
THE EXPERIENCES OF PARENTS WITH LEARNING DISABILITIES

RECEIVING FORMAL SUPPORT:

THE INTERPERSONAL CONTEXT OF PARENTING

Hannah Moore

May 2013

Supervisors:

Dr Rosemary Jenkins

Dr Julia Frearson

Thesis submitted in partial fulfilment of the requirement for the degree of D.Clin.Psy.

at

Cardiff University and the South Wales Doctoral Programme in Clinical Psychology

ACKNOWLEDGMENTS

Firstly, I would like to say thank you to the parents who gave up their time and kindly agreed to share their stories with me. It was a privilege to sit alongside you and learn about your experiences. Without your voices this study would not have been possible. I would also like to say thank you to all the people who helped in the recruitment of the study. In particular, to Susi de Lacey, your enthusiasm and determination for supporting parents with learning disabilities was inspiring.

I would like to thank my supervisors, Rosemary Jenkins and Julia Frearson, and also Neil Frude and Jane Onyett, for your support at the start of the project. Rosemary, thank you for your guidance and support, particularly through ethics! Thank you for having faith in my original ideas and giving me the opportunity to create this project. Julia, you have been my inspiration right from the beginning, from my first days as an Assistant Psychologist, and I have so much to thank you for. Without your containment, understanding, insight, encouragement and your proof reading (!) I would not be the Psychologist that I am today.

With the risk of this sounding like an endless Oscar's speech...I owe massive thanks to all of my friends, even if it's not been possible physically, you have *all* been by my side and helped me through this journey. I'm sure you will all be pleased to read this, knowing that I have finally finished it! To my cohort, I would like to say a big thank you, your constant peer support and guidance has been invaluable!

Finally, I would like to thank my family: my rock. Thank you for being so interested in this study, for your constant reassurance and belief in me, for helping me with those pesky apostrophes and for being there for me throughout my training as a Psychologist. Gavin, your tolerance, patience, acceptance, your genuine interest in my work and most of all your love has given me the strength to achieve what I have.

ABSTRACT

Background: Traditionally parental learning disability has been understood through an individual perspective. As a result, much of the focus of clinical practice and research has been on factors pertinent to the individual, such as, parental competence. Given that the majority of parents with learning disabilities receive support in parenting, research has started to emerge exploring parents' views on how support is delivered. This study aims to explore, from the parents' point of view, what it is like to be a parent with learning disabilities receiving formal support, how parents make sense of the relationship with a professional and the impact of that relationship.

Method: Using semi-structured interviews 10 parents with learning disabilities were interviewed about their experiences. The data were collected and analysed using Interpretative Phenomenological Analysis: IPA.

Results: Four superordinate themes emerged from the data with accompanying subordinate themes: "*Stepping up*": Expectations; Partnership and perceived experiences of support; "*Getting through it*": Coping, and "*Who is the parent here?*": Identity.

Conclusions: The findings revealed the need to think about the interpersonal contexts of parenting, in particular the context of acceptance, and the impact of receiving formal support on shaping the identity of parents with learning disabilities. Parents' perceived experience of support was influenced by their experience of working in partnership with the professional. Implications and recommendations for future research, clinical practice and service delivery are made.

Keywords: Learning disabilities; Parenting; Formal support; Interpretative Phenomenological Analysis

CONTENTS

Chapter 1:

INTRODUCTION

1:1 CHAPTER OVERVIEW	1
-----------------------------------	---

PART 1: SETTING THE SCENE

1:2 DEFINITION OF TERMS	1
1:2:1 Learning Disability	1
1:2:2 Formal support	3
1:3 WHO ARE PARENTS WITH LEARNING DISABILITIES?	3
1:3:1 The ‘hidden’ population	3
1:3:2 Common challenges faced by parents with learning disabilities ..	4
1:4 SERVICE PROVISION	5
1:4:1 The current picture	5
1:4:2 Legislation, policy and ‘best practice’ guidance	6
1:4:2:1 Legislative framework	6
1:4:2:2 Policy framework	7
1:4:2:3 ‘Best practice’ guidance	8
1:4:3 Summary of service provision	9

PART 2: THE LITERATURE

1:5 TRENDS IN RESEARCH	10
1:5:1 Outcomes for children born to parents with learning disabilities ..	10
1:5:2 Parental adequacy and ability to be ‘good enough’	11
1:5:3 Intervention programmes and their effectiveness	12
1:6 A SYSTEMATIC REVIEW OF PARENTS’ EXPERIENCES OF RECEIVING FORMAL SUPPORT	13
1:6:1 Introduction	13

1:6:2 Method	15
1:6:2:1 The search strategy	15
1:6:2:2 Inclusion criteria	15
1:6:2:3 Exclusion criteria	16
1:6:2:4 Assessment of quality	16
1:6:3 Results	17
1:6:3:1 Type of support	18
1:6:3:2 Attitude and approach	19
1:6:3:3 Outcomes	21
1:6:4 Discussion	22
1:6:4:1 Summary of findings	22
1:6:4:2 Strengths and limitations of the key studies	23
1:6:4:3 Integration of review findings with wider literature	25
1:6:4:4 Implications for research	27
1:7 SYNTHESIS OF FINDINGS	27

**PART 3: THE INTERPERSONAL CONTEXTS OF PARENTING:
THEORETICAL PERSPECTIVES**

1:8 OVERVIEW	28
1:9 THE INTERPERSONAL PERSPECTIVE (BRONFENBRENNER, 1979)	28
1:9:1 Interpersonal models of parenting	29
1:10 THE CONSTRUCTION OF MEANING	30
1:10:1 Social constructionism and learning disability	31
1:10:2 Social constructionism and identity	31
1:10:3 Social constructionism and language	32
1:10:4 Conclusions	32
1:11 THE CONTEXT OF ACCEPTANCE	33
1:11:1 Acceptance-based approaches	33
1:12 CONCLUSIONS	35

PART 4: STUDY AIMS AND RATIONALE

1:13 STUDY RATIONALE	36
1:14 STUDY AIMS	37

Chapter 2:

METHODOLOGY

2:1 CHAPTER OVERVIEW	38
2:2 DESIGN	38
2:3 INTRODUCTION TO QUALITATIVE METHODS	38
2:4 INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS	39
2:4:1 Background and philosophy	39
2:4:2 Rationale for using IPA in this research	40
2:4:3 Consideration of the researcher's position	40
2:5 ENSURING QUALITY IN IPA RESEARCH	43
2:5:1 Owing one's perspective	43
2:5:2 Situating the sample	43
2:5:3 Grounding in examples	44
2:5:4 Providing credibility checks	44
2:5:5 Coherence	45
2:5:6 Accomplishing general versus specific research tasks	45
2:5:7 Resonance with the reader	45
2:6 ETHICAL CONSIDERATION	45
2:6:1 Ethical approval	45
2:6:2 Informed consent	46
2:6:3 Confidentiality	47
2:6:4 Managing distress in interview	47
2:7 PARTICIPANTS	48
2:7:1 Deciding on a sample	48
2:7:2 Inclusion and exclusion criteria	48
2:7:3 Recruitment	49
2:7:4 Response rate	50

2:7:5 Description of participants	50
2:8 INTERVIEWS	51
2:8:1 Semi –structured interview schedule	51
2:8:2 Development of the semi-structured interview schedule	51
2:8:3 Interview procedure	52
2:9 DATA ANALYSIS	53

Chapter 3:

RESULTS

3:1 CHAPTER OVERVIEW	56
3:2 SUPERORDINATE THEME 1 – “STEPPING UP”: EXPECTATIONS	57
3:2:1 “Extra” expectations	57
3:2:1:1 External “Extra” expectations	57
3:2:1:2 Internal “Extra” expectations	59
3:2:2 Presumption of incompetence	59
3:2:3 Awareness of difference	61
3:3 SUPERORDINATE THEME 2 – PARTNERSHIP AND PERCEIVED EXPERIENCE OF SUPPORT	64
3:3:1 Dimensions of helping	64
3:3:2 Professional’s qualities	66
3:3:3 Degrees of empowerment	68
3:3:4 “Understanding what I’m going through” : Connectedness	71
3:4 SUPERORDINATE THEME 3 – “GETTING THROUGH IT”: COPING	73
3:4:1 Sense of coping	73
3:4:2 Emotional impact	75
3:4:3 Strategies for coping	77
3:5 SUPERORDINATE THEME 4 – “WHO IS THE PARENT HERE”: IDENTITY	79
3:5:1 Beliefs about parental ability and skill	79
3:5:2 The importance of time	82
3:5:3 Dependent position	84
3:6 SUMMARY	87

Chapter 4:

DISCUSSION

4:1 CHAPTER OVERVIEW	88
4:2 RESEARCH FINDINGS IN RELATION TO EXISTING LITERATURE	88
4:2:1 Superordinate Theme 1: ‘Stepping up’: Expectations	89
4:2:2 Superordinate Theme 2: Partnership and perceived experience of support	93
4:2:3 Superordinate Theme 3: ‘Getting through it’: Coping	96
4:2:4 Superordinate Theme 4: ‘Who is the parent here?’: Identity	100
4:2:5 Understanding the links between the themes	104
4:3 SUGGESTIONS FOR FUTURE RESEARCH	106
4:4 CLINICAL AND SERVICE IMPLICATIONS	108
4:4:1 Transferable skills: The working relationship	108
4:4:2 Communication	110
4:4:3 Interventions and clinical skills	111
4:4:4 Service delivery	113
4:5 METHODOLOGICAL STRENGTHS AND LIMITATIONS	115
4:5:1 Aims and design	115
4:5:2 Sampling	116
4:5:3 Data collection and data analysis	118
4:6 CONCLUSIONS	119
REFERENCES	121

LIST OF FIGURES AND TABLES

List of figures

Figure	Page number
1. Ecological model of parenting and social support (replicated from Booth and Booth, 1994, p64)	30
2. Diagrammatic representation of the Superordinate and Subordinate themes	56
3. Feedback loop : “ <i>Extra</i> ” Expectations	91
4. Feedback loop: Collaboration	96
5. Feedback loop: Strategies for coping	100
6. Feedback loop: Identity	103
7. Diagrammatic representation of the interpersonal contexts of parenting with formal support	105

LIST OF APPENDICES

Appendices

- | | |
|-------|--|
| I | Summary of The Systematic Review Search |
| II | Quality Framework for The Systematic Review |
| III | The Systematic Review Table |
| IV | Extracts from Reflective Log |
| V | Extracts from 'Bracketing Interview' |
| VI | Data Analysis Procedure: Table of Integrated Themes |
| VII | Ethics Committee Approval Letter |
| VIII | NHS Research and Development Committee Approval Letter |
| IX | Statement of Approval from Third Sector Organisation |
| X | Participant Information Sheet |
| XI | Consent form |
| XII | Professional Information Sheet |
| XIII | Semi-Structured Interview Schedule |
| XIV | Examples of Images to Supplement Interview Schedule |
| XV | Data Analysis Procedure: Extracts from Transcript |
| XVI | Data Analysis Procedure: Example of Clustered themes |
| XVII | Data Analysis Procedure: Table of Clustered Themes with Quotes |
| XVIII | Research Design Dilemma |
-

Chapter 1

INTRODUCTION

1:1 CHAPTER OVERVIEW

This chapter is split into four parts. Part 1 outlines the definition of terms; introduces the reader to the population and the common challenges faced, and describes the service, policy and legislative context, to 'set the scene' for understanding parents' experiences. Part 2 presents an overview of the literature in the area of parenting with a learning disability, including a systematic review of parents' experiences of working with professionals who provide formal support. In Part 3 the theoretical perspectives are presented. An interpersonal perspective, social constructionism and the theory of acceptance are drawn on to describe the interpersonal contexts of parenting and a lens through which parents' experiences can be understood. Part 4 outlines the rationale and aims for exploring parents' experiences of receiving formal support.

PART 1: SETTING THE SCENE

1:2 DEFINITION OF TERMS

1:2:1 Learning disability

It is necessary to think about the term '*learning disability*' as different terms exist and are used interchangeably. This is partly a result of the fact that the term is socially constructed, therefore, what it means and how it is defined has changed over time (Hatton, 2012). The main commonality can be found in the fact that the different classifications are focused on the person's deficiencies. The most commonly used terms in the UK are '*learning disability*' or '*intellectual disability*' (McGaw, 2012), other terms include '*learning difficulties*', '*mental retardation*', '*mental handicap*' and '*developmental disability*'.

In *Valuing People: A New Strategy for Learning Disability for the 21st Century*, the Department of Health (2001a, p14.) describes an individual with learning disabilities as having:

- “A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development”.

In the paper, adults are further categorised in terms of mild/moderate disabilities and severe and profound disabilities, depending on the level of impairment. It is proposed that most parents with learning disabilities fall within the mild/moderate grouping (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008). Similar definitions are proposed in Welsh policies such as, *Fulfilling the Promises: Report of the Learning Disability Advisory Group* (Learning Disability Advisory Group, 2001). A recent revision of the classification, provided by The American Association on Intellectual and Developmental Disabilities (AAIDD, 2010), replaces the term ‘social functioning’ with ‘adaptive functioning’, and clarifies this in terms of everyday social and practical skills.

Authors such as, Olsen and Tyers (2004, p33) consider the definition more widely as an *‘inclusive definition of disability’*. It incorporates factors such as, learning disabilities, mental health, physical and sensory impairment and chronic illness, due to: “*the similar structural barriers that all disabled parents face irrespective of their particular impairments*” (Olsen and Tyers, 2004, p33.).

This study uses the term ‘learning disabilities’ in keeping with the British Psychological Society (BPS, 2000). However, the researcher was careful to think about the parents as individuals in context rather than by their label, as McGaw (2012, p.294) explains: “*Regardless of the term adopted by professionals, it is important to remember that parents usually reject such classifications anyhow and view themselves, first and foremost, as a parent rather than someone with an academic label’*”.

1:2:2 Formal support

The terms 'formal support' and 'professional support' are used interchangeably throughout this study to describe people who are paid to provide advice and support to parents with learning disabilities specifically around parenting (e.g. social workers, support workers, therapists, health visitors, midwives and community nurses). 'Informal support' is considered advice and support provided by family members, friends and members of the parents' community who are not paid.

1:3 WHO ARE PARENTS WITH LEARNING DISABILITIES?

1:3:1 The 'hidden' population

Since the deinstitutionalisation and normalisation movement in the 1960s many adults with learning disabilities have enjoyed greater freedoms, including choosing to have relationships and children. It is difficult to capture the prevalence of parents with learning disabilities in the UK due to a number of factors, namely, the poor and ever changing definition of terms (as discussed above); the practices used to screen the population, and, the: "*invisibility of many parents to official agencies*" (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008, p297). This led Booth *et al.*, (2005, p7) to describe parents with learning disabilities as a "*hidden population*".

In *A Jigsaw of services: Inspection of services to support disabled adults in their parenting role* (Goodinge, 2000), the Department of Health estimated the population of disabled parents in the UK as 1.2 to 4 million. However, the proportion of learning disabled parents is unknown. Based on a survey of 2898 adults with learning disabilities in England across 2003/4, Emerson *et al.*, (2005) found that 1 in 15 (7%) were parents. Howarth (2009) reported the approximate number of parents with learning disabilities in Wales using questionnaires and short assessment tools sent to services. She found that 12% of people with learning disabilities in Caerphilly are parents, which extrapolated across Wales, gave a total of 1, 210 families, where at least one parent has a learning disability. To contextualise the international figures, Pixa-Kettner (2008) completed a nationwide questionnaire survey in Germany in 2005 of service provider reports, and found 1584 families headed by persons with learning disabilities, with 2164 adults becoming parents between 1990 and 2005. A

40% increase was reported in the number of people with intellectual disability becoming parents compared to an earlier study in the 1990s. The author highlights the limitations of comparing international data due to the differences in the definition of terms.

Despite the lack of clarity around prevalence, parents often feature on the caseloads of practitioners (e.g. nurses; social workers; therapists, and health visitors), with involvement often starting too late, in response to difficulties. The result: *“all too often ends with [children] being taken away”* (Booth *et al.*, 2005, p8). Based on their survey, Emerson *et al.*, (2005) reported that only 52% of parents looked after their children. A wealth of literature documents the outcomes of care proceedings for such parents (Booth *et al.*, 2005; Booth & Booth, 2005; Pixa-Kettner, 2008), which highlight negative and traumatic experiences. Interestingly, based on their nationwide survey in Germany, Pixa-Kettner (2008, p315) concluded that: *“parents who live without professional support seem to have better chances of living with their children than parents who draw on professional support”*.

1:3:2 Common challenges faced by parents with learning disabilities

Even if adults with learning disabilities are able to overcome the huge challenge of becoming parents, they are often left to face a number of other significant challenges in their role. Mayes and Bjorg Sigurjonsdottir (2010) describe the oppositional attitudes parents face from the people in their support network, including suggestions for abortion and (or) adoption, due to concerns about the parent’s ability. Mayes *et al.*, (2008) reported that one of the ways that mothers cope is to ‘*actively negotiate*’ their support networks to include only people who acknowledge them as the most important people for their baby.

Significant environmental stressors and poverty, poor standards of living, and a lack of social support are key determinants of parental difficulties (McGaw & Newman 2005). Resources that are lacking in this population, such as, safe housing and amenities (e.g. food, clothing, toys) are key resources that most parents rely on. IASSID: Special Interest Research Group on Parents and Parenting with Intellectual Disabilities (2008) report poorer psychological well-being relative to other non-disabled parents in their community. They report how parents with learning

disabilities are often unable to access opportunities afforded to parents without disabilities, such as, parenting role models, educational materials and a support network providing guidance and practical help. Mirfin-Veitch (2010 p96) describe how *'Citizenship'* and *'Community participation'*, that is, feeling part of a range of social networks and a sense of belonging in a community, are missing for parents with learning disabilities. As a result, many advocate a need for long term, flexible support for parents to enable them to overcome these social disadvantages (McGaw and Newman, 2005).

Even when parents are able to access formal support, one of the challenges they face is the: *"considerable -and probably permanent- tension between protecting children and upholding the rights of parents"* (McGaw & Newman, 2005, p3), Typically, formal support is focused around risk to the child, and while maintaining the welfare of the child is paramount, this approach often ignores both the sources of resilience in the child's life and the needs of the parent (McGaw & Newman, 2005). In addition, Booth and Booth (2005, p.109) stated that parents with learning disabilities: *"... are more likely to be involved in child protection investigations, more likely to be subject to a care application and more likely to lose their children than any other group of parents."*

1:4 SERVICE PROVISION

1:4:1 The current picture

The service provision for parents with learning disabilities across the UK is variable and inequitable. Based on responses to a website questionnaire, Tarleton *et al.*, (2006) provide an insight into the wide range of services supporting parents with learning disabilities in the UK. This included: community learning disability teams; social services; advocacy services; children's services (e.g. home start and sure start) and People First. Whilst fluctuating in size, the teams were typically small. The degree to which supporting parents was a priority varied greatly. In addition, the eligibility of services varied (i.e. what services classified as impaired intelligence as measured by a IQ test) and the number of parents supported by these services ranged from fewer than 10 to more than 50. Just under half of those who responded

reported receiving specific training for working with parents with learning disabilities, but the majority received no support in their role.

Local services are recognising the need to think about the provision of support to parents with learning disabilities. In the adult and children's services in Aneurin Bevan Local University Health Board, and Carmarthenshire's Family and Children Team, policies are being developed. Cornwall set up the first specialist parenting team, and others now exist across the rest of the UK. Tarleton and Porter (2012) have recently evaluated and reported the success of the Valuing Parents Support Services (VPSS) in Bristol. In addition to public services, People's First is an invaluable support to many adults with learning disabilities and Carmarthenshire's People's First, in 2010, became the first to employ a family advocate to work solely with parents with learning disabilities. Furthermore, a number of parent networks have been setup across the UK (e.g. in Bristol and in north and south Wales).

1:4:2 Legislation, policy and 'best practice' guidance

1:4:2:1 Legislative framework

The responsibilities of children and adult services in supporting parents with learning disabilities are outlined by the following legislative frameworks:

- The implications for children of having inadequately supported parents are described in the National Health Service and Community Care Act (1990). It stated that where possible children should be looked after by their own parents, and that parents should be offered respite care services and practical support to facilitate parenting.
- The Disability Discrimination Act (1995; 2005) demands that services adhere to the rights of adults with learning disabilities to have information made accessible through 'reasonable adjustments'.
- Service provider's attention to the rights of disabled individuals has been invigorated once again through the Equality Act (2010) which promotes equality of opportunity for disabled parents.

1:4:2:2 Policy framework

Relevant policy frameworks and their implications for services supporting parents with learning disability are described below:

- The aims of: *A Jigsaw of services: Inspection of services to support disabled adults in their parenting role* (Goodinge, 2000, p1) is: “*Providing support for parents to help them bring up their children better*”. The policy states that critical decisions surrounding children of learning disabled parents should not be made on inappropriate or inadequate information and: “*a philosophical and practical shift in the approach to working with disabled parents is required.*” (Goodinge, 2000, p2).
- The White Paper: *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Department of Health, 2001a). In recognising the needs of parents with learning disabilities, it stipulated that services should work together so that parents are given support to enhance the well-being of their children. The rights of people with learning disabilities to become parents was emphasised in the revised Department of Health (2009) *Valuing people Now: A new three year strategy for people with learning disabilities*.
- In Wales, *Fulfilling the Promises: Report of the Learning Disability Advisory Group* (Learning Disability Advisory Group, 2001) outlined the role of services to offer good quality information, and emphasised the need for well trained staff, who are able to work in ways that don't take away the control people want over their own lives.
- *Every Child Matters: Change for Children* (HM Government, 2003) aims services towards supporting children to be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic well-being. It stipulates the need to deliver better support to parents with children across the age range to achieve its five outcomes.
- The National Service Framework for Children and Young People and Maternity Services (Department of Health and Department for Education and Skills, 2004) highlights the need for the early identification of support needs and evidenced-based, multi-agency support.
- In: *A life like any other?* (Joint Committee on Human Rights, 2007-08) parenting and family life was examined. Conclusions were made that for

adults with learning disabilities, their right to respect for family life was not being upheld and recommendations were made for more information for parents to be made more accessible.

- Commission for Social Care Inspection (CSCI, 2009): *Supporting disabled parents: A family or fragmented approach* reported how disabled parents struggle to access all services, that professionals make assumptions about parents with learning disabilities capacity to parent, that expectations were tougher than for other parents, and that parents want support in their own right and to have their parenting role recognised. It advocates better joint working between adult and children's services.

1:4:2:3 'Best practice' guidance

Much of the research around parenting with a learning disability has led to 'good practice' guidance. Booth and Booth (1994), in the context of their own study and the existing literature, provide a set of good practice guidelines grounded in the parents' accounts of their needs and concepts of: normalisation; 'ordinary living'; community care; rights and citizenship; good parenting, and social justice and discrimination. A number of documents (Social Care Institute for Excellence: SCIE, 2005; Goodinge, 2000; Olsen & Tyers, 2004) also outline best practice principles and structural models for delivering services. Key messages are: to recognise parents' needs, increase parent training programmes, increase parents' social networks, overcome barriers to multi-agency working and change negative attitudes towards parents with learning disabilities.

Good practice guidance has been produced for services to improve their support to parents with learning disabilities, and to increase the chances of their children living with them:

In England:

- *Good Practice Guidance on Working with Parents with a Learning Disability* (The Department of Health and Department for Education and Skills, 2007).

In Scotland, based on *Fair Deal for Families: Learning from the Experiences of Parents with a Learning Disability* (The Scottish Consortium for Learning Disability: SCLD, 2008):

- *Scottish Good Practice Guidelines for Supporting Parents with Learning Disabilities* (The Scottish Consortium for Learning Disability: SCLD 2009).

Both focus on things that can be changed and how to meet the needs of parents, rather than on impairment and limitations. Key features of good practice were: accessible information and communication; coordinated work, including referral and assessment procedures; support based on parents' needs and strengths; long term support, and access to independent advocacy.

The Department for Education and Skills and the Department of Health (Davis & Meltzer, 2007) in their document: *Working in Partnership through Early Support* developed a model of helping. 'The Family Partnership Model' identified five aspects a practitioner should know in order to be most helpful to parents. These are: 1) Helper qualities (e.g. respect, empathy and genuineness); 2) Helper skills (e.g. attention and enabling change); 3) The helping process (e.g. building a relationship); 4) Partnership (e.g. sharing power with parents leading), and 5) Outcomes (e.g. to do no harm).

1:4:3 Summary of service provision

This review of service provision has highlighted how parents with learning disabilities need to be granted equal opportunities and that services should work together to provide early, multi-disciplinary support to improve the outcomes of families. A preventative model is recommended with an approach that focuses on what can be changed to meet parents' needs rather than focusing purely on parental impairments. This approach fits with the social model of disability (Oliver, 1983). Further research is needed to increase evidence-based practice and for service development.

PART 2: THE LITERATURE

1:5 TRENDS IN RESEARCH

Llewellyn *et al.*, (2008) propose that over the last six decades of research on parenting with a learning disability, there have been three distinct phases in the literature. The first focuses on the heritability of learning disability and the vulnerability of children born to parents with learning disabilities. Llewellyn *et al.*, (2008) note that, thankfully, the question of whether adults with learning disabilities should be able to have children is no longer being investigated. The second phase shifted focus to the question of parental adequacy and the efficacy of intervention programmes aimed at improve adequacy. The third, current, wave (of which the current study is aligned) focuses on 'the family in context', with researchers seeking to understand more about the conditions and lives of parents with learning disabilities. To set the scene for the current study, key research aligned with the first two phases are described below, and research from the third phase is addressed in the systematic review.

1:5:1 Outcomes for children born to parents with learning disabilities

Findings from studies investigating developmental vulnerability, report lack of clarity about what developmental changes occur as a result of being born and raised by parents with learning disabilities (McGaw & Newman, 2005). However, associations between the parental psychopathology (due to childhood trauma) and the child's attention difficulties, expressive language skills and emotional wellbeing (McGaw *et al.*, 2007) have been shown. Significant correlations were found between parenting stress, parenting style and perceived child problem behaviours (Aunos *et al.*, 2008). The cause is proposed to be a result of neglect, due to poor education and lack of support systems (McGaw & Newman, 2005; McGaw, 2012).

McGaw *et al.*, (2007) noted that study designs limit understanding of the developmental trajectory of the child's psychological well-being in the longer term. Cleaver & Nicholson (2007) conducted multifaceted, longitudinal research over six years. They compared the developmental needs and circumstances of a large sample of children referred to social care living with a parent with learning disabilities

with those who do not, across the years. They found: enduring problems for children classified as having developmental needs or experiencing multiple problems, families with committed support from a non-abusive adult enabled the safeguarding and welfare of their children, and a need for continual informal and formal support. Llewellyn (2013) advocates for further research regarding the long term needs of children born to parents with learning disabilities, for example, for when they become parents themselves.

1:5:2 Parental adequacy and ability to be ‘good enough’

Research exploring parental competence has revealed both, the over-representation of parents in care/court proceedings regarding the welfare of their child (Booth *et al.*, 2005) and parents ability to be ‘good enough’ (Booth and Booth, 1994; 1997; Llewellyn, 2013). The concept of ‘good enough’ parenting was coined by Winnicott (1974), however, there is a lack of clarity surrounding what is ‘good parenting’. In her paper, Llewellyn (2013, p83) uses Hoghughi and Speight (1998) to present the following definition: “ *‘Good enough parenting’ may be defined as a process that adequately meets the child’s needs, according to prevailing cultural standards which may change between generations. The care needs include physical care, nutrition and protection. The emotional needs may include: (1) love, care, and commitment; (2) consistent limit setting; and (3) the facilitation of development.*”

In reflecting on her research Tarleton (2010, p161) explains: “*Parenting is not an ‘exact science’ and each of the often numerous professionals who came into contact with parents with intellectual disabilities had his or her own concept of ‘good parenting’*”. Interesting findings have emerged from studies exploring the perceptions of parenting. Willems *et al.*, (2007) asked caregivers to measure, through questionnaires, ‘successful parenting’ by adults with learning disabilities and found 51% of cases were regarded ‘not good-enough’, 33% were ‘clearly good enough’ and 16% were ‘doubtful’. A difference in perception of need was identified between parents, workers and significant others (Llewellyn *et al.*, 1998).

