dad takes her to school, if I've got anything
> on dad takes her or he'll pick her up"* (P03, page 8, lines 4-5).

> *"My wife would bath her and that, and I would make the bottles up on
> a morning for the day"* (P07, page 4, lines 30-31).

Specifically, participant 5 spoke of the value in having a partner to share the tasks of
parenting with. She recalls the difficulties she experienced in a previous relationship,
in which parenting tasks were solely carried out by her.

> *"I felt it hard when I was on my own, erm I wasn't with ** (name of
> husband) at that time, well I had another partner, but he didn't want
> anything to do with what we did. But when I met ** (name of husband)
> it got better and it was not that hard to have been on my own coping wi
> ** (name of daughter)".* (P05, page 2, lines 5-9).

Although she makes no direct reference to the sharing of tasks, participant 5 implies
that simply having an available partner, who is willing to help and support her as a
mother is of great benefit.

The accounts of a few participants suggested that parenting in a partnership creates a sense of reciprocity and equality, in which both parent and significant others are equally invested in the outcome of the tasks. Extracts from participants 2 and 3 demonstrate this.

> " P02- But now like my wee sister has come along I'm trying to pay my mum back for the help she gave me with my wee one, you know like we have arrangements so if my mum is wanting to go out to the shops or whatever, I will look after her wee one, but if we're wanting to go out, like me and my girlfriend say to the pictures then mum will look after my daughter.
> I – So you are supporting each other now?
> P02- Yeah, like half and half". (P02, page 7, lines 30-35).

> "Er yeah, I mean ** (name of daughter) has got some friends now and I've made pals with their mum's, so sometimes she'll go down to play with them and then I'll go into to visit my pal. But sometimes, my pal will just say to me to leave her there and I could come back to get some jobs done. And then sometimes, I'll have the girls at ours so my pal can have some time too, you know to do whatever she's needin without the kids in her way. They have been here for tea too, and then like me and my pal help each other out by taking turns about with tea". (P03, page 8, lines 10-16).

3.4.7 Relationships between master themes

When analysing data from larger samples (more than six participants), Smith *et al*. (2009) recommend that there should be a connection between themes, which allows the data to move to a more theoretical level. In moving from a description of the five master themes, the researcher hypothesised possible relationships between the themes.

Participants compartmentalised the ways in which they perceived being a person with a learning disability, being a parent and being a individual with personal likes and strengths (outside both having a learning disability and being a parent). This created three distinct identities. However, in becoming a parent, participants acknowledged that others formed opinions of them based on their difficulties and deficits only, which emphasised their identity as being a person with a learning disability. Participant narratives suggested it was the opinions of others (often in a more powerful position to them) that mattered and what they thought themselves about their situation was of no value. For some, the opinions of others had become relied upon in their evaluation of themselves as a parent. The parenting experiences of participants were in part, shaped by the opinions of others. Specifically, involvement with services often created standards for living which had to be accepted and adhered to. Participants were all too aware and fearful of the consequences of not adhering to these set standards; the threat of losing their child. The acknowledgement of common parenting experiences conveyed a sense of sameness between them and any other parent, however the often dismissive position of participants in accepting and adhering to the standards set by others conveyed feelings of difference to the experiences of other parents. In accepting their realities of being viewed as a parent with a learning disability, participants described a number of ways in which they have learned to cope, some of which are of particular value in contributing to their most valued role as a parent.

These relationships between the themes are presented in Figure 3.3.
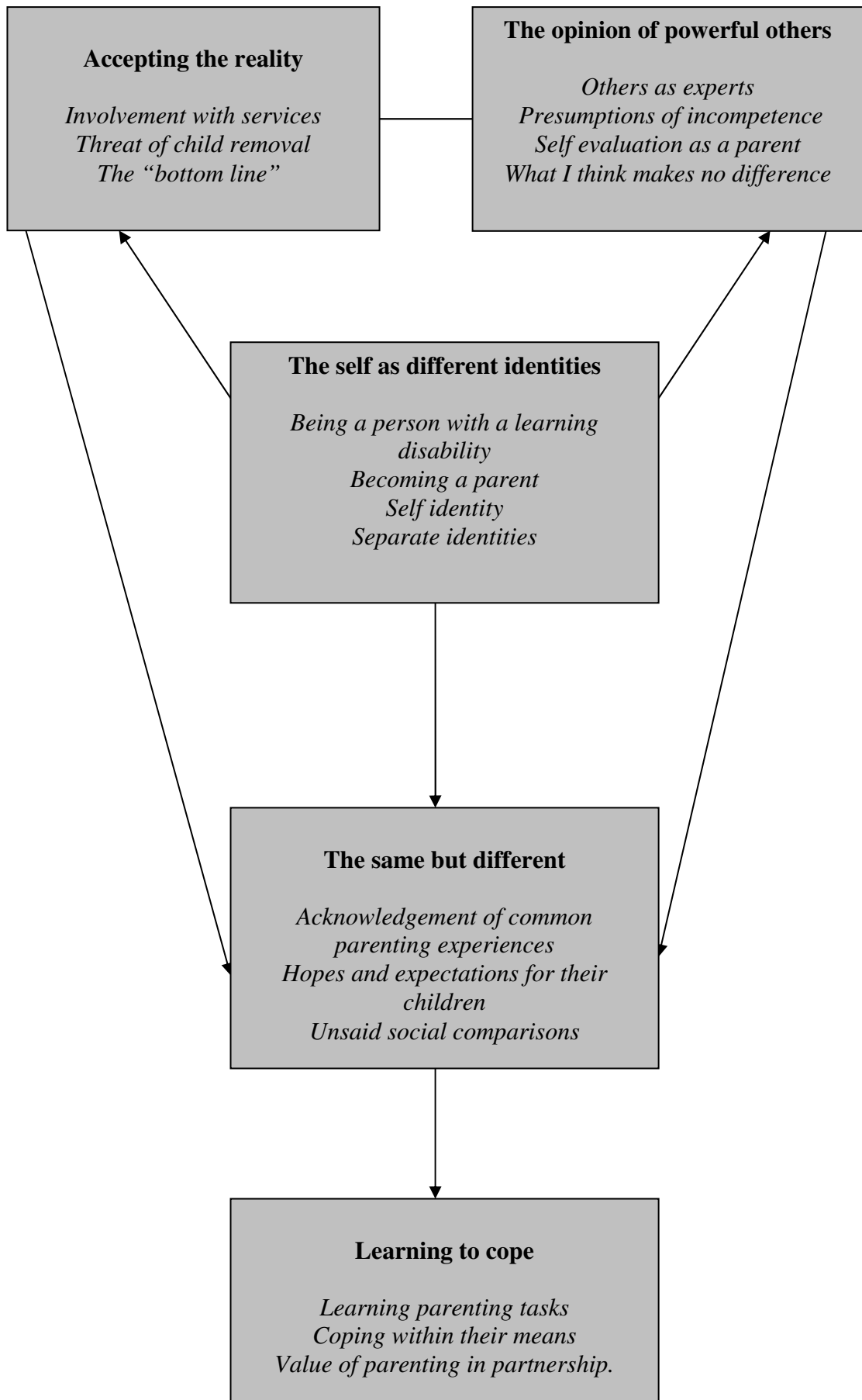
Figure 3.3: Identified master themes and super-ordinate themes relating to participants understanding and perceptions of being a parent with a learning disability

3.5 REFLECTIONS ON THEMES

3.5.1 Researcher's reflections

Within IPA, it is recommended that researchers clearly reflect upon their position within the research process (Smith *et al.,* 2009; Willig, 2001). This not only aids the transparency of the results but also makes the reader aware of the ways in which the researcher's experiences, beliefs, theoretical stance and personal identity may have impacted on the research. For this reason, the researcher kept a reflective diary throughout the study to record any experiences during the research process, including reactions to participant's interviews, and the process of transcribing and analysing.

The following section is written in the first person to capture the reflections of the researcher. Extracts from the diary are also included.

In the early stages of the study, I initially felt anxious and apprehensive as I had limited experience in conducting qualitative research and had never used IPA. The first couple of interviews were difficult as I adjusted to carrying out a research interview as opposed to a clinical interview, which I was much more familiar with and comfortable in doing. I was also conscious of the need to avoid any questions of a leading or suggestive nature when trying to gather the participant's accounts. Although the interview schedule was used flexibly I felt an overwhelming sense of responsibility to gather as much information as I could.

> " Did my first interview today. I really enjoyed the experience,
> although felt strange, almost 'lost' without my clipboard and had to
> consciously resist the urges to scribble down notes from my
> participants accounts as I would in clinical sessions. The interview
> lasted over 40 minutes but I'm not sure I have got enough description
> of his experiences for the analysis, but was aware that I don't want to
> came across as too 'pushy' or potentially leading during the interview.
> Having never met this man before I feel very 'humbled' and
> appreciative of his openness and honesty in the recalling of his
> accounts. I gained a real sense from the language he used that he was
> telling his 'story' as it was, with no attempts to 'dress up' his
> experiences in anyway. I hope that when analysis begins I am able to
> fully capture this and in a sense do 'justice' to his account" (Extract
> 1).

During transcription, I quickly felt reassured that the amount of information I

gathered is enough, in fact I felt overwhelmed at the amount of information I had.

> " Half way through transcribing my third interview. Even with
> warnings from supervisors and colleagues who had also completed
> qualitative theses, I totally underestimated how long it takes. I worked
> out averagely it is taking me an hour to transcribe between 7 and 12
> minutes of interview. However, despite sore wrists from typing! I have
> found the process of transcribing a helpful first step in 'immersing'
> myself with the data".   (Extract 2).

As I began my first analysis, I again felt apprehensive due to my inexperience with

qualitative research and IPA. However, I took comfort in and felt reassured with the

step by step process of analysis as set out by Smith *et al.* (2009).

> "Analysing my first transcript. I feel unsure, hopefully this is just
> because of my unfamiliarity of this. I keep my IPA book close by, which
> makes the process seem more accessible, especially to me as a novice
> qualitative researcher...." (Extract 3).

Later, I reflect on the completion of my first analysis;

> " Finished full analysis of my first transcript. I know this sounds cliché
> but I have enjoyed the process and I feel in a sense privileged to have

had such in depth access to the accounts of my participants. Although I know that there is no 'correct' interpretation, in the back of my mind I am hoping my interpretation is good enough". (Extract 4).

As recommended by Yardley (2008), I acknowledge how my position as the principle researcher may have impacted on the analysis process. With both a personal and professional interest in working with people with a learning disability, I was keen to highlight their lived experiences of being a parent, including the positive and negative aspects. When discussing emerging themes with my supervisors they commented on the level of 'passion' with which I conveyed the participants' accounts. This may have reflected my strong desire to provide a 'voice' not only to my participants, but to people with a learning disability in general. In essence, I may have adopted a role in part as an advocate in my interpretation of the participant narratives. I realised it is impossible to carry out this type of research and remain completely distanced, without reflecting on wider issues.

In my reflective diary, I noted how my personal position (as a person who is not a parent) may have influenced my interpretation of the data and I worried that because of this I may overlook key experiences.

> *"Theme of feeling the same but different is emerging from the interviews so far. I wonder if my analysis would be different if I myself were a parent? I wonder if these feelings may be common to general parenting experiences, but I am interpreting them to be specific to parents with a learning disability? It will be interesting when I meet with my supervisor to discuss the emergence of themes as she is a parent of a young child"* (Extract 5).

I also began to reflect on my clinical practice as a Trainee Clinical Psychologist, specifically within the assessment and diagnosis of a learning disability.

> *" So far in the analysis of interviews, participants have spoken about their learning disability as specific difficulties, with not one referring to them as global difficulties. This has made me think about how assessment and diagnosis of a learning disability is fed back to clients. Do I always make it clear that diagnosis is being made on the presence of global difficulties?....."* (Extract 6).

I felt overwhelmed with the amount of data that resulted from the eight interviews. I was aware of the need to maintain an interpretative position and continually moved between the emerging themes and the original transcripts. Discussions with my supervisors reassured me, as their reading of the transcripts and anecdotal experiences from them supported my interpretation, as well as suggest refinements for theme titles.