These studies raise questions about the definitions of ‘good enough’ and ‘successful parenting’ and despite researchers going to great lengths to define their use of terms in studies, it is impossible to know what respondents base their judgements of

parenting on. Despite criticisms, the studies provide the context in which adults with learning disabilities are expected to parent. McConnell and Bjorg Sigurjonsdottir, (2010, P184) state: *“practitioners must ensure that when assessing parenting capacity, they do not use a yardstick based on the ‘ideal’ parenting that represents a particular privileged socioeconomic group”*.

The literature clearly states that: *“competent parenting is not solely dependent on the abilities of the parent”* (Booth & Booth, 1997, p3). Cleaver and Nicholson (2007) reiterate this in their longitudinal study, which identifies the influences of wider social and historical factors and the environment on parental ability. Thus, the dimensions of child outcomes, social support and parental competence are considered interconnected (Booth & Booth, 1997). Olsen and Tyers’ (2004) review on disabled parents concludes there is the need to challenge an automatic focus on the capacity to parent.

1:5:3 Intervention programmes and their effectiveness

These studies raised the question of whether or not parents’ with learning disabilities can be adequate parents, and many deemed that parents needed training to be ‘good enough’. Wade *et al.*, (2008) reviewed types of interventions offered and identified; group and individual education programmes (typically with a behavioural focus and both at home and in centres), booklets posted to parents, informal visits, and self-instructional pictorial manuals and audiotapes. The usefulness of parent education programmes (i.e. teaching methods matched to the parents’ learning needs) has been extensively evaluated (Mildon *et al.*, 2008). However, McGaw (2012) said the comparability across studies is difficult due to poor definition of terms such as, ‘success’ and the differences in the population sampled.

Feldman (1994) and Wade *et al.*, (2008) reviewed 27 studies exploring the effectiveness of parent training interventions and found the skills trained included, basic child-care, safety, nutrition, problem solving, positive parent-child interactions, and child behaviour management. The most common instructional approach was behavioural (e.g. task analysis, modelling, feedback, reinforcement). Wade *et al.*, (2008) extended the literature by showing how self-instructional manuals appear to have positive implications for teaching new skills to parents in a cost-effective way.

The efficacy of interventions is questioned due to the fact that they typically fail to account for contextual factors related to intervention success, such as on-going simultaneous interventions (Wade *et al.*, 2008). Many interventions are brief, and while typically one year follow-up's show the impact for parents overcoming challenges in the short term, there are still questions over their ability to effect change in the long term. Furthermore, the findings are based only on the participants 'willing' to take part, which reduces wider generalisation of effectiveness (Mildon *et al.*, 2008).

1.6 A SYSTEMATIC REVIEW OF PARENTS' EXPERIENCES OF RECEIVING FORMAL SUPPORT

1:6:1 Introduction

The current study aimed to understand what it is like to be a parent with learning disabilities receiving formal support. This is aligned with the third phase of research on parenting with a learning disability. By focusing on the 'family in context' the third phase has moved away from focusing just on the parent, their ability and whether they respond to intervention programmes (i.e. thinking about parents in terms of the academic label given to them). Instead, researchers have sought to better understand the lives of people with learning disabilities. Much of the research examines the support networks of parents, in keeping with the policy and legislative context (which highlights the roles and responsibilities of formal support networks). The role of family members has been identified as '*bridging*' the relationship between parent and services (Traustadottir and Bjorg Sigurjonsdottir, 2008); it has been found to be '*actively negotiated*' by expectant mothers (Mayes *et al.*, 2008), and as providing the most help to parents in their parenting role, boosting self-esteem and increasing positive affect (Kroese *et al.*, 2002).

Studies exploring the composition of support networks found parents with learning disabilities: are typically isolated from their communities (Llewellyn & McConnell, 2002); have higher levels of service-centred networks when they have less family members (Llewellyn & McConnell, 2002; Llewellyn *et al.*, 1999); view the most important people in their lives as family members, professionals and friends (Guinea,

2001), and, want more knowledge of, and support from, community services (Llewellyn *et al.*, 1998). This is mirrored in the wider disability literature which highlights the role of professionals in enabling and disabling successful parenting, and of advocacy and peer support networks in supporting disabled parents (Olsen & Tyers, 2004).

The research, both quantitative and qualitative, has moved towards asking parents about their experiences, but typically with mothers of young children. Research focused on learning disabled fathers, while limited, has revealed how fathers are disadvantaged and disempowered by services which typically focus on mothers and the child (Bjorg Sigurjonsdottir, 2004). Literature where the parents have been involved in the writing of papers has also started to emerge. Strike and McConnell (2002) present Robert Strike's personal account of being a parent with a learning disability. Robert's key message is that there is not 'one way' of parenting and parents should have the choice to choose how they want to parent.

What parents think about their interactions with professionals, how they relate, what barriers to working together exist and the impact of receiving formal support is less well known. In order to identify previous research, and provide up-to-date knowledge regarding the experiences of parents with learning disabilities receiving formal support, a detailed 'systematic review' was conducted. The specific aim of the review was to better understand: *What are parents' experiences of working with professionals who provide formal support?*

In the following sections of the systematic review the reader is taken through the search strategy (section 1:6:2:1), the inclusion criteria (section 1:6:2:2), and the exclusion criteria (section 1:6:2:3) used for identification of relevant studies. The framework used for assessing the quality of the key studies is introduced (section 1:6:2:4), followed by the results of the review (section 1:6:3). In the discussion (section 1:6:4) the results of the systematic review are integrated with the wider literature (section 1:6:4:3).

1:6:2 Method

1:6:2:1 The search strategy

Five electronic databases were searched: PsycINFO; EMBASE; Ovid Medline (R); AMED and PsychArticles Full Text. Additional papers were also found manually through a search of the Cochrane Library and through the reference list of other articles and key journals, such as, *The Journal of Applied Research in Intellectual Disabilities*.

The researcher was unsure of the number of explorative studies relevant to the topic so conducted three separate searches, starting with a broader search and narrowing search terms to increase funnelling. Appendix I presents a diagrammatic summary of systematic review search process. The search terms: Learning Disabilit*; Intellectual disabilit*; Developmental Disabilit*; Parent*; Child*; Service user*; Perspective; View*, and Service*, were combined with 'and' / 'or' / 'not' Boolean operators. Titles and article abstracts were reviewed (N= 2675) in accordance with the inclusion and exclusion criteria, resulting in 10 studies for detailed systematic review. These search terms also generated articles and literature that is discussed in the wider exploration of literature.

1:6:2:2 Inclusion criteria

The following criteria were used to identify studies relevant to the systematic review question:

- evaluative studies across the time period of 1990-2012 in the English language;
- studies that qualitatively examined parents' views of formal support, and
- studies with parents who had at least one child living at home.

An initial review of the literature identified a number of studies split into two parts, exploring both parents' and professionals' views (N=4). Due to the limited amount of research focused purely on parents' views (N=6), the researcher decided to include these studies, but only review and comment on the data referring to parents' views.

1:6:2:3 Exclusion criteria

The search strategy identified quantitative and qualitative literature with different research aims. This included: *professionals' views* of the experiences of parents with learning disabilities (Tarleton *et al.*, 2006; Llewellyn *et al.*, 1998; Howarth, 2009); parents' perception on *support needs* during pregnancy (Mayes *et al.*, 2008; Conder & Mirfin-Veitch, 2010) and during parenting (Llewellyn *et al.*, 1998); parents' views and experiences of *informal support networks* (Kroese *et al.*, 2002); and quantitative research using measures, such as tick lists, to elicit parents' experience (Guinea, 2001). This study aimed to elicit parents' views and experiences of receiving formal support around parenting. The aim of the systematic review was to identify existing literature with similar aims to enable a thematic analysis of findings. Therefore, studies, such as these, were excluded from the review because of their different research aims, or because the lack of rich detail of parents' accounts did not enable sufficient understanding of their experiences.

Specifically, studies were excluded from the systematic review when:

- Quantitative in nature, or when quantitative analysis was used despite a mixed methodology (due to the lack of 'rich' detail in data).
- The focus was on parents with all children removed.
- Not focused on parents with learning disabilities.
- Focused purely on identifying types of support, rather than exploring perceptions of support.

Studies reported in book form were excluded, but, as is the case with much of the excluded literature, they contributed to the wider discussion of findings.

1:6:2:4 Assessment of Quality

The 10 studies included in the systematic review were assessed for reliability using a quality framework (see Appendix II). The systematic review table (see Appendix III) incorporates a brief description of each study together with an assessment of the quality criteria, according to the quality framework. Based on Chenail (2011) a simple ranking scale ranging from 0-2 was used to assess the quality criteria in relation to the specific components of each study: aims and design; sample; data collection and data analysis, and findings and discussion of findings. The total quality rank for each

study was 16. A total ranking of less than 50% (8/16) rendered the study unreliable and untrustworthy and, therefore, excluded from the analysis.

The total ranking for studies in the review ranged from 7 to 15. Tymchuk's (1999) study (using parent focus groups with the aim of eliciting their views on the possibility of integrating services and making support more 'even') scored 7 / 16. Examples of poor quality in this study included no description of the sample and no quotes to support findings. Therefore, the study was excluded from this review because it did not meet quality standards and the results could not be reliably interpreted.

Two further studies (Wade *et al.*, 2007; Ehlers-Flint, 2002) were also excluded because their use of open ended questionnaires and inventories rather than semi-structured interviews, meant a lack of richness in detail of accounts (i.e. data), which was not conducive to the thematic analysis employed in this review. However, their findings are integrated in the discussion of the systematic review. This left the researcher with seven explorative studies of good quality, which are now presented and systematically reviewed.

1:6:3 Results

The results are presented in three sections. The first section, 'Type of support', describes the different types of support the parents received, for example, practical support. It also outlines recommendations for professionals providing formal support. The second section, 'Attitude and approach', is used to describe the interaction between the professional and the parent, and draws on concepts such as, power, communication and key professional qualities. The third section, 'Outcomes', is used to describe the parents' experience of the impact of receiving formal support, including, isolation, dependency and the learning of new skills. The reader is first taken through a summary of each study before the main findings are explored. A detailed summary of each study, including their design, sample, data collection and data analysis procedures and the findings can be found in Appendix III.

By adopting a qualitative framework, all the studies included in the review used semi-structured interviews to elicit parent's views on working with professionals who provide formal support. Starke (2010) interviewed seven Swedish mothers to elicit

their views regarding their interaction with health and social care practitioners. Llewellyn (1995) interviewed six couples about their relationships and social support in parenting. MacIntyre and Stewart (2011) interviewed five mothers, five advocates and four stakeholders to elicit views on the lived experiences of parents living in Scotland, and the role of advocacy in supporting parents. Booth and Booth (2005) interviewed 25 parents to explore their experiences of care and court proceedings. Tarleton and Ward (2007) interviewed 30 parents to explore their views on 'positive practice' by professionals. Wilson (2011) interviewed six mothers to explore their experiences of postnatal care. Howarth (2009) interviewed 11 parents to elicit parents' views on examples of good professional support.

1:6:3:1 Type of support

The parents described the different types of support experienced in all of the studies. Support was not always welcome, especially when the professionals gave conflicting advice (Llewellyn, 1995). In fact, some aspects of the support, such as assessment of parental ability and court proceedings, were viewed by parents as traumatic (MacIntyre and Stewart, 2011; Booth and Booth, 2005). Advocates were viewed as helpful in mediating some of the challenges with other support received (Booth and Booth, 2005; MacIntyre and Stewart, 2011).

Alongside these challenges, helpful practical support for overcoming problems was central to many parents' experiences (Howarth, 2009; Tarleton and Ward, 2007). This included, resolving problems that the extended family were unable to accomplish (e.g. debt and poor housing). The parents in Starke's (2010) study valued information that helped them to better understand everyday life and make better decisions for their children. Other parents in this study described how techniques used by the professional (e.g. videoing their interactions with their children and positive feedback) were empowering. As well as practical advice, emotional support was valued by the parents in Wilson's (2011) and Tarleton and Ward's (2007) studies. It was important to the parents in this study that the professionals made themselves available and that they had someone to talk to. This was often a professional the parent had regular contact with and was most familiar with.

Llewellyn (1995) and Starke (2010) identified that parents felt that they ‘needed’ their formal support network, despite some of the negative outcomes experienced. Starke (2010) noted how encounters with professionals became an important part of everyday life. In her analysis of parents’ experiences, Llewellyn (1995) identified a preferred sequence of helping, starting with the parent’s partner, then family members and ending with the professional. This sequence depended on the type and urgency of the support required and on the confidence in the person providing it. Llewellyn (1995) noted that the parents in her study sought support from professionals in novel or emergency situations.

Recommendations regarding the delivery of support were made as a result of parents’ experiences in these studies. This included the need for long term support and to see the role of support as a fluid package (i.e. meeting the needs of each parent in their particular circumstances over time) (Howarth, 2009). Parents’ also gave advice to professionals, regarding treating the parent in the context of their family, not as a separate entity (Howarth, 2009; Booth and Booth, 2005). Joint working between agencies and a need for early intervention and a move away from short term, crisis driven support, was recommended in Tarleton and Ward (2007) and MacIntyre and Stewart’s (2011) papers. Howarth (2009) also highlighted that the only service parents wanted more of was respite care for their children.

1:6:3:2 Attitude and Approach

A shared experience across all studies reviewed was how the attitude and approach of the professional was central to the parents’ experience of receiving formal support. Starke’s (2010) theme summed this up well; she wrote how parents wanted to be: ‘*supported in a meaningful way*’. Booth and Booth (2005, p115) stated that the factor that determined whether the parent got on with the social worker or not: “*all boiled down to their attitude and to the parents’ perception of what their practitioner thought of them*”. Howarth (2009) found, in exploring: ‘*what is good support?*’, that it is something with minimal cost implications as it is mainly down to attitude and approach. The communication skills of the professionals were important to the parents in many of the studies. Starke (2010) described parents’ experiences of incomprehensible or a ‘*lack of*’ information. MacIntyre and Stewart (2011) reported parents’ experiences of a lack of reasonable adjustments to make meetings more

accessible. In comparison, Tarleton and Ward (2007) explained how professionals acted as mediators in supporting the parents to understand events and become active participants in court proceedings.

Being reliable (Howarth, 2009), trustworthy (Wilson, 2011; MacIntyre and Stewart, 2011), helpful (Booth and Booth, 2005) and respectful (Tarleton and Ward, 2007) were named as important qualities in parents' interactions with professionals. Overwhelmingly, the importance of being listened to was central to the parents' experiences of receiving formal support in all of the studies reviewed. Llewellyn (1995) and Wilson (2011) described how parents found support to be unwelcome when they felt ignored. These qualities determined whether the parent could use the expertise of the professionals and they appeared to influence the relationship between parent and professional.

Power, or more accurately, disempowerment, was central to parents' experiences of receiving formal support in all of the reviewed studies. In Wilson's (2011) study, a theme around: *'Feeling told what to do'* highlighted a lack of collaboration between parent and professional. MacIntyre and Stewart (2011) described how some parents described experiences of being disempowered by their professionals (e.g. *doing* the cooking rather than *showing* them). Booth and Booth (2005) considered the imbalance of power in relation to those parents who do not accept the professionals' interpretation of the situation. Such parents are more likely seen by professionals as incapable. In Tarleton and Ward's (2007) study, their parents valued services that treated them as equals and as adults.

Six of the seven studies named the unhelpful impact of feeling judged by professionals. While some reported how being judged enabled the parents to also receive positive feedback (Wilson, 2011), feeling accused, *'not being believed'* and having their ability questioned was difficult for parents (Starke, 2010). MacIntyre and Stewart (2011) wrote how the parents in their study felt criticised, stigmatised and discriminated against. Howarth (2009) explained how being judged led the parents in her study to be suspicious of their professionals as they often felt watched rather than supported. Booth and Booth (2005) described parents' experiences of not knowing what standards to live up to. Tarleton and Ward (2007) highlighted how

parents valued professionals who treated them with an open mind, and did not have negative expectations of them. They described how good support can enable parents to be: *'good enough parents'*.

1:6:3:3 Outcomes

Integral to the experiences of the parents across all studies was the outcome of receiving formal support in parenting. Outcomes are described in terms of intrapersonal and interpersonal factors.

Many of the reviewed studies described the intrapersonal outcomes of working with professionals. Llewellyn (1995) described how the parents had a negative appraisal of self which left them isolated. Wilson (2011) described how being judged by professionals led parents to put extra pressure on themselves and it challenged their ability to cope with childcare. She also described how the continued presence of a professional, which exceeds the usual pathway of care, appeared to lower the parents' expectations of ability.

Most of the studies also talked about the emotional impact of professional involvement. Booth and Booth (2005) reported the negative emotional impact of child care proceedings. Starke (2010) described how *'Improper treatment'* typically led to frustration and associated expressive reactions. Wilson (2011) highlighted the wariness from parents of professionals and the difficulty they had in believing that they would keep their child[ren]. In contrast, Tarleton and Ward (2007) described how some parents felt that professional support enabled them to show off their skills which ultimately enabled them to keep their child[ren].

Tarleton and Ward (2007) described how 'good support' helped parents to build confidence, to feel better, and to get their voices heard. Advocacy had a specific role in supporting parents to have a voice (MacIntyre & Stewart, 2011). Tarleton and Ward (2007) also described how professionals supported parents to: *'develop and learn'*. This included learning about practical tasks such as buying children's items, routines for the children, how to deal with paperwork and how to control the home environment. They discussed the relevance of the professional fostering

relationships between parents and other professionals, in particular, those from children and family services.

Llewellyn (1995) named the isolation that many of the parents in her study experienced. This meant that many of the parents across the studies were reliant on support, either professionally (Llewellyn, 1995; MacIntyre and Stewart, 2011; Booth and Booth, 2005) or informally. Three of the studies specifically reported how parents benefited from peer support (Tarleton and Ward, 2007; Howarth, 2009 and Wilson, 2011). Tarleton and Ward (2007) described how parents enjoyed the support they received from other parents. New friends seem to restore their sense of being listened to and of having someone else to talk to. However, parents often relied on professionals in the design and organisation of peer support groups (Howarth, 2009). This high level of dependency, led to a sense of being out of control and a need for the professional to be reliable (Howarth, 2009).

1:6:4 Discussion

1:6:4:1 Summary of findings

The studies reflect the different ways in which parents were supported and their experiences of receiving formal support in parenting. There was ambivalence around the helpfulness of support despite most parents acknowledging the role of professionals as part of their everyday life. Types of support described as helpful included advice and practical support (e.g. solving problems that those in the informal support networks were unable to). Parents valued emotional support from professionals they were most familiar with. The attitude and approach of the professional was core to the parents' experiences. Parents valued professionals who were reliable, trustworthy, listened to them and treated them fairly. The common outcomes of receiving formal support included: a reliance of informal and other forms of formal support, specifically advocates; negative emotional impact and wariness about whether or not they would keep their child[ren]; learning new skills, and, an altered perception of self.

1:6:4:2 Strengths and limitations of the key studies

Data analysis and the presentation of findings

Of the seven studies reviewed only four provided an interpretative account using: Textual Analysis (Starke, 2010); Grounded Theory (Llewellyn, 1995; Tarleton and Ward, 2007), and Interpretative Phenomenological Analysis: IPA (Wilson, 2011). The remaining three studies did not specify a model of data analysis, giving a descriptive account of findings (Booth and Booth, 2005; MacIntyre and Stewart, 2011; Howarth, 2009). In MacIntyre and Stewart (2011), because the main themes reflected the integration of the different participants' views (parents and professionals), it is unclear when reading the results the origin of quotes. Furthermore, the lack of 'thick' description of quotes brought further doubts on the credibility of the findings. In comparison, while Howarth (2009) and Booth and Booth (2005) did not specify the type, a clear process of data analysis was specified in both, demonstrating good transparency and credibility. On the whole, multiple sources of data, or methods of collection and triangulation evidenced good credibility, making findings trustworthy.

Only two studies (Llewellyn, 1995; Wilson, 2011) provided a self-reflexive account outlining the researcher's subjective values and biases. In other studies the researchers' contribution to the construction of meaning in the findings was not made clear (Willig, 2008). Howarth's (2009) findings would be more sincere with the inclusion of a self-reflexive account, especially due to personal judgements included such as: "*it is unacceptable*".

Sampling

Four of the studies had small sample sizes (Starke, 2010; Wilson, 2011; Llewellyn, 1995; MacIntyre and Stewart, 2011). Howarth (2009) reported findings on a sample of 11 parents and Booth and Booth (2005) and Tarleton and Ward (2007) had large samples increasing the transferability of findings. However, a common limitation across the studies was a female only (Starke, 2010; MacIntyre and Stewart, 2011; Wilson, 2011) or majority sample composition (Booth and Booth, 2005; Howarth, 2009; Tarleton & Ward, 2007). The wider literature has already highlighted an abundance of data related to mothers, with that of fathers lagging behind. Only Llewellyn (1995) had equal numbers of mothers and fathers, as she interviewed the parents as a couple.

While this sampling bias towards mothers brings this into question slightly, the main strengths of all studies was the significant contribution they have brought to the research literature. All studies were timely, and all of the studies except for Starke (2010) made recommendations for clinical practice or further research. The transferability was enhanced by the fact that the studies present parents' views on interactions with multiple professionals. Furthermore, while the age range of the children was not specified in Booth and Booth (2005) all the other studies included older children, contributing to the gap identified in the wider literature around the focus on younger children.

The heterogeneity of the sample was a common challenge for the researchers in the reviewed studies. Wilson (2011) acknowledges that in her study there was a mixture of first time mothers and mothers with other children. In Starke's (2010) study there was a mixture of parents who lived with their children and those that did not. Whilst appreciating that this reflects the reality of the complex lives that parents with learning disabilities face, and that there are no set rules around homogeneity, a heterogeneous sample has implications for what particular experience, and consequently, what meaning, is being explored (Willig, 2008). Sampling brought up further questions in the critical review of both Howarth (2009) and Tarleton and Ward (2007) as, because their studies were focused on providing 'good' or 'best practice' examples of support, the findings may not be representative of the parents' experiences with professionals more widely, and the parents whose experiences were less positive were not captured.

Interviewing people with learning disabilities

One of the challenges of completing qualitative research with adults with learning disabilities is, at all stages of the research process, making information accessible, not least so that the adults are able to consent to taking part. This often means that the literature reflects only a proportion of experiences, those adults who are not cognitively able to give consent do not have the opportunity to tell their stories. The main strengths of the studies in this review included the procedural and relational ethics. Many of the researchers went to great lengths to make their materials accessible, and many were mindful of taking time to build the relationship with

parents (Llewellyn, 1995). Therefore, it is likely that these procedures enabled researchers to access a more varied proportion of stories. However, the researcher was mindful of the limitations of Wilson's (2011) study, due to its retrospective nature it is possible that findings could have been affected by challenges with recall and cognitive difficulties.

Definition of terms

The resonance and transferability of the findings in the studies are brought into question by the poor definitions of terms. Given the historical evolution of the classification of what is now termed '*learning disability*', and the international grounding of the papers, it was surprising to find that most of the studies did not define this, or provide some indication as to whether the parents had mild/ moderate or severe and profound learning disabilities (Starke, 2010; MacIntyre and Stewart, 2011; Booth and Booth, 2005; Tarleton and Ward, 2007; Howarth, 2009). Whilst appreciating the sensitivity and challenges of the classification and the acknowledgement that many parents want to be seen first as parents rather than a label (McGaw, 2012), maximising the transferability of findings and successful implementation of the recommendations made, is dependent on the reader knowing the population of the sample.

A lack of clear definition of terms also extended to other key concepts in the studies. For example Wilson (2011) failed to classify what she meant by the term '*postnatal period*'. The time frame of this period was not specified, therefore, it was not clear what type of phenomenon she was exploring and ultimately how to implement the recommendations made. Furthermore, as explained earlier, this study was retrospective in nature, but the researcher failed to specify the time frame that parents reflected back on. Studies, like Llewellyn (1995), that clearly defined what type of support was experienced (e.g. friend, family, professional), or like MacIntyre and Stewart (2011) that named a specific group of professionals (e.g. advocates) were more transparent.

1:6:4:3: *Integration of review findings with wider literature*

In their two-stage longitudinal study with 25 parents with learning disabilities, Booth and Booth (1994) reported a theme of: "*The price of support*". This reflects many of

the same themes presented in the review studies, including: wanting support for emotional needs, being judged against inappropriate standards, and the professional taking control and not enabling decision making. As opposed to the studies in the review, Booth and Booth (1994) used psychological theory to understand how the professionals' perceptions of parental competence influenced how they provided support to parents, *and* the parents' ability. It also highlighted the need for practical support over the longer term, the need for continuity in care and coordination amongst different providers.

There are contrasting findings from studies surrounding what parents' value most from caregivers. Ehlers-Flint (2002) used a series of questionnaires with 20 mothers. They found perceptions of support (particularly emotional support) to be of most value rather than interference from their social networks (which included therapeutic workers). The therapists' abilities to genuinely hear their concerns, their attitude, and the quality of the relationship were highlighted. The importance of the relationship between therapeutic interventions and parenting attitudes in mothers, specifically their perceptions and attitudes of parental ability, especially around disciplining their child was apparent.

This contrasts with Wade *et al.*, (2007), who categorised the responses of 32 parents using Dunst *et al.*, (1991) and Dunst's (2002) concepts of family-centred and professionally-centred care. The study reported that parents found 'family-centred practices' (i.e. practices focused on parents' strength's, where the parent is an active agent and can make informed decisions) more helpful than those that were 'professionally centred' (i.e. practices where the professional is the expert). However, parents found 'participatory help-giving' more helpful than 'relational help-giving'. Parents preferred practices that were capacity building and focused on practical support, rather than the relational aspects such as the helper's qualities. The studies in the systematic review, by emphasising the importance of the attitude and approach of the professional, refute the second finding from Wade *et al.*, (2007) and are consistent with Ehlers-Flint (2002). This finding is consistent with the wider literature in the learning disabilities field, which has evidenced the way in which caregivers deliver support as more important in treatment success (Roeden *et al.*, 2011).

1:6:4:4 Implications for research

The views and perspectives of parents are only recently starting to be represented in the research. Of the seven studies in the review, only six are relevant to the UK, and together only represent a small proportion of voices. Much of the research is based on mothers' views, and the experiences of parents of older children are still not well understood. Findings are not integrated with psychological theory and the quality of current studies is questioned by the subjective nature of terminology such as, 'good enough' and 'supportive parenting'. To increase understanding about the lived-experience of parents with learning disabilities further research is needed.

1:7 SYNTHESIS OF FINDINGS

The literature reviewed has revealed a number of quantitative and qualitative studies that have explored the lives of parents with learning disabilities. Key messages from this literature are:

- Professionals appear readily in the lives of parents with learning disabilities, and mothers living alone are more likely to have service-centred support networks.
- The welfare and safeguarding of children born to parents with learning disabilities is highest when parents have continued informal and formal support.
- Parents with learning disabilities are able to learn skills in childcare, safety and interacting with their children.
- The notion of parental incompetence is unhelpful and inaccurate.
- Parents with learning disabilities are over represented in care / court proceedings, and this is usually due to risk of harm due to neglect rather than abuse.
- Parents with learning disabilities are ambivalent around the helpfulness of formal support.
- Types of support described as useful include advice, practical support and emotional support.
- Parents regard the attitude and approach of the professional providing support as important.

PART 3: THE INTERPERSONAL CONTEXTS OF PARENTING: THEORETICAL PERSPECTIVES
1:8 OVERVIEW

The reviewed literature highlights a number of factors that appear to have contributed to parents' experiences of receiving formal support. Whilst theoretical concepts such as, power, control and confidence, were identified in the literature, these were poorly integrated with findings. Overall, there was very little integration with psychological models or theory. By reflecting on the wider social factors involved in parenting, studies such as, Llewellyn (1995) and Booth and Booth (1994) imply a need to take an 'interpersonal' perspective (Bronfenbrenner, 1979) to understanding the experiences of parents with learning disabilities who receive formal support.

Complimentary theoretical perspectives such as, the interpersonal perspective (Bronfenbrenner, 1979), social constructionism (Gergen, 1990; Freedman & Combs, 1996) and acceptance theory (Hughes, 2006; Hayes *et al.*, 2012) are discussed. While, individually each approach outlines the way in which parents' experiences can be understood, together the approaches provide a novel way of understanding experiences. Taken together it is proposed that they provide an interpersonal and contextual lens through which parents' experiences of receiving formal support can be understood. These theories are also used in understanding the results from the current study.

1:9 THE INTERPERSONAL PERSPECTIVE (BRONFENBRENNER, 1979)

The wider review of the literature demonstrated that parents with learning disabilities often have service-centred support networks but few with their community. The interpersonal perspective offered by Systemic approaches provides one way of understanding the nature of these interactions and how they may influence the parents' experiences of receiving formal support. Dallos and Draper (2010) explain that interpersonal approaches consider context and the feedback 'between' people. Namely, that an individual both affects and is affected by other people. Different systemic levels make up a person's social network (e.g. the immediate family, the

extended family and the social system) and the beliefs held by the different members in this support network shape actions and attempted solutions to problems. This results in a mutual pattern of interaction, influencing actions and process of change.

This perspective holds that parental ability is not a consequence of individual skill alone, but instead is constructed in the context of the parent's own models of parenting in childhood, childhood adversities, environmental constraints and pressures, discrimination, social support (or more commonly isolation) and the behaviours and expectations of others key to the parent's social network (Booth and Booth, 1994). Through their research, Booth and Booth (1994) propose that these factors make it hard to meet standards of 'good enough' parenting.

1:9:1 Interpersonal models of parenting

Many models of parenting exist that emphasise interpersonal factors and the role of social support. To measure 'good enough' parenting in adults with learning disabilities, McGaw and Sturmey (1994, p37) developed the 'Parental Skills Model'. They believed that when professionals assess parents: "*underlying many decisions is concern over the adequacy of their parenting skills*". They propose that alongside measuring 'childcare and child development', assessment should combine environmental factors such as, the 'parent's life skills', 'family history' and their 'support and resources'.

Booth and Booth (1994; 1997) adapted Tucker and Johnson's (1989) 'Model of Social Support for Retarded Parents and their Children' and demonstrated feedback loops between different contexts and people in a parent's environment. The role of the professional was highlighted more directly, they identified the detrimental impact of negative perceptions of parental competence and concluded: "*that the attitude of people providing support for parents with learning difficulties is one of the key features determining its success*" (Booth and Booth, 1994, p81). Figure 1 shows how alongside environmental pressures, the professional's attitude and approach (e.g. competence promoting or competence inhibiting) influences a parent's actual level of competence. This suggests that, professionals, with their own ideas and expectations, together with their service ideologies and contexts, both are influenced by and influence the parent's competence.

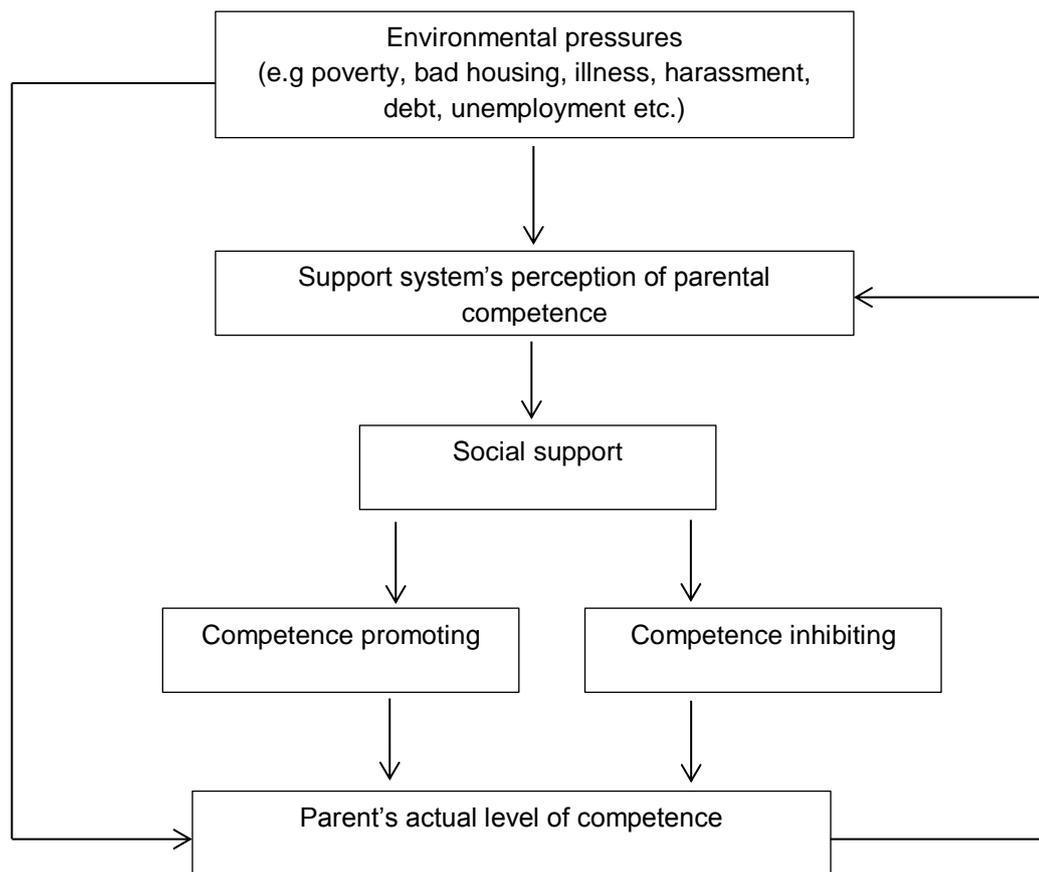


Figure 1: Ecological model of parenting and social support (replicated from Booth and Booth, 1994, p64).

1:10 THE CONSTRUCTION OF MEANING

Social constructionism and in particular, looking at how the discourse of individualism and the 'deficit model' of learning disability has shaped the approach to working with people with learning disabilities (Dudley-Marling, 2004), builds on the interpersonal perspective and provides further understanding of parents' experiences of receiving formal support. Social constructionism (aligning with a social model of disability) proposes that concepts (including parenting) need to be understood in the context of particular beliefs and ideologies of people directly involved in an interaction *AND* as being determined by wider social and cultural structures and ideologies (Dallos and Draper, 2010). In the case of ideas being explored in the present research, the theory would suggest that both the parents' and the

professionals' ideas and beliefs are shaped by shared societal and cultural values as well as personal characteristics.

1:10:1 Social constructionism and learning disability

Reid and Valle (2004) describe learning disabilities as a 'socio-political enterprise' due to the fact that experts decide the allocation of resources and the conditions of support, meaning that the disability experience cannot be separated from economic and social ideologies. In the current context, such interpretation could add understanding to some of the determining factors for experiences for both the parent and the professional (e.g. providing support using an expert or 'top-down' approach, and a negative appraisal of self).

Dudley-Marling (2004) explained that the concept of learning disability only makes sense in a context where ability (or disability) and skill is paramount, that is, a person cannot be learning disabled on their own. He gives an example of this in relation to the conceptualisation of shyness: "*Shyness can emerge in a classroom setting only if there is an expectation of conversational interaction*" (Dudley-Marling, 2004, p485). This suggests that the concept of being a learning disabled parent can only emerge if there is another person holding an expectation around ability and when an interaction takes place that requires the parent to use their skills in a certain way. Both context and expectations are fundamental to the experience. It makes sense then that parental 'ability' can only be defined in relation to the people with whom the person interacts, and receives support from, not solely in terms of personal characteristics.

1:10:2 Social constructionism and identity

Social constructionism assumes an individual's sense of self is constricted in the interaction with others (Freedman & Combs, 1996). It is thought to be made up of multiple identities (e.g. mother, friend, wife, daughter etc.) and different identities emerge in different social and cultural contexts (Gergen, 1990). Therefore, a fluid, rather than static approach to people's abilities is proposed. Dudley-Marling (2004, p484) describe how this is in contrast to dominate narratives about people: "*having essential identities that reside somewhere inside their skin.*" The researcher suggests that the label: 'parent with a learning disability', is an *identity* with its own

set of assumptions from which both parents and professionals (and people in wider society) act in accordance with.

1:10:3 Social constructionism and language

Emphasis is also given to language and labels and how this perpetuates dominant ideas and assumptions of a culture (Pearce, 2007). Furthermore, labels and meanings are shaped and perpetuated according to the differing distributions and structures of power (Dallos and Draper, 2010). Those with power are considered able to create and define labels: *“It is not simply suggested that there is a ‘real’, objective world ‘out there’ but that there are dominant beliefs, explanations, ways of thinking about the world, and in particular a shared language which construct how we see the world”* (Dallos and Draper, 2010, p96).

Dudley-Marling (2004) states that Individualism dominates Western culture, which has led to the prioritisation of success, achievement and ability. Consequently anybody who does not meet these expectations can be regarded disabled. He explains that such discourses and the *‘in-the-head perspective’* of learning disabilities has led those with power to define learning disability in terms of ‘in-ability’, ‘deficiency’, ‘dependency’ and, therefore, ‘weakness’ (Dudley-Marling, 2004, p482) . It is possible to see how this approach has driven many terms and concepts that dominate in the literature, such as ‘good enough’ parenting, and ‘competence’ versus ‘incompetence’. This has also driven services to find ways of solving or improving the deficits caused by what is predominantly seen as an ‘organic’ problem. This is evident in the parenting literature which has a wealth of studies examining the efficacy of intervention programmes, which locate the need for change within the individual (i.e. skills teaching).

1:10:4 Conclusions

Dudley-Marling (2004) describe how through a social constructionist position the label of learning disability constitutes a person’s social experience. It shapes aspirations and beliefs, and ways of being and behaving that fit with these assumptions develop. The parents’ sense of being disempowered, dependent and ‘not good enough’ may be explained by this. For those supporting people with

learning disabilities, the 'deficit model' shapes their aspirations and approaches to supporting parents with learning disabilities.

An alternative social constructionist perspective of learning disability, which may be helpful in the context of parenting with formal support, is: "*Learning problems dwell in activities and cultural practices situated in the context of social relations rather than in the heads of individual students*" (Dudley-Marling, 2004, p482). This alternative may shift the thinking, behaviour and language of others and consequently provide a less blaming and negative experience for parents.

1:11 THE CONTEXT OF ACCEPTANCE

So far, the context for parenting has been defined in interpersonal terms. The relationship has been defined as providing a context in which and out of which individuals act (Pearce, 2007). The social constructionist approach has been employed to describe how social and cultural factors shape the context for this relationship and create dominant narratives about individuals in the relationship. The systematic review highlighted the attitude of the professional as central to the parents' experiences of receiving formal support. Overwhelmingly, parents felt that they weren't being valued or listened to, and were being judged as not 'good enough' parents. Observing and understanding through the context of 'acceptance' is proposed as providing further understanding regarding relationship interactions, and parents' experiences of receiving formal support.

It is important to note that in drawing on the literature from the attachment field the adult with learning disabilities is not considered in a 'child' role or the professional in the 'parent' role. The literature is applied and adjusted to adult-adult interactions.

1:11:1 Acceptance-based approaches

The theory of acceptance is integral to both Attachment-Focused Family Therapy, also known as Dyadic Developmental Psychotherapy (DDP) (Hughes, 2006), and Acceptance and Commitment Therapy (ACT) (Hayes *et al.*, 2012). In DDP, acceptance is considered a vital component of an individual's attitude, central to the development of a supportive relationship and a key vehicle for change. Golding and Hughes (2012) describe acceptance as an attitude of open engagement with

another. In ACT, acceptance refers to an intrapersonal process of ‘opening-up’ the mind to fully experiencing difficult events as they are (e.g. thoughts, feelings and body sensations) and dropping the struggle with trying to change them (Hayes *et al.*, 2012). A lack of intrapersonal acceptance (i.e. struggling to change internal experiences, to avoid the pain associated with them) has been found to influence psychological ill-health and ‘psychological inflexibility’ (Hayes *et al.*, 2012). An intrapersonal account of acceptance may also help to understand parents’ experiences of receiving formal support, for example, their beliefs about self or ability as a parent. It is also possible to consider the two perspectives on acceptance as interconnected. For example, it seems reasonable to suggest that a lack of acceptance from ‘another’ can influence an individual’s intrapersonal experience of acceptance and lead to psychological ill-health (i.e. low self-esteem or sense of coping). Whilst an intrapersonal perspective provides another level to the ‘context of acceptance’, given the interpersonal nature of this study, the following section focuses more on the interpersonal application of acceptance.

In DDP, acceptance forms part of the ‘*attitude*’ of PACE (e.g. Playfulness; Acceptance; Curiosity and Empathy), which is one of the main techniques parents are encouraged to use with their children to increase feelings of safety. Challenging traditional behavioural approaches, this approach considers relationships to be much more complex reciprocal interactions, as opposed to behavioural responses to specific actions (Golding and Hughes, 2012). Similarly in ACT, a person is considered much more than their behaviour (Hughes, 2009). A distinction is made between behaviour and the inner experience / world (i.e. motivation, thoughts and feelings behind the behaviour). In being able to accept another’s inner world one must acknowledge and accept that everyone has a different inner world.

Golding and Hughes (2012, p91) state: *“Most people equate their thoughts, feelings and wishes as aspects of themselves. When someone evaluates these qualities, the person often feels judged and criticised as a person”*. This is thought to lead to resistance where others will hide their feelings and experiences. This reduces the reciprocity and formation of the relationship and leads to a sense of isolation and loneliness. The experiences of parents with learning disabilities receiving formal support seem to reflect this. When observing and understanding in the context of

acceptance it is possible to disagree with a choice or way of doing something while at the same time accepting the rationale and motives behind the behaviour. When the behaviour is separated from the inner experience, and only the behaviour is evaluated, this is associated with increased motivation for change (Golding and Hughes, 2012).

The concept of acceptance has now been evidenced neurologically through the 'Polyvagal theory' (Porges, 2011), and demonstrates the bridge between the intrapersonal and interpersonal context of acceptance. Hughes (2009) described it as enabling safety and facilitating areas of development such as; emotional regulation, self-reliance, resilience and self-worth, amongst others. A person is more able to explore and invest in relationships, communicate, problem solve and remain open, resolve conflict, and accept others when they are accepted. Furthermore, if an individual can accept another's experience, they can explore it and learn about how they relate to it (Hughes, 2009).

Hughes (2009, p82) states: "*experience is not right or wrong, bad or good, fair or unfair, it simply is*". The aim is to become aware of another person's thoughts and inner experience without trying to change them or be compelled to try to resolve differences in opinions (Golding and Hughes, 2012). Perhaps then, in relation to the findings in the systematic review, a lack of acceptance which shapes the contextual relationship between parent and professional, may also explain parents' sense of being judged, in particular, and their experiences of receiving formal support more generally.

1:12 CONCLUSIONS

Psychological theory has been drawn on in a novel way to provide an interpersonal and contextual lens through which the experiences of parents receiving formal support can be understood. It is a lens that emphasises the different contexts to parenting and fundamentally the importance of the relationship. Firstly, the relationship between the parent and the professional is understood and defined in interpersonal terms and indicate that they both influence and are influenced by the other person's thoughts, feelings and behaviour. Secondly, the social construction of meaning offers an explanation of how social and cultural narratives (e.g. the deficit

model of disability) and the different structures of power provide a key context in which the interactions between parent and professional take place. Finally, observing and understanding through acceptance, is seen as a powerful and integral context that shapes the parent and professional's relationship.

PART 4: STUDY AIMS AND RATIONALE

1:13 STUDY RATIONALE

Despite research in the area of parental disability spanning many decades, the third wave of research, focusing on meaning and the context of parenting, is still in its infancy, and: *“To improve the experiences of parents with a learning disability, we must look to what we can learn from the stories that they tell”* (Conder & Mirfin-Veitch 2010, p106). Most of the research that exists contains the assumption of ‘in-ability’ and an *‘in-the-head perspective’* on parenting with a learning disability, which narrows understanding of parents’ experiences (Dudley-Marling, 2004). While the recent research aims to think more widely about context, still, terminology such as, ‘good enough parenting’ dominates the literature. This perpetuates unhelpful narratives and again narrows the understanding of experiences. Further research is needed to open up and widen avenues for understanding. It is proposed that further understanding can be provided by integrating parents’ experiences with the psychological theory, and interpersonal and contextual lens provided.

Discussions around the relationship between parent and professional, and concepts such as empowerment, control and self-esteem are typically bi-products of research exploring the efficacy of interventions and the role of support systems on outcomes for parents’ competence. There is a gap in research focused on exploring the relationship between a parent and a professional, and what impact this has on the parent. It is important to understand more about parents’ experiences of the relationship with professionals, to better prevent it from breaking down. The literature reviewed has also highlighted contrasting findings around which is more important to parents, the types of support offered or the attitude and approach of the professional.

Further exploration of this may lead to better understanding and prevention for relationship breakdown.

The systematic review revealed 'messy' data collection procedures, limited sample populations, poor definitions of terms, culturally specific findings and the fact that parents' voices are only just being heard in the research arena. There is a need to explore the views of fathers and of parents with children across the ages. This research is particularly important now, as recognised by the researcher's in the 80s. They stated that parents needed to be given the opportunity of living in the community for longer before true understanding about experiences could be gained (Andron & Tymchuk, 1987 in Booth & Booth, 1994).

1:14 STUDY AIMS

The study aims to explore, from the parents' point of view, the question: *what is it like to be a parent with learning disabilities receiving formal support?*

The specific aims are:

1. To explore how parents experience and make sense of their relationship with a professional whose job it is to provide support and advice around parenting.
2. To elicit the parents' views on a range of elements relevant to their lived experience of receiving formal support in parenting, in particular, the impact of receiving the support on the parent.

This qualitative investigation will provide a timely, detailed exploration of the lived experiences of parents with learning disabilities receiving formal support. It will provide an important piece of evidence focused on the relationship between the parent and the professional. It will inform the evidence-base by integrating parents' experiences with psychological theory and, by looking at all cases, not just 'best practice' examples. Most importantly, it gives both mothers and fathers with learning disabilities an opportunity to have their voices represented in the research arena and contribute to the discussions and recommendations for service delivery. It will, therefore, provide a significant contribution to evidence-based practice for professionals working with parents with learning disabilities.

Chapter 2

METHODOLOGY

2:1 CHAPTER OVERVIEW

This chapter starts with a description of the design of the study. Consideration is then given to how aspects of the researcher's position may have influenced the research. Next, an introduction to qualitative research and description of the background and procedure of Interpretative Phenomenological Analysis (IPA) is discussed. A rationale for selecting the approach is included and consideration is given to issues of quality when conducting IPA research. The second half of this chapter details the methods used, the specific procedures followed, including recruitment procedures, a description of participants, and processes of data collection and analysis.

2.2 DESIGN

The study utilised a qualitative design. Semi-structured interviews were conducted with all participants, who were all parents with learning disabilities. The interview was designed to elicit the parents' lived experiences and perspectives of their relationship with a professional, and their experience of the impact of receiving formal support. The qualitative data was collected and analysed in accordance with IPA methodology.

2.3 INTRODUCTION TO QUALITATIVE METHODS

Coyle (2007, p15) states that qualitative psychological research is a 'bottom up' approach concerned with providing rich descriptions of people's '*meaning-making*'. Qualitative methods do not construct an objective account of an experience, but instead seek insight into an individual's personal lived experience. Qualitative research is exploratory (rather than confirmatory) where the participants: "*represent a perspective rather than a population*" (Smith *et al.*, 2009, p49). Methods are flexible and dynamic, allowing the participant to discuss experiences and topics not anticipated by the researcher. The approaches realise that the researcher is part of

the research process, and emphasis is first and foremost with the individual participants' experiences. Consideration of the need to generalise findings is secondary to this.

2.4 INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

2.4.1 Background and philosophy

Interpretative Phenomenological Analysis (IPA) is concerned with 'what it is like' and what it means to a participant to experience particular events or live within specific circumstances, in order to understand how they make sense of their world (Coyle, 2007). IPA takes an empirical and phenomenological epistemological position and assumes that people try to make sense of their experience (Willig 2008). The approach is also informed by hermeneutics, the theory of interpretation, and idiography (Smith *et al.*, 2009).

Fundamental assumptions include:

- the meaning that people attribute to events or phenomenon, shape that individual's experience of the event or phenomena;
- value is placed on the diversity of experience, that is, what matters is *how* participants experience events (Willig 2008);
- experience is constructed, as it is a product of interpretation, but one that is 'real' and "*meaning-full*" to the person (Smith *et al.*, 2009, p66; Willig, 2008);
- a 'double hermeneutic' exists (Smith & Osborn, 2003 cited in Smith *et al.*, 2009, p35), that is: "*the researcher is making sense of the participant, who is making sense of x*" (Smith *et al.*, 2009 p.35), and,
- '*The phenomenological analysis produced by the researcher is always an interpretation of the participant's experience*' (Willig, 2008, p10, 57).

The researcher tries to 'put themselves in the shoes' of the participant to understand the phenomena under investigation and has to stand alongside the participant to ask questions and analyse what is said (Smith *et al.*, 2009). Becoming immersed in the data enables the researcher to make sense of what is said, keeps the data grounded in meaning, and the participant at the centre of the research. Smith (2011, p24)

outlines criteria for *'What makes a good IPA paper'* and emphasises the need for a clear focus; strong data; rigorous methods; elaboration of themes; interpretation rather than description; convergence and divergence of themes, and, careful writing. It is acknowledged that: "...*there is not a direct route to experience and that research is really about trying to be 'experience close' rather than 'experience far'...*" (Smith, 2013, p10).

2.4.2 Rationale for using IPA in this research

Other qualitative designs were considered, including, Grounded Theory (Glaser & Strauss, 1967), and Thematic Analysis (Boyatzis, 1998). However, the goal of the research was not to develop a theory, and the epistemological assumptions and methodological procedures of IPA were viewed by the researcher as complementary to, and consistent with, her position and aims. This included, a focus on the participants own words, the value of 'subjectivity' over reality, the person-centred approach, and most of all, this approach offered the researcher the ability to 'voice' stories typically marginalised and devalued in society and research. It was also consistent with the aims of the study as the approach makes it possible to identify particular themes which include: "...*a concern with identity and a sense of self...*" (Smith & Eatough, 2007, p38). Given its flexibility (e.g. "*to modify protocols when collecting data*") the approach was considered appropriate to use with adults with learning disabilities (Smith, 2004, p49).

The researcher wanted to avoid using methodology that overtly implied judgement or assessment of parental ability, to not collude with, or add to, the reported unhelpful experiences that many parents with learning disabilities have with professionals (as specified in the introduction).

2.4.3 Consideration of the researcher's position

IPA takes a reflexive position regarding the role of the researcher (Willig, 2008). The researcher is expected to frequently consider their connection with the phenomena being studied and their "*speaking position*" (i.e. the framework which shaped the research questions) when engaging with and interpreting the participant's account of the phenomenon (Coyle, 2007, p18). It is recognised that an open-mindedness

embodies the IPA approach, and the researcher should first reflect and then try to suspend their “*speaking position*” when designing and conducting interviews.

A reflection on the researcher’s previous knowledge of, and experience with, the participant group is described below. Specifically, the researcher’s interest in this population group is detailed, a statement about the research position is given, and attention is brought to the extracts of the ‘live’ reflections from the researcher’s reflective log. The researcher was mindful that she would not be able to access all of her preconceptions at the outset and that some would evolve over the course of the research project. This consideration of the researchers’ *‘speaking position’* will help to increase transparency in the process and contribute to explaining the rationale for the research (Coyle, 2007, p18).

The researcher was a 27 year old white, British female training as a Clinical Psychologist on the South Wales Doctoral Programme in Clinical Psychology. Previously, the researcher worked for two and a half years as an Assistant Psychologist in Community Learning Disabilities Services. This involved assessing ability in parents with learning disabilities, liaison with multi-professional groups, providing advice and attending multidisciplinary meetings with parents. This led to preconceptions around: issues of power imbalances between parents and professionals and the degree of choice afforded to the parent, the impact of stigma, and a parent’s sense of being ‘not good enough’. At this stage the researcher was made aware of how devalued the label of learning disability is in society. This experience also informed the researcher’s interest in Person-Centred approaches and the Social Model of Disability (Oliver, 1983), in particular, concepts of enablement.

Such reflection enabled the researcher to prepare for dynamics that might play out in the research process. For example, the researcher was mindful that power imbalances could challenge the semi-structured interview because participants may present themselves as they perceive others expect them to. The researcher also considered how the parents could view her with suspicion (due to the high level of professional input they receive) and could perceive her to be influential in their support package.

Whilst training, the researcher developed a particular interest in Social Constructionism (Freedman & Combs, 1996; Gergen, 1990) and how different people construct their sense of reality within different social and cultural contexts. The interpersonal relationships between people, specifically people with learning disabilities were of key interest. Drawing on previous clinical experience with parents with learning disabilities she became curious about the experiences of parenting with a learning disability and the perceptions of support from professionals. This initial interest was brought into focus through discussions with the academic staff and the clinical supervisor. It formed the basis for the broad research questions and design for the current study.

In accordance with IPA process, an initial, short, literature review was conducted. This revealed a lack of literature exploring the relationship between parents with learning disabilities and professionals and the impact of this relationship. This further alerted the researcher to a need to support adults with learning disabilities to speak out and 'have a voice' in research. To help design the study, the researcher met with a sample of parents with learning disabilities receiving support from professionals, and also professionals involved in supporting parents. Their reflections contributed to the development of the semi-structured interview prompts and design of the written information sheets. Initial assumptions were also confirmed and others, such as, the unequal rights for parents, were introduced.

The researcher did not have formal experience of providing support and advice to parents beyond cognitive and psychological assessment. Direct experience of the relationship under investigation was absent. The researcher did not know any of the participants prior to the research process and was not working in the geographical area in which the study took place.

Throughout the research process, the researcher engaged in reflective practice through the use of a reflective log, conversations with the projects clinical and academic supervisors and other trainees engaged in the research process. This helped the researcher to take a curious and reflexive stance, to identify which aspects of their '*speaking position*' were present in the research (i.e. at the design stage, analysis and in the final product), to facilitate a process of self-awareness,

and discuss possible themes. Extracts from the reflective log are provided in Appendix IV to evidence the development of the researcher's thinking and understanding.

2.5 ENSURING QUALITY IN IPA RESEARCH

Elliot *et al.*,(1999, p216) developed seven research guidelines with scientific principles aimed at ensuring quality in qualitative research and evaluating whether a piece of research provides: *'meaningful and useful answers to the questions that motivated the research in the first place'*. These criteria were used as a guide to review the quality and rigour of the current study. The guidelines as presented by Elliot are given first, followed by an account of how the current study achieved the principles.

2:5:1 Owing one's perspective

'As an on-going process, the researcher should identify and communicate their preconceptions, assumptions, prior experiences and values which shaped the research question and the role that these had in understanding the phenomenon investigated. This enables the reader to contextualise the data presented and consider how the influences may have contributed to the researcher's interpretation.'

Section 2:4:3 outlines the researcher's position. In order to promote the reflexive position the researcher received regular supervision and kept a reflective diary. An extract of the researcher's diary can be found in Appendix IV. In addition, based on Rolls and Relf (2006) the researcher engaged in a 'bracketing interview' with fellow trainees. Through conversation with another, this process helped to reveal any unconscious processes not identified through self-reflection alone. Extracts from the bracketing interview can be found in Appendix V.

2:5:2 Situating the sample

'The researcher should describe their sample and their specific circumstances to enable the reader to think about to whom and how the findings might be relevant.'

Section 2:7:5 outlines a description of the participants. Given the small size of the population studied, minimal information is presented to protect anonymity.

2:5:3 Grounding in examples

'The researcher should provide specific examples in the data for each theme to demonstrate the analytic process, and to enable the reader to explore the relationship between the data and the author's interpretation, and consider alternative meanings.'

The researcher has situated themes and categories in the data, by using specific quotes from participants.

2:4:4 Providing credibility checks

'Researchers should check the credibility of their theme and category development with another person.'

The researcher employed credibility checks at several stages of the data analysis with the researcher's academic and clinical supervisors (who collectively have an extensive knowledge of the participant group and the methodology). The researcher met with her supervisors after stage four of the data analysis (see section 2:9) to discuss the themes developed and substantiate them in the context of the original data. Themes were also checked by trainee clinical psychologists.