> *"Feeling reassured about my results, just a few title refinements to make to better capture the sub-themes. It really helps to get another's perspective especially when they have experience in the area (both clinical and research). It's good to know I'm on the right lines".* (Extract 7).

In general, the entries in my diary highlight my initial anxieties and need to gain reassurance from others in a process which felt unfamiliar and somehow new to me as a researcher. I also felt an underlying feeling of having to provide the 'right' interpretation of the participant's accounts. However, as the process unfolded I gained confidence and was able to acknowledge that there are no 'right' or indeed 'wrong' answers in interpretations, but instead that people's experiences are complex. Therefore, any attempt to understand this should reflect this complexity.

3.5.2 Participants' reflections

At the end of the interviews participants were asked to reflect on their experiences of the interview process. All participants felt that their involvement in the research was a positive experience and allowed them to speak about their experiences as being a parent.

> *"Aye the questions were fine like (..) It's nice to be asked about being a dad in a good way"* (P01).

> *" It was good, well I like talking about being a mum so it was good "* (P05).

To seek respondent feedback for the findings, the researcher contacted a random selection of three participants (P03, P04, P06) following completion of data analysis. The emergent themes were discussed with the participants.

All three participants expressed their general agreement with the themes and that they represented their own experiences. Some themes were agreed with more than others, which supported the variation in the spread and depth of themes across participants. The following quotes from participant 3 (in response the master theme, The same but different') and participant 6 (in relation to experiencing specific difficulties as a result of having a learning disability and the presumed level of incompetence within the opinions of others) demonstrate their level of agreement with the emergent master themes.

> *" That is exactly it, being a parent is not easy for anyone you know…."*(P03).

" Well yeah that is true, 'cause for me, like I'm okay with money and numbers but wi words and forms my mind goes completely blank" (P06)

"Yeah totally, 'cause for me I had 12 year of that, them thinking that I couldn't look after my bairns properly or like thinking that I wasn't feeding them enough" (P06).

In discussion of the final master theme, Learning to cope, participant 4 expressed feelings of reassurance in being heard. He also acknowledged the value in the acknowledgement of his ways of coping.

" I think that is right (…) It's good to hear that you think we are, that we cope okay" (P04).

It must be acknowledged that this is only a sub-section of participants and that this same level of agreement may not be representative of the participant sample as a whole. It is also important to highlight that perceived power differentials may have impacted on the participants' reflections as they may have been reluctant to 'disagree' with the researchers findings.

3.6 DISCUSSION

This section will begin with a summary of the current research, followed by a reflection of each master theme in relation to the existing literature. A critique of the current study, including methodological limitations will then be presented. Finally the clinical implications along with recommendations for future research will be discussed.

3.6.1 Summary of results

The aim of the study was to explore what parents with a learning disability understood about their learning disability and how they perceived this to impact on them in their role as a parent.

Eight participants took part in the current study (3 mothers, 5 fathers). The age of participants ranged from 23-46. All participants were identified as having a diagnosed learning disability in the mild range. All participants were parents but not all had their children living with them. Participants were recruited via an index worker from the local area adult learning disability service.

The current study employed a qualitative methodology using IPA (Smith, 1996, Smith *et al*., 2009) as a method of analysis. Data was collected using semi-structured interviews and transcribed verbatim.

Analysis of interviews revealed five master themes: *The self as different identities; The opinions of powerful others; Accepting the reality; The same but different* and *Learning to cope*

These themes capture the understanding and perceptions of parents with a learning disability about their learning disability and parenting role, but also reflect additional experiences of this group of people.

3.6.2 Reflections on themes

3.6.2.1 Reflection on *'The self as different identities'*

Participant narratives suggested that three identities were held; as a person with a learning disability, as a parent, and as individual, with personal likes and strengths (outside being a person with a learning disability or as a parent).

Within the wider learning disability literature it is well recognised that having a diagnosis of 'learning disability' is associated with stigma, and it affects most other social identities that the individual may have (Hughes, 1945, as cited in Davies & Jenkins, 1997). Despite this, little is known about what people with a learning disability understand by this diagnosis or how it relates to them. The few studies that have attempted to investigate this suggest a number of key findings. Firstly that many people appear to be unaware of their identity of learning disability or that they do not see learning disability to be an identity that relates to them (Finlay & Lyons, 1998; Jahoda *et al.*, 1989). Secondly, a small number of studies suggest that people

with a learning disability do not have the same understanding about what a learning disability is, in comparison to the diagnostic framework that the majority of professionals work from. For instance, Thomson and McKenzie (2005) reported that people with a learning disability do not have a clear understanding of what a learning disability is, often relating it to specific learning difficulties. This finding is supported by the current research, in that participants' difficulties were perceived as specifically related to cognitive tasks and often linked back to the problems they had experienced at school. In addition, a study by Davies and Jenkins (1997), which interviewed 60 young adults with a diagnosed learning disability, indicated that 40 per cent were unsure what it meant, with a further 16 per cent stating that the definition of a learning disability did not apply to them. Such findings were partially supported in the current research, as some participants saw their learning disability as a bi-product of the other difficulties they experience (e.g. epilepsy).

The results of the current study suggest that parenthood was a welcomed identity for all participants. This supports previous research in the area (Booth & Booth, 1995; Booth & Booth, 2005). Such research indicated that the adoption of a parent role affirms transition into adulthood and provides a valued social status, which previously may have been lacking. The current study suggests that participants compartmentalised their identities with identity as a parent and as a person with a learning disability being viewed as separate. These findings are in line with the above research, as Booth and Booth (2005) highlight that parenthood provides people with a learning disability with an identity that is not a function of, or directly associated with that of their learning disability. However, as was the case for a few

participants in the current study, it is important to note that the initial reactions by others to their becoming parents were not positive. This finding is in line with those by McConnell and Strike (2002a) who highlight that when people with a learning disability announce they are to become a parent they experience opposition and scrutiny from family members or professionals.

More specifically, the accounts from mothers within the present study suggested a strong identity with motherhood. This supports previous research that has specifically focused on mothers with a learning disability. For instance, Edmonds (2000) concluded that motherhood is viewed as a primary identity, which inexplicitly provides a defence to their identity as an individual with a learning disability. Further research by Baum and Burns (2007) highlighted that having a learning disability is regarded as a threat to being a parent, as identity with a learning disability is associated with deficits and inadequacy only. The findings of the current study also suggested that there are some differences in how mothers and fathers identify with becoming a parent. Although it is widely acknowledged in the literature that very little is known about the experiences of fathers with a learning disability (O'Hara & Martin, 2002), this finding is in line with the work of Mayes and Sigurjónsdóttir (2010). Their study compared the experiences of a group of mothers (from Australia) and a group of fathers (from Iceland) and found that in preparation for and becoming a parent, mothers and fathers with a learning disability developed different identities. The authors also point out the importance of gender perspectives within people with a learning disability, which is also an area of research which has been under explored.

3.6.2.2 Reflection on '*The opinion of powerful others'*

Participant narratives in the current study indicated the important role that the opinions of others have in their experiences of being a parent. Within this, others were viewed as experts or were perceived as being in positions of power. This theme is consistent with the findings of previous research in the topic area (e.g. Baum & Burns, 2007; Llewellyn, 1997; McConnell & Strike, 2002a). In Llewellyn's (1997) study of the role of experience in parents with a learning disability, the importance of advice from family members was highlighted. For instance, parents reported that much of their learning of parenting tasks was accomplished by taking advice from family members and following the examples they set. Baum and Burns (2007) reported that as a result of perceiving professionals as being in a position of power, mothers felt intimidated during involvement with them. Similarly, McConnell & Strike (2002a) highlighted that in making decisions about being a parent, others were viewed to be the "experts in charge" (p13). These authors also point out that the position of others as experts is an example of the deficit model used in the approach to parents with a learning disability, which supports the current study's super-ordinate theme of '*Presumptions of incompetence'*. This approach, which has been further highlighted by Campion (1995) and more recently by MacIntyre and Stewart (2011), suggests that society, including professional services, place more emphasis on what parents with a learning disability cannot do rather than utilising and building on the skills that they already have. Furthermore, within this deficit model, Tymchuck (1999) suggests that problems that are encountered by parents with a learning disability in their parenting role are too readily attributed to their learning disability rather than the likely influence of any social or psychological factors.

As a result of feeling 'under' others in a more powerful or expert position, participants' accounts suggest that they had become reliant on what others thought of them in their evaluations of themselves in their parenting role. Consequently, what they thought about themselves or the situation they were in was not worth expressing. These findings are again similar to the issues that are highlighted in the existing literature. For instance, McConnell & Strike (2002a) argue that, due to a combination of low expectations from others plus limited social opportunities, parents with a learning disability are likely to become dependent on what others think of them in order for them to form an evaluation of themselves. Furthermore, it is suggested that during periods of involvement with professional services, in particular when there is involvement with child protection systems, parents feel unable to voice their own opinions because of the fear that they would be seen as questioning those in a position of power or would be marked as having made a mistake in the assessment process (Baum & Burns, 2007; MacIntyre & Stewart, 2011).

3.6.2.3 Reflection on *'Accepting the reality'.*

The current study indicated that parents adhere to and accept the often controlling opinions of others. For the majority, this acceptance is adopted with a submissive stance. Similar to these participant narratives, previous research by Booth and Booth (2005), which explored the views and experiences of parents with a learning disability who were involved in the child protection system, highlighted that parents showed a resignation to the decisions and judgements made by others in relation to their ability to care for their children. In addition, the authors suggested that those

parents who complied with the advice of professionals were seen to be more co-operative and therefore more likely to be considered for a rehabilitating intervention. In contrast, those parents who did not accept the advice and opinions of professionals were more likely to be regarded as a risk to their children or as incapable of caring for them. McConnell and Strike (2002a) also highlight that within the deficit approach, parents with a learning disability are implicitly expected to be passive and compliant, and accept that following the opinions of experts is the best way forward for themselves and their children. In cases where children have been removed, Baum and Burns (2007) suggest that, although disappointed and upset, some mothers were accepting and seemed resigned to the fact that their children had been taken, and that they could do very little to change the outcome.

However, not all participant accounts in the present study indicated a submissive acceptance of what others thought. This was particularly evident in the account of participant 6. This more assertive position is reflected in the literature written by David and Julie Strike, who are themselves parents with a learning disability. Their accounts suggest they do not simply accept the advice of others without question, but rather that they listen to it and carefully consider it and then try out the several strategies before deciding which way works best for them (McConnell & Strike, 2002a; McConnell & Strike, 2002b).

The theme of child removal found in the current study is acknowledged to be a key issue faced by people with a learning disability when they become parents. Early reports on this issue suggest that high rates of child removal (between 40-60 per

cent) are present in parents with a learning disability (Accardo & Whitman, 1990). More recent estimates (specifically from the UK) suggest that 48 per cent of parents with a learning disability were not directly looking after their children. The results of the current study also suggested that, even in the absence of involvement with child protection systems, parents still experienced a sense of threat from others (including family members) that their children were going to be taken from them. This finding is similar to those reported by Booth and Booth (1995), in their interviews with 20 parents living in different situations (including those who lived and cared for their children), in that they reported to "live with the ever-present fear of having their children taken away" (p31).

3.6.2.4 Reflection on *'The same but different'*

In their experiences of being a parent, participant accounts conveyed feelings of sameness yet also difference to other groups of parents (without a learning disability). Feelings of sameness were conveyed through acknowledgement of common parenting experiences whilst comparisons made towards others as parents created feelings of difference. These findings are consistent with those reported by Strike and McConnell (2002a) who highlighted that the ways in which parents with a learning disability are "Just the same, but only different" (p11). For instance, parents with a learning disability were found to be the same as any other parent group in many of their parenting experiences, including the opportunity to develop a loving relationship with their child, finding that parenthood comes with both rewards and challenges and the need to learn the tasks associated with parenting. However, parents with a learning disability were also highlighted to encounter extra-ordinary

experiences which make them different to other parents. These extra-ordinary experiences include having to contend with opposition and scrutiny from others in the evaluation of them as a parent, limited social support networks and an underlying fear that their children may be taken away from their care (Strike & McConnnell, 2002a). Similarly, participant accounts from Booth and Booth's (1995) study highlight how in becoming a parent people with a learning disability may experience the same thoughts and emotions as any other expectant parent. The authors also point out that this ordinariness in the experiences of parents with a learning disability is overlooked, as more focus is placed on the difficulties they have.