In stage five of the data analysis, the researcher cross referenced each subordinate theme with the line numbers from each participant to ensure validity when identifying recurrence across cases (see Appendix VI). The degree of recurrence was determined by the frequency across the participants (Smith *et al.*,2009). If the theme was prevalent in over half of the cases it was classified as recurrent, and included. The researcher met with her supervisor again following stage five of the data analysis (Section 2.9) once the themes had been integrated across cases, to check the credibility of the process. Superordinate themes were also checked with a sample of participants to see if they were still grounded in the data and meaningful.

2:5:5 Coherence

‘The researcher should present an integrated and coherent summary or narrative of their analysis, depicting hierarchical relationships among themes and categories.’

This process was checked by the researcher’s academic and clinical supervisors.

2:5:6 Accomplishing general versus specific research tasks

‘The researcher should make clear whether their aim is to achieve a general understanding of a phenomenon, or whether it is to explore a deeper level of understanding of specific instances.’

The researcher aimed to explore in detail the experiences of parents with a learning disability who receive formal support in parenting. Methodological techniques used in IPA enabled systematic and comprehensive analysis of the specific cases. The limitations of this approach, including extending findings to other contexts and instances is considered in section 4:5.

2:5:7 Resonance with the reader

‘The researcher should present information in such a way that the reader is able to connect with and have a deeper understanding of the phenomena studied, and deem it to accurately represent the subject matter.’

Resonance was checked by the researcher’s academic and clinical supervisors through supervision and ‘drafting’ chapters for review.

2.6 ETHICAL CONSIDERATIONS

2.6.1 Ethical approval

To ensure the safety of the participants, and to ensure that the study was ethically robust, the study was subject to a full ethical review. The application was approved by the South East Wales Panel C Research Ethics Committee. A copy of the approval letter can be found in Appendix VII. In addition the study was assessed by the Research and Development Committee in the NHS trust in which the researcher

was employed, and in the NHS trust in which the research was undertaken. The approval letters can be found in Appendix VIII. The researcher also sought management permission to conduct the research in the third sector organisation People's First. Their letter of approval can be found in Appendix IX.

2.6.2 Informed consent

To ensure that participants were making an informed decision about participating in the study, consent was viewed as an on-going process and sought at different stages of the research process. Participants were provided with an information sheet to help them to make their decision about whether or not to participate in the study. The participant information sheet can be found in Appendix X.

The information sheet, and consent form (Appendix XI), was based on the NHS National Patient Safety Service (2011: Information Sheets & Consent Forms Guidance for Researchers & Reviewers. Version 3.6.1) guidance and contained the following information:

- An invitation paragraph about research;
- The purpose of the study;
- Information about the research procedure and what their participation would involve;
- Information about confidentiality and a participants right to withdraw at any time, and
- Information about data collection and analysis.

To aid this process, a 'known' person to the parent (who had already been briefed by the researcher) was identified to go through the information sheet and consent form with the parent, allowing opportunities to ask questions and clarify queries. The use of a 'known' person was consistent with Cameron and Murphy's (2006) guidance for assessing informed consent. The consent form can be found in Appendix XI. Further information about the process of gaining informed consent can be found in section 2.7.3.

Consent was reaffirmed at the outset of the interview, and in line with the evidence base the researcher gave the parent extra time when making a decision, used a variety of ways of communicating and aimed to establish rapport and 'social closeness' with the participant (Cameron & Murphy, 2006, p117). The researcher was guided by the Department of Health (2001b) *Seeking Consent when Working with People with Learning Disabilities Guidelines*.

An information sheet was given to all professionals working with the parent to ensure all parties were aware that the parent was taking part in the research. To protect the parent's anonymity, this information sheet did not specify which professional relationship the parent was reflecting on, but just outlined the aims and procedures for the study. This information sheet can be found in Appendix XII.

2.6.3 Confidentiality

Participants who consented were assigned a unique identification code. The list with each participant and their identifiable code was kept locked in a secure cabinet. This code was then used on all audio material and transcripts to ensure that the data remained confidential and anonymous. No identifiable information was included in the transcriptions or in the study write-up. All data was stored in the researcher's place of work and was only accessible by the researcher and the academic supervisor. It was kept in a separate lockable cabinet to the list with the identification codes. Following their transcription, the audio recording was destroyed to further strengthen confidentiality.

2.6.4 Managing distress in interview

The researcher carefully worded questions so that they were accessible to the parent with a learning disability. The researcher was mindful that the parent would not necessarily be thinking about their relationship with the professional in this way if they were not taking part in the research study. Therefore, it was made clear to participants in the information sheets and throughout the interview that if they were upset by any part of the research process then the researcher would stop the process immediately and provide emotional support. The researcher was experienced in supporting adults with learning disabilities, but this was typically in a clinical setting, not a research setting. As a result, both the clinical and academic

supervisor were prepared to make themselves available to provide additional support to the parent, in addition to their accessing friends and family and other professional support. However, none of the participants became distressed during the interviews.

2.7 PARTICIPANTS

2.7.1. Deciding on a sample

Smith *et al.*, (2009) state participants are chosen because they provide a particular perspective on the phenomena under investigation, thereby representing a perspective rather than a population. In accordance with its idiographic assumption, the aim is firstly, to say something in detail about the experiences of the individuals, and secondly, by exploring similarities and differences between each case, reflect a shared experience. As a result, Smith *et al.*, (2009) state that samples tend to be relatively small, homogenous and selected purposively. While the claims are somewhat bound to the group studied, Smith *et al.*, (2009, p4) state that: '*an extension can be considered through theoretical generalisability*'. It is emphasised however, that the boundaries of homogeneity vary and are often determined by the topic under investigation.

Based on a dynamic assessment of the quality of data obtained during data collection, the present study has a homogenous sample of 10 parents with learning disabilities. The homogeneity of the sample was bound by the relatively low numbers of this specialist population and by the constrained lives imposed on them by numerous professional meetings and appointments. Nonetheless, the participants are all parents; they all have a learning disability, and all have at least one paid professional whose role it is to provide support and advice around parenting for their children aged between 0-16 years.

2.7.2 Inclusion and exclusion criteria

Participants were deemed suitable for participation if they were:

- A parent who had a diagnosis of a learning disability and (or) whose case was open to health and social community learning disability teams.

- Part of a family where at least one parent had a learning disability. In families where both parents had a learning disability, the parents were interviewed separately as two separate participants, or only one, if only one agreed.
- A parent who was currently receiving support from a professional whose job it was to support or advise around parenting.
- A parent of children on the child protection register, who were not involved in care proceedings.
- A parent who was able to give informed consent.
- A parent over age 18 years (no upper age limit).
- A parent (of at least one child) who had regular contact with child and had (some) parental responsibility regardless of residence (i.e. child may live with parent some of the time and with grandparents for some of the time).
- A parent of children aged 0-16 years.

Participants were deemed unsuitable if they were:

- A parent with an acute episode of a mental health problem.
- A parent undergoing care proceedings: where the local authority felt that they needed a court decision to say what should happen to a child.
- A parent who had no contact with their children.
- A parent involved in other research.

2.7.3 Recruitment

The researcher established links with a South Wales People's First organisation and with the 2Gether NHS Foundation Trust, in which the researcher's clinical supervisor was based. The researcher visited People's First and the clinical supervisor met with the team managers in the NHS trust, and both presented the study and asked for assistance in identifying potential participants. The team within People's First was made up of managers and advocates who support adults with learning disabilities, and the NHS trust consisted of paid health care staff who worked in Community Learning Disabilities Teams. Within both research sites, the managers were asked to meet with their teams and tell them about the study. Team members were asked to identify potential participants. These team members were then asked to present

potential participants, who met the inclusion criteria, with an information sheet (as discussed in section 2.6.2).

The information sheet provided parents with information about the aims and procedures of the study and enabled them to make an informed decision about taking part in the study. It was made clear that participants had the right to withdraw from the study at any stage and that their support from services would not be affected. If the parents agreed to participate in the study they were asked to sign a consent form, provide their contact details and return them (see Appendix XI). This recruitment procedure ensured that the participants were able to make independent and fully informed decisions about participation; it also ensured that the researcher had minimal identifiable information at this stage of the study. On receipt of the consent form, the participants were contacted to arrange how and where best to organise interviews and to answer any further questions about the study.

2.7.4 Response rate

As introduced in section 1:3:1, the precise number of parents with learning disabilities in the UK is unknown. However, as part of the Learning Disability Wales (2009) research Joyce Howarth estimated that based on the 2001 census there were 1210 parents with learning disabilities in Wales. The sample for the current study was selected purposively and due to the limited number of potential parents available, and the desire for a fairly homogenous sample only the 10 participants who took part in the study were contacted.

2.7.5 Description of participants

Due to the sensitive nature of the study aims, the limited number of parents with learning disabilities in the UK, and the small sample size, the researcher wanted to minimise the possibility of identification. Therefore, only basic demographic and background information is described, to contextualise the information gained, to inform the qualitative analysis and to guide future research.

Of the ten participants interviewed, seven were female and three were male. All participants were White British, lived in both urban and rural areas of South Wales and South West England and were aged between 21 to 47 years old. One parent

was single, all the others were either married or in a relationship. Parents had between one and six children, and four of the parents had children on the child protection register. While some parents also had children over 16 years, all discussions in the interviews focused on what it was like having support from a professional to parent the children under the age of 16 years.

The most common type of professional discussed, was a Child Social Worker, while other types of professionals included Health Visitors and Support Workers. Each parent had a long history of working with a number of different professionals, and often with multiple professionals at any one time. Each participant has been given a pseudonym, along with all of the family members and professionals that were identified during the interview to ensure confidentiality and anonymity.

2.8 INTERVIEWS

2.8.1 Semi-structured interview schedule

The aim of the semi-structured interviews is to have '*a conversation with a purpose*' (Smith *et al.*, 2009, p57). The researcher aims to facilitate a conversation which invites the participant to give a detailed description of their experience of a phenomenon, to tell their story in the participants own words, including perceptions, thoughts, feelings and actions. Smith *et al.*, (2009) explain that the preparation of the semi-structured interview schedule allows the researcher to form a loose agenda, it enables some degree of consistency in approach across interviews, it enables the researcher to plan the wording of questions carefully (avoiding leading and closed questions) and to predict any difficulties that might arise. The interview is guided by the schedule not dictated by it, and the approach allows the participant to take the interview in the direction that is most meaningful to them.

2.8.2. Development of the semi-structured interview schedule

The semi-structured interview schedule was developed based on the review of literature on parenting with a learning disability, on the researcher's own interests and curiosities and through collaboration with a sample of parents with learning disabilities. Initial ideas were presented to a group of five parents with learning disabilities and the researcher sought feedback on the relevance and

meaningfulness of the area of investigation, the interview procedure, the types of questions asked, the wording of questions, and the images used. Whilst demonstrating a model of service user involvement and a person-centred approach, this process added significantly to the overall design and shape of the schedule, and on reflection, is believed by the researcher to have contributed to the richness of the data collected. The schedule is presented in Appendix XIII.

Images were used to supplement questions and facilitate communication and understanding during the interview. The visual aids used were from a specific package for parents with a learning disability made by CHANGE. The images included pictures depicting emotions and common scenes. Examples of the images used are presented in Appendix XIV.

2.8.3 Interview procedure

The interviews were arranged at a time and location convenient for the participant. From the outset, participants were given an opportunity to ask any questions and address any concerns about taking part in the study. They were reminded that they were able to withdraw their involvement in the study at any time, and their anonymity and the confidential nature of the interview would be reiterated. The researcher informally assessed the participants' suitability for taking part, their understanding of their involvement, and consent was also verbally reaffirmed before the start of the interview. Each interview was recorded using a digital recorder before being transcribed and analysed. The interviews varied in length from 60 to 90 minutes.

In the first part of the interview, the researcher gained background information and had available the prepared 'circles of support' exercise (Snow, 1994). This was designed to enable the parent to identify a professional to think about during the semi-structured interview (Appendix XIII: Semi Structured Interview Schedule incorporates this exercise). In this exercise the parent would be asked to think about all the paid professionals supporting them with parenting and choose one to think about during the interview. The use of subjective criteria for identification of a professional is consistent with the aims of understanding the experiences and interactions of parents with all professionals, rather than one specific group. It is also consistent with the wider aims of using person-centred approaches to working with

people with learning disabilities, empowerment and service user involvement. The process of choosing one professional who at the time was providing support was intended to make the exercise of thinking about their experiences more concrete and accessible for the parent.

In the second part of the interview, parents were asked to describe their experiences of their relationship with their professional and the impact of that relationship using the semi-structured interview schedule. At the end of the interview, participants were asked to reflect on how it felt to be interviewed, whether it raised any issues, feelings or thoughts that they were not aware of before, and if they had any concerns or questions. Participants were then reminded of the contact details of both the researcher and their clinical supervisor should they wish to discuss any issues.

2.9 DATA ANALYSIS

What follows is an outline of the analytical process conducted in the present study which is grounded in the analytical description by Smith *et al.*, (2009).

Stage one

Following transcription of all of the interviews, the researcher familiarised herself with the text. Each account was read several times enabling the researcher to become immersed in the data and develop a sense of meaning. Initial ideas were written in the left-hand margin of the transcripts. This initial noting included ideas regarding language use, descriptive labels and potent comments.

Stage two

The researcher, now with a very familiar model of the interview, went back through the transcripts and the initial comments in the left hand margin, and identified emergent themes, that were written down in the right-hand margin of the transcript. These were typically expressed at a theoretical level rather than in the participants own words. This process required the researcher to focus on discrete sections of the data, and to reflect on the whole process of initial noting. Appendix XV provides an example of a transcript which outlines these initial stages of data analysis.

Stage Three

Smith *et al.*, (2009, p 96) state that at this stage the researcher is looking for a way of: “*drawing together the emergent themes and producing a structure ... to point to all the most interesting and important aspects...*” With the specific research questions in mind, the researcher listed the emergent themes and either discarded or grouped the themes by looking for the connections between them. By oscillating between the whole text and particular parts, the researcher used the hermeneutic circle process to create broader clusters or ‘subordinate’ themes and gave them a label. Labels remained grounded in the data, but captured the connection and pattern between the emerging themes. Many dialectical positions across the themes were noted and grouped using a common concept. The themes were then presented in hierarchical order. Appendix XVI provides an example of clustered themes for one participant

Stage Four

The researcher presented the subordinate themes within a summary table together with quotes and the line locations in order to evidence and illustrate each theme. Appendix XVII provides an example of a summary table for one participant. Following this stage of analysis, the researcher met with her supervisors to discuss and check the credibility of the identified subordinate themes in the context of the original transcripts. This resulted in the reorganising of some emergent themes and renaming of some of the subordinate themes to better reflect the experiences and concepts within the data.

Stage Five

The researcher looked for patterns across cases and integrated the themes. In line with Smith *et al.*, (2009) the researcher analysed each transcript anew, completing stages one to four for each transcript, and produced 10 summary tables. Patterns across cases were established and a list of recurrent superordinate themes, that reflected both unique idiosyncratic accounts and the participants shared experience, was compiled. Where appropriate, this led to the integration of some themes and the renaming of others to reflect the experiences of the group as a whole. The superordinate themes were checked against the transcripts to ensure that they remained grounded in the data. Appendix VI provides the summary tables that

contain the subordinate themes and the respective line numbers for all participants, for each superordinate theme (as outlined in section 2.5). To ensure quality in the analytical procedure, the researcher met with her supervisors again to check the credibility of the superordinate themes. The quality of the themes were checked back with two of the participants and other trainees.

Chapter 3

RESULTS

3:1 CHAPTER OVERVIEW

The following chapter outlines the key findings that emerged from the IPA analysis of the data collected from the ten participants. Four superordinate themes emerged out of the data analysis, each with a number of subordinate themes. An overview of the themes is outlined in Figure 2.



Figure 2: Diagrammatic representation of the Superordinate and Subordinate themes

Each superordinate and subordinate theme is discussed in turn and is illustrated by relevant quotes. Similarities and differences contained within the themes are highlighted as the data is described. Quotes were chosen to demonstrate a range of perspectives within each theme, and, where possible, to capture the interactive

nature of their accounts. Words that have been added to enhance understanding of the data are inserted in brackets, for example: [text]. Words or phrases that have been omitted from quotes to improve the readability of the text are designated as follows: (...).

3:2 SUPERORDINATE THEME 1 : “STEPPING UP” : EXPECTATIONS

In summary, all participants spoke in detail about both internal and external expectations of being a parent with a learning disability receiving formal support. **“Extra” expectations**; a **Presumption of incompetence**, and an **Awareness of difference** were integral to their experiences. For the majority, there was a sense of needing to, as one parent described, “*Step up*” to meet the many different expectations. The usefulness and impact of the expectations were perceived differently across the parents.

3:2:1 “Extra” expectations

All of the parents described **EXPECTATIONS** about having to do **“Extra”** in their parenting role. These expectations were described by the parents as experiences that came both externally, from the identified professional and, internally, from within the parent. The external and internal origin of the expectation is seen as influencing, and as influenced by, each other. The title of this theme came from Rebecca who explained:

“I just think I have got to fight extra for Andrew [child] and my husband as well, he feels a bit like that (...) so we gotta just step up that extra bit for Andrew.”

3:2:1:1 External “Extra” expectations

Many of the parents shared how professionals placed multiple demands on them, some of which did not appear integral to parenting ability, and were, therefore, viewed as **“extra”** expectations. This included, doing the garden, decorating the house, and making sure the dog was walked, as Helen explained:

“Do their bedrooms, decorate their bedrooms, we’ve done that for her. We have done the house for her, decorated the house, done the carpets. Let the dog out”.

Amy described how a professional expected her to keep her house “extra” tidy:

“(...) they used to tell me off for toys in the house (...) you could easily fall over those toys, and I said: ‘it’s kids, that’s kids for you’”.

Helen also described how her identified professional had placed “extra” rules around not letting people in her house after 7 O’clock, and in response to this said:

“I would like to know what she is doing, if she is doing it herself?”.

Karen described how challenging these “extra” demands were, she explained how she wanted to be able to:

“Walk in and don’t have to worry about painting and decorating, just walking in to deal with normal stuff, not painting and decorating as well. Just a normal reaction of, cleaning, eating, feeding and potty training”.

Another common “extra” expectation experienced was the pressure of having to do typical parenting tasks whilst talking to the professional. It appeared that sometimes the professional support got in the way of the parents ability to parent. Helen explained:

“(...)she’ll say, come and sit next to me and talk to me, and then she’s like giving negatives, saying you shouldn’t be sat next to me, you should be doing the food for the kids. So I’m like, do I sit here or do I not sit here?”.

In addition to having “extra” expectations, many parents shared the experience that the professional held very high expectations of them. Simon explained:

“[it] doesn’t matter if we were doing good things, it was bad for her”.

And:

“(...) she was trying to blame anything, she was looking everywhere for any faults, she was going up stairs, she was looking, well this is not good enough, that is not good enough”.

Paul explained that professionals will be:

“Taking records and in those records he would be saying, he hasn’t done well enough”.

3:2:1:2 Internal “Extra” expectations

Some parents also described internal “extra” expectations. Rebecca stated:

“(...) the extra pressure is because (...) you have a learning disability, so you have got to get that extra help (...) and the right support, so you have got to step up more than other people”.

In the context of receiving formal support Zara appeared to have developed “extra” expectations around the need to keep the house tidy:

“I used to keep all the clutter, but now I, you know when the boys like with their toys, if they’ve finished and they don’t want them anymore, put them in a bag and give them to the charity shop and stuff”.

Many parents also described very high internal expectations about what they should be doing as parents. Amongst these parents, there was a shared experience about a need to get things right and to parent ‘perfectly’ all of the time. Paul stated:

“I didn’t want to do nothing wrong”.

Simon talked about needing to do “*the perfect thing*”. It appeared that a common factor embedded within this experience included worry around losing their child[ren], as Simon stated:

“(...) if we do make a mistake, are we gunna lose the boys?”.

In contrast, Jeremy was able to hold different, perhaps more balanced, internal expectations, he explained:

“(...) I can’t give them the world but I try my best for my children”.

3:2:2 Presumption of incompetence

Another fundamental **EXPECTATION** that, for most parents, reinforced the need to “*step up*”, was a perceived assumption made by the professional that the parent was uninterested, incompetent and unskilled in some areas. The impact of this assumption, for most parents, was negative. Karen explained that:

“She thought I didn’t understand, and I did, I was just taking it into my brain, and then kept repeating it for a while, getting annoying, it bugged me”.

Karen described how she would:

“Do what she [professional] thought I couldn’t do. Wiping his bum and changing him and keeping him clean”.

Whilst naming the direct link between this negative assumption and having learning disabilities, it appeared for Jane that a product of the professional holding this assumption was:

“(...) I thought Rita [child] would have been gone, because of my learning disabilities (...) they don’t give us a chance with nothing”.

Some parents described how the professional then acted in accordance with this assumption. Some parents described examples of how they were personally criticised and condemned by their identified professional. Amy described how one professional said in a meeting:

“(...) all she does is sit on her backside”.

Angela described a similar experience; she described how her identified professional said:

“I think you just want your mum to have your kids and you to go out”.

For some parents this **Presumption of incompetence** appeared linked with the timeliness of the support. Many parents did not seem to know the rationale for the instigation of support. For example, Angela said:

“I’m not even sure why they came in.”

Simon outlined an inherent presumption of incompetence held by his identified professional when thinking about why they became involved, he explained:

“I think her role was making sure that the kids didn’t come to harm (...) [but] the kids have never been to harm”.

Simon was frustrated by the reactive response by services, who he perceived held the assumption that he could not have been doing a ‘good enough’ job before they came along. He explained:

“Before, we were a long time having social workers, when we lived back in XX, it was about months we didn’t hear from nobody, and then there was a mad rush then, everybody pointing fingers. Oh ‘have you done this, have you done that?’ We had been so used to, when the children were small, not having nobody to take us to appointments. If it was raining quite heavy we used to take them, not cancel appointments, we used to take them out in the rain and everything. When the social workers got involved then, they were

like, you have got to do this, you have got to do that. 'You don't need to point the finger', I said. 'Where have you been for the last couple of, for the last months? We have been doing this'.

Paul was ambivalent about the experience of the professional holding the assumption that he was incompetent. He recognised that this assumption led to further scrutiny, but was not totally adverse to this. However, he did acknowledge problems with this process, he explained that being observed:

"(...) might make things better, but then there'd be danger of the professional [saying] well he could have done better, he's not interested".

In the context of his children being physically ill as very young children, and parenting with professionals, who he perceived, presumed he was incapable of being a 'good enough' father and was somehow to blame for their ill health, Jeremy reflected back on his thoughts prior to having children:

"I said to myself, 'I don't think I will have any children, as soon as I have them something will go wrong', and I was right".

Jeremy's use of language is interesting; it appears that parenting with professionals, who he perceived presumed his incompetence, led him to think about parenting in right and wrong ways.

3:2:3 Awareness of difference

Integral to the parents' experiences of **EXPECTATIONS** was an **Awareness of difference**. This concept appeared to have different dimensions and underpinning each dimension appeared to be the parents' drive for acceptance. Many of the parents named a sense of being different; for some parents this was conceptualised in terms of the label of learning disabilities. Most parents were very aware of the label and named the fact that they had learning disabilities. In the context of talking about attending meetings Simon said:

"The reason I am asking her to come (...) I have learning difficulties, you know, (...) I wouldn't be able to explain to you the following day, what he said".

Integral to the experience of parenting in the context of formal support, was the conflict between a sense of being different and a strong desire from parents to be viewed as “normal”. Many parents defended their status as a “normal” parent. This conflict appeared to play out within Karen, she explained:

“I am normal like you, and I understand like you, it’s just I don’t look like, I just pretend I don’t, I just don’t approach it the way that you do”.

And:

“I am normal, I just see things differently that’s all”.

Jeremy also recognised the need to defend his status as a dad, but reflected a more certain position, he explained:

“(..) I think I do what any other dad does”.

For Zara, the formal support she received from her identified professional reduced her sense of being different, as described by her use of the term “basic stuff” (which possibly implies that she believed the skills she has learnt through formal support are central to parenting, and are what everyone does). She described how having support helped her to:

“(..) do basic stuff (..) like every year I make Easter bonnets for the boys, hats and that, I made a couple for a friend last year and everybody said wow, and my boys always used to win, and that so, so it’s something I never could do(..)”.

It would appear that the sense of being different was for many of the parents influenced by an experience of being treated differently by the professional, in comparison to parents without learning disabilities. Paul experienced this as positive, as being treated differently enabled him to get his needs met as a parent. Paul stated that the way the professional treated him: “*proves that they are taking an interest*”, and are: “*paying attention*”, which meant: “*then they help us*”.

However, there was a shared experience amongst most parents of the negative impact of being treated differently. For some, this led to them feeling like a child, feeling not ‘good enough’, or feeling like they have missed out on opportunities.

Karen explained:

*“(..)*we had more pressure because (...) they came and weighed him here, which we could have gone to the place where they do it, but they didn’t (...) we could have gone with, like everybody else, but they gave us, because we were, because she thought that we were, have more problems (...) they used to come here more often (...) because they thought we couldn’t cope (...) but we could have gone there and that might have taken the pressure off a bit, because we would have felt like everybody else(...) we could have gone up with all the others. It made us feel that there was something wrong with us(...) she thought I had problems, she went a bit too far”.

For many parents this sense of difference permeated more widely and had social implications. Many parents felt judged by members of their community. Some parents reflected on judgement in the context of having a learning disability. Zara appeared really self-conscious when in the community, but also described how having formal support helped her to build up her confidence, which she attributed to helping her to overcome her sense of being judged:

“[before] I would have sung a little bit, not, I would have done it at home, but I wouldn’t have done it outside. I would have been so ashamed at that, but now it just doesn’t bother me. It’s the confidence and you know, you’re not doing nothing wrong when you are singing to a child, you are just making them happy (...) I think that’s what knocked my confidence, when people looks and say oh what’s she talking about”.

For other parents the judgement was associated directly with having a professional formally support them in their parenting role. In the context of her friends and family, Helen explained:

“ [if] you have a social worker, you’re no good, gets all the bad feedback”.

In comparison, for Jeremy, the social impact of having formal support was that he perceived his neighbours to be jealous of him:

“(..) it’s a bit of jealousy I think, because I have someone here helping us with the children, and they couldn’t get anybody, they never had any help. We asked for help”.

3:3 SUPERORDINATE THEME 2: PARTNERSHIP AND PERCEIVED EXPERIENCE OF SUPPORT

In summary, all the parents reflected on their experiences of working in **PARTNERSHIP** with the professional. All of the parents recognised the different **Dimensions of helping** and described ways in which the professional supported their parenting. The **Professional's qualities**, the perceived **Degree of empowerment** experienced by the parent, and the level of **Connectedness** between the parent and the professional appeared linked to the perceived experience of receiving formal support. Whilst most parents identified both positive and negative experiences, for some, the overall experience of receiving formal support was experienced more negatively than others. Integral to each subordinate theme, and therefore, integral to whether the parent and professional were able to work in partnership, was the degree of mutuality.

3:3:1 Dimensions of helping

There was a shared experience across all of the parents of the ways in which the professionals supported them in their parental role. Most parents talked about the ways in which the professional provided scaffolding to improve learning. This included giving advice, modelling skills, providing aids, such as, dolls or books to help develop skills, implementing routines and learning about safety. Karen explained how the professional used a doll to let them:

"(...) practice, to show us, to show us what she means (...) with weighing (...) and putting nappy on".

When asked what things his professional helped with, Paul said:

"all sorts, bathing, cooking his tea, help putting him to bed (...) make sure we change his nappy on time (...) she told us what to do (...) it was nice to have the support and nice for people to show me what to do because I was a first time dad".

For Rebecca, this type of support was helpful because it was managed contingently.

Rebecca explained:

"(...) before there was no-one there (...) I felt like I was on my own a bit, and now I know there is someone there I can always go to, so it's good [someone is there] in the background, and if I need anyone she is there".