Within the theme of *'The same but different'*, some participant narratives suggested that they did not want to 'pass their learning disability on' to their children. This suggested that parents in the current study did have expectations for their children in terms of their educational attainment and achievement that was perhaps higher than the educational attainment that they themselves had achieved. Although, little is known about the expectations of parents with a learning disability for their children (Whitman *et al.,* 2001), there is some evidence to suggest that parents with a mild learning disability have lower expectations for the academic achievement of their children in comparison to other parent groups (Taylor *et al*., 2010). Findings from the current study would not support such findings, however it should be noted that no attempt was made in the current study to compare the experiences or views of parents with a learning disability with any other groups of parents within society.

3.6.2.5 Reflection on *'Learning to cope'*

Consistent with previous research (Llewellyn, 1997; McConnell & Strike, 2002b) participant narratives suggested that they had learned ways of coping in their experiences and realities of being a parent. Specifically, Llewellyn (1997) suggests that parents with a learning disability learn to cope with the often competing demands of being a parent in a number of ways including learning from others and learning from their own mistakes and trying alternatives.

The accounts of fathers in the current study suggested that an aspect of learning was required when they became a parent. For one father in particular he perceived his need for learning to be associated with his learning disability, whereas for other fathers they reported their need for learning was as a result of previous in experience at being a parent. This finding partially supports those by Tarleton and Ward (2007) who reported that both mothers and fathers acknowledged the need to learn new skills once they had a baby. The authors also point out that the mothers and fathers in their study recognised that the need to learn parenting tasks was not unique to them, but that all parents need to learn some skills (Tarleton & Ward, 2007). The accounts of mothers in the current study suggest that the same amount of learning was not required when they became a parent. The early work of Espe-Scherwindt and Crable (1993) could be used to explain these differences, as they indicate that learning how to parent is linked with the parent's wider life experiences. Within this, they suggest that people with a learning disability are not likely to have had the experience of caring for children (e.g. younger siblings, baby-sitting), nor is it likely that parenthood was ever discussed with them. It is possible, that the fathers within the

current study had significantly less experience or opportunity to care for children as they were growing up than the mothers in the study did.

Despite some differences in how much learning was perceived to be required, most participant accounts were characterised by a value of previous experience, either from other people (in cases of having their first child) or their own previous experience (when they had more than one child). This finding extends the work of Llewellyn (1997), in that her study emphasised the importance of experience in how parents with a learning disability learn to cope.

The super-ordinate theme of value of parenting in partnership highlights the perceived benefits of sharing parenting tasks within an equal and reciprocal relationship. These findings have been widely reported in the existing literature, which highlights the importance of supportive yet reciprocal relationships for parents with a learning disability (Llewellyn, 1994; Sternfert-Kroese *et al.,* 2002). The value of parenting within a partnership is an example of 'competence promoting support' (Tucker & Johnston, 1989) in which parents feel valued and are empowered in their role as parent.

3.6.2.6 Reflection on themes in relation to the wider parenting literature

Although the theme *'The same but different'* suggested that parents with a learning disability share similar experiences to those parents who do not have a learning disability, no direct comparisons were made, However, research from the wider parenting literature indicates many similar findings to the current research.

Studies carried out with other groups of parents suggests a high degree of similarity in terms of experiences of being a parent. For instance, in a meta-synthesis of the parenting experiences of adolescent mothers, Clemmens (2003) highlighted a number of similar themes to those of parents with a learning disability in the current study. These themes included a positive identity with motherhood, motherhood bringing a reality of hardship and competing identities as an adolescent and a mother. Another group of parents to show similar findings to the current research are mothers with mental health difficulties. In a series of focus groups and individual interviews with mothers with diagnosed mental health problems, Bassett *et al*., (1999) identified themes of fear of losing custody of children, the importance of having a 'bond' with children and the value of supportive and equal relationships. All of which resonate with some of the themes of the current research.

In addition to studies carried out with specific groups of parents, research carried out with parents from the 'general population' also highlights some similarities to the themes identified in the current study. For example, Bloomfield *et al.,* (2005) carried out a qualitative study with parents of children under the age of six years old. The results revealed that the parents could often feel under pressure to meet the expectations of others, in particular family members who had already successfully raised children. Similarly, and in line with the theme of 'The opinions of powerful others', parents tended to focus on what other people thought about them as parents, and consequently they often compared themselves to other parents in order to evaluate their own performance as a mother or father. Finally, the parents' accounts

in Bloomfield's study suggested that becoming a parent was a positively overwhelming experience which nothing could have prepared them for (Bloomfield *et al.*, 2005). All of the themes above are similar to the findings of the current study, therefore suggesting that the themes identified are not unique to parents with a learning disability, but are more reflective of wider issues within general parenting.

3.6.3 Methodological critique

3.6.3.1 *Strengths*

As far as the researcher is aware, this is the first study which has specifically focused on how parents with a learning disability understand their learning disability in relation to their parenting role. Previous research has either investigated the perceptions and identities attached to having a learning disability in the general learning disability population, or if in relation to parents with a learning disability, has tended to focus on the views and parenting experiences of mothers only.

Although there were some problems highlighted in the recruitment process (see limitations section), the fact that the current sample consisted of more fathers than mothers should be recognised as a further strength of the study. It is acknowledged within the literature that very little is known about the experiences of fathers with a learning disability (Llewellyn *et al.,* 2010; O'Hara & Martin, 2002). Due to various reasons including the continued pivotal role of the mother in child rearing and difficulties in identification and access, fathers with a learning disability tend to be overlooked in research. Even when studies have attempted to represent the voices of

fathers, these have often been in the minority (Llewellyn *et al.,* 1998; Tarleton & Ward, 2007), and have often been overshadowed by the majority voices of mothers. However, in the current study the experiences of fathers are represented in the majority alongside the experiences of the mothers, and any apparent differences between their perceptions have been highlighted.

The current study adopted a qualitative approach to gain an in-depth description of the understanding and perceptions of parents with a learning disability, detailing the complex nature of accounts. It is likely that the complexities of parents' experiences would not have been captured by using quantitative methods alone. In addition, the researcher took a number of steps to enhance the methodological rigour of the current study, including the utilisation of multiple reviewers to corroborate themes, respondent feedback and a reflexive diary. The researcher also presented examples of quotations from across the full participant sample.

3.6.3.2 *Limitations*

A number of difficulties in the recruitment of the current participant sample were encountered. Firstly, in the absence of direct access to the potential participants, the researcher became dependent on others to initially approach participants. Although recruiting via other professionals or workers is recommended when conducting research with people with a learning disability (Nind, 2008) the reliance on others meant that the researcher could not directly control the recruitment process. Furthermore, the geographical spread of the teams across the local area meant that

the researcher was not always physically available at the work bases to prompt and remind index workers to approach potential participants.

Once recruited into the study, the researcher continued to encounter difficulties in accessing the participants. For instance, despite arranging introductory and interview meetings at times and places most convenient to the participants, a number of them either did not attend (when carried out at a clinic base) or were not in at their homes when the researcher visited. As highlighted in Figure 3.1 in the methods chapter, four participants declined participation following the introductory meeting. Three of these had initially indicated that they wanted to be interviewed and further meetings were then arranged. However, all three either did not attend the arranged clinic base or were not in at their homes on more than one occasion. When they were contacted following this, they said that they had changed their minds, and no longer wanted to take part in the study. Although initially frustrating for the researcher, on reflection, the issues the researcher faced in trying to access the participants sample may have been reflective of the wider engagement difficulties that this group of people often face when trying to access services (Tarleton *et al.,* 2006).

It is recommended that IPA involves the use of a homogeneous sample (Smith *et al.,* 2009). However, the level of homogeneity varies depending on the topic of investigation and practical issues such as access to the required sample group. Although the current participant sample were regarded as generally homogenous (e.g. in terms of socio-economic status and ethnic backgrounds), they only represented those parents with a learning disability who were known to formal health

and social care services. As Edgerton (2001) highlights the majority of parents with a learning disability are unknown to services and very little is known about their experiences unless a crisis point is reached. Therefore, the current sample represented a specific group of experiences which suggests that involvement with formal health and social care services does influence perceptions and experiences of being a parent with a learning disability.

Finally, weaknesses in the quality of data analysis should be considered within the limitations of the current study. Miles and Huberman (1994) argue that researchers may attach more weight to certain participant's accounts because of articulateness and level of reflexivity that the participant shows. In the current study participants 1,2,3, and 6 spent greater time talking about their experiences and these were often richer in depth. Although attempts were made to represent all participant narratives through the use of a range of extracts, the researcher is aware that there may be a bias towards greater use of extracts from the more articulate participants.

3.6.4. Clinical implications

Based on the themes identified in the current study, a number of recommendations can be made for clinical practice and the provision of services to parents with a learning disability.

In the current study, participants expressed that their identities as a person with a learning disability, as a parent and as an individual were separate. Within their

identity as a person with a learning disability, participants' narratives conveyed that their understanding of what a learning disability is was based on specific difficulties only. Often these difficulties were related to 'school' tasks, such as reading, writing and maths work. This understanding of learning disability does not match wider professional understanding of what constitutes a learning disability. Such a discrepancy in understanding raises questions about how people with a learning disability are given information about their diagnosis. While it could be argued that people with a learning disability should be told directly that they meet the diagnostic criteria of a learning disability and what this means in practical terms, research by Davies and Jenkins (1997) and Beart *et al.* (2005) suggest that in providing such an explanation, clinicians run the risk of contributing to potential stigma surrounding the label of a learning disability. This may leave people feeling further disempowered and confused about their social identity. Professionals working with this client group should not make assumptions that a shared awareness is held about what a learning disability is or how this impacts. In order to create a more shared understanding, clinicians should make it clear to parents why a specific assessment is being done or why a particular support intervention is being provided. Cleaver and Freeman (1995) indicate that a shared understanding increases the likelihood of a positive outcome for both parents and children. Recent good practice guidelines have been developed by the Scottish Consortium for Learning Disability (SCLD) for health and social care professionals working with parents with a learning disability. Within these, it is recommended that; " Parents should be told, in plain language, what the assessment is, what it is for, what it will involve, and what will happen afterwards" (SCLD, 2009, page 23).

Professionals working with parents with a learning disability should also be aware of the separate identities held by this group of people. Previous research by Walmsley and Downer (1997) highlights that practitioners and researchers often fail to acknowledge that people with a learning disability have other social identities which are important to them. This notion was particularly supported in the current study as participants clearly conveyed self identities (expressed through accounts of personal likes and strengths). When gathering information from parents with a learning disability for the purposes of assessment, practitioners should attempt to gain a holistic understanding of the individual, including their different identities and perceived likes and strengths. Finally, the valued role of being a parent that was present in all participants' accounts should be acknowledged. Specifically, the socially confirming role of being a parent should be recognised by practitioners and should not be unnecessarily undermined or threatened. Furthermore, clinicians working with this client group should recognise that the challenges and rewards they face in their role as parents are in many ways the same as those of other parents who do not have a learning disability.

An analysis of participant narratives suggests they rely heavily on the opinion of others when evaluating themselves as parent to the extent that they frequently discount their own opinions. The salient opinions are most commonly from those perceived to be in a position of power. Professionals working with this group of people should, therefore, be aware of the potential power imbalances that are present between themselves and those they support, and its potential impact on the

establishment of a working relationship. One method for overcoming these issues is for parents to have an advocate. Existing research into advocacy for parents with a learning disability suggests that it plays an important role in ensuring that parents are not disempowered and that their voices are able to be heard (MacIntyre & Stewart, 2011). The value of an advocate has particularly been emphasised for parents who are involved in child protection and resultant legal proceedings (Booth & Booth, 2004). Good practice guidelines strongly emphasise the need for access to independent advocacy, particularly when parents have involvement with child protection systems (SCLD, 2009).

The presumption of incompetence was highlighted within the theme of '*The opinions of powerful others'*. Many participants felt that the opinions of others were based on their deficits only, with no acknowledgement of their strengths. Professionals working with this client group need to challenge and positively refute the commonly held belief that parenthood in people with a learning disability is automatically going to be problematic (Llewellyn, 1997). Assessment and intervention with parents with a learning disability should move away from a problem focused model and instead acknowledge and importantly build on the already existing strengths of individuals. In addition, as opposed to attributing all parenting difficulties to having a learning disability, professionals should consider the wider contexts in which these parents live. This includes the environmental and psychological factors that also are likely to impact on them in their experiences of parenthood (Cleaver & Nicholson, 2007). Given their extensive level of training in the interplay between biological, social and

psychological factors, Clinical Psychologists are in a key position to deliver training on the effective assessment of this client group.

In the process of discussing ways of coping, a number of participants expressed the value of parenting in a partnership. In particular, the perceived benefits of having a reciprocal relationship were conveyed. The above finding highlights the importance of support being provided on the basis of equal relationships. Services that provide parents with support should be aware of this in the establishment and maintenance of working relationships. In the presentation of a seven-point plan for workers who support parents with a learning disability, McConnell and Strike (2002b) emphasise the importance of other people doing things *with* parents as opposed to *for* them. When things are done for them the authors point out that parents can feel that their role as a parent is undermined and taken over by others. Furthermore, Tarleton and Ward (2007) highlight that parents most value support from services that treats them as equals and encourages the development of parenting skills rather than presuming inability and incompetence.

The findings from the current study have importantly highlighted the perceptions and experiences of fathers, which remains an under investigated area within the wider literature on parents with a learning disability. Specifically, the fathers in the current study were active in their parenting role, with the super-ordinate theme of '*Value of parenting in partnership'* highlighting that fathers were heavily involved in the providing of parenting tasks. Professionals working with parents with a learning disability should consider the role that fathers may play, and regard parenting as a

joint undertaking between mothers and fathers. This supports recommendations made by Booth and Booth (2002) who conclude that; "Supporting parents with intellectual disabilities means learning to work with fathers and partners as well as mothers" (p198).

Finally, the findings from the current research could be incorporated into staff training for other health and social care professionals involved in assessing and supporting parents with a learning disability. The sharing of these findings via presentations and discussions may act as a means of consciousness raising about some of the key issues in the experiences of this group of people. Such training would not only be appropriate for those professionals working within specialist learning disability services, but would also be of benefit to other services who are likely to come into contact with parents with a learning disability, including General Practitioners, child and family services, midwives and health visitors.

3.6.5 Possibilities for future research

Whilst support for the current study's findings has been located in the existing literature and clinical implications have been indicated, a number of additional areas and questions for further research have been highlighted.

Firstly, although the theme '*The same but different'* emerged from participants' narratives, the current study did not attempt to compare the experiences of parents with a learning disability with other groups of parents in the community. Future

research may seek to explore the experiences and views of other groups of parents in society, in order for such comparisons to be made.

Another area for future research might be to explore the views and experiences of those parents with a learning disability who are not involved with professional services. As discussed above, the findings of the current study are limited in terms of generalisability to the wider group of parents with a learning disability as they focussed on those parents who were known to the learning disability service. However, continued difficulties in the proactive identification of parents with a learning disability within the UK may make this area of research problematic.

Unlike the majority of previous research in the area, the views of fathers were represented in the majority in the current study. Within this, some differences between the perceptions of mothers and fathers were identified. Such differences may be related to wider gender issues within parenting, and the differences between identities as a mother and a father (Connell, 2009), however as this remains an under explored area within the learning disability literature, further exploration of this is limited (Thomas, 1999). Furthermore, as such differences were not the focus of the current research question, in depth analysis and interpretation has not been carried out. It would be of particular value for research to specifically explore the views and experiences of a group of fathers only. Although it is acknowledged that the participant sample may be small due to identification and access difficulties, it would be a significant and positive move towards gaining an insight into these previously unheard voices.

Finally, to support the above research developments it is vital that improvements are made in the identification of this group of parents. Within this, there needs to be a move towards pro-active identification as opposed to re-active and crisis driven identification, which may ultimately change the experiences that this group of parents face.

3.6.6 Conclusions

The current study has provided a greater insight into the views and experiences of parents with a learning disability. Specifically, the findings suggest that this group of parents hold three separate identities. However, in becoming a parent their identity as a person with a learning disability is emphasised through the opinions or assumptions of others. Furthermore, the overall parenting experiences of participants appeared to be shaped by what others think about them as a parent. The reality of living with involvement with services creates standards which have to be adhered to and accepted. In line with previous research in the area, parents were all too aware and fearful of the consequences of not accepting their realities, the removal of their child from their care.

These findings may be of particular interest to health and social care professionals involved in assessing and supporting parents with a learning disability. Specifically it should be acknowledged that this group of parents hold a number of different identities, within which a person with a learning disability is only one part. It should also be recognised that a shared understanding about what a learning disability is and

how this impacts on them in their parenting role is not held between professionals and parents themselves.

The dissemination of these findings will contribute to the third wave of research into parents with a learning disability, which not only provides the professionals that work with them with more insight into the lived experiences of this group, but also emphasises the importance of carrying out research from an insider perspective.

Title.

A qualitative exploration of the identities of parents with a learning disability.

Written in accordance with author guidelines for:
British Journal of Learning Disabilities.

Abbreviated title for running head:
Identities of parents with a learning disability.

4.1 Accessible summary

- The number of parents with a learning disability in the United Kingdom (UK) is growing.

- Parents with a learning disability do have some difficulties.

- Parents with a learning disability see that their learning disability is separate to being a mum or dad.

- Becoming a parent is important to people with a learning disability.

4.2 Summary

There are an increasing number of parents with a learning disability in the UK. Existing research in the area suggests that this group of parents face a number of issues including social isolation and over-representation in child protection systems. This study explored what parents understood about their learning disability and how they perceived this to impact on them in their parenting role. This exploratory study adopted a qualitative approach, involving semi-structured interviews with 8 parents (3 mothers, 5 fathers). The study suggested that as a result of having a learning disability parents experience some difficulties, however these tend to be related to specific tasks only. In their parenting role three separate identities were conveyed: as a person with a learning disability; as a mother or father, and as an individual (outside of their identity with learning disability or parenthood). The findings presented here are drawn from a larger qualitative study.

Key words- parents, learning disability, perceptions, difficulties, identities.

4.3 Introduction

People with a learning disability share the same needs as other adults, to form friendships, engage in sexual relationships and bear children (McGaw, 1998). Since the introduction of philosophical and political changes, such as Normalisation and the disability rights movements, people with a learning disability are no longer prevented from realising any of these ambitions. Although exact figures remain unknown (International Association for the Scientific Study of Intellectual Disabilities [IASSID], 2008), research in the area has consistently highlighted that the numbers of people with a learning disability who are becoming parents within the UK is increasing (Emerson *et al*. 2005).

Parenthood is widely recognised to be a desirable and highly valued role in today's society. Morahan-Martin (1991) suggests that becoming a parent confirms adult status and creates a positive self image, as well as providing the continuation and tradition associated with being part of a family. However, existing research suggests that when people with a learning disability become parents this is often viewed with concern and disapproval from others. Specifically, as a result of having a diagnosis of a learning disability, an individual's ability to manage the complexities of parenting is questioned and assumptions of incompetency are made (Murphy & Feldman, 2002).

The majority of what is known about parents with a learning disability has been gained from research conducted from the perspectives of professionals only, and has

tended to focus on how the parental competency can be improved with interventions from support services (Wade *et al.* 2008). Until twenty years ago very little was known about the views and experiences of these parents. However, this is beginning to change and a number of qualitative studies, carried out from an insider perspective are now emerging (Llewellyn *et al.* 2010).

A few studies have explored how people with a learning disability view parenthood. Both, Edmonds (2000) and Mayes *et al.* (2011) specifically investigated the mother identity in women with a learning disability. Results from both studies highlighted the central role that motherhood plays in the identities and life experiences of this group of people. Specifically, Edmonds (2000) concluded that having an identity as a mother is not only a significant indicator of gender identity and adult status, but also refutes the label of a learning disability. Such findings are also reflected in the research by Booth and Booth (2005) and Baum and Burns (2007), who explored the views and experiences of parents with a learning disability who had lost custody of their children. The latter study only interviewed mothers with a learning disability, but both studies suggested that parenthood is viewed as a significant and personal achievement which increases positive self image. In situations where children are removed, parents reported feeling a loss of their valued identity as a parent, which consequently emphasised their label of being a person with a learning disability (Baum and Burns, 2007).

The research in this area suggests the importance of becoming a parent for people with a learning disability. However, there are a number of limitations in applying the

findings to the wider group of parents with a learning disability. Firstly, there is a strong emphasis on the views and perceptions of mothers only, with the perspectives of fathers often not being acknowledged. Although fathers were included in the participant sample used by Booth and Booth (2005), they were in the minority (only 4, compared to 18 mothers). This limitation is not exclusive to the above studies, but is mirrored in the wider literature base on parents with a learning disability. In addition, the studies by Booth and Booth (2005) and Baum and Burns (2007) were carried out with a sub-group sample (parents who had lost custody of their children or were involved in child protection systems) of the wider group of parents with a learning disability. Although it is recognised that a high proportion of parents with a learning disability do lose custody of their children (Emerson *et al*. 2005) the findings of such studies may not be representative of those who have not lost custody of their children. Given the above limitations further research is needed to explore how parents, including fathers and those who have not lost custody of their children, perceive their identities in relation to having a learning disability and parenthood.

4.3.1 Aims of the study

The present study aimed to address the gap in the literature identified above, by exploring how parents with a learning disability understand their learning disability and how they perceive this to impact on them in their role as a parent.

4.4 Method

Interpretative Phenomenological Analysis (IPA) (Smith, 1996; Smith *et al*. 2009) was adopted. IPA aims to gain an understanding of how participants view and

experience their world. IPA researchers accept that such an understanding can only be gained through the researcher's engagement with an interpretation of the participant's account. As a result, the analysis is both phenomenological (in that it aims to represent the participant's view) and also interpretative (in that it is dependent upon the researcher's own stance).

4.4.1 Ethics

The research proposal for the study was initially reviewed and approved by the University of Edinburgh DClinPsychol ethics committee. Ethical approval was also sought and approved from the local area NHS Medical Research Ethics Committee and NHS Research and Development Department.

4.4.2 Participant recruitment

Participants were eligible to take part in the study if they had a diagnosed learning disability and had current involvement with the local adult learning disability service. Participants had to be parents, although it was not necessary that their children lived with them. They also had to be able to provide informed consent to take part in the study.

Participants were excluded if there were increased vulnerability issues, such as severe mental health difficulties or substance abuse (to such an extent that functioning was significantly impacted). Additionally, participants who were actively involved in legal proceedings resulting from child protection issues or those who had

lost the primary care of their child/ children in the last 18 months as a result of child protection issues were excluded.

Potential participants were identified via an index worker from the local adult leaning disability service that was currently supporting the participant e.g. Community Nurse, Clinical Psychologist. The index worker approached potential participants and provided verbal and written information about the study. The information sheet was designed to be accessible to people with a learning disability and contained information about what the study was about, why it was being carried out and what it would involve, using plain language, symbols and photographs.

If participants agreed to be contacted, they provided contact details and the first author contacted them to arrange an introductory meeting to further discuss the study. They were given a week to decide and those who wished to participate provided written consent which was witnessed by the index worker.

4.4.3 Participants

IPA studies are usually conducted with relatively small samples which are guided by striking a balance between allowing an in-depth analysis with individual cases, whilst exploring a full range of issues across the sample (Smith *et al.* 2009). Eight participants took part in the study (3 mothers and 5 fathers). Ages ranged from 23-46. A summary of participant characteristics are presented in Table 4.1.

Participant	Age	Gender	Level of LD	Number of children	Ages of children **	Number of children living with them	Previous child removal
P01	31	M	Mild	3	13y, 3y, 4 m	1	Yes
P02	23	M	Mild	1	4y	1	No
P03	38	F	Mild	1	9y	1	No
P04 *	36	M	Mild	3	11y, 6y, 5m	3	No
P05*	35	F	Mild	3	11y, 6y, 5m	3	No
P06	46	F	Mild	4	20y, 18y, 12y, 10y	2	No
P07	43	M	Mild	1	15y	0	No
P08	44	M	Mild	2	30y, 25y, 1 due.	0	No

Table 4.1: Summary of participant characteristics.