For other parents, such as Jane, they perceived that the professional had not got the balance quite right. She explained how the support was not meeting her needs because she was not getting enough if it, she felt isolated and unable to do the things she wanted with the children, she explained:

“Well I think we should, all of us who has got learning disabilities with parents, sit down with all out staff and everybody we know and say right, we want this in place, because at the moment I don’t know what is going on with [organisation] at the moment, they’re just, they’re not, they are going downhill since the boss has gone. There has been nothing being done and everything. It’s just going downhill at the moment (...) yeah I think everybody who has got learning disabilities should sit down and say right I want this in place, we want more hours, we want to get the kids out on the weekend and everything like that”.

Validation was a core **Dimension of helping** for most parents. Parents sought feedback and emotional support from their professional. Amy explained how her identified professional was:

“(...) rewarding us, telling us that we are doing things right, he is not nasty he is really good towards us, the positive things he says about us and things he puts on the piece of paper(...)”.

In her ambivalence about what it was like receiving support, Helen described how the times when it is “good” is when the identified professional provided one-to-one time to talk and (or) positive feedback, for example:

“That I am doing well with the kids”.

Zara appeared to seek validation and reassurance from her identified professional around her use of strategies in parenting. She said:

“It’s just like, she can explain more things, I can explain then what I feel like and you know if I can’t cope sometimes, like when Guy does have a megger tantrum, I feel sometimes: ‘oh why, why has it got to be me and all that’, and she said: ‘all kids are gunna have a tantrum, but just you know, just do what you want do, put them in the naughty corner or whatever, and the he’ll come,

come then, he's gunna think well I'm not gunna be naughty or I'm in the corner all the time' ”.

Angela presented a different experience of validation. She reported what it was like when validation was missing:

“He just brings up child in need meetings every now and again, he doesn't come and check nothing(...) well for one he is meant to make sure all the support is working and everybody is coming out like they should be”.

The last dimension of helping, that was integral to the experiences of just over half of the parents, was how the professional provided practical support. This included for example, attending meetings, making referrals to other services for extra support, organising courses, liaison with services around the child, helping out with transport and helping the parent to organise affairs in the house. Rebecca explained how her identified professional:

“told me about disability living allowance, told me about getting Andrew statutory assessed in school, getting a meeting in the school, finding out what's going on, sending me emails, just checking that I'm ok with everything what's going on, and I needed that you know, it's good”.

Amy explained how her professional:

“ (...) picks Jamie up from school and brings him down (...) out of his own way, he took Simon to have his teeth done, teeth out, and stayed with him all day, yeah so it's really good. He picked us up at half past 6 in the morning, because his appointment was half past eight, so he took us up to clinic up in [location] and he took us up there, so he's really good yeah”.

3:3:2 Professional's qualities

All of the parents talked about the importance of the **Professional's qualities** when working in **PARTNERSHIP**. It appeared that part of whether the parent experienced the overall support as positive or negative was their perception of the professional's qualities. Nearly all of the parents reported a range of positive qualities in the professional. This included qualities such as, technical knowledge, humour, being friendly and playfulness. In describing her experience of her professional's qualities, Rebecca said:

“ [she is] positive, and very open as well, you know, she’s very yeah, on the ball, she knows what she is talking about as well, so it’s good”.

For Paul, the factors that helped to build the relationship between him and his identified professional were her reliability, the fact that she came at times that suited him, and her caring nature:

“The service that she provided, the hours that she was doing, making sure everything was going ok (...) she was a good worker she used to come in and she just got stuck in to it”.

Zara described her experience of mutual trust:

“It’s just like, she can explain more things, I can explain then what I feel like, and you know, if I can’t cope (...) I think because she is more nice, she is friendly, she explains, she is just one of those person, she’s a caring person”.

Other qualities appeared to reside on a continuum of positive and negative experience, often with each professional moving across this continuum over time. This included qualities such as; reliability, personal integrity, honesty, trustworthiness, openness and their ability to be caring. Many parents talked about both positive and negative experiences of the same professional quality. Amy was frustrated by the professional’s inconsistent reliability, but for her it was important that her children felt able to trust the professional, and this was often born out of personal integrity, she explained:

“He is listening more and is helping more, the other one’s didn’t, they criticised us most of the time. If he sees something wrong he tells us without, he tells you to your face, instead of behind your back, or getting someone else involved. The other ones didn’t, they went and told other professionals about us. But here, this one, John seems a lot better. Kids seem a lot better, the kids trust him more than the rest of them”.

Some parents described purely positive experiences with regard to the professional’s qualities, whereas, for others, negative experiences dominated. For these cases, this was integral to their overall experience of receiving formal support. Jane described how a lack of playfulness and humour impeded the development of her relationship with the identified professional, she explained:

“Well she don’t have a joke anyway, she don’t have no jokes, I have a joke with the other girls, but have no chance with this one. (...) Just don’t take things serious I say, but she does”.

Sadly, for Angela, her experience was dominated by the professional’s lack of helpful qualities. She described her professional as *“patronising”* and said:

“I just can’t talk to him (...). I just don’t feel safe to talk to him no (...). because if he passes the information on (...).”

Helen described her professional as: *“not trustworthy”*. Similarly, for Karen, her overall experience of the support was dominated by her experience of the professional’s qualities. She described the professional’s *“attitude”* as:

“[she was a] bit of a know it all (...). Yeah nose pointed up in the air a lot (...) Posh in it (...) Posh and know it all kind of person (...) What are those people, you call them, snobby”.

In Simon’s description, he revealed a vulnerability in the professional and explained how this shaped his experience of working with her, he said:

“She’s a young social worker (...) It must be a lot, because sometimes it is for somebody young to do that job, you know what I mean? (...) it’s a lot of responsibility you have got to cover yourself back to your boss (...) I do understand and I’ve never said nothing bad about her”.

3:3:3 Degrees of empowerment

There was a shared experience amongst all of the parents of the importance of the **Degree of empowerment** when working in **PARTNERSHIP** with the professional. Whether the parent perceived the professional as adopting an expert approach or one of collaboration was integral to the perceived experience of the support. For all parents who perceived their professional as adopting an expert approach, this was perceived negatively. Whereas, for all parents that perceived their professional as working in collaboration with them, this was perceived positively. Half of the parents experienced aspects of both, and half of the parents reported experiencing one or other approach. There were central aspects integral to both approaches, for example, power, choice, control, having an equal voice, communication, and

mutuality. These appeared to lay on a continuum with the respective approaches at opposite ends.

Karen described how her identified professional gave her: *“the power vibe”*: Helen outlined themes around a lack of choice and freedom when describing the impact of the expert approach:

“I feel like a prisoner (...) Got to do what they say and everything (...) Got to be in when they want me to be in”.

Helen described feeling *“intimidated”* by her professional. For Simon, he reported an experience of being disempowered by his identified professional. The language he used was very passive, and when thinking about following advice Simon said:

“We’ve always done everything what people tells us, and we’ve never had words with social workers, or nothing(...) I always, I always follow it [if I don’t] straight away I won’t be talking to my sons tomorrow”.

Angela had a similar experience, she described the common experience of a lack of disagreement with the professional. She explained:

“I do whatever they say like should be done (...) Stay in the good books (...) because they are Social’s, if you don’t do what they ask sort of thing, then they can get funny can’t they”.

The concept of power had different dimensions; there appeared to be levels of power, for example, many parents talked about the need to talk to their professional’s boss. For Jane, there was a different type of power process happening, she described an internal power battle, on the one hand her advice to other parents was:

“I would say to them, go along with it and then if you really have the struggle, tell them straight , tell them that you need help and that you have got to get it all sorted”.

On the other hand her experience was:

“You have to get on with them, because if we don’t they go back to the office and say look, so and so is not doing this and we are not getting on with them (...) if we don’t get on with them, they will feed that back and then there will be a meeting and stuff like that (...)”.

Simon also described being in a power battle, but one with his professional. He described how he sought additional support from others, because:

“You have to go a step ahead of them (...) when we got the solicitor involved everything hit the roof, and they weren’t very happy: ‘Why have you got a solicitor involved? (...) and since the solicitor has been involved I can’t fault it. It’s been fantastic”.

In contrast, Zara described a collaborative experience of being able to have a voice, being allowed to disagree and feeling confident in her identified professional responding well to this. A sense of feeling empowered enabled Zara to provide the following advice to other parents:

“It’s just to work with them, and just, you know, you gunna be nice to them and they are gunna be nice back to you and give you all the support that you need and that(...) you don’t have to do it, it’s just she can give you the advice, it’s up to you then to think yes or no”.

Amy shared a similar experience and outlined the value of clear communication between her and her professional. She explained:

“(...) he talks the level towards us as well, yeah he treats us not like children, he treats us like adults and parents as well, so explains stuff and he um, he don’t contradict like the other one’s”.

Simon described that the best ways of communicating with his identified professional were when:

“We sit down together, like you and me are doing now, and speak genuine around it (...) but sometimes I have felt, by telling the truth to the social worker, I felt worse. I felt like um, I have always told her the truth. If you’re gunna tell a lie one of these days it’s gunna catch up with you, pointless lying about it. It’s like: ‘right, he’s done this today now’, or if he’s fallen, I would tell the truth”.

It appeared for Simon that sometimes, telling the social worker the truth resulted in more worry.

3:3:4 “*Understanding what I’m going through*”: Connectedness

Integral to each parent’s experience of **PARTNERSHIP** was the degree of **Connectedness** between the parent and the identified professional, which was described by Jane as whether or not they could: “*Understand what I’m going through*”. While some parents described feeling completely connected to their professional, that is they perceived that the professional understood them, the majority of the parents experienced both helpful factors and barriers to connectedness.

It appeared that the professional having experience with children, especially having their own children, was a shared experience integral to building connectedness. There appeared to be a perception across parents that being a parent themselves enabled the professional to better understand their experience. For Helen, it meant:

“(...) she knows how I feel inside (...) It’s more comfier and all that, if people don’t have children of their own they don’t know what the experience is (...)”.

For Zara, it meant:

“I think because she understands then like, you know, how the way kids grow up, so then, she can give me advice then, the way what I’m gunna learn(...)”.

For Rebecca, the fact that her identified professional had a child with the same condition as her own meant that:

“She is on our side, and she knows what it’s like”.

Having shared values appeared fundamental to building connectedness between the parent and the professional. For the parents that this related to, it seemed that having a professional who shared their value of being there for the children was important. Amy explained:

“(...) he talks to the kids (...) and he is involved with the kids, what they does and different things, and the kids talk to him more than the rest of the social workers did (...) Talking, explaining, listening to the kids, and see what they wants out of him, So I am the kids Social Worker, so what do you want out of me (...)”.

Further evidence for the importance of having shared values in building connectedness came from Angela's very different experience. She perceived her identified professional as not doing things "*properly*", and that:

"(...) it's meant to be about the kids, so everything about the kids, he should be there, you know".

The impact of the professional's demographics appeared integral to the experience of connectedness. For the parents that this theme related to, all expressed a preference for having matched demographics with the professional. This included gender, age and for one parent their ethnicity. Amy explained:

"So, he seems more down to earth, like kids level, he's been with teenagers, he knows what teenagers like and different things (...) he is younger (...) down to their level and things (...)".

Where there was a lack of matching, this was a significant barrier to connectedness. For Angela this was fundamental to her experience with the professional. She explained:

"(...) he asked me what do I want from all this, and I was like, I don't know, because I don't like talking to men so I just don't say anything, I just say, I don't know".

Whether or not the parent perceived the professional to fully accept them, that is, understood their needs and accept their experience without evaluation, was also integral to whether the parent felt connected to the professional. Zara explained how with other professionals she didn't feel accepted as she felt evaluated by them, for example, through their judgements about the tidiness of the house. Karen seemed to sum up the idea of acceptance in her advice to other parents, she said:

"Make sure that you, they got somebody who understands how you tick".

Simon compared his current experiences with his identified professional with that of a previous one, and explained that with a previous professional:

"It was a bit of misunderstanding at the start (...) but it went fantastic. She was like a mother to us in the end, she did understand our problems (...)".

Simon's quote links to another concept integral to connectedness, that of the intensity of the relationship. Half of the parents made reference to the intensity of the

relationship with their identified professional. As in Simon's quote, Jeremy referred to his professional as:

"like part of the family".

Helen described a different type of experience. For her, the intensity of the relationship was perceived negatively, she explained how her husband described her identified professional as:

"(...) like another wife (...)".

"Pressure" was a theme experienced by many parents as key to the intensity of the relationship, and many reflected on the challenges of seeing the same person frequently. Jane had many different people coming in, in addition to her identified professional, and explained:

"(...) I used to have Helen five days a week and it used to do my head in (...) If I had Helen coming all the time, I would have murdered her by now."

3:4 SUPERORDINATE THEME 3: "GETTING THROUGH IT": COPING

In summary, parenting in the context of formal support appeared to lead to differing levels of **COPING** in parents. The *Sense of coping*, the *Emotional impact* of receiving formal support and their *Strategies for coping* were integral to this experience. All parents reported a level of negative emotional impact on receiving formal support in parenting. Whilst recognising a degree of ambivalence, most parents reported a general sense of coping and "**GETTING THROUGH IT**".

3:4:1 Sense of coping

All of the parents reflected on their **Sense of coping** in the context of receiving formal support around parenting as all of the parents had experienced significant amounts of adversity. However, most parents evidenced significant inner strengths and were able to maintain a positive sense of coping. Rebecca sense of coping was:

"Put your head up high and you keep going".

For Angela, her sense of coping in the context of receiving formal support was connected to her children, she explained:

"It's easy really, as long as your child has got what you know, what they [need], social workers can't really say anything about it".

While Jane's perceived ability to cope was more negative, she expressed a similar inner strength, she explained:

"Well I struggle, but I have got to go through it and all that lot".

For many, as a result of different adversities, their sense of coping was established prior to receiving support from their identified professional. Simon described his experience of becoming a dad as challenging, he explained:

"I've learnt the hard way to being a dad, I didn't have a clue, honest to god (...) I didn't have a clue to be a dad, but live and learn the hard way to be a dad".

He also explained that despite this:

"(...) before we had her I just, we coped with it, we didn't have nobody(...)".

It appeared for some parents that receiving formal support had a direct impact on their coping ability. There was a shared experience amongst parents of how having a professional supporting them in parenting created extra demands. In the context of what it was like managing the different demands that professionals placed on her, Zara explained:

"Oh it is hard, but in the end you do do it, but sometimes you are like: oh no I don't want to do this, it's so much then, but in the end it comes easier then, trying to work around things and that...".

Amy explained:

"(...) some people uh, can't understand how I put up with all this over the years (...) and they say I'm strong and different things (...)"

For Karen, her experience was that the professional added to her sense of not being able to cope. She explained:

"(...) I didn't really need, I don't, I didn't need them really, it's just when they wind you up, I wasn't very good at coping (...)"

For many of the parents a sense of coping also appeared linked to confidence and degrees of social isolation. In describing her experience of not coping, Jane wanted

her identified professional to give her confidence, whereas for Zara, as a result of the support given by her professional she explained:

“(...) I think I have got more stronger, and I know now I need to stick up for me and my family and that.”

Helen described a direct link between her sense of coping, social isolation and her identified professional. She described being more isolated from her friends and explained that she didn't see much of her family anymore because:

“I have Sarah or someone else in the house, to do with Sarah [this is a] bad thing in one way(...) [my family] don't help me because I got a Social Worker, and they don't like the Social Worker themselves (...)They are digging and digging and it feels like they are digging the hole deeper and deeper”.

She explained:

“I would cope if they stopped keep coming in and out and if they didn't come in all the time”.

Karen described the social isolation associated with her identified professional treating her differently, for example, when not being able to go to the clinic to have her child weighed, she explained:

“I kept missing out on the company as well with others, because I would have sat and waited and chatted with them while I was waiting my turn”.

It appeared that for nearly all of the parents, the main rationale for coping was a drive to keep their children. Simon explained:

“(...) I just cope with things, I have to (...) I've got to be strong for the boys, if I'm not going to be strong for the boys, nobody else is gunna be (...)”.

3:4:2: Emotional impact

There was a shared experience amongst all of the parents of a negative **Emotional impact** of receiving formal support. While for some this negative emotional impact dominated, most parents described a mixture of a both a positive and negative emotional impact of receiving formal support. The parents described a number of different emotions. This included feeling: happy, relief, pride, strength, pressure,

shame, guilt, loneliness, sadness, anger, and frustration. Rebecca explained how positive feedback from her identified professional made her feel:

“(...) positive and we think, oh yeah I’m doing good, we are doing a really good job, and we are proud, and we put our heads up high and yeah we think, carry on”.

In contrast, Jane explained how angry she felt at the lack of communication between her and her identified professional, she explained that when they don’t get cover properly she feels:

“Bloody cheesed off, because they don’t tell me, they don’t tell me nobody is coming in and nobody rings me or nothing, and tells me”.

Karen had a similar experience, she explained:

“(...) they are always late (...) we always tell them to come at certain times, because he would be ready for them, but they always used to be late and that used to really wind me up, that really bugged me that did”.

Zara described a mixture of emotions, but in particular she described feeling guilty about the things she was not able to do for her children:

“but I do feel sometimes, oh are we leaving the boys down, but I know if I had a car, they would go everywhere then they want to go and that. Guy had a thing in school, because it was in XX and it was awkward with the buses, and I would have to wait an hour and half for a bus to come back so, then one of us would have to be back her waiting for William to come home from school in XX so it’s all awkward (...) so sometimes it’s like, I feel guilty now, do you know what I mean, it’s not that, it’s just because I haven’t got no way of getting up there”.

The overriding shared experience was of fear and worry. Simon described an overriding sense of worry about being a parent. He described feeling stuck, he described feeling blamed by his identified person, who he described as *“pointing the finger”* at him all the time. In response he described being frustrated and scared:

“(...) I’m a bit scared, I think, one of these days he is going to fall at home (...) and they are gunna ask thousands of questions, well where were you, why has it happened?”

It appeared that this worry was linked to a fear that their children would be taken away. Helen explained that having support from her identified professional was “hard” because:

“I think they are taking the kids all the time”.

Whilst recognising a worry about having his child taken away, Paul described how his identified professional reduced this worry, his rationale was because:

“Penny [professional] loves him as well”.

3:4:3 Strategies for coping

The majority of parents described both practical and emotional **Strategies for coping** with receiving formal support around parenting. This included coping with: the demands placed on them by the professional; the expectations; the intensity of the relationship and feeling disempowered. The use of strategies appeared to influence the parents’ relationship with their identified professional. The use of some strategies also questions the true extent of whether the parent fully accepted the professional’s support.

Many of the parents described practical ways of coping, this included smoking, writing things down, or getting more help, for example, from an advocate or solicitor. It appeared that some of these strategies were aid memoirs that enabled the parent to utilise the support more effectively. For others, the strategies appeared to be employed as a means of avoiding direct confrontation with the professional. For example, Angela spoke of how ‘going out for a smoke’ was helpful in the sense that it stopped her children from seeing how stressed she was, but it left her emotions bottled up inside. Simon explained how getting in extra support has made the many meetings he attends bearable, he explained:

“(...) when we got a solicitor involved everything hit the roof, and they weren’t very happy (...) since the solicitor has been involved I can’t fault it, it has been fantastic (...)”.

Many parents had the shared experience of adopting emotional coping strategies. Some developed general mottos, for example, Jane said:

“(...) I just get on with it, I just get on with it, go along with it all, you have got to (...)”.

For other parents, putting on a front was integral to their experience of coping with receiving formal support. These parents had developed emotional coping strategies such as placating the professional, and appeasing them whilst with them and then doing what they had always done. Helen said:

“Around people you have got to listen”.

However, she also said one of the ways that she manages her disagreement with the rules imposed by the professional is:

“Don’t tell her nothing” and: “I just ignore her and do whatever I have to do”.

Karen shared a similar experience, she explained:

“I used to say to Ray, don’t worry about it, let her do what she wants and we do it anyway, then we do what we want anyway. As long as Charlie is clean and not sore when she comes, just forget about it”.

It appeared that for some parents, one way to manage parenting in the context of support was to develop strategies that were self-protective and acted as a defence against the challenges associated with receiving the formal support. For example, Simon’s emotional coping strategy appeared incongruent with his experience. He described some very difficult experiences with his identified professional, and yet followed this up with the phrase: *“it’s fine”*. This response appeared almost automatic, it was as if this was Simon’s way of avoiding thinking about the fact that it really wasn’t ok or *“fine”*. Similarly, it appeared for Karen that her experience was that of, ‘if you think that I can’t do something, I will show you that I can’t’. She explained how she chose not to share with her identified professional her existing knowledge and skills:

“Well I wasn’t sure if I was supposed to tell her or not, because I’m not supposed to be able to do things you see (...) because of my disability things you see, I get into trouble with other people, If I know what, if I can do everything(...)”.

Interestingly, many of the parents talked about the fact that the professionals were: *“just doing their job”*. As a result, many of the parents used other strategies as a way of retaining information in spite of their existing strategies, such as ignoring them.

Karen explained:

“Well after she had gone I used to write down what she used to say and thought, maybe she was right”.

3:5 SUPERORDINATE THEME 4: “WHO IS THE PARENT HERE?”: IDENTITY

In summary, integral to all parent’s experiences of receiving formal support was negotiating their **IDENTITY** as a parent. Central to this experience were **Beliefs about parental ability and skill**, **The importance of time**, and being in a **Dependent position**. This led one parent to ask the question: **“WHO IS THE PARENT HERE?”**.

3:5:1 Beliefs about parental ability and skill

All of the parents reflected on their **Beliefs about parental ability and skill** whilst parenting in the context of formal support. Less than half of the parents perceived themselves as purely doing a good job as a parent. For other parents, their perception of parental ability and skill moved across a continuum with a sense of failing at one end and believing that they were doing a good job at the other. Unfortunately, for one parent, the sense of failing dominated. There was also a shared experience amongst parents of the formal support impacting on their perception of self.

Paul described himself as a *“brilliant”* dad, and believed that other people saw him as an *“amazing”* dad, he described that this was because:

“(...) maybe, I’m there if he [child] needs me”.

Over half of the parents were able to identify strengths and skills as parents. Jeremy described his skills as a dad as:

“Listening to them read, play games with them, play games with them now and again if I’m not too tired(...) I talk to them (...)”.

Karen believed that with regard to skills around feeding and potty training:

“I just come natural to that (...) because of the work I did”.

Rebecca said that she was good at:

“Looking after them [children], caring for them and making sure they have everything they need, not want, need. Clothes, shoes, making sure they look nice when they walk out that front door”.

Helen described the importance of other people’s perception of her abilities as a mother. Integral to this experience appeared to be a drive for acceptance and also links to the ideas around judgement presented in section 3:2:3:

“They all kept saying you’re good, my Nan said you’re a good mum (...) she said I’m more, more gooder (...) I said: ‘cheers Nan, what does that make me before then?’ (...) she said: ‘no you was good, but you got more better’ (...) if other people see it then that’s it I’ve been noticed (...) I like the feedback to be honest, it gives me more confidence”.

However, half of the parents described a belief of failing in some way, and some parents appeared to have a negative attribution style and focused in on what they perceived they couldn’t do. Parents described this sense of failure in relation to skills and for some, their body. For Karen, part of this experience was:

“(...)I wanted to give Charlie all the milk I could get but I couldn’t get it all the time, and it kept getting too thick, my boobs weren’t working properly”.

Simon explained:

“ One thing I can’t do, I would love to do, I can’t read for the boys. A lot of things now he is getting older, I used to read like, joking reading the book, what was Fireman Sam was doing, or Thomas, I could do it, but I couldn’t read it, I was making my own story up. But now he is getting older: ‘that doesn’t say that dad’. But he knows my problems, he is telling me the stories now”.

Jane’s account of her ability as a mother was ambivalent. She described her skills in the context of receiving support but also in the context of her earlier experiences. This led her to attribute blame externally and to how she was parented. She explained:

“Well, people say that I am a good mum, but my mum, some people we know are saying ‘you’re a bad mum’. I said: ‘how can I be a bad mum, if I’m a bad

mum', I said: 'they would be off me and in bloody care by now. (...) well I discipline them, but right every time I, I just, mum just thinks that, I just need some help, go to a parent course and get some parent skills into me and everything (...) yeah screaming and shouting at them, but I don't need to scream and shout at them, but I'm just saying mum and all that, I have been brought up with it and violence in my family, you can't blame me'.

For some parents their perception of self was directly linked to receiving professional support. Karen explained:

"She made me a good mum, made me more, you know, to cope better (...) it kept my brain ticking".

For Zara, she believed that what she was good at before she had support from her identified professional was:

"Just doing the house work".

In comparison, with support she believed that she was good at:

"nearly everything now (...) how to do more fun cooking with the kids (...) the cakes and pastry, and instead of buying it, make your own, it is more fun to do (...)".

For Helen, her sense of failing was directly linked to receiving support from her identified professional. Helen's experience was that her identified professional asked her children questions about her including if they love her, she explained that this made her feel like:

"A bad mother".

She also described how her identified professional reinforced her awareness of difficulties:

"She asks me to read a book. I can't read a book. She says you have got to read [and] write in the diary to the kids. You can't. If you have a disability and you can't read and write, you can't do it".

Simon's parental identity appeared shaped by his relationship with his professional and appeared was caught up in a sense of failing. He said that he felt blamed by his identified professional, he described them as *"pointing the finger"* at him and *"putting*

him down”, so much so that when at a big meeting with lots of different professionals, he explained:

“But what I couldn’t understand was that all the people around the table with us, were putting positive things about us, but I couldn’t knock it into my head, and that’s why as soon as they mentioned the boys I thought we’ve done something wrong (...).”

There was a shared experience amongst the parents that parenting in the context of a learning disability and of formal support was “hard work”. Most parents, like Angela, said:

“It’s good to be a mum, it’s hard work”.

For Helen, what made the experience “hard” was the amount of “learning”. Rebecca had a similar experience, her sense of it being “hard” appeared to be directly linked to her and her husband’s extra learning and physical needs. For Paul, what he found “hard” was doing things the “correct” way as defined by his identified professional. Karen described some aspects of being a mother receiving formal support as “bloody awful”. This was particularly with respect to the “**Extra**” expectations placed on her by the professional. This led her to give the following advice for parents who are planning to have children:

“Don’t have them, they are hard work, and make sure the house is tidy, make sure the house is done up before you have them”.

3:4:2 The importance of time

There was a shared experience amongst parents of **The importance of time**, when parenting in the context of formal support. It appeared that the parents’ role was significantly shaped by meetings and having an identified professional regularly in their home. As a result time became really important. Many of the parents reflected on the number of meetings or appointments both with their identified professional, and other’s in their wider network. Zara explained:

“(...) appointments, well appointments, I’ve got appointments coming in left, right and centre”.

Simon explained how at the time of the interview he had meetings about the children every three months, whereas before:

“We used to have a lot of meetings, once every three months, or sometimes, before, twice every three months, and we used to have meetings sometimes, in the house and there was 26 of us”.

Jeremy talked about his professional earning his right to ‘time off’, emphasising the difference in role between them. For the professional this was a job that they could take time off from, whereas, for the parent time centred around the children. He explained, that relying on the professional was:

“Hard, but at the end of the day he has got to have his leave like everybody else, because if he didn’t have his leave by April next year he’ll lose his holiday, so he has got to have his leave like everybody else”.

Associated with this experience was a shared frustration of the lack of notice that the identified professional gave around when they would visit. Jeremy explained:

“I can’t make any plans for next Tuesday until I find out what time he is coming”.

There was also a shared frustration amongst parents of the time that their identified professional came in. Helen explained that her identified professional came in at tea time when:

“You are trying to do everything at once, and she wants to talk to the girls and you’re trying to make tea, or the kids are eating their tea and she’s talking, oh god (...) I try to wait till she goes and then that’s when I tries to make it (...) but she doesn’t like it, she wants me doing it when she’s there”.

For Amy, having lots of meetings and professional involvement made her question her role as a parent:

“It feels like they are planning it instead of you doing it, that’s how it feels. It feels like they are planning your children’s life, instead of the parents doing it”.

It seemed for Karen, regular professional support shaped her sense of what a mum’s role is. She explained:

“I was tense anyway to figure out what a mum’s role is”.

As stated in section 3:2:1, due to the **“Extra” expectations** and demands placed on her by the professional, Karen described how she thought a mum’s role, alongside caring for her child was:

“Making sure the house is tidy”.