*- P04 and P05 were a married couple, however were interviewed separately.
**- y= years old, m= months old.

4.4.4 Data collection

Semi-structured interviews were conducted, with the use of an interview schedule. As highlighted by Willig (2001) this format enables specific questions to be asked, whilst allowing for flexibility. The interview schedule consisted of a number of open-ended questions which addressed the following areas; 1) participants' understanding of their learning disability, 2) how participants perceived their learning disability to impact on them in their role as a parent and 3) participants' experiences of support to them in their parenting role. In accordance with the guidance of Booth and Booth (1996), each question contained a number of further

prompt questions to encourage participants to expand on their answers and ground their responses with examples.

Interviews took place at either the participants' home or the learning disability clinic base that was most convenient to them. The length of interviews ranged from 22 to 67 minutes, with an average interview time of 42 minutes. All interviews were recorded using a digital voice recorder.

4.4.5 Data analysis

The interview recordings were transcribed verbatim. They were then analysed in accordance with the principles of IPA, as set out by Smith *et al*. (2009) as a six stage process. A summary of the analysis involved in each stage of this process is outlined in Table 4.2. A qualitative data analysis package (N-Vivo 9-QSR) was used for the storage and refinement of coded data.

4.4.6 Study rigour

As recommended by Yardley (2008), a number of methods were utilised to strengthen the rigour of the study. The first author conducted the analysis and transcripts were reviewed by colleagues who were experienced in qualitative research and working with individuals with a learning disability. The first author also sought respondent feedback from three of the participants to assess whether the findings accurately represented their views. In addition, the first author kept a reflective diary throughout the study to maintain a reflexive stance.

Step	Description of process
1. Reading and re-reading.	The researcher becomes actively engaged with the data through repeated reading of individual transcripts.
2. Initial noting.	Initial notes were made on a line by line basis on the content of the accounts as well as the language used
3. Developing emergent themes.	Through an exploration of patterns within the initial notes, the researcher began to identify themes.
4. Connections across emergent themes.	The researcher explored connections between the themes to produce a higher level, 'super-ordinate' themes to describe or label similar themes.
5. Moving onto the next case.	Steps 1-4 were repeated for each transcript, allowing new themes to emerge from each account.
6. Looking for patterns across cases.	Super-ordinate themes from each transcript were compared to identify recurrent themes and examples of isolated themes. The researcher then integrated the themes to produce 'master' themes which represent the group as a whole.

Table 4.2: Summary of six stage IPA process.

4.5 Results

The identities, or expressions of self, of the participants were conveyed in three different ways. Firstly, as a person with a learning disability, secondly, as a parent, and finally as an individual with personal likes and strengths (i.e. outside both having a learning disability and being a parent). Thus a theme of 'The self as different identities' was created. The next section will provide a detailed description of this theme along with demonstrative extracts from fully anonymised transcripts.

4.5.1 Being a person with a learning disability

All participants acknowledged having a learning disability, however the way in which they identified with this varied. Some participant accounts suggested that having a learning disability was an integral part of them, as the difficulties that they associated with having a learning disability had been present since they were children.

> " I canna mind about really ever been told, but going back when I was younger I've always been like that" (P06, page lines 35-36).

Other participants however, did not relate to having a learning disability in the same way. Instead their perceptions were embedded in other difficulties, suggesting that for them, their learning disability was a bi-product of other difficulties.

> " I- So do you see yourself as having a learning disability?
> P03- Well yeah, 'cause I've got epilepsy" (P03, page 2/3, lines 38/1).

> " I feel like people no understand me because of my learning difficulty, 'cause I got a speech impairment" (P07, page 1, line 18).

Although different in the way that they identified with being a person with a learning disability, all participants provided examples of their difficulties. For the majority of participants their difficulties were perceived as specific. These specific difficulties were in relation to cognitive tasks and were often related back to problems they had experienced at school.

> "Yeah erm and difficulties with my sums (..) and that" (P08, page 1, line 34).

> " I feel it hard reading long er, long letters" (P05, page 1, line 11).

A number of participants also described how such difficulties continue to impact upon them in their day to day lives, including within their role as a parent.

> " It is difficult see 'cause I can't really help with my girls homework 'cause I can't read that well" (P06, page 3, lines 24-25).

A number of participants made reference to their childhood and experiences at school. This was often framed in terms of hardship

> "School was a nightmare eh (..), I was in and out of school, I was like a yo yo eh. I was always bottom of the class and would get thrown out of school quite a lot….."(P01, page 1, line 27).

Furthermore, some participant accounts created a sense of feeling singled out, which was perceived to be directly associated with having a learning disability

> "…but that is what the teachers did, you know pick on the simple ones (..) well that is very difficult, it's very difficult being at school for a long time and being picked on." (P08, page 3, lines 14-16).

Perceptions of difficulties, experience of hardship and feeling singled out cumulatively created a sense that having a learning disability was negatively viewed and an un-welcomed identity by most participants. The following quote from participant 3 demonstrates this.

> "yeah when I was at school I did (..) I really wished I did na have it" (P03, Page 1, line 23)

4.5.2 Becoming a parent

In contrast to the negative associations of being a person with a learning disability, all participant narratives were characterised by a welcomed and positive identity with parenthood. This was particularly evident in the interviews with mothers, as they conveyed their strong identities with motherhood.

> " I've always wanted to be a mum and then when it happened I kept thinking to my sel I'm gonna be a mum, I'm gonna be a mum!" (P03, page 5, lines 15-16).

When her first baby was born, participant 6 suggested that for the first time in her life she felt a sense of positive ownership in her identity.

> "I was over the moon, you know being a first mum, having a first child of my own (…) It was a lovely time". (P06, page 5, lines 13-14).

Although the theme of becoming a parent was evident in most of the interviews with fathers, it was not as strong or expressed in the same way as for mothers. When asked about their reactions to finding out that they were going to become a father, some reported mixed feelings.

> " I was excited, really excited eh (…) till I realised that stuff, everything was gonna change in my life" (P02, page 2, lines 15-16).

The apparent differences between mothers and fathers may be as a result of gender role beliefs within parenting, but may also be related to proximity of the child, as three out of the five fathers interviewed did not have daily involvement with their children compared to all of the mothers.

As a result of a positive and welcomed identity with parenthood, participants' narratives conveyed feelings of joy, happiness and pride in becoming a parent and embarking on the journey of raising their children.

> " It feels great [laughs] (…) erm you know seeing her from a wee baby crawling about to look at her now, she's almost a lady now. She is growing up just so fast" (P06, page 10, lines 1-3).

> "Ken[8] (….) Can't explain (…) makes you feel, erm makes me feel happy. Happy inside to watch them from a wee baby into a big girl" (P07, page 5, lines 24-25).

Despite parenthood being viewed as a welcomed role by most participants, the same cannot be said about the reactions of others. Some participants spoke of their fear about telling other people, including members of their family and professionals, about becoming a parent, because they were uncertain about how they might react.

> " P02- Well my mum did na ken ** (name of girlfriend) was even pregnant (..) I was a wee bitty scared to tell her.
> I- Can I ask why you were scared to tell your mum?
> P02- 'Cause I could na speak to my mum, 'cause I was kind a scared eh (..) scared what she would say" (P02, page 3, lines 8-12).

In telling other people about becoming a parent, participant 8 conveyed a sense of judgement and disapproval from the responses of others.

> " She was rowing with me and saying like 'you should have told me your girlfriend was pregnant', ken, you know I thought, I thought I don't need to tell you nothing again with what happens in my life. If I want to have a baby to her it's up to me and she can't give me a row for it". (P08, page 4, lines 19-22).

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[8] In the local dialect, "ken" is colloquial for 'you know' or 'know'.

4.5.3 Self identity

Within their identities as a person with a learning disability and being a parent, some participants also described their personal qualities. This included the expression of their beliefs about themselves, their likes and perceived strengths.

> *" I'm crazy on country and western, I've just ordered a John Wayne clock for my wall. I mean it was a bit expensive (…) it's to go on my lounge wall. But I love country and western so I really wanted it". (P06, page 10, lines 22-24).*

> *"I'm good at cooking and all that (..) I like to cook for other people. See ** (name of partner) reads the recipe out to me and then I do the ingredients. Well I went to college for 3 years and did cooking and then I got a certificate at the end". (P08, page 2, lines 20-23).*

Within the extracts above, no reference is made to either having a learning disability or being a parent, thus creating a sense of self which was separate to other identities.

4.5.4 Separate identities

As implied by the distinction of the three previous themes, most participants conveyed that their identity as a person with a learning disability and identity as a parent were separate. The extracts below represent how participants compartmentalised their identities, and clearly separate them out.

> *" Well I've always blamed that for getting made a fool of (..) I've always blamed myself, well not myself but the difficulties for getting made a fool of at school" (P03, page 1, lines 24-25).*

This extract demonstrates how participant 3 clearly distinguishes between her self identity and having a learning disability. In the process of doing so, she externalises her identity with learning disability in that she refers to it as 'that' and 'the

difficulties', yet speaks of her self identity as being integral to her as she uses the word 'myself'.

Having a learning disability was also separated from being a parent;

> *"I just care about being a dad and put my difficulties to the back of my mind and get on with it"* (P04, page 3, lines 16-19).

Finally, all three identities were perceived as being distinct from one another.

> *"It wasn't about me or my difficulties it was mainly my girls. The girls were more important than that"* (P06, page 8, lines 28-31).

Here the language creates separation of the three identities with the words 'me' to reflect identity with the self, 'difficulties' to refer to her identity as being a person with a learning disability, 'my girls' to represent her identity with parenthood.

Not all participant accounts conveyed such clear compartmentalisations. Some participants made reference to how the different identities influence one another, creating relationships between them. This was most evident in the relationship between the sense of self and becoming a parent and was present in the accounts of fathers.

> *"I'm settled, I've no moved on. Like when I was younger and growing up I would move from place to place, like never stay anywhere too long, a bit of a tear away really, but now I've stayed put".* (P04, page 5, lines 2-4).

The above extract demonstrates how the sense of self was modified as the result of becoming a parent, suggesting that although the three identities are perceived to be separate, they did impact on each other.

4.6 Discussion

Participant narratives suggested that three identities were held; an identity as a person with a learning disability, an identity as a parent, and an identity as an individual, with personal likes and strengths (outside being a person with a learning disability or as a parent). The findings echo and extend on previous research in the area, as well as support research from the wider learning disability literature.

Within their identity as a person with a learning disability, most participants viewed their difficulties to be specific and therefore impacted on them in specific ways. Such difficulties were often in relation to cognitive tasks, which many of the participants related back to their difficult experiences of being at school (e.g. difficulties with reading and writing). This finding supports research by Thomson and McKenzie (2005), who reported that people with a learning disability do not have a clear understanding of what a learning disability is, often relating it to specific learning difficulties. In addition, some participants in the current study did not directly relate to their diagnosis of a learning disability, but instead viewed it as a bi-product of the other difficulties they experience (e.g. epilepsy, speech impairment). Similarly, in the wider learning disability literature, research suggests that people with a learning disability do not always relate to their diagnosis, nor feel that the definition of what a learning disability is applies to them (Beart *et al.* 2005).

The results of the current study suggest that parenthood was a welcomed identity for all participants. This supports previous research in the area (Booth & Booth, 1995; Booth & Booth, 2005). Such research indicated that the adoption of a parent role affirms transition into adulthood and provides a valued social status, which previously may have been lacking. However, as was the case for a few participants in the current study, it is important to note that the initial reactions by others to their becoming parents were not positive. This finding is in line with those by McConnell and Strike (2002) who highlight that many people with a learning disability experience opposition and scrutiny from family members or professionals when they become parents.

More specifically, the accounts from mothers within the present study suggested a strong identity with motherhood. This supports previous research that has specifically focused on mothers with a learning disability (Edmonds, 2000; Mayes *et al*. 2011). The findings of the current study also suggested that there are some differences in how mothers and fathers identify with becoming a parent. Although it is widely acknowledged in the literature that very little is known about the experiences of fathers with a learning disability (O'Hara & Martin, 2002), this finding is in line with the work of Mayes and Sigurjónsdóttir (2010). Their study compared the experiences of a group of mothers (from Australia) and a group of fathers (from Iceland) and found that in preparation for and becoming a parent mothers and fathers with a learning disability developed different identities. The authors also point out the importance of gender perspectives for people with a learning disability, which is also an area of research which has been under explored.

Based on the themes identified in the current study, a number of recommendations can be made for clinical practice and the provision of services to parents with a learning disability.

Firstly, professionals working with this client group should not make assumptions that a shared awareness is held about what a learning disability is or the impact of this. In order to create a more shared understanding, clinicians should make it clear to parents why a specific assessment is being done or why a particular support intervention is being provided. Cleaver and Freeman (1995) indicate that a shared understanding increases the likelihood of a positive outcome for both parents and children.

Secondly, professionals should also be aware of the separate identities held by this group of parents. Research by Walmsley and Downer (1997) highlights that practitioners and researchers often fail to acknowledge that people with a learning disability have other social identities which are important to them. When gathering information from parents with a learning disability for the purposes of assessment, practitioners should attempt to gain a holistic understanding of the individual, including their different identities and perceived likes and strengths.

Finally, the valued role of being a parent that was present in all participants' accounts should be acknowledged. Specifically, the socially confirming role of being a parent

should be recognised by practitioners and should not be unnecessarily undermined or

threatened.

4.7 Acknowledgements

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APPENDICES

Appendix 1: Systematic review quality assessment criteria

Appendix 2: Participant information sheet

Appendix 3: Participant consent form

Appendix 4: Disclosure management pathway

Appendix 5 (a): Letter of approval- Local Research Ethics Committee.

Appendix 5 (b): Letter of approval- Local Research and Development Department

Appendix 6: Interview schedule

Appendix 7: Demographic data collection sheet

Appendix 8: Example of coded transcript from participant 6

Appendix 9: Mind map demonstrating emergent themes for participant 6

Appendix 10: Table of themes generated for participant 6

Appendix 11: Table of distribution of themes across participants

Appendix 12 (a): Journal scope and author guidelines- Journal of Applied Research in Intellectual Disabilities

Appendix 12 (b): Journal scope and author guidelines- British Journal of Learning Disabilities.

APPENDIX 1:

Systematic review quality assessment criteria.

1. **<u>Aims and Objectives</u>**.

- *Is there a clear statement of the research aims*

- *Is there a consideration of why the research is important/ how the research is relevant?*

2. **<u>Research setting/ Context.</u>**

- *Is the research setting/ context explicitly mentioned?*

- *Is there a clear description of the research setting/ context?*

3. **<u>Research Design.</u>**

- *Are qualitative methods appropriate*

- *Is the research design appropriate to address the aims of the research?*

- *Has the researcher provided justification for the research design method used?*

4. **<u>Sample Characteristics.</u>**

- *Is the participant sample relevant to the research question?*

- *Is the participant sample clearly described?*

- *Is there a clear description of how the participant sample was selected (inc recruitment process)?*

3= Well addressed, **2**= Adequately addressed, **1**= Poorly addressed, **0**=Not reported

5. **Data Collection.**

- *Is there a clear description of how data was collected (inc use of interview topic guides)?*

- *Are methods of data collection appropriate for the research questions and research design?*

- *Is the form of data clear (e.g. tape recordings, field notes etc)?*

6. **Data Analysis.**

- *Is there an in-depth description of the analysis process?*

- *Is an established qualitative method of analysis referenced (e.g. IPA, grounded theory etc)*

- *Is it clear how categories/themes were derived from the original data?*

7. **Findings.**

- *Are the findings clearly stated?*

- *Are the findings discussed in relation to the original research questions?*

- *Is data presented alongside the findings to support them (e.g. use of direct quotes).*

- *Is the credibility of the findings discussed (e.g. more than one analyst, triangulation, respondent feedback etc)?*

- *Are strengths and weaknesses of the research addressed?*

3= Well addressed, **2**= Adequately addressed, **1**= Poorly addressed, **0**=Not reported

8. **Reflexivity.**

- *Is the relationship between the researcher and participants considered within the research process?*

- *Do researchers reflect on their own personal viewpoints and experience that they may contribute to the research process?*

9. **Ethical Issues.**

- *Have ethical issues been considered (N.B- issues of informed consent)?*

- *Has ethical approval been sought and explicitly referenced?*

10. **Contribution to existing Knowledge.**

- *Does the research add knowledge or increase confidence to existing research in the area?*

- *Are clinical implications of the research considered?*

- *Are future areas for research identified?*

3= Well addressed, **2=** Adequately addressed, **1=** Poorly addressed, **0=**Not reported

APPENDIX 2:

Participant information sheet.

Hi,

My name is Laura Shewan.

I am training to be a Clinical Psychologist at the University of Edinburgh and work for NHS (local health board).

I have to do a project as part of my training and invite you to take part in a study.

Before you say 'yes' or 'no' I want to tell you why the study is being done and what you would do if you take part.

Please read it carefully, or be sure that someone reads it to you. If there are any bits you do not understand, please ask questions.

You do not have to make a decision right away and can talk to your friends and family about it.

What is the study about?

Lots more people with a learning disability are becoming parents.

I want to know what it is like to be a parent with a learning disability?

I would like to talk to you about this. I will be asking other people who are parents too.

BUT….. I will not be asking you any questions that may upset you
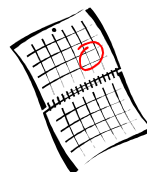
What will I be asked to do?

I will ask you take part in a study, but you do not need to make a decision straight away.

If you think you would like to take part, I would like to come and visit you at home to talk more about the study and answer any questions you might have.

You will then have **one week** to decide if you want to take part.

1 week

If you decide to take part, I'll ask you to sign and write your name on a consent form. This says that you agree to take part.

If you agree to take part, we can then arrange where and when we meet the second time. This can either be at your home or the learning disability clinic base.

The second time we meet, I will ask you some questions about having a learning disability and being a mum or dad. This talk will last no longer than 1 hour.

1 hour

We may need to meet to talk more than once, but we will not meet to talk more than **3** times. This is to make sure I have enough information to write about in my project.

If there are any questions that you do not want to answer that is OK.

If it is okay with you, I would like to record what you say using a voice recorder. This is so I don't forget anything that you have said.

I am hoping to meet with other parents too.

The information that I collect from you will be used to tell people more about what you think and feel about being a parent with a learning disability.

Do I have to take part in the study?

It is up to you if you take part in the study or not.
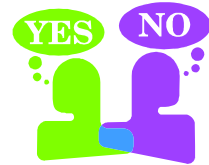
If you say 'no', this is okay.

NO!

Taking part in the study will not make a change to the support you receive from the learning disability service.

You can change your mind any time and don't have to tell me why.

Will anyone know what I have said?

I (Laura Shewan) will be the only one allowed to listen to the recording of our talks.

After our talks have finished I will type up what you said. When I type this, I will remove all names from our talks. This means that no one will be able to tell it is you.

After I have typed this, th of our talks will be deleted.

If you tell me anything tha think you are at risk of harm, or others around you are at risk, I will have to tell someone. This is to make sure that you and other people are safe. This person will be the worker who told you about the study in the first place.

Will I find out the results of the study?

I will tell you what I have found out. If you want, you can have a written summary of the study.

I will tell the people I work with about what I find by giving them a talk.

Next steps………

I want to know more about the study- what should I do?

If you want to take part, or would like to meet with me to talk more about the study, please fill in your name and phone number on the next page and give it back to the person who gave you the information sheet.

I will then phone you to arrange a time to meet.

Or…..

You can phone me to talk more about this.

Phone-

I don't agree with the study- what should I do?

If you don't agree with any parts of this study and would like to make a complaint, you can do this through:

Phone-

Write a letter- Send it to-

Thank you for taking the time to read this.

Please complete this if you would like to meet with Laura to find out more information.

☐   I agree to be contacted by Laura to meet with her and talk more about the study.   (please tick this box).

Name…………………………………………………

Phone Number…………………………………..

Name of person who gave you the information sheet………………………………………………………….

APPENDIX 3:

Participant consent form.

I have had a look over the Participant Information Sheet (version 6; 05/01/2011)

☐

I have had a chance to talk to someone about the study

☐
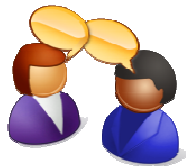
I know that I do not have to take part in this study and that I can stop at any time. I will not have to tell anyone why I want to leave the study.

☐

I know this will not affect the care that I receive from the learning disability service.

☐

I understand it involves meeting with Laura Shewan up **3** times

☐
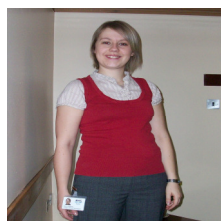
I agree to our talks being recorded and that Laura will type them up afterwards

I know that if I say something about me, or other people, being at risk this will need to be passed on to someone else

YES.
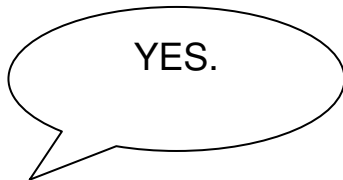
I agree to take part in this study:

Participant Name_____

Signature_____

Date_____

Witness Name_____

Signature_____

Date_____

Researcher Name_____

Signature_____

Date_____

APPENDIX 4:

Disclosure management pathway.

DISCLOSURE OF INFORMATION DURING INTERVIEW:

Discussion with clinical supervisor and index worker- Is the index worker aware of this information?

YES

NO

Does the information indicate **risk/ harm to self**

YES

NO

Further discussion with index worker. Visit with index worker arranged to risk assess.

No indication of increased vulnerability

Participant remains in the study.

Does the information indicate **risk/ harm to children/ others?**

CHILDREN-
Further discuss with clinical supervisor and index worker

ADULT- OTHERS-
Further discuss with clinical supervisor and index worker

Refer to department policy on child protection

Refer to department policy of adult protection.

Vulnerability issues increased- REMOVE from study.

APPENDIX 5 (a):

Letter of approval- Local Research Ethics Committee.

NHS

Fife

NHS

Forth Valley

NHS

Tayside

East of Scotland Research Ethics Service

Tayside Committee on Medical Research Ethics B
Research Ethics Office
Tayside Academic Health Sciences Centre
Ninewells Hospital & Medical School
Residency Block, Level 3
George Pirie Way
Dundee
DD1 9SY

Miss Laura Shewan
Trainee Clinical Psychologist
NHS Tayside
Psychological Therapies Service
Wedderburn House
Dundee
DD1 5NS

Date:	17 December 2010
Your Ref:	
Our Ref:	LR/10/S1402/65
Enquiries to:	Mrs Lorraine Reilly
Extension:	Ninewells extension 40099
Direct Line:	01382 740099
Email:	Lorraine.reilly@nhs.net

Dear Miss Shewan

Full title of study: How do parents with a learning disability understand and perceive their learning disability in relation to their parenting role?

REC reference number: 10/S1402/65

The Research Ethics Committee reviewed the above application at the meeting held on 10 December 2010. Thank you and Professor Power for attending to discuss the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

The following points require to be addressed by letter and submission of revised documentation where requested. **Please note that there is no requirement to amend your application form.**

1. Regarding the Participant Information Sheet (PIS):

   - The Information sheet states it will not be asking any upsetting times but it relates to children being taken away. Please reword as a bit confusing.

   - Under 'what will I have to do?' – the Committee felt it would be better to start the information sheet with 'I will ask you to take part in a study but you do not need to decide to take part straight away' rather than 'I will meet with you four times'.

   - Under 'Will anyone know what I have said?' – 'Only me (Laura Shewan) will be allowed to listen ...' should read 'I (Laura Shewan) will be the only one allowed to listen ...'.

Please submit revised Participant Information Sheets, which should include page numbers, a new version number and new full date.

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2.   Regarding the consent Form:

Please submit revised Consent Forms, which should include a version number and full date as a footer and the new date and version number of Participant Information Sheet in Statement 1.

3.   Regarding the Interview Schedule:

- Under Topic 2 –Parenting Role – 'Do you think having a learning disability has impacted on this in anyway' could perhaps be simplified for the participant.

The following points were clarified on the application form:

- Ms Shewan confirmed she will ensure before the interview that the participants know what is involved by reiterating what the questions are about and will inform them they do not have to answer any questions they do want to.