In addition to how receiving formal support around parenting influenced some parents’ sense of who they were and their parental role, it also appeared to shape their perspective on time, and for many these two aspects appeared linked. For many parents their main drive and priority, as Helen described, was:

“My kids. Me and my children at the moment, and Robert [husband]”.

For Simon this meant,

“(…) if something happened to the children, it is pointless me being alive”.

For many there was a sense of there being no time left for anything else. Helen described how all of her time was taken up by being a parent, and the appointments with the different professionals. It appeared that Zara didn’t feel like time was hers to spend on herself, she explained:

“We normally keep a Wednesday free for me just me and Stuart to have me time together, because we never had me time, but like sometimes it can’t be helped, some people [professionals] are like, oh can we come around, we can’t do this date, or I can’t do the following week, so some Wednesday’s we don’t mind it, now and again, but not all the, if it’s all the time, it’s like ‘no’, it’s not working then”.

Zara also explained how her professional directly reinforced this idea:

“She said: ‘You need to start going out and meeting people, but like I said, you’re a mum, you’re so busy with the kids, so really you don’t have the time, so when the boys are in school you can have a bit of time, but then you have got to do the housework, you have got to do those things, so by the time the boys come home, you really haven’t, you have been doing stuff all the time’ ”.

3:5:3 Dependent position

All of the parents accepted the formal support that they were offered. However, for some this was not a choice afforded to them, and the true extent of this acceptance

should be viewed in the context of the types of coping mechanisms parents used, for example, placation. However, in light of this acceptance, it appeared that a shared experience for parenting in the context of formal support was the negotiation of self-agency, and the continuum of self-agency to being in a **Dependent position**. The majority of parents described how important it was to them to do things for themselves. Rebecca explained:

“That is my choice, I would rather just have her there, saying you can do this, and then I do it, and I did”.

There was a shared experience amongst all of the parents of being dependent on others in spite of this self-agency. All of the parents shared how they used their identified professional for support. Some acts of self-agency were bound up in dependency, for example, Jeremy stated:

“We asked for help and we got help”.

Jane’s support hours had reduced, and she described how previously she used to do more with the children:

“I was fine, I was fine. We used to take them out, go up Winston’s ice-cream, go to the cinema, go to McDonalds, everything, but now, it’s just like, nothing, we can’t do that with them”.

It also appeared that the parents’ assertiveness skills were integral to their ability to do things for themselves. For Amy there was a balance to be struck with the formal support offered. She described a previous experience of being in a meeting with professionals, in that meeting she said:

“ ‘Well who are you talking to, who is the parent here? I said: ‘You are talking to each other about us, instead of to us’ ”.

Amy was able to stand up for herself which contributed to her sense of self-agency. Whereas, Simon’s use of language suggests high levels of dependency, he described his identified person as:

“(...) in charge of the two children and everybody who works with us”.

Amy's advice to other parents with learning disabilities receiving formal support was:

“Just get them, get the help, the more help they deserve, if they have got thing, get more help, if they have got learning problems, get, accept the help. Accept the help that is there, but not for them to take over, so not to take over their son. Explain to the professional that they are here to help us, not to take over, this is what I have told thing, you are here to help, not to take over. John said that, I am here to help, not to take over, you are the parents, so you are the parents, you have got to prove to me that you can be parents”.

Helen described how her confidence and assertiveness skills, and therefore, her self-agency, developed over time:

“If there is something I don't like I just snap [before] I would have sat there and cried (...) I have got myself good confidence and said, no one is going to take the mick out of me no more, I have got to do this for my kids (...) I have got to do it myself. I thought, no one's gunna be there, I've got to stand up for myself. Get a bit of back bone and say nope you're not having this no more, for a change”.

This dependency also extended to family members as half of the parents described a reliance on informal support, particularly their own parents in parenting. Jane explained:

“If I want to do things, I have to take my mum and my daughter with me and stuff, because I don't know what my boys are going to be like, whether they are going to play me up you see”.

Rebecca explained how her mother and stepfather have been her “rock” and how their parenting of her has been so empowering:

“Because they say you can do anything you want to do. I mean, it took me three years to pass my driving test and I just wanted to give up, and he [stepfather] said, ‘you are not going to give up I have paid out too much money every week and you're not going to give up’, and I thought you don't give up without a fight, because I have been through so much as a child, and I think that's where I get it from with Andrew, You don't give up”.

3:6 SUMMARY

The analysis of the data identified four superordinate themes:

- “*Stepping Up*”: Expectations;
- Partnership and the perceived experience of support;
- “*Getting through it*”: Coping, and
- “*Who is the parent here?*”: Identity.

The superordinate themes have a focus on both interpersonal aspects and also the intrapersonal impact of receiving formal support. It appeared that core experiences integral to receiving formal support and the key concepts that underpinned the themes were acceptance and mutuality. Each of these superordinate themes consisted of further subordinate themes.

In Summary, it appeared for most parents, parenting with a learning disability in the context of receiving formal support meant managing a number of different expectations. For most parents integral to this experience was an awareness of difference. All parents talked about the ways in which their identified professional provided support in parenting. The professional’s qualities, their degree of empowerment and how connected the parent and professionals were, contributed to the parents perceived experience of receiving support. Most parents described a positive sense of coping despite adversity, and for some parents the formal support received had a direct impact on their sense of coping. There was a shared experience amongst the parents of the emotional impact of receiving formal support and most parents identified both emotional and practical ways of coping. Finally, for all parents, receiving formal support appeared to impact on their parental identity. Parents described mixed beliefs about parental ability and skill, a sense that all time was focused on the child[ren] and a conflict between dependency and self-agency.

Chapter 4

DISCUSSION

4:1 CHAPTER OVERVIEW

This chapter summarises and examines the findings of the current study in relation to existing literature and psychological theory. Suggestions for future research are proposed, followed by a discussion of clinical and service implications. Finally, a discussion around the methodological strengths and limitations of the study is provided.

Many theories could have been used to embed the themes. Baumrind's (1989) styles of parenting could have been adapted to understand the links between the behaviour of the professional and the outcomes for the parent. Models of loss (Bowlby, 1980; Stroebe & Schut, 1999) could have been used to explore the way in which parents cope with changes and loss of roles. The findings could have also been understood through trans-generational patterns of parenting (Fonagy *et al.*, 1991). However, the interpersonal and contextual lens presented in the introduction is used to understand the findings and in discussion of the implications and recommendations for the research and clinical practice. For ease of reading and to ensure consistency with the results section, **SUPERORDINATE THEMES** are written in bold and are capitalised, and **subordinate themes** are written in bold and lower case. Further categories in subordinate themes are presented in lower case and are underlined.

4:2 RESEARCH FINDINGS IN RELATION TO EXISTING LITERATURE

The aim of this research was to explore how parents made sense of their relationship with a professional and how this impacted on them as a parent. The researcher identified only a handful of previous studies exploring parents' experiences of receiving formal support, most of which did not integrate findings with psychological theory. For this alone, this study adds significantly to the evidence-base. The themes presented typically represent both divergence and convergence

in accounts, and therefore, presented a more holistic picture and wider understanding of parents' experiences.

The findings are first considered in relation to how they support, refute or add to existing studies exploring parents' experiences of receiving formal support. Given the shortage of studies in this area, where appropriate, the findings are considered in relation to wider literature on parenting with learning disabilities. This is contained within the learning disability field, to enable reasonable exploration of detail, and remain consistent with the concept of idiography which shaped the design of the study.

In an attempt to better understand the experiences of parents, findings are then integrated with psychological theory. As described in the introduction, the interpersonal perspective, social constructionism and acceptance create an interpersonal and contextual lens from which the findings can be understood. Hypotheses and socially constructed feedback loops describe possible ways for how the parent and professional reinforce experiences. Within these feedback loops dominant narratives as perceived by the parent are presented (these are hypothesised by the researcher in the context of the parents' accounts). To the researcher's knowledge, this was the first piece of research to understand parents' experiences of receiving formal support in relation to the contexts of parenting specified through these theories, in particular, providing support in the context of acceptance.

Links between themes are made and are integrated in the discussion of each theme in accordance with the interpersonal and contextual lens. Section 4:2:5 provides an overview of the interconnectedness of the themes based on Bronfenbrenner (1979).

4:2:1 Superordinate Theme 1: "STEPPING UP": EXPECTATIONS

The findings describe the different types of **EXPECTATIONS** placed on parents with learning disabilities. Parents described "**Extra**" expectations, the **Presumption of incompetence** and an **Awareness of difference**. Previous studies have described a number of issues: namely, the challenges for parents in not knowing what expectations to live up to (Booth and Booth, 2005); the inflexibility of professional

expectations (Howarth, 2009); the negative expectations of parents (Tarleton and Ward, 2007), and experiencing high expectations (Howarth, 2009). The parents' fears of the involvement of services and pressure to parent '*perfectly*' in Howarth (2009) is supported in the current study through parents' sense of needing to "*step up*" and meet the "**Extra**" expectations.

This study extends understanding of the experience of expectations by attempting to distinguish parents' accounts of "*Extra*" expectations from high expectations. For example, "*Extra*" expectations centred around tasks that were not deemed integral to parenting, such as, following tighter rules and restrictions around who and what time people came into the house, and being expected to complete a number of tasks at once. In comparison, high expectations were concerned with doing tasks more associated with parenting, but to a very high standard, such as, the cleanliness of the house (e.g. never leaving toys lying around). A distinction was also made between external and internal expectations. In the context of the external expectations, parents also described internal "*Extra*" and high expectations. For example, parents reported needing to do more than parents without learning disabilities and needing to get things right all of the time.

The interpersonal and contextual lens provides one way of understanding these experiences. Figure 3 shows how a possible feedback loop may play out between the dominant narratives of the parent and the professional and maintain negative external and internal expectations. Parenting in the context of external "*Extra*" and high expectations may shape the parents' appraisal and thinking processes, possibly leading them to develop consistent internal "*Extra*" and high expectations. Having internalised the expectations, it is possible that parents then act in accordance with them (e.g. by keeping the house 'extra' tidy and decorating the bedrooms), which confirms their original value to the professional, who is likely to impose new ones (e.g. the garden must be 'extra' tidy).

Neill and Cottis (2009, p119) state: "*the client's anxiety about the task of learning, and fear of being judged for not meeting required standards, may well be so high as to be an obstacle in itself to learning.*" The parents' experiences of having to do "*Extra*" may also be born out of the professionals' **Presumption of incompetence**

and the **Awareness of difference**, and in particular feeling that they were Being treated differently to other parents without learning disabilities.

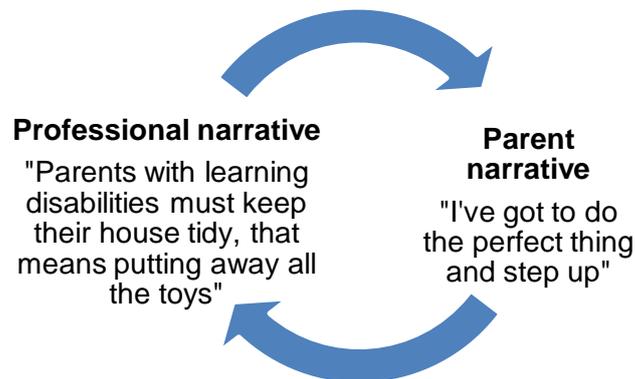


Figure 3: Feedback loop: “Extra” expectations

The **Presumption of incompetence** was a dominant theme in this study, and is well documented in the literature on parents’ experiences of receiving formal support (Booth and Booth, 1994; 2005; Howarth, 2009). In Strike and McConnell (2002, p62), Robert Strike described how “[support] *people are ready to see what you cannot do*”, which Booth and Booth (1994) attribute to a presumption of incompetence. The perceived criticism and condemnation faced by parents in the current study, for example, the assumption that a parent wants to ‘sit on their backside’ rather than care for their child, is consistent with the idea that the professionals were acting in accordance with the presumption of incompetence. This perceived criticism was also reported by the parents in Ehlers-Flint’s (2002) study. The notion presented by Robert Strike (Strike and McConnell, 2002), that there is not one right or wrong way to parent, is supported by the parents in the current study, who were frustrated by the insinuation that they could not have possibly coped prior to support from professionals.

Tarleton and Ward (2007) in their report of the ‘best’ ways to provide support to parents, describe similar findings around the need to quash negative assumptions around ability. However, the idea that the presumption of incompetence was entirely negative was not the whole experience in the current study. For example, one parent reflected on the usefulness of the presumption of incompetence, stating how

the extra scrutiny enabled greater levels of support. Thus, it would appear that the findings in the current study provide a more holistic picture, perhaps because the study did not specify an aim of providing 'best practice' examples.

The dominance of this theme provides support for Booth and Booth's (1994) model of parenting which has, as its foundations, the idea that whether the professional assumes incompetence or competence is integral to parents' adequacy in parenting. In addition to the presumption of incompetence, it is also hypothesised that for some parents there was a social incongruence between their own and the professional's expectations. It seemed that for many of the parents, the cultural and social 'diversity lens' that shaped the professionals' expectations (i.e. the filter or way in which they looked at things), for example, regarding the tidiness of the house, were socially out of context and this appeared to hinder the relationship development between them.

The experience of Judgement by a professional was a significant component of the **Awareness of difference** and was common in all studies in the systematic review (Tarleton and Ward, 2007; Llewellyn, 1995; MacIntyre and Stewart, 2011; Booth and Booth, 1994; Booth *et al.*, 2005; Wilson, 2011; Strike and McConnell, 2002). The findings that parents lacked confidence when in the community and felt stigmatised, support the findings from MacIntyre and Stewart (2011), where parents reported being discriminated against. This links to the sense that parents in the current study had around being treated differently. How the experience of being treated differently was influencing Karen's experience of difference can be seen in her switching between an internal and external attribution: "...because we were..." and "because she thought we were...". In the current study, parents reported how the learning disability label contributed to the sense of being different, and how receiving formal support both increased and decreased parents sense of being different. Parents wanted to be seen as "*normal*"; an experience evidenced in the wider literature (Race, 1999). It also highlights how providing support in the context of acceptance, appears to underpin much of the parents' experiences.

4:2:2 Superordinate Theme 2: PARTNERSHIP AND PERCEIVED EXPERIENCE OF SUPPORT

The parents in the current study described key characteristics of **PARTNERSHIP** in terms of **Dimensions of helping**, **Professional's qualities**, **Degrees of empowerment** and their **Connectedness** with the professional, which one parent described as whether or not they: "***Understand what I'm going through***". It appeared that underlying much of the parents' experience was a desire for mutuality and acceptance. The perceived experience of support was influenced by the relationship between the parent and professional rather than the dimensions of helping.

The value of advice; help to sort out problems; using learning aids and tools; positive feedback, and, practical support, such as transportation, as reported in the current study, have been widely documented (Howarth, 2009; Tarleton and Ward, 2007; Llewellyn, 1995; Starke, 2010). However, this study has broadened understanding of the **Dimensions of helping** as, in addition to Validation and Practical support, the parents described the need for professionals to Scaffold their learning contingently. Scaffolding is a term described by Bruner (1983) and Vygotsky (1978) as a method of structuring and simplifying the environment to facilitate learning. This requires the helper to informally assess ability and provide guidance contingently, that is, in accordance with the learner's needs. The ability to scaffold learning contingently appeared central to the formation of the relationship for the parents in the current study. For Rebecca, the fact that her professional was able to increase and decrease support in relation to her needs, by sitting '*in the background*', decreased her sense of isolation. Unfortunately, some professionals did not manage support contingently, which impacted on the relationship development with the parent.

Studies provide similar findings to the current study, for example, around the value of positive feedback (Starke, 2010; Tarleton and Ward, 2007); the frustration with conflicting advice (Llewellyn, 1995), and the need for accessible information (Starke, 2010; Tarleton and Ward, 2007; Howarth, 2009). However, the current findings have specifically highlighted the challenges and what it is like for parents when certain dimensions of helping, in particular, validation, are missing. It appears that practical

support and scaffolding of learning was more abundant than emotional support, which appeared to heighten its value.

The perceived experience of support appeared related to the **Professional's qualities**. This is in contrast to the findings from Wade *et al.*, (2007) which emphasised the role of participatory help-giving (e.g. practical support) over relational help-giving (e.g. attitude and approach of supporter). However, it is consistent with the findings from Howarth (2009), Tarleton and Ward (2007), Booth and Booth (2005) which described the experience of receiving support as being: "*all about the attitude*" of the professional. It is also consistent with the wider literature, from the perspective of adults (rather than specifically parents) with learning disabilities. For example, Roeden *et al.*, (2011) described how a caregiver's reliable, empathic and non-patronising attitude is more important than the particular types of support in terms of treatment success. In keeping with these studies, the key professional qualities reported by parents in the current study included reliability, technical knowledge, trustworthiness, personal integrity, being caring and open and playful. Many of the parents reported frustration by the professional's lack of reliability and trustworthiness; these appeared to be core qualities in determining the overall experience of the support.

Six of the seven studies in the systematic review discussed the concept of **Empowerment** when exploring parents' experiences of receiving formal support (Wilson, 2011; Starke, 2010; MacIntyre and Stewart, 2011; Booth and Booth, 2005; Howarth, 2009; Tarleton and ward, 2007). Power is a concept that has been explored extensively and used as a framework from the implementation for early intervention services for families headed by parents with learning disabilities (Espe-Sherwindt & Kerlin, 1990). The findings in the current study represent experiences of both powerlessness and empowerment, and the degree to which the professional adopted an Expert approach or worked in Collaboration with the parent. Previous studies have considered these concepts. In her interpretation of findings, Starke (2010, p18) briefly mentions the disempowering impact of '*paternalistic attitudes*' of professionals. Wade *et al.*, (2007) found that parents valued support that was family-centred (i.e. person-centred and collaborative).

The researcher found that by examining the convergence and divergence of these opposing concepts, it became clear that integral to both were: choice, control, having an equal say, being able to have a voice, communication, and, mutuality. All of these components have been considered in the literature (Tarleton & Ward, 2007; Howarth, 2009). However, the different accounts grounded in data from one study enabled the researcher to think about conceptualising parents' experiences of power in terms of a continuum, which is novel. It was proposed that a continuum provided a better picture of: the diversity of experience, the fluidity of power and the ambiguity felt by many parents regarding the degree of empowerment afforded to them. All of the parents in the current study valued collaboration, rather than the expert approach, which is consistent with findings from Wade *et al.*, (2007). The impact for those parents, who reported predominantly expert support, was a high level of passivity, which was evident for some in their language. The concept of power is complex in all relationships, but the parents in the current study emphasise how equal power is at the core of successful **PARTNERSHIP**.

The current study adds significantly to the underdeveloped understanding of the relationship development between parent and professional, in particular, what parents view as important factors in building the relationship, and conversely the barriers to the relationship development. This was referred to in the current study as **“Understanding what I’m going through”**: **Connectedness**. The term connectedness derived from what appeared to be an importance of emotional understanding between the parent and the professional. This means, connecting at an emotional level, rather than at a social level (i.e. being physically together; reducing isolation). This is a concept that Hughes (2006) refers to as ‘Attunement’. Components that increased emotional understanding included whether: the professional had experience with children; they had shared values of being there for the children; their demographics matched; the parent felt accepted by the professional, and the intensity of the relationship. Matching of one component appeared to increase the connectedness of the relationship, that is, the degree to which the pair were attuned. This concept adds to the literature on creating a working relationship between people with learning disabilities and professionals, which typically focuses on the redistribution of power (Brechin & Swain, 1988; Jones & Donati, 2009).

There appeared to be reciprocal influences between the contexts of the **Degrees of Empowerment**, the **Professional's qualities**, **EXPECTATIONS**, and **Awareness of difference**. Some of the parents' experiences depicted a battle of: wanting to be more assertive, to have a 'voice' and to stand up for themselves, but at the same time thinking that this might reinforce unhelpful **EXPECTATIONS** and Judgement from the professional. Booth and Booth (2005) described how sometimes assertiveness can be viewed by professionals as a lack of insight surrounding a problem and an inability to change. This seemed to leave some parents stuck in a vicious powerless cycle. In comparison, at the opposite end of the continuum, for those parents who experienced collaboration, different narratives dominated. A different self-maintaining feedback loop between the dominant narratives of the parent and professional appeared to play out, as depicted in Figure 4. Parents described how, when the professional was nice, enabled them to have a voice, and treated them like an adult, they felt able to disagree and felt "*normal*": like everybody else and felt better able to learn.

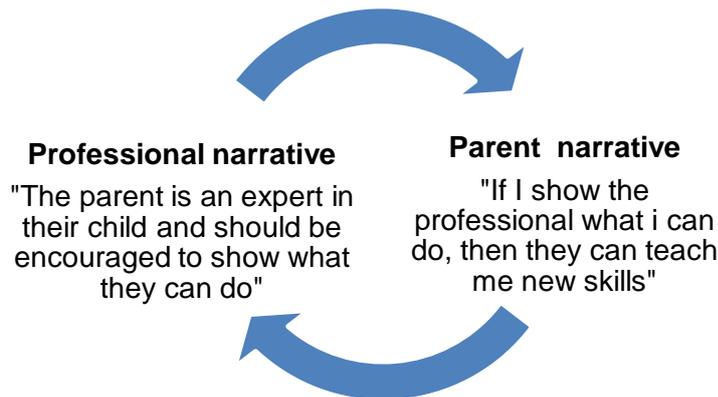


Figure 4: Feedback loop: Collaboration

4:2:3 Superordinate Theme 3: "GETTING THROUGH IT": COPING

The concept of **COPING** is one that is not new in the literature around the experience of parents with learning disabilities receiving formal support. However, by nature, it is a concept that is subjective and further exploration brings new meanings

and understanding. Parents' experiences were grouped into three subordinate themes of: **Sense of coping**, **Emotional impact** and **Strategies for coping**.

The adversity experienced by the parents in the current study was a common experience for the parents in Howarth (2009). Similarly, pressure from professionals reported by the parents in Howarth (2009) is consistent with the findings in the current study. This study extends these findings by describing how, for some parents, this pressure contributed to a perceived reduced **Sense of coping**. Wilson (2011) described the theme: '*Learning to cope*', which detailed how parents' experiences of services during the postnatal period, led to a sense of struggling to cope with their new role, mood changes and the hospital environment. However, this was not considered directly in relation to receiving professional support.

Despite adversity, most of the parents in the current study described inner strengths and were incredibly resilient. Interestingly, for some, the sense of coping appeared to be established prior to receiving formal support. This added to many of the parents' frustration when they perceived professionals as assuming that they were not coping prior to their involvement. The perceived ability to cope appeared associated with confidence. For some parents, receiving formal support directly increased their confidence, whereas for others, receiving support led to greater social isolation and a sense of missing out on opportunities such as, going to the weight clinic. The rationale for coping presented by the parents in the current study, appeared to be related to their drive to keep their children. Tarleton and Ward (2007) reported that receiving 'good support' was one of the main factors that enabled parents to show what they could do, and therefore, keep their children. The findings in the current study have shown the impact when support is not as 'good', as for some of the parents, receiving formal support decreased their ability to cope and made it harder for them to show what they could do. This highlights the interpersonal context of individual coping, which resonates with Walsh's (2003) family resilience framework. She explains that it is necessary to think about resilience (i.e. inner strength) in relation to broader sociocultural and developmental contexts, particularly the influence of significant relationships, which includes crucial members outside of the family network.

The **Emotional impact** of receiving formal support was integral to all of the parents' experiences in the current study. Most parents described a mixture of positive and negative emotions, but sadly for some, the negative emotional impact dominated. The range of emotions was large, most of which are evidenced in the literature: stress (Wilson, 2011), happiness (Tarleton and Ward, 2007), frustration and anger (Starke, 2010; Booth and Booth, 2005); distress (Booth and Booth, 2005) and tension / not able to relax (MacIntyre and Stewart, 2011). The most common emotion was worry, this typically centred around the children, skills in parenting, and the fear that the children would be taken away. While some parents reported how professional support reduced their worry, similar to the findings in Tarleton and Ward (2007), many parents named how the involvement increased their worry, similar to some of the parents' reports in Howarth (2009). This worry is further contextualised when considered in light of the research that has reported how typically only half of parents look after their children (Emerson *et al.*, 2005). These findings appear to synthesise the findings from previous studies, and the convergence and divergence of accounts present the diversity of experiences. Again, it highlights the interpersonal context of the parents' emotional well-being, which is in part, determined by the relationship with the professional.

The parents in the current study identified both practical and emotional **Strategies for coping** with receiving formal support. It is hypothesised that the strategies were employed either to better utilise support or to avoid confrontation with the supporter. This brings in to question the extent to which parents truly accepted the formal support. The current findings, that family members play an important role in supporting parents with learning disabilities who receive formal support to cope, support the findings in existing literature (Wilson, 2011; Llewellyn, 1995). The strategy reported by the parents in the current study of getting more support, such as a solicitor or advocate, to better cope with their relationship with an identified professional is consistent with findings in the wider literature. For example, Traustadottir and Bjorg Sigurjonsdottir (2008) reported how the mothers of parents with learning disabilities '*bridged*' the relationship between the parent and the professional. Advocates were reported by parents in a number of studies as a useful way of dealing with services and professionals (MacIntyre and Stewart, 2011; Booth and Booth, 2005; Traustadottir and Sigurjonsdottir, 2010).

The use of placation when coping with the challenges of formal support, reported by parents in the current study, is consistent with the findings in Traustadottir and Sigurjonsdottir (2010). They report the frequency with which parents '*pretend to conform*' as a way of dealing with conflicting advice or with advice that does not fit with their own values. They described how parents often acquiesced with professionals and then did what they deemed best anyway. This was true for many of the parents in the current study.

It is proposed that some of the strategies that were considered self-protective can be understood through the interpersonal and contextual lens, together with Sinason's (1992) concepts of 'secondary handicap' and the 'handicapped smile'. Sinason (1992) describes how people develop secondary handicaps such as, smiling all the time, or in the cases of some of the parents in the current study, reporting "*It's fine*" or pretending not to listen, as defences against the knowledge that they are being treated differently, because they have a learning disability. Mark Lington (2002, p409) states: "*A handicap is the consequence of a persistent failure to recognise who we are. We become handicapped when we are seen as someone/something we are not, or when we are not seen at all*".

In Figure 5, a possible feedback loop between the dominate narratives of the parent and the professional is proposed which maintains the professionals' **EXPECTATIONS** and the parents' **Strategies for coping**. It is possible that, in the context of the assumptions and Judgements from the professional about not being 'good enough', the parent feels that their inner self is not fully accepted. As a result, it is possible that many parents did not feel safe to fully express their experience to the professional and, therefore, acted in a way as to hide their true experience. This reinforces to the professional the assumption that the parent is incompetent. Interestingly this feedback loop also fits with the previously unreported accounts from parents, that the professionals: "*were just doing their job*".

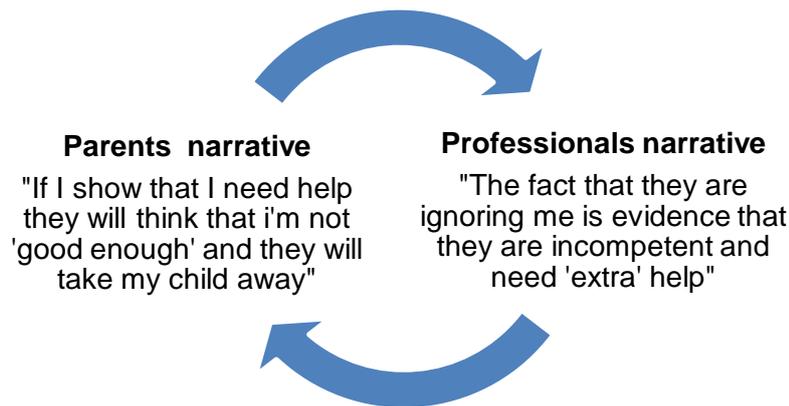


Figure 5: Feedback loop: Strategies for coping

4:2:4 Superordinate Theme 4: "WHO IS THE PARENT HERE?": IDENTITY

Identity is a concept that is difficult to define, and one with no right, wrong or definitive answers. The parents' **IDENTITY**, that is, their sense of self, was defined in this study in terms of their **Beliefs about parental ability and skill**, **The importance of time** and being in a **Dependent position**. These findings add significantly to the literature as, to the researcher's knowledge, no other study has explicitly explored the impact of receiving formal support on parents' sense of self, and most studies only reference how the support has influenced parental skill. For example, findings from Starke (2010) and Tarleton and Ward (2007) refer to how receiving support made parents more aware of their parenting skills and enabled them to learn skills that enabled them to be 'good enough' parents. In both studies, no reference was made to what parents thought their strengths or weaknesses were in parenting or what the impact of this 'good support' had on their sense of self.

Beliefs about parental ability and skill were reported by all of the parents in the current study. These beliefs represented dialectal positions of a sense of self as failing versus a belief that they were doing a good job as a parent. Many parents were able to identify skills and strengths in parenting, such as playing and reading with their children. However, a negative attribution style appeared to dominate a number of parents' accounts; there was a definite automatic focus for some around what they couldn't do. This extends findings from Llewellyn (1995) as, while links

were not made specifically with his concept and receiving formal support, parents were reported to engage in 'negative self-questioning' based on how they experienced other people in their lives.

For the parents in the current study, beliefs around parenting appeared directly linked to receiving formal support. For some, formal support led to skill development and a sense of achievement, for others, formal support added to their sense of self as different and failing. This adds to Booth and Booth's (2005) consideration of parents' perception of self in their discussion of findings. They described how becoming a parent affords parents a better status and class identity, but that this identity is frequently threatened because parents are too often told by services that they are failing. Howarth (2009, p17) reported how all of the parents in her study "*loved being a parent*". Interestingly for many parents in the current study, parenting in the context of formal support was perceived as "*hard work*". This is not to suggest that parents did not enjoy parenting, but that it appeared that it was made harder for some parents through the receiving of formal support. Findings in the current study, around how formal support contributed to a sense of failure for some parents, challenge findings that professional support is entirely helpful.

The second subordinate theme focused on **The importance of time**. Research has shown that parents typically have higher levels of service-centred networks (Llewellyn & McConnell, 2002; Llewellyn *et al.*, 1999) and due to the fact that they are disproportionately represented in care proceedings, they have multiple appointments and meetings to attend. The findings in the current study extend thinking in this area by proposing that the multiple demands and appointments should be considered as shaping the parents identity. It appeared that for many parents in the current study their parenting role was shaped by the time taken up by multiple meetings and appointments. This led some to question their parental role and who was in charge of planning their child's life. One parent described asking her professional: "**WHO IS THE PARENT HERE?**" For most parents, their identity had been swallowed up by parenting, leaving no time left for, as one parent described: "*Me time*".

Whilst, in the wider literature the social identity of people with learning disabilities has been considered in relation to the power of the learning disability label and the stigma associated with this dominant identity (Beart *et al.*, 2005), the impact of receiving formal support as shaping identity has not been widely reported in the literature. Shewan *et al.*, (2012) interviewed parents to hear their views on how having a learning disability impacted on how they perceive their parental role. They described how parents were able to separate their parental role with that of being an: '*individual outside of their identity with learning disability or parenthood*' (Shewan *et al.*, 2012, p1). This is in contrast to the findings in the current study which found that the parental identity dominated. Whilst appreciating that the different findings may be due to a multitude of factors, this disparity suggests that there is something about the interaction between parent and professional in this study that may force the dominance of the parental role at the expense of others (e.g. being an individual outside of parenting).

This hypothesis is supported by Mayes *et al.*, (2011) who reported that the mother identity for women with learning disabilities developed in the context of the people in their support network and in particular the way that these people viewed them. The Social Constructionist model proposes a way of understanding these experiences. It is suggested that people are made up of different identities and that the sense of self is fragmented, complex and multiple, and is shaped according to social and cultural factors. It is suggested that certain aspects of one's identity can dominate another according to the social and cultural context. Thus, the interpersonal context between the parent and the professional appears to have led to the dominance of the parental identity at the expense of all others. For parents whose identity is caught up in failure, the dominance of this identity appeared very difficult.

Parents' identity was also bound up in their negotiation of self-agency and their **Dependent position**. The parents in the current study reported needing help, which is consistent with the theme: '*Understanding oneself as needing help*' in Starke (2010). Similarly to the parents in Starke (2010) many of the parents in the current study actively sought help, and therefore, did not perceive themselves as passive recipients of help. Nonetheless, inherent in these acts of self-agency is in fact dependency: needing help. However, in the current study, for some, dependency

appeared associated with helplessness. Some of the parents reported a loss of parental ability when the support was no longer available, thereby fostering a perpetual cycle of dependency. The advice from most parents was to get help and to accept it. However, it appeared that there was an important balance to be struck between receiving help and the parent still feeling in control, and feeling that they were in fact able to be the parent. When this balance was not quite right, it led some parents in the current study, similarly to some parents in Booth and Booth (2005), to challenge their professional. In this study, this appeared to be in more passive ways, for example, the use of the coping strategy, placation.

In Strike and McConnell (2002), Robert Strike describes how parental dependency is historical. He explained that because the expectation of adults with learning disabilities is low, people do everything for them. This highlights the reciprocal influences between the dominant narratives of the professionals and those belonging to the parent, and highlights the interconnectedness between the themes of the **Awareness of difference** the **Presumption of incompetence**, **Empowerment**, validation and **“WHO IS THE PARENT HERE?”: IDENTITY**. Figure 6 outlines how a possible feedback loop may play out between the parent and professional and maintain unhelpful patterns of interacting.

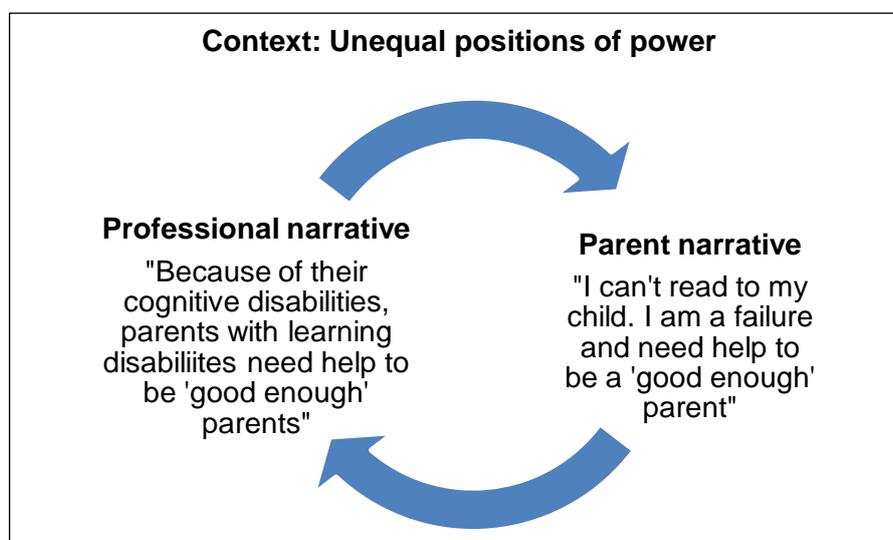


Figure 6 : Feedback loop: Identity

It is possible that due to the social construction of the learning disability label, and in the context of unequal positions of power and status, the presumption of incompetence shapes the professionals expectations and the inability of parents dominates. This may lead them to do things for the parents. It is possible that for some parents, this could lead to a negative attribution style: a focus on what they can't do and the belief that they are a failure. This may in turn encourage them to rely on others even more and seek validation for actions. This then reinforces the professionals' expectations that parents are incompetent and need support. It is also possible to see how this pattern forces the dominance of the parental identity at the expense of all others.

Tarleton and Ward (2007) highlighted that learning skills in parenting is something that all parents face. However, this feedback loop provides one way of understanding why parents with learning disabilities have a different experience, and believe that a lack of knowledge and skill is evidence of failure and not being 'good enough'. It would appear that the parents interpret this pattern of interacting as an attack on their identity: their inner self. Providing support in the context of acceptance, making a distinction between the parents' inner self: their thoughts, feelings and abilities, and their behaviour, may help to break the unhelpful patterns of interacting, and enable different aspects of parents' identities to come to the fore.

4:2:5 Understanding the links between the themes

The study aimed to explore how parents experienced and made sense of their relationship with a professional and how this relationship impacted on them. The findings have revealed the need to think about the interpersonal contexts of parenting, in particular the context of acceptance, and the impact of receiving formal support on shaping the identity of parents with learning disabilities.

Based on Bronfenbrenner's (1979) interpersonal model, Figure 7 outlines a diagrammatic representation of one way of understanding the links and 'layering' of the themes. This diagram proposes that the **EXPECTATIONS** for parenting are influenced by, and influence, the **PARTNERSHIP** between the parent and professional, the parents' **COPING** and also their **IDENTITY**. It proposes that each theme has developed in the context of the others, and that **IDENTITY** is the core

layer, closest to the parent. Within the discussion of each theme, connections have been made with the other themes, highlighting the contextual and implicative influences and links between them (Pearce, 2007). Examples of some of these connections are diagrammatically represented in Figure 7.

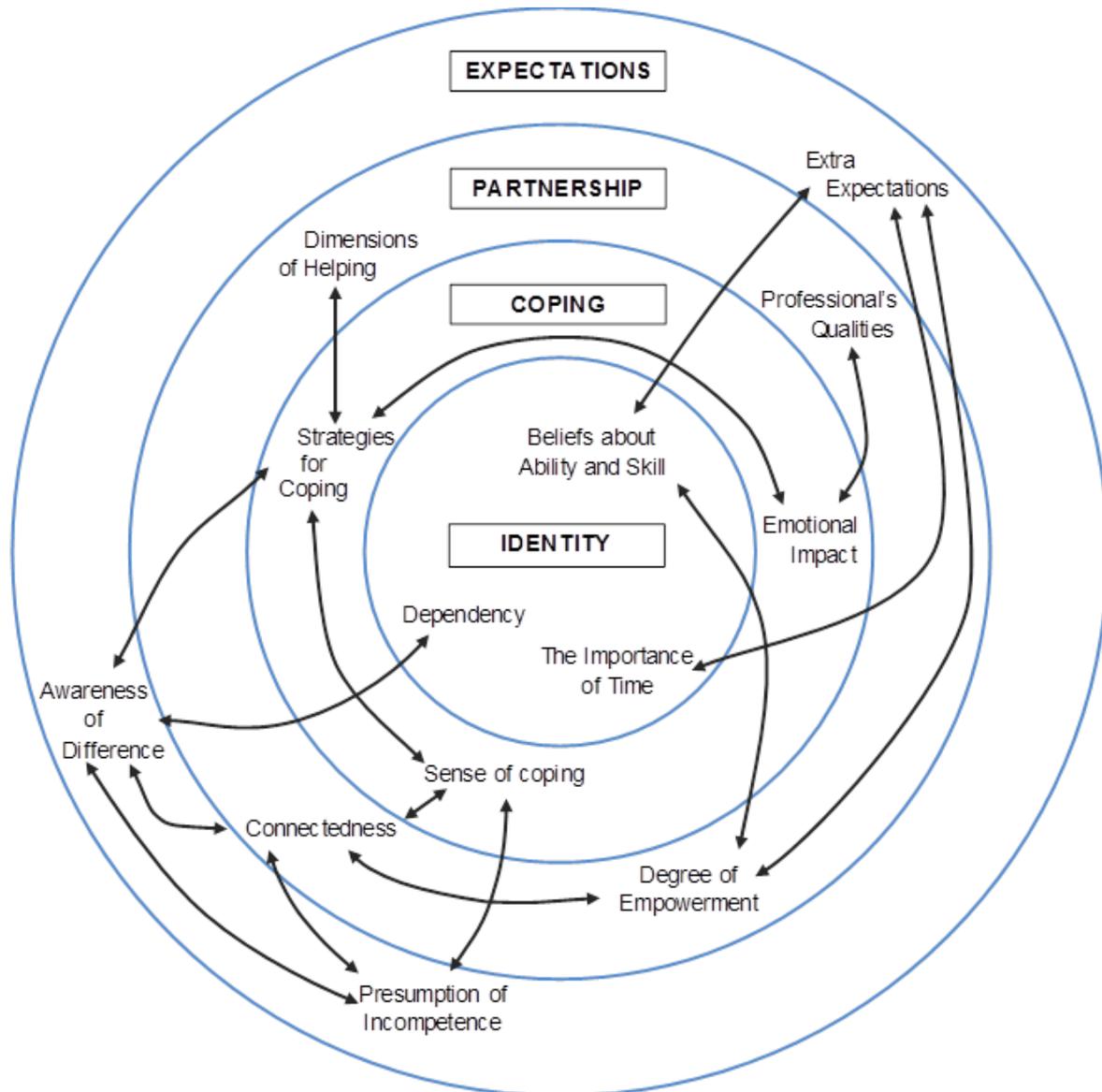


Figure 7: Diagrammatic representation of the interpersonal contexts of parenting with formal support

The reciprocal nature of the interaction imparts responsibility for the maintenance of problems in a relationship on the interaction between the parent and the professional, rather than in one or other of them. It is proposed that understanding

the experiences of parents in this way, extends the parenting model proposed by Booth and Booth (1994), presented in Figure 1, in section 1:9:1. It is proposed that the '*Support system's perception of parental competence*', which correlates with: **EXPECTATIONS** in the current study, should be extended to incorporate the aspects of **PARTNERSHIP**, in particular, the **Professional's qualities**, the levels of **Connectedness**, and the relational context of **COPING** and **IDENTITY** formation.

4:3 SUGGESTIONS FOR FUTURE RESEARCH

This study adds to the emerging literature eliciting parents' views and experiences of receiving formal support in parenting. The systematic review (section 1:6) revealed that there are only a handful of studies that share similar aims, therefore, further research of any design is needed. In reinforcing the messages from other research, the current study has highlighted the need for further research to uncover the experiences of this '*hidden*' population (Booth *et al.*, 2005, p7).

This study has identified a number of areas and ways in which the evidence base could be extended in qualitative ways. Given the lack of studies that have integrated findings with psychological theory, many of the hypotheses presented in this study are novel. Therefore, they require further exploration for validation, given the relatively small sample from which they are based. In particular, further investigation around the impact of receiving formal support on self, especially **IDENTITY** formation, and the parents' views on factors contributing to **Connectedness**, is needed. Further research is also needed to explore the hypotheses presented around providing support in the context of acceptance. The first step would be to seek out the views of parents regarding these hypotheses. A qualitative survey where parents give answers to open ended questions (designed on the back of the current themes) could be one way of eliciting a wide range of parents' views on the validity of the themes presented.

Based on the findings, suggestions have been made to expand existing models of parenting to incorporate the wider interpersonal contexts of parenting with learning disabilities whilst receiving formal support. A qualitative study using Grounded Theory (Glaser & Strauss, 1967) could be used for this purpose. It could also be used to explore some of the socio-economic barriers identified in the research, and to test

out the hypotheses and feedback loops presented. Qualitative studies, perhaps using Foucauldian Discourse Analysis (Parker, 1992), may enable further integration of theory and exploration of social constructionist ideas.

Many of the parents in this study reflected on the Intensity of the relationship with the professional in the context of **Connectedness**, referring to them as being like another wife, mother, and friend. In the context of this, and the current hypotheses around the influence of formal support on parents' identity development, it would be interesting to explore whether the role and identity of the parent's partner was also shaped by the professional involvement, and also the impact of working with a professional on the relationship between parents.

The findings point to the need to use quantitative research to devise outcome measures around the key areas identified by parents as integral to their experiences of receiving formal support. This could include a measure of: **COPING**, **PARTNERSHIP** working, parents' beliefs around failing, **IDENTITY**, and, the professional's attitude and approach, especially the **Professional's qualities**. This could help professionals to consider the *impact* on the parent of receiving formal support.

This study has provided further evidence for the busy lives of parents, the experience of '**Extra**' **expectations**, pressures and demands, and it has highlighted that, while parents with learning disabilities have multiple transitory relationships, a service-centred support network is common. However, the findings represent only one snapshot in time. Further longitudinal research is needed to explore parents' relationships with professionals over time and across the life transitions that they face, including becoming grandparents. This is a significant gap in the evidence base, as only a few longitudinal studies exist (Tarleton & Ward, 2007; Howarth, 2009; Cleaver & Nicholson, 2007).

Finally, this study involved service users in its design. While a few studies have been written by parents (Strike & McConnell, 2002; Murshed, 2005), research conducted with service user involvement is scarce. Service user involvement, at multiple levels, is an area with great impetus in Clinical Psychology currently, the impact of which

has been reported as positive from all parties involved (Riddell, 2013). Research involving parents is more likely to be relevant to their needs and be more meaningful, harness multiple viewpoints or positions, make services service-user orientated, and address the themes of collaboration, partnership and equality that have been found to be so important in this and most other studies that have elicited parents' views. It is also consistent with the '*inclusive*' approach to disability that is advocated (Olsen and Tyers, 2004).

4:4 CLINICAL AND SERVICE IMPLICATIONS

The current findings have been considered in the context of the wider literature around parenting with learning disabilities. These findings have a number of clinical and service implications. Pending further research to check out the validity of themes and to test out the hypotheses presented, clinical and service practice recommendations are made. Whilst acknowledging that this study has not reviewed the experiences of parents without learning disabilities who receive professional support, many of the recommendations may be appropriate in this context as well. The implications are presented according to areas of competence with specific recommendations made for new ways of working. They are presented in this way to increase transferability and usage for the wide range of professionals supporting parents with learning disabilities, and for ease of application.

4:4:1 Transferable skills: The working relationship

Neill and Cottis, (2009, p124) state: *"...key to beginning actually to help is to build a relationship with the parents, based not around what the parents do, or on how effective they are as parents, but first and foremost on a simple valuing of them as people..."*

PARTNERSHIP, or the working relationship, as it is typically defined in competency frameworks, has been identified in the current study as the core transferable skill required for all professionals working with parents with learning disabilities. The current findings provide the parents' views of the components of the working relationship. Developing the working relationship comprises a number of essential tasks and skills, and should be the first task in the process of helping. In order to facilitate an effective partnership, the findings suggest that there are core **qualities**

required of the professional. These include: trust, reliability, humour and playfulness, technical knowledge, personal integrity, and, being friendly and caring. Qualities are different from skills as they are internal to the individual and form part of their attitude and approach. As a result, they are difficult to measure and evaluate. As recommended for further research, outcome measures need to be developed to monitor the professional's qualities (and the emotional impact for the parent) and used by professionals in routine daily practice. Supervision and observation of work are also tools that will enable professionals to better monitor the development of the working relationship.

The current findings suggest that professionals need to place as much emphasis on their 'attitude' to working with parents as they do in planning and implementing interventions. In order for this to happen, a re-adjustment needs to occur regarding the **EXPECTATIONS** and assumptions around competence reported by some of the parents in the current study. This could be achieved through training in compassion and the development of standards and templates regarding what are the minimal standards that parents would expect every professional to achieve, to avoid social discourses (i.e. dominant narratives) impacting on the relationship.

Other factors identified by parents as important in the working relationship included, the **Degree of empowerment** afforded to the parent, in particular, working in collaboration, and their **Connectedness**, that is, whether the professional understands what the parent is going through. The current findings point to the prevention of relationship breaking down, and include:

- Gaining experience working with children.
- Taking care to match the parents' demographics.
- Increasing shared values by maintaining the welfare of the child[ren].
- Monitoring the intensity of the relationship by enabling open communication and encourage parents' feedback.
- Enlisting the support from Advocates and informal supporters has been identified as beneficial in building the relationship between the two parties.
- Acknowledging the power dynamic and how this can get in the way of effective partnership if not acknowledged.

- Professionals should be offered training to help them understand the conflict inherent in their two roles. For example, many professionals supporting parents with learning disabilities are in a position of assessing competence, yet it is also suggested that they should focus on qualities, in how to build up the relationship. Professionals need to 'own' their two roles and be explicit about them right from the beginning to re-balance power.
- Given the finding that there is something about the interaction between the pair that leads to the dominance of the parental identity when receiving formal support, there is a need for the professional to 'buffer up' the other roles and identities of the parent (e.g. the role as a friend, employee etc.) to maintain the 'pre-parenting' identity. This could be helpful for the parent and also the development of the relationship.

Neill and Cottis (2009, p134) state: *“An intervention that addresses the inner emotional / psychological experience of the client / parent will be far more cost-effective in the long term than one directed primarily at the outer events and behaviour”*.

4:4:2 Communication

The parents have highlighted a major flaw in the communication skills of professionals when working with people with learning disabilities. They described how professionals: nagged them, placed multiple demands on them, did not let them know when they were visiting, or would visit at inappropriate times, and, did not outline clearly their expectations of them. Whilst appreciating that this may be due in part to the requirements of observation and assessment, much of this appeared to be a consequence of the professionals' **Presumption of incompetence**. Communication is arguably the core skill and foundation upon which all other skills are built. It requires, and also demonstrates, high levels of attention and appreciation for the parent. It is integral to **PARTNERSHIP** and is a tool for enabling the parent to become equal in the relationship and helping process. Successful communication, therefore, overcomes many of the challenges with receiving support, identified by parents in the current study.

Based on the findings specific recommendations for professionals are made:

- Professionals should attend training on ‘what is a learning disability?’ to highlight known challenges of problems with executive function (i.e. problem solving, planning and organising), all of which are prerequisite for ‘good enough’ parenting.
- Giving parents sufficient time to process requests and demands expected of them, and not giving multiple demands.
- Not to assume that a delay, or lack of immediate response is evidence of incompetence.
- Providing parents with tools for remembering, such as, pictorial or physical aids, summarising or using anchor events to frame tasks or questions.
- Developing tools with parents to ensure that they are meaningful and appropriate to their needs.
- Using appropriate vocabulary, short words and sentences, and avoiding jargon, colloquialisms, double negatives, and language that is abstract in nature.
- Using open ended rather than closed questions to avoid acquiescence.
- Regularly checking back understanding with the parent, that is, asking them to state what is expected of them. This skill first requires professionals to be clear around what it is they are expecting of the parents.
- Showing through practical role modelling and learning through doing.
- Revisiting practical role modelling, and not assuming doing it once is enough.
- Breaking steps into bite size chunks before setting goals.
- Training from speech and language therapists about how to communicate effectively with adults with learning disabilities.

4:4:3 Interventions and clinical skills

The dimensions of helping outlined further skills and types of support that parents’ with learning disabilities valued. The core dimensions of helping included, contingently scaffolding the parents’ skill development, providing practical support, and validation. The parents identified the need for the professional to develop effective skills, not only in the development and maintenance of the relationship and communication, but in, enabling change rather than prompting a **Dependent**

position, embracing the parents' inner strengths and in developing parents' **Strategies for coping** and skills in confidence and assertiveness.

The experiences of parents with learning disabilities have been understood through the interpersonal contexts of parenting. Therefore, it is recommended that an interpersonal perspective is taken to approaching formal support with parents with learning disabilities. This means, thinking about how the pair work together rather than just focusing on individual parental skill. In addition, it is proposed that acceptance-based interventions, and providing support in the context of (and in the attitude of) acceptance, may: increase the professionals' awareness of what they are doing; be preventative of relationship breakdown; reduce dominant negative narratives around incompetence and difference; promote more effective coping strategies; improve psychological wellbeing, and, reduce social isolation. It is recommended that professionals provide support in the context of the following acceptance-based strategies:

- Hughes' (2006) '2 hands approach', where a distinction is made between experience, which is always accepted and behaviour, which may be evaluated.
- Mindfulness (Hayes *et al.*, 2012), an ACT based intervention which involves focusing on the present moment, nonjudgmentally. This could be practiced by professionals as a way of improving their acceptance skills. It could also be taught by professionals to parents to enable them to accept their internal experiences (which may have the benefit of increasing their sense of coping, improving their mood and view of self).
- 'Defusion' (Hayes *et al.*, 2012), an ACT based process that 'opens-up' the mind to the multiple possible ways of thinking about a situation in the present moment, rather than becoming 'fused' with one thought. Again, this strategy could be practiced by both the professional and the parent to improve acceptance skills.

Professionals should also use their skills in evaluation to monitor the effectiveness of these skills.

4:4:4 Service delivery

The first recommendation is to use audit tools to identify the parents that are being offered a service and to make this population less *'hidden'*. In keeping with the theme of awareness, the research has highlighted the need for professionals to become more aware of, monitor and better communicate their **EXPECTATIONS** of parents, and also to consider their role in parental competence. The findings also show how **PARTNERSHIP** is also determined by the **Degree of empowerment** afforded to the parent, and the professional actively reducing the parents' **Awareness of difference**. There is a current culture in institutions, for example, 'Payment by Results' in the NHS, which is focused on evaluation, change outcomes and measuring the impact of interventions to see what it is that is making the difference. It is proposed that professionals routinely check out parents' views on these aspects through regular use of clinical and service outcome measures and reviews. In particular, more attention needs to be given to increasing opportunities of monitoring and gaining feedback on the attitude of professionals and the ways in which relationships are formed during clinical work. Attribution (of blame) questionnaires could be used to see whether professionals' attributions about a parent have shifted from an individual to interpersonal perspective and whether professionals have adjusted expectations.

This research has had at its core the concept of service user involvement, and parents with learning disabilities have been involved at multiple stages. This research has reinforced the notion that in order to improve the services for parents, their views must be sought. This approach is consistent with the findings in this study related to **PARTNERSHIP**, the **Degrees of empowerment**, **Awareness of difference**, and being in a **Dependent position**. The evaluative process is one way of involving service users in the design and running of services. However, there are many other opportunities for parents to shape service delivery, for example, being involved in the selection processes for recruitment of the staff that will be supporting them. This fits with the Government's philosophy behind Direct Payments (Department of Health, 2001a; 2007).

The service delivery to parents could be enhanced by the running of reflective practice groups for professionals providing support. The benefits of reflective

practice are related to reduced stress, and increased discussion and open mindedness (Onyett, 2007). When thinking about acceptance based principles and social congruency of expectations, reflective practice may provide the space to *notice* thoughts and feelings, thereby, increasing awareness and psychological mindedness. In *New Ways of Working for Applied Psychologists in Health and Social Care: Working psychologically in teams* Onyett (2007) highlights how, using the leadership skills of Clinical Psychologists to facilitate reflective practice groups, not only brings benefits to the professionals but also provides the opportunity to understand parents' difficulties in a psychological context. This recommendation fits well with other recommendations made in the literature around increasing communication across services, and better joined-up working (McGaw, 2012; McGaw and Newman, 2005; Davis and Meltzer, 2007; Llewellyn *et al.*, 2010; Department of Health, 2007).

The other key implication for service delivery is the need to re-evaluate the pathways of care, in particular, providing earlier intervention and, given the global nature of learning disabilities, long-term support. In this study parents talked about the timeliness of support and the Intensity of the relationship as linked to the **Presumption of incompetence**. For many, the support came too late which resulted in a lot of panic, which typically drove professionals to do “**Extra**” visits to rigorously judge the parents' abilities. A template or model of working needs to be developed for professionals which highlights the need to make changes to direct interventions (e.g. visiting more often, at appropriate times as negotiated with the parent, and do more hands-on work). In order for this change to occur, the experiences of parents with learning disabilities need to be on the radar of service leads, and better audit and service evaluation is a safer way of doing this, rather than waiting for serious case reviews. This is a recommendation made in almost every example of literature produced on the topic of parenting with learning disabilities. However, it appears that there is a gap between publication of policy and guidance and its implementation. Therefore, it is recommended that further training is provided to reintroduce and implement the existing policies and best practice guidance already in existence.

4:5 METHODOLOGICAL STRENGTHS AND LIMITATIONS

4:5:1 Aims and design

It was noted by the researcher, the frequency with which parents with learning disabilities were appearing in various media outlets, such as radio plays and newspaper articles. However, their voices were not as present in the literature. Therefore, a real strength of the current study is its worthy and timely topic and attempts made to ensure service user involvement in its design. This study also adds to the contribution of IPA in research, as it provides an alternative to the predominant focus on illness experience (Smith, 2011).

A limitation of this study, given the interpersonal and contextual emphasis used to understand parents' experiences, is why the study was designed to represent only the parents' views. Other designs were considered, the researcher considered conducting joint or paired interviews with the parent and a professional. It was thought that while this would be consistent with a social constructionist position, and would have increased the understanding of the phenomenon (e.g. the relationship) from more than one perspective, and potentially the richness of data, the researcher was left with many ethical concerns. An account of the researcher's thinking processes is outlined in Appendix XVIII. Jonathon Smith's (author of IPA) advice was sought directly on this issue and he advised that the interviews be conducted just with parents due to ethical concerns regarding the use of pairs and joint interviews (personal correspondence dated: 01/05/2012, See Appendix XVIII for the full account).