- Are they already engaged in the service or are they uncomfortable with the service.

- Ms Shewan confirmed that the inclusion criteria for the study is to have a parent with learning disability. If both parents have a learning disability they will be interviewed separately. Parents who do not have a learning disability will not be interviewed.

- She also confirmed that there is no age limit of the child, the parent could have given birth last year or have grown up child/children. The answers could vary depending on whether it is the first child, second etc.

- Miss Shewan confirmed that a written summary of the results will be available for the participants as well as written up for her thesis.

- She also clarified that the study will depend on social support provided as it may make a difference but she will be looking at a variety of different social circumstances also looking at how parents with learning disability cope with their children.

- Sample size 16 – Professor Power confirmed that any varies that occur will be from the diversity of the group and the variant factors will be looked at to reflect the diversity.

- Clarification was given that the Index Worker will discuss with yourself the level of disability and ability of the participant to consent in the study

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	3	09 September 2010
REC application		25 November 2010
CV - Dr Ethel Quayle		
Participant Information Sheet	5	15 November 2010
Interview Schedules/Topic Guides	4	22 November 2010
Evidence of insurance or indemnity		01 August 2010
Referees or other scientific critique report	2	19 November 2010
Investigator CV		24 November 2010
Participant Consent Form	3	22 November 2010
Covering Letter		24 November 2010
Summary/Synopsis	2	22 November 2010
CV - Dr Karen McKenzie		
Demographic Data Collection Sheet	2	10 October 2010

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- ☐ Notifying substantial amendments
- ☐ Adding new sites and investigators
- ☐ Progress and safety reports
- ☐ Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/S1402/65	Please quote this number on all correspondence

Yours sincerely

L. Reilly

Dr Robert Martin
Alternate Vice-chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers"

Copy to: Gemma Watson, Queens Medical Research Institute, Edinburgh
NHS Tayside R&D Office

APPENDIX 5 (b):

Letter of approval- Local Research and Development Department.

20 January 2011

Miss Laura Shewan
Trainee Clinical Psychologist
Psychological Therapies Service
Wedderburn House
DUNDEE
DD1 5NS

Dear Miss Shewan,

R & D MANAGEMENT APPROVAL - TAYSIDE

Title: How do parents with a learning disability understand and perceive their learning disability in relation to their parenting role?

Chief Investigator: Miss Laura Shewan   **Principal Investigator: Miss Laura Shewan**

Tayside Ref: 2010LD03   **NRS Ref: N/A**

REC Ref: 10/S1402/65

EudraCT Ref: N/A   **CTA Ref: N/A**

Sponsor: University of Edinburgh

Funder: Unfunded

Many thanks for your application to carry out the above project here in NHS Tayside. I am pleased to confirm that the project documentation (as outlined below) has been reviewed, registered and Management Approval has been granted for the study to proceed locally in Tayside.

Approval is granted on the following conditions:-

- ALL Research must be carried out in compliance with the Research Governance Framework for Health & Community Care, Health & Safety Regulations, data protection principles, statutory legislation and in accordance with Good Clinical Practice (GCP).

- All amendments to be notified to TASC R & D Office.

- All local researchers must hold either a Substantive Contract, Honorary Research Contract, Honorary Clinical Contract or Letter of Access with NHS Tayside where required (http://www.nihr.ac.uk/systems/Pages/systems_research_passports.aspx).

- TASC R & D Office to be informed of change in Principal Investigator, Chief Investigator or any additional research personnel locally.

- Notification to TASC R & D Office of any change in funding.

Version 2 – 26/11/10

- As custodian of the information collated during this research project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT Security Policies, until destruction of this data.

- Recruitment numbers on a quarterly basis to be reported to TASC R & D Office.

- Annual reports are required to be submitted to TASC R & D Office with the first report due 12 months from date of issue of this management approval letter and at yearly intervals until completion of the study.

- Notification of early termination within 15 days or End of Trial within 90 days followed by End of Trial Report within 1 year to TASC R & D Office.

- You may be required to assist with and provide information in regard to audit and monitoring of study.

Please note you are required to adhere to the conditions, if not, NHS management approval may be withdrawn for the study.

<u>**Approved Documents**</u>

Document	Version	Date
IRAS SSI Form		25/11/10
IRAS R&D Form		24/11/10
Protocol Flowchart	2	15/11/10
Protocol	3	09/09/10
PIS	6	05/01/11
Consent Form	4	05/01/11
Interview Schedule	3	05/01/11
Demographic Data Collection Sheet	2	10/10/10
Disclosure Management Pathway	2	22/11/10
References	2	19/11/10
CV – Karen McKenzie		
CV – Ethel Quayle		
CV – Laura Shewan		24/11/10
Sponsor Letter – University of Edinburgh		10/12/10
Insurance – University of Edinburgh		13/09/10
IRAS REC Form		25/11/10

* Protocol Flowchart (Version 2 dated 15/11/10) does not appear on the favourable ethical opinion letter dated 17/12/10; however, it is in the Ethics file.

May I take this opportunity to wish you every success with your project.

Please do not hesitate to contact TASC R & D Office should you require further assistance.

Yours sincerely,

Elizabeth Coote
R&D Manager

Version 2 – 26/11/10

APPENDIX 6:

Interview schedule.

INTERVIEW SCHEDULE.

Topic 1- Understanding of Learning Disability.

> ➤ Key Question- Tell me what you understand about your learning disability

Possible prompts:
-Could you describe to me what you think a learning disability is?
-How long have you known about having a learning disability?
-Can you remember when you were told you had a learning disability?
-What can you remember from this time, e.g. how did it make you feel?
-What were you told about having a learning disability?
-What was it like growing up with a learning disability (e.g. experience of school, work etc)?
-Do you see yourself as having a learning disability?

Topic 2- Parenting Role

Key Questions
> ➤ Tell me about being a parent?
>   -Tell me the good things about being a parent?
>   -Tell me the bad/ difficult things about being a parent?
>   -What do you think makes a good parent?
>   -What do you think makes a bad parent?
> ➤ Do you think having a learning disability has made a difference to you as a parent- if so tell me how?

Possible prompts:
-How much do you think about your learning disability in you role as a parent?
-Have you faced any challenges being a parent?, if so, how much of this do you think was because you had a learning disability?

Topic 3-Support

Key question.
> ➤ Tell me about the support you get as a parent?

Possible prompts:
-What kind of support/ help do you get?
-Who supports you?
-Can you give me any examples of when the support/help you have been given has been good?
-Can you give me example of when support/ help has been bad?

-Looking back on your time as a parent, what kind of support would have been most helpful?
-In your current situation, what kind of support would be most helpful for the future?

N.B- This is an interview guide rather than a strict interview schedule. This means that although the topics and general framework will remain similar the structure of the questions will be flexible.

APPENDIX 7:

Demographic data collection sheet.

DEMOGRAPHIC DATA COLLECTION SHEET.

Participant code- _____

Participant age-_____

Participant Gender-_____

Level of learning disability-_____

Number of children-_____

Age of children- _____

Children living with them?- _____

Services involved?- _____

APPENDIX 8:

Example of coded transcript from participant 6.

Step 1- Initial noting	Participant Transcript (I= interviewer, P06= participant 6). (<u>Underlined</u>= descriptive coding, *Italics*= language coding, **Bold**= conceptual coding).	Step 2- Emerging themes
Specific difficulties, related to forms, reading, Perceived strengths Difficulties viewed as deficits. ? what/ who decides if it is important.	I: So you're seen by ** (name of psychologist) who works for services for people with learning disabilities. Can I ask you what you understand about having a learning disability? P06: Well I can't, erm <u>I'm *not very good* with forms, I can't fill forms in very good</u> erm (..) and <u>*I'm not a very good* reader.</u> <u>I know about money and can deal with things like that</u>, but I sometimes get confused, I get confused about things and <u>like when I'm speaking to people on the phone</u> about **important stuff** I get confused so I have to get **someone to speak for me**. Like my other half I get him to do that for me 'cause I'm a bit slow. Like I can be on the phone and it gets kinda confusing so I put the other half, him on to help me out. I: So you've mentioned there a couple of things like struggling with forms and reading and sometimes getting confused on the phone. Is there anything else that you have difficulties with, you as part of your learning disability?	Identity with LD- Difficulties as specific. Difficulties viewed as deficits.
? difficulties not viewed as global.	P06: **<u>Erm, not really</u>** I: How about thinking about a day to day basis?	LD= Specific difficulties
Most noticeable difficulty with forms. Strengths- use of word good.	P06: Not really no, I mean there are <u>some forms that I can fill in</u>. Like when I go to give blood, *I'm good* at filling that form in 'cause it's just like ticking yes or no boxes and, well most of the answers are no. Yeah, *I'm good* wi that form.	Difficulties with cognitive tasks.

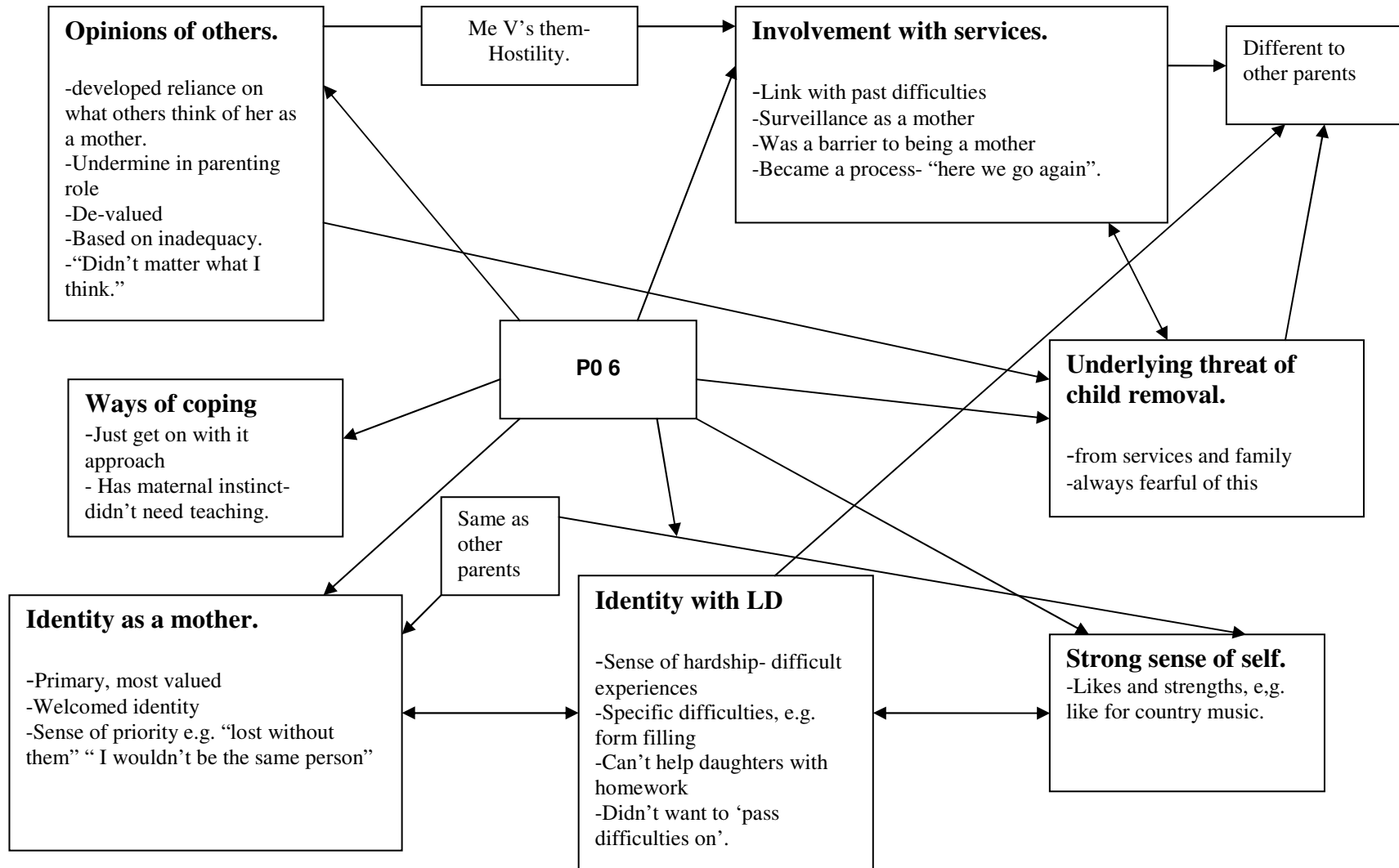|		
	I: So some forms are easier then others.	
Sense of self. Value of previous experience ? Is it the way forms are presented Consequences of difficulties. Perceived needs, support from others.	P06: Yeah, well I suppose I've got used to filling that form in **'cause I'm a donor so I know what to do.** But with other forms I can't really do, yeah others are more difficult and **ask really awkward questions that I don't know**, <u>I just don't know what to put</u>. Like forms about money and stuff 'cause a while back my money just stopped out the blue, so I had to get a load a forms to sort that out or I didn't get my money. ***I needed* **(name of support worker) to help me wi those forms.**	Sense of self identity (unrelated to having LD) Difficulties as deficits.
	I: How about thinking about, well can you remember when you told you had a learning disability?	
Link with childhood, LD as part of her.	P06: <u>I've *always* been like that</u>, but going back to when I was **younger** I cannae mind about really ever been told?	Identity with LD.
	I: So what was it like growing up with a learning disability, you know school	
Sense of difficulty Reflections back- ? is this change related to LD.	P06: ***It not easy*** (laughs), *it's hard* 'cause see at school, well its different to now from when I was at school 'cause your mind changes, 'cause you get confused when you get your age (laughs). My eyes aren't what they used to either, like **<u>I can't read the books like I used to.</u>**	Sense of hardship
	I: You mentioned there that it's not easy, can I ask a little bit more about that?	
Examples of difficulties impacting on life	P06: Well when you look at a form or paper, <u>there have been times when I get stuff through the post that I put to one side 'cause I don't understand them</u> so I have to get like ** (name of support	

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Difficulties seen as deficits, link with feelings. Unpleasant feelings. Expecting the worst. Impact of what others say. ? Feelings of inadequacy.	worker) to read it out for me and explain it you know 'cause there are some parts that I don't know about like big words and that so. <u>But when something comes through the post and *I don't understand* it I **get this feeling** that it's from the court or something, like a *horrible* feeling that **I've done something wrong**. So then, when they read it out for me *they say* **so you're not in trouble** then.</u> I can read some words ***but not like good enough*** for the forms and stuff? I: So you feel like you've done something wrong when you get forms or letters through?	Reassurance seeking.
Acknowledgement of own thoughts Repeated experience. Wrong= not right? ? confused associated with LD	P06: Yeah I think "what is it" or you know <u>"what will I have to sign *this time"*</u> or just a feeling that <u>I've done something *wrong*</u>. I panic a bit (laughs) It's a funny old feeling like yeah that I've done something wrong. I do that sometimes, **I get that confused**. I: Why do you think you might have done something wrong?	
Part of her, is this habit related to LD? Seeking of others opinion.	P06: Well it a funny, **it's a habit** its this funny old feeling that I've done, or someones going to come and take me away. <u>Don't you ever get that feeling that when you get a letter its from the *courts* or something</u>, I hate courts or think that it might be a letter from the *police* saying I've done something wrong. I: Have you ever done anything wrong?	Importance in what others say to her.
Police= authority figures. What others think of her.	P06: Never, I've never been in trouble wi the police. But I still get that *horrible feeling* when the police call at the door, like the other day they were at the door and <u>*I said* "what have I done wrong?"</u> <u>and *they said* "nothing, you haven't done anything wrong"</u> and I was like *oh*	Unable to rely on own judgements.

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	that alright then. They just came over 'cause they were a bit concerned about the neighbours across the road see and they were just asking me how I got on wi them and stuff (….) But no I've never been done by the law,	
	I: But it sounds like that is something that you worry about?	
Expecting the worst, done things 'wrong'. Feelings in relation to children.	P06: I do yeah, like thinking is it something I've done or something that *my kids* have done.	
	I: Can you think why you have those worries?	
? Habit, seen as part of her. Threat of removal of children, loss of contact with her children,	P06: I don't know, **like I say it's a habit, It's always been like that**. It's just this horrible feeling that they are going to take me away or take *my kids* away from me.	Threat of child removal.
	I: So thinking a little bit more about having a learning disability, you've said that filling forms in and reading and things like that are not easy	
Repetition of the word 'wrong'. Reliance on others for support.	P06: They're really not. Like some forms I don't know what to do and then I worry that I've done them *wrong*, so now I just wait and get some help from someone else.	Feelings of inadequacy.
	I: Do you ever think about being a parent, because you said you have got * daughters er do you ever think about or did you ever think about having a learning disability and being a mum? Did you ever think about that?	
Didn't want to 'pass difficulties on' to her children. Similarities to daughters difficulties.	P06: Well I suppose I didn't want my girls to have difficulties *like me*, you know *be like me,* but my daughter ** (name of daughter) has got disabilities too, you know she can't read or that either. I mean she is grown up and left	Passing on of LD.

	home now 'cause she will be 20 this year but she has got disabilities, she's got a card and gets money every month. <u>She can't fill forms in either</u> 'cause she is slow, you know a very bad disability. She's worse, well a <u>bit different to me</u> like that.	Expectations for children.
Differences to daughter.		
	I: Did you ever think about when you were being a mum, did you ever think that having a learning disability made things difficult?	
Difficulties influencing role as a mother, can't help with homework.	P06: It is *difficult*, it is *difficult* see <u>'cause I can't really help with my girls homework 'cause I can't read that well,</u> but some words I can read like well like **(name of youngest daughter) <u>I can help her with her homework 'cause she's coming up 10 now </u>but she's got difficulties too an she's been put back a year at school 'cause she's well behind where she should be with her school work (….). But I can't help wi **'s (name of daughter) homework, 'cause **she's quite bright**, she's like one of the top girls in her class so her homework is too hard. <u>If I can't help ** (name of youngest daughter) wi her homework then I ask ** (name of daughter) to 'cause she is bright and can do it no bother</u>. I can't do the spellings work either so ** (name of daughter) has to do it for me (…) I can spell easy words but not some of the words they get for homework or you know <u>I don't know what to say to help them </u>(….) That is *hard.*	Impact of specific difficulties.
Developmental stage of child.		
? differences to daughter (academic).		Coping within cognitive means.
Ways of coping		
Difficulties as deficits. Finds this hard.		
	I: So it sounds like not being able to help the girls with their homework is difficult?	
Feelings of hardship.	P06: Yeah, *that is hard*	

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APPENDIX 9:

Mind map demonstrating emergent themes for participant 6.

Opinions of others.

-developed reliance on what others think of her as a mother.
-Undermine in parenting role
-De-valued
-Based on inadequacy.
-"Didn't matter what I think."

Me V's them- Hostility.

Involvement with services.

-Link with past difficulties
-Surveillance as a mother
-Was a barrier to being a mother
-Became a process- "here we go again".

Different to other parents

P0 6

Ways of coping
-Just get on with it approach
- Has maternal instinct- didn't need teaching.

Underlying threat of child removal.

-from services and family
-always fearful of this

Same as other parents

Identity as a mother.

-Primary, most valued
-Welcomed identity
-Sense of priority e.g. "lost without them" " I wouldn't be the same person"

Identity with LD

-Sense of hardship- difficult experiences
-Specific difficulties, e.g. form filling
-Can't help daughters with homework
-Didn't want to 'pass difficulties on'.

Strong sense of self.
-Likes and strengths, e,g. like for country music.

APPENDIX 10:

Table of themes generated for participant 6.

Super-ordinate Theme/ Sub-Themes	Page/ Line	Data Extract
Identity of LD		
Difficulties are specific	1/8	"I'm can't fill forms in very good erm (..) and I'm not a very good reader"
	3/33	" I can't do spellings work either"
	3/19	"it is difficult see 'cause I can't really help with my girls homework"
Difficulties viewed as deficits	1/10	"Like with important stuff…..I get confused"
	1/13	"….'cause I'm a bit slow"
	2/15	"…..but like not good enough"
	3/8	"I worry that I've done them wrong".
Difficulties make her different.	10/5	"….a lot a people can't fill forms out but I dunna cairn what they like a t being a mum".
LD is part of her.	1/35.	"but going back when I was younger I've always been like that"
Identity as a mother		
Strong role identity	8/26	"I can't afford to lose my girls (…) that would be me"
	8/30	"If they'd taken my kids off me I'd be lost, you know I wouldn't be the same person"
Always a mother	8/20	"But when they're not wi me, I'm still their mum and I worry about them"

Welcomed identity	5/12	"I was over the moon, you know being a first time mum…."
Being a parent/ a person with a LD as separate	8/28	"It wasn't about me or my difficulties it was mainly my girls. The girls were more important than that"
Pride and joy as a mother.	10/1	" It feels great [laughs] (…) erm you know seeing her from a wee baby crawling about to look at her now, she's almost a lady now. She is growing up just so fast"
Self Identity.		
Expression of personal likes and strengths.	10/22	" I'm crazy on country and western…."
Information about herself as a person (i.e. not related to LD or being a parent).	1/26	"cause I'm a donor so I know what to do"
Opinions of others.		
Developed reliance on what others think	2/16	"So then when they read it out for me they say so you're not in trouble then"
Opinions of others undermine	5/33	"so I went to see her 'cause she knew me from before and I just wanted to see what she said about it"
It doesn't matter about what I think.	6/38	"like they would say things about me wee one and bring you down, it just wasn't fair"
	7/11	"….it makes no difference what I think (..) or what I do (..)…."

Created an underlying threat of removal.	8/11	"well my ** (family member) done that a few times, tried to get social work to put my kids into care"
	8/34	"….all I was thinking about at the end of the day was that they were gonna go into care and be taken off me, that was all I worried about"
Involvement with services		
Surveillance as a mother from social services.	6/27	"….like they were in everyday checking on them, checking for marks on them and stuff like that. I felt like they were at my door all the time. I used to hate it……"
	6/33	"There was a time when they were at the door like every week or everyday (…) they just wouldn't leave us alone"
Created a sense of inadequacy as a mother	8/38	"….I would get those feelings and worry about things, like was I feeding my bairns enough or was I neglecting em…."
Acted as a barrier to being a mother	6/31	"I do remember family life wi them 'cause they were always at the door, I just couldn't get on"
Evaluation as a process	7/8	"You know I know what it's all about….it would be here we go again…"
Hostility towards services	8/39.	"I'm not gonna let that happen and I would fight for them….."

APPENDIX 11:

Table of distribution of themes across participants.

Distribution of master and super-ordinate themes across the participant sample.

Master theme	Super-ordinate theme	P01	P02	P03	P04	P05	P06	P07	P08
The self as different identities	Being a person with a learning disability	**x**	**X**	x	x	x	**x**	x	x
	Becoming a parent	x	**X**	**x**	x	**x**	**x**	**x**	x
	Self Identity	x	**X**		x		**x**		x
	Separate identities		**X**	x	x		**x**		
The opinions of powerful others	Others as experts	x	**X**				x		x
	Presumptions of incompetence	x	**X**	x			x		
	Self evaluation as a parent	**x**		x		x	**x**		
	What I think makes no difference	**x**	**X**				**x**		
Accepting the reality	Involvement with services	**x**		x	**x**	x	**x**		x
	Threat of child removal	x		**x**	x		**x**		x
	The 'Bottom-line"	**x**	**X**	x	**x**		x	**x**	
The same but different	Acknowledgement of common parenting experiences	x	**X**	**x**		x	**x**	**x**	
	Hopes and expectations for their children.				**x**		x	x	**x**
	Unsaid social comparisons.	x		x	x		**x**		**x**
Learning to cope.	Learning parenting tasks	**x**	**X**			x	x	x	**x**
	Coping within their means		**X**		**x**		x	x	
	Value of parenting in partnership		**X**	x		**x**		x	

x= discussed in less depth   **x**= richer accounts, discussed in more depth.

APPENDIX 12 (a):

Journal scope and author guidelines:

Journal of Applied Research in Intellectual Disabilities.

Journal of Applied Research in Intellectual Disabilities

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APPENDIX 12 (b):

Journal scope and author guidelines:

British Journal of Learning Disabilities.

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Author Guidelines

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