Other approaches such as, Grounded Theory or Foucauldian Discourse Analysis may have enabled the researcher to further develop her interest in integrating parents' findings with psychological theory, or enabled further exploration of social constructionist ideas, including, the use of language. However, the current study was designed with the concept of meaningful coherence in mind. The researcher was keen to give pride of place to the views of parents' with the aim of understanding their relatedness to the world through the meanings they made. Given the limited amount of detail in the existing literature, and the underrepresentation of parents' voices, it was felt that greater understanding of the lived experiences of parents was

the necessary first step. Furthermore, the aim was not to develop a theory, and the researcher was reluctant to use methods that focused on specific cognitive skills such as language, given that parents with learning disabilities are a population group that already have their cognitive skills closely examined and evaluated. It was felt that the epistemological position of IPA complemented the aims, together with the data collection procedures and interpretation of findings.

The researcher considered the criteria and procedures used for selection of the professional. One way could have been to define a professional group. Whilst this may have increased homogeneity in findings, the researcher's use of subjective criteria is more in keeping with the epistemology of the study. Furthermore, due to the fact that parents with learning disabilities have typically large professional support networks, the aim of the study was to reflect on relationships with all professionals, not just one group, thereby, increasing transferability of findings. The 'circles of support' exercise (see Appendix XIII for the semi-structured interview schedule which includes this procedure) was intended to support parents to make their decision by helping them to think about all the different professionals, and how close they were to each one. This was devised to ensure consistency in how the professional was chosen. However, the procedure was not used, as all parents came with a particular professional in mind to talk about. This negated worries that parents would only choose someone that they liked. The researcher was careful not to locate blame on either parent or professional, or in one type of professional group. This was also in keeping with the theoretical position that the problem lay in the interaction between the parent and professional.

4:5:2 Sampling

The systematic review highlighted criticisms with the sampling of the studies, in particular, the predominant female composition, the dominance of parents with younger children and the sample size. It is appreciated that this is often a reflection of recruiting this '*hidden population*' (Booth *et al.*, 2005, p7). This research provides a significant contribution methodologically with regard to sampling. It contained a sufficient sample size, of which, just under a third were male; it comprised of all cases of relationship interactions, not just 'best practice' examples, and, reflects a wider age range of children. Whilst this is a relative strength, the researcher was

mindful of the fact that parents of children of different ages would have different experiences, showing change over time and with age. However, this was reasoned less important, due to the fact that the aim of the study was looking at the relationship between the parent and the professional rather than parents' skills. Furthermore, whilst for IPA, the sample is a reasonable size (Smith *et al.*, 2009), still only a small proportion of voices have been heard and, therefore, further research is needed.

Further methodological strengths come from the efforts made to reduce sampling biases and social desirability effects when recruiting. For example, by identifying a 'known person' who supported the parent to make the informed decision about taking part, and due to the fact that parents had a choice of which professional they talked about, it was not necessarily the 'known person' involved in the recruitment. A potential limitation of the sampling (partly due to the desire for homogeneity) was that the diversity of the sample gained was comprised. All parents reflected a westernised perspective, that is, one that emphasised individuality and independence, one predominantly represented in the existing literature, thereby, limiting the transferability and significant contribution of findings.

The systematic review also highlighted the lack of definition of terms, and how it is assumed that parents with mild/moderate learning disabilities comprise most of the sample. Making all materials accessible (i.e. using pictorial aids, see Appendix XIV), enabled parents with ranging intellectual ability to take part, adding significantly to the range of voices represented in the evidence-base. However, ultimately this is constrained by the cognitive abilities required to provide informed consent to take part. It is, therefore, possible that the voices of some parents are still unheard in the evidence-base. Whilst this study clearly provides definitions of certain terms such as, learning disability and formal support, in the interest of meaningful coherence and to enable consistency with the theoretical approaches, the researcher avoided defining parents in terms of levels of ability. Whilst theoretically consistent and, indeed, more consistent with the parents' views of being seen first and foremost as a parent, and despite legislation such as, the Equality Act (2010), services are typically still designed according to ability (or disability) and the lack of specification limits the transferability of findings in clinical contexts.

4:5:3 Data collection and data analysis

The use of a semi-structured interview schedule ensured consistency across interviews. Smith *et al.*, (2009) recommends between 6-10 questions with prompts, as the aim is for participants to say something in detail about an experience rather than something little about lots of different experiences. In this study two main questions were produced with different prompts. The researcher sought direct advice from Jonathon Smith regarding the need to structure the interview more heavily and prompt participants more, due to potential cognitive limitations (personal correspondence dated: 01/05/2012). In hindsight, the researcher has reflected on how she was perhaps too driven by this worry, and that perhaps just one main question would have enabled greater depth and exploration of the phenomena. A number of methods were followed to ensure that the semi-structured interview procedure was accessible to parents. Firstly, service users contributed to the question formation and to the design of the information sheets. Secondly, pictorial aids were first validated by the service users, and then used to aid communication and understanding in the interview. Service user involvement in the data collection and analysis would have enhanced the meaningful coherence of this research.

To ensure rich rigour in data analysis, the researcher developed detailed and thorough data analysis procedures, such as, cross referencing line numbers of quotes for each participant and each subordinate theme (see Appendix VI). A number of credibility checks were also made at multiple stages of the data analysis, enhancing the trustworthiness of findings, for example, checking the different stages of theme development with the research supervisors and other trainees. The researcher also received respondent validation from a small sample of participants. However, this was informally collected through discussions. A more thorough, and measurable procedure with all participants, would have increased the credibility of findings and the degree of user involvement; which would have enhanced the meaningful coherence even further. A particular strength of this study in comparison to the critique of others is the extensive self-reflexivity. The researcher's subjective values and biases are clearly outlined, which again, enhances the trustworthiness of the findings.

Despite the researcher utilising various measures to try to ensure quality in the study, some variables, not yet accounted for may have contributed to the study findings. For example, it is impossible to know how much of an influence the power differential between the parent and professional may have had on the parents' description of events. It is possible that because of their disempowered position some parents' may not have admitted to certain experiences, such as being unable to cope, for fear of losing their child[ren]. It is also possible that these same variables influenced the relationship between the researcher and the parent, as the parent may have categorised the researcher as another professional. The researcher did her best to explain her role, reassure parents and maintain an equal position of power in the interview (and throughout the research), to try to overcome some of these difficulties. Furthermore, the epistemology of the approach stipulates that the research is not interested in finding out 'the truth', but instead, how parents make sense of their lived experiences.

4:6 CONCLUSIONS

Traditionally parental learning disability has been understood through an individual perspective. As a result, much of the focus of clinical practice and research has been on factors pertinent to the individual, such as, parental competence. Given that the majority of parents with learning disabilities receive support in parenting, research has started to emerge exploring parents' views on how support is delivered. This research is in its infancy and was identified as needing further exploration, especially following methodological appraisal. The current study aimed to explore, from the parents' point of view, what it is like to be a parent with learning disabilities receiving formal support, how parents make sense of the relationship with a professional and the impact of that relationship.

The study identified the four superordinate themes of: "*Stepping up*": Expectations; Partnership and perceived experience of support; "*Getting through it*": Coping, and "*Who is the parent here?*": Identity. Feedback loops were presented and described the way in which patterns of interacting between the parent and professional were being maintained. The findings highlight the need to think about the interpersonal contexts of parenting. It appeared that underpinning much of the parents' experience of receiving formal support was a drive to be supported in the context of acceptance.

The parents' perceived experience of support was influenced by their experience of working in partnership with the professional. The findings also revealed the impact of receiving formal support on shaping the identity of parents with learning disabilities. The researcher identified a gap between the existence of policies and guidance for working with parents with learning disabilities and their implementation, and recommendations were made regarding new ways of working with parents with learning disabilities and ways to further develop the literature.

This research, together with the wider literature, has not only tried to uncover the experiences of this '*hidden*' population (Booth *et al.*, 2005, p7), it has revealed that more needs to be done to understand the experiences and the meanings that parents make of what it is like to be a parent with learning disabilities receiving formal support. This is essential in order to bring their lived experience of parenting more akin to that of parents without learning disabilities.

References

American Association on Intellectual and Developmental Disabilities. (AAIDD, 2010). *Intellectual Disability: Definition, Classification, and Systems of Supports* (11th Edn). Washington DC: American Association on Intellectual and Developmental Disabilities.

Andron, L., & Tymchuk, A. (1987). Parents who are mentally retarded. In Craft, A. (ed.) *Mental Handicap and Sexuality: Issues and Perspectives*. Tunbridge Wells: D.J. Costello.

Aunos , M., Feldman, M., & Goupil, G. (2008). Mothering with intellectual disabilities: Relationship between social support, health and well-being, parenting and child behaviour outcomes. *Journal of Applied Research in Intellectual Disabilities*, 21, 320-330.

Baumrind, D. (1989). Rearing competent children. In Damon, W. (ed) *Child Development Today and Tomorrow*. [Rev edn. 349-378]. Fransisco: CA: Jossey-Bass: San.

Beart, S., Hardy, G., & Buchan, L. (2005). How people with intellectual disabilities view their social identity: A review of the literature. *Journal of Applied Research in Intellectual Disabilities* ,18, 47-56.

Bjorg Sigurjonsdottir, H. (2004). Intellectually limited father, their families and formal support services. In Kristiansen, K., & Traustadottir, R. (eds) *Gender and Disability Research in the Nordic Countries*. [Rev edn. 239-254]. Sweden: Studentlitteratur.

Booth., T., & Booth.W. (1994). *Parenting Under Pressure: Mothers and Fathers with Learning Difficulties*. London: Open University Press.

Booth, T., & Booth, W. (1997). Growing up with parents who have learning difficulties. *Social Policy Research*, 113, 1-4.

- Booth, T., & Booth, W. (2005). Parents with learning difficulties in the child protection system: experiences and perspectives. *Journal of Intellectual Disabilities, 9*, 109-129.
- Booth, T., Booth, W., & McConnel, D. (2005). The Prevalence and Outcomes of Care Proceedings Involving Parents with Learning Difficulties in the Family Courts. *Journal of Applied Research in Intellectual Disabilities, 18*, 7-17.
- Bowlby, J. (1980). *Attachment and Loss: Volume 3: Loss, Sadness and Depression*. New York: Basic Books.
- Boyatzis, R. E. (1998). *Transforming Qualitative Information: Thematic Analysis and Code Development*. London: Sage Publications, Inc.
- Brechin, A., & Swain, J. (1988) Professional/client relationships: creating a 'working alliance' with people with learning difficulties. *Disability, Handicap and Society, 3*, 213-226.
- British Psychological Society. (2000). *Learning disability; definitions and contexts*. Leicester: British Psychological Society.
- Bronfenbrenner (1979) *Ecology of Human Development*. Cambridge: Harvard University Press.
- Bruner, J.S. (1983). *Child's Talk: Learning to Use Language*. Oxford: Oxford University Press.
- Cameron, L., & Murphy, J. (2006). Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities, 35*, 113–120.
- Chenail, R. J. (2011). Learning to appraise the quality of qualitative research articles: A contextualised learning object for constructing knowledge. *The Qualitative Report, 16*, 236-248.

Cleaver, H., & Nicholson, D. (2007). *Parental learning disability and children's needs: Family experiences and effective parenting*. London: Jessica Kingsley Publishers.

Commission for Social Care Inspection. (2009). *Supporting disabled parents: A family of fragmented approach?* London: Commission for Social Care Inspection.

Conder, J., & Mirfin-Veitch, B. (2010). Planned pregnancy, planned parenting: enabling choice for adults with a learning disability. *British Journal of Learning Disabilities*, 39, 105-112.

Coyle, A. (2007). Introduction to Qualitative Psychological Research. In, Lyons, E., & Coyle (eds.) *Analysing Qualitative Data in Psychology* [rev edn. P9-29]. London : Sage.

Dallos, R., & Draper, R. (2010). *An Introduction to Family Therapy: Systemic Therapy and Practice*. McGraw-Hill.

Davis, H., & Meltzer, L. (2007). *Working in partnership through early support: distance learning text*. London: Department for education and skills and the Department of Health.

Department of Health. (2001a). *Valuing People: A new strategy for Learning Disability for the 21st Century*. London: Department of Health.

Department of Health. (2001b). *Seeking consent when working with people with learning disabilities*. London: Department of Health.

Department of Health. (2009). *Valuing people now: A new three year strategy for people with learning disabilities*. London: Department of Health.

Department of Health and Department for Education and Skills. (2004). *The National Service Framework for Children, Young People and Maternity Services: Maternity Services*. London: Department of Health.

- Department of Health and Department for Education and Skills. (2007) *Good practice guidance on working with parents with a learning disability*. London: Department for Health.
- Dudley-Marling, C. (2004). The Social Construction of Learning Disabilities. *Journal of Learning Disabilities, 37*, 482-489.
- Dunst, C. J. (2002). Family-centred practices: birth through high school. *Journal of Special Education, 36*, 139-147.
- Dunst, C. J., Johanson, c., Trivette, C. M., & Hamby, D. (1991). Family-oriented early intervention policies and practices: family-centred or not? *Exceptional Child, 58*, 115-126.
- Ehlers-Flint, M.L. (2002) .Parenting perceptions and social supports of mothers with cognitive disabilities. *Sexuality and Disability, 20*, 29-51.
- Elliot, R., Fischer, C.T., & Rennie, D.I. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *The British Journal of Clinical Psychology, 38*, 215-229.
- Emerson E., Malam S., Spencer I. D. & Spencer K. (2005). *Adults with Learning Difficulties in England 2003/4*. NHS Health and Social Care Information Centre.
- Espe-Sherwindt, M., & Kerlin, S. L. (1990). Early intervention with parents with mental retardation: Do we empower or impair? *Infants and Young Children, 2*, 21-28.
- Feldman, M. (1994). Parenting education for parents with intellectual disabilities: a review of outcome studies. *Research in Developmental Disabilities, 15*, 299-332.
- Freedman, J., & Combs, G. (1996). *Narrative therapy: The Social Construction of preferred realities*. New York: Norton.

Fonagy, P., & Targat, M. (1997). Attachment and reflective function: the role in self-organization. *Development and Psychopathology*, 9, 679-700.

Gergen, K. J. (1990). Social understanding and the inscription of self. In Sigler, J.W., Shweder, R.A., & Herdt, G. (eds) *Cultural Psychology: Essays on Comparative Human Development*. [Rev edn. 569-606]. New York: Cambridge University Press.

Glaser, B.G., & Strauss, A.L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York: Aldine.

Golding, K.S., & Hughes, D. A. (2012). *Creating loving attachments: Parenting with PACE to nurture confidence and security in the troubled child*. London: Jessica Kingsley Publishers.

Goodinge, S. (2000). *Inspection of services to support disabled adults in their parenting role*. Department of Health Publications, London.

Guinea, S. M. (2001). Parents with a learning disability and their views on support received: a preliminary study. *Journal of Learning Disabilities*, 5, 43-56.

Hatton, C. (2012). Intellectual disabilities-Classification, Epidemiology and Causes. In Emerson, E., Hatton, C., Dickson, K., Gone, R., Caine, A., & Bromley, J (eds) *Clinical Psychology and People with Intellectual Disabilities* [Rev edn. 3-22]. Chichester: Wiley-Blackwell.

Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (2012). *Acceptance and Commitment Therapy: The Process and Practice of Mindful Change*. New York: Guildford Press.

HM Government. (2003). *Every child matters: Change for children*. London: The Stationary Office: TSO.

Hoghugh, M., Speight, A.N.P. (1998) Good-enough parenting for all children- A strategy for a healthier society. *Archives of Disease in Childhood*, 78, 293-296.

Howarth, J. (2009). *Being a Family: Parents with Learning Disabilities in Wales*. Learning Disability Wales.

Hughes, D. (2006). *Building the Bonds of Attachment*, New York: Guilford.

Hughes, D. (2009). *Attachment-focused parenting: Effective strategies to care for children*. New York: Norton & Company.

IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities. (2008). Parents labelled with intellectual disability: Position of the IASSID SIRG on parents and parenting with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21, 296-307.

Joint Committee on Human Rights. (2007-08). *A life like no other? Human rights of adults with learning disabilities: Seventh report of session 2007-08: Volume 1*. London: The Stationery Office: TSO.

Jones, R.A., & Donati, M. (2009) The therapeutic relationship in psychological therapy for individuals with learning disabilities: a review of existing literature. *Advances in Mental Health and Learning Disabilities*, 3, 47-51.

Kroese, B, K., Hussein, H., Clifford, C., & Ahmed, N. (2002). Social support networks and psychological well-being of mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 324-340.

Law, M., Stewart, D., Letts, L., Pollock, N., Bosch, J., & Westmorland, M. (1998). *Guidelines for Critical Review of Qualitative Studies*. Retrieved 11/04/2013 from: <http://fhs.mcmaster.ca/rehab/ebp/pdf/qualguidelines.pdf>

Learning Disability Advisory Group. (2001). *Fulfilling the promises: report of the Learning Disability Advisory Group*. Cardiff: National Assembly for Wales.

Linington, M. (2002). 'Whose handicap?' Psychotherapy with people with learning disabilities. *British Journal of Psychotherapy*, 18, 409-414.

Llewellyn, G. (1995). Relationships and social support: views of parents with mental retardation / intellectual disability. *Mental Retardation*, 33, 349-363.

Llewellyn, G. (2013) Parents with intellectual disability and their children: Advances in policy and practice. *Journal of Policy and Practice in Intellectual Disabilities*, 10, 92-85.

Llewellyn, G., Mayes, R., & McConnell, D. (2008) Editorial: Towards acceptance and inclusion for people with intellectual disability as parents. *Journal of Applied Research in Intellectual Disabilities*, 21, 293-295.

Llewellyn, G., & McConnell, D. (2002). Mothers with learning difficulties and their support networks. *Journal of intellectual disability research*, 46, 17-34.

Llewellyn, G., McConnell, D., & Bye, R. (1998). Perception of service needs by parents with intellectual disability, their significant others and their service workers. *Research in Developmental Disabilities*, 19, 245-260.

Llewellyn, G., McConnell, D., Cant, R., & Westbrook, M. (1999). Support network of mothers with an intellectual disability: An exploratory study. *Journal of Intellectual and Developmental Disability*, 24, 7-26.

Llewellyn, G., Traustadottir, R., McConnell, D., & Bjorg Sigurjonsdottir, H. (2010). *Parents with Intellectual Disabilities: Past, Present and Futures*. Chichester : Wiley-Blackwell.

MacIntyre, G., & Stewart, A. (2011). For the record: the lived experience of parents with a learning disability – a pilot study examining the Scottish perspective. *British Journal of Learning Disabilities*, 40, 5-14.

Mayes, R., & Bjorg Sigurjonsdottir, H. (2010). Becoming a mother- Becoming a father. In Llewellyn, G., Traustadottir, R., McConnell, D., & Sigurjonsdottir, B (Eds) *Parents with Intellectual Disabilities: Past Present and Futures*. [rev edn 17-31]. Chichester: Wiley.

Mayes, R., Llewellyn, G., & McConnell, D. (2008). Active negotiation: Mothers with intellectual disabilities creating their social support networks. *Journal of Applied Research in Intellectual Disabilities, 21*, 341-350.

Mayes, R., Llewellyn, G., & McConnell, D. (2011). "That's who I choose to be": The mother identity for women with intellectual disabilities. *Women's Studies International Forum, 34*, 112-120.

McConnell, D., & Bjorg Sigurjonsdottir, H. (2010). Caught in the child protection net. In Llewellyn, G., Traustadottir, R., McConnell, D., & Sigurjonsdottir, B (Eds) *Parents with Intellectual Disabilities: Past Present and Futures*. [rev edn 171-187]. Chichester: Wiley.

McGaw, S. (2012). Working with parents who happen to have intellectual disabilities. In Emerson, E., Hatton, C., Dickson, K., Gone, R., Caine, A., & Bromley, J (eds) *Clinical Psychology and People with Intellectual Disabilities* [Rev edn. 293-312]. Chichester: Wiley-Blackwell.

McGaw, S., & Newman, T. (2005). *What works for parents with learning disabilities?* Ilford: Barnardo's.

McGaw, S., Shaw, T., & Beckley, K. (2007). Prevalence of psychopathology across a service population of parents with intellectual disabilities and their children. *Journal of Policy and Practice in Intellectual Disabilities, 4*, 11-22.

McGaw, S., & Sturmey, P. (1994). Assessing parents with learning disabilities: The parental skills model. *Child Abuse Review, 3*, 36-51.

Mildon, R., Wade, C., & Matthews, J. (2008). Considering the contextual fit of an intervention for families headed by parents with an intellectual disability: An exploratory study. *Journal of Applied Research in Intellectual Disabilities, 21*, 377-387.

- Mirfin-Veitch, B. (2010). Citizenship and community participation. In Llewellyn, G., Traustadottir, R., McConnell, D., & Sigurjonsdottir, B (Eds) *Parents with Intellectual Disabilities: Past Present and Futures*. [rev edn 95-106]. Chichester: Wiley.
- Murshed, M. (2005). Good practice... parents with learning disabilities. *Disability, Pregnancy and Parenthood International*, 50, 16-17.
- Neill, C., & Cottis, T. (2009). Going on down the line: Working with parents who have intellectual disabilities. In, Cottis, T. *Intellectual Disability, Trauma and Psychotherapy*. [rev. end. p114-130] East Sussex: Routledge.
- Oliver, M. (1983). *Social work with disabled people*. Basingstoke: Macmillan.
- Olsen, R., & Tyers, H. (2004). *Think parent: supporting disabled adults as parents*. London: National Family and Parenting Institute.
- Onyett, S. (2007). *New Ways of Working for Applied Psychologists in Health and Social Care: Working Psychologically in Teams*. British Psychological Society, Leicester.
- Parker, I. (1992). *Discourse Dynamics: Critical Analysis for Social and Individual Psychology*. London: Routledge.
- Pearce, W. B. (2007). *Making social worlds: A communication perspective*. Oxford: Blackwell publishing.
- Pixa-Kettner, U. (2008). Parenting with intellectual disability in Germany: Results of a new nationwide study. *Journal of Applied Research in Intellectual Disabilities*, 21, 315-319.
- Porges, S. W. (2011). *The Polyvagal Theory: Neurophysiological foundations of emotions, attachment, communication, and self-regulation*. New York: Norton & Co.

Race, D.G. (1999). Hearts and minds: social role valorization, UK academia and services for people with learning disability, *Disability and Society*, 14, 519-538.

Reid, K., & Valle, J. W. (2004). The discursive practice of learning disability: implications for instruction and parent-school relations. *Journal of Learning Disabilities*, 37, 446-481.

Riddell, B. (2013). Just do it! Thoughts about involving service users/carers in clinical psychology training. *Clinical Psychology Forum*, 243, 48-51.

Roeden, J. M., Masskant, M.A., & Curfs, L. M. (2011). The views of clients with mild intellectual disabilities regarding their working relationships with caregivers. *Journal of Applied Research in Intellectual Disabilities*, 24, 398-406.

Rolls, L., & Relf, M. (2006). Bracketing interviews: Addressing methodological challenges in qualitative interviewing in bereavement and palliative care. *Mortality*, 11, 286-305.

Scottish Consortium for Learning Disability. (2008). Fair deal for families? *Learning from the experiences of parents with a learning disability*. The Baring Foundation.

Scottish Consortium for Learning Disability. (2009). *Scottish Good Practice Guidelines for Supporting Parents with Learning Disabilities*. The Baring Foundation.

Shewan, L., Crawley, R., McKenzie, K., & Quayle, E. (2012: Early Version). A qualitative exploration of the identities of parents with a learning disability. *British Journal of Learning Disabilities*. Early Version: Unpublished.

Sinason, V. (1992). *Mental Handicap and the Human Condition: New Approaches from the Tavistock*. London: Free Association Books.

Smith, J.A. (2004). Reflecting on the development of Interpretative phenomenological analysis and its contributions to qualitative research in psychology. *Qualitative Research in Psychology*, 1, 39-54.

Smith, J. (2011) Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, 5, 9-27.

Smith, J.A., & Eatough, V. (2007). Interpretative Phenomenological Analysis. In Lyons, E., & Coyle, A., (eds). *Analysing Qualitative Data in Psychology*. [Rev edn. pp 35-50]. London: Sage.

Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis*. London: Sage.

Snow, J. (1994). *What's really worth doing and how to do it*. Toronto, Canada: Inclusion Press.

Social Care Institute for Excellence: SCIE. (2005). *Helping parents with learning disabilities in their role as parents*. SCIE.

Spencer, L., Ritichie, J., Lewis, J., & Dilon, L. (2003). *Quality in Qualitative Evaluation; A Framework for Assessing Research Evidence*. Government Chief Social Researcher's Office.

Starke, M., (2010) Encounters with professionals: views of mothers with intellectual disability. *Journal of Intellectual Disabilities*, 14, 9-19.

Strike, R., & McConnell, D. (2002). Look at me, listen to me, I have something important to say. *Sexuality and Disability*, 20, 53-63

Stroebe, M. S., & Schut, H. (1999). The dual process model of coping with bereavement: rationale and description. *Death Studies*, 23, 197-224.

Tarleton, B. (2010). Turning policy into practice. In Llewellyn, G., Traustadottir, R., McConnell, D., & Sigurjonsdottir, B (Eds) *Parents with Intellectual Disabilities: Past Present and Futures*. [rev edn 155-169]. Chichester: Wiley.

Tarleton, M., & Porter, S. (2012). Crossing no man's land: a special support service for parents with learning disabilities. *Child and Family Social Work, 17*, 233-243.

Tarleton, B., & Ward, L. (2007). "Parenting with Support": The views and experiences of parents with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 4*, 194-202.

Tarleton, B., Ward, L., & Howarth, J. (2006). *Finding the right support? A review of issues and positive practice in supporting parents with learning difficulties and their children*. The Baring Foundation

Tracy, S., (2010) Qualitative Quality; Eight 'Big-Tent' Criteria for Excellent Qualitative Research. *Qualitative Inquiry, 16*, 837-851.

Traustadottir, R., & Bjorg Sigurjonsdottir, H. (2010). Parenting and resistance: strategies in dealing with services and professionals. In Llewellyn, G., Traustadottir, R., McConnell, D., & Sigurjonsdottir, B (Eds) *Parents with Intellectual Disabilities: Past Present and Futures*. [rev edn 107-119]. Chichester: Wiley.

Traustadottir, R., & Bjorg Sigurjonsdottir, H. (2008). The 'mother' behind the mother: three generations of mothers with intellectual disabilities and their family support networks. *Journal of Applied Research in Intellectual Disabilities, 21*, 331-340.

Tucker, B, M., & Johnson, R. (1989). Competence promoting Vs. competence inhibiting social support for mentally retarded mothers. *Human Organisation, 48*, 95-107.

Tymchuk, A. T. (1999). Moving towards integration of services for parents with intellectual disabilities. *Journal of Intellectual and Developmental Disability, 24*, 59-74.

Vygotsky, L.S. (1978). *Mind in Society*. Cambridge: Harvard University Press.

Wade, C. M., Mildon, R. L., & Matthews, J.M. (2007). Service delivery to parents with an intellectual disability: Family Centred or Professional Centred? *Journal of Applied Research in Intellectual Disabilities, 20*, 87-98

Wade, C., Llewellyn, G., & Matthews, J. (2008). Review of parent training interventions for parents with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 21*, 351-366.

Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process, 42*, 1-18.

Willig, C. (2008). *Introducing Qualitative Research in Psychology: Adventures in theory and method*. Berkshire: McGraw-Hill.

Willems, D. L., de Vries, J.-N., Isarin, J., & Reinders, J.S. (2007). Parenting by persons with intellectual disability: an explorative study in the Netherlands. *Journal of Intellectual Disability Research, 51*, 537-544.

Wilson, S. (2011). *Mothers with a learning disability: Their experiences of service provision during the postnatal period*. Unpublished Doctoral Dissertation. University of Edinburgh.

Winnicott, J. (1974). *Playing and Reality*. Middlesex: Penguin Books

LIST OF APPENDICES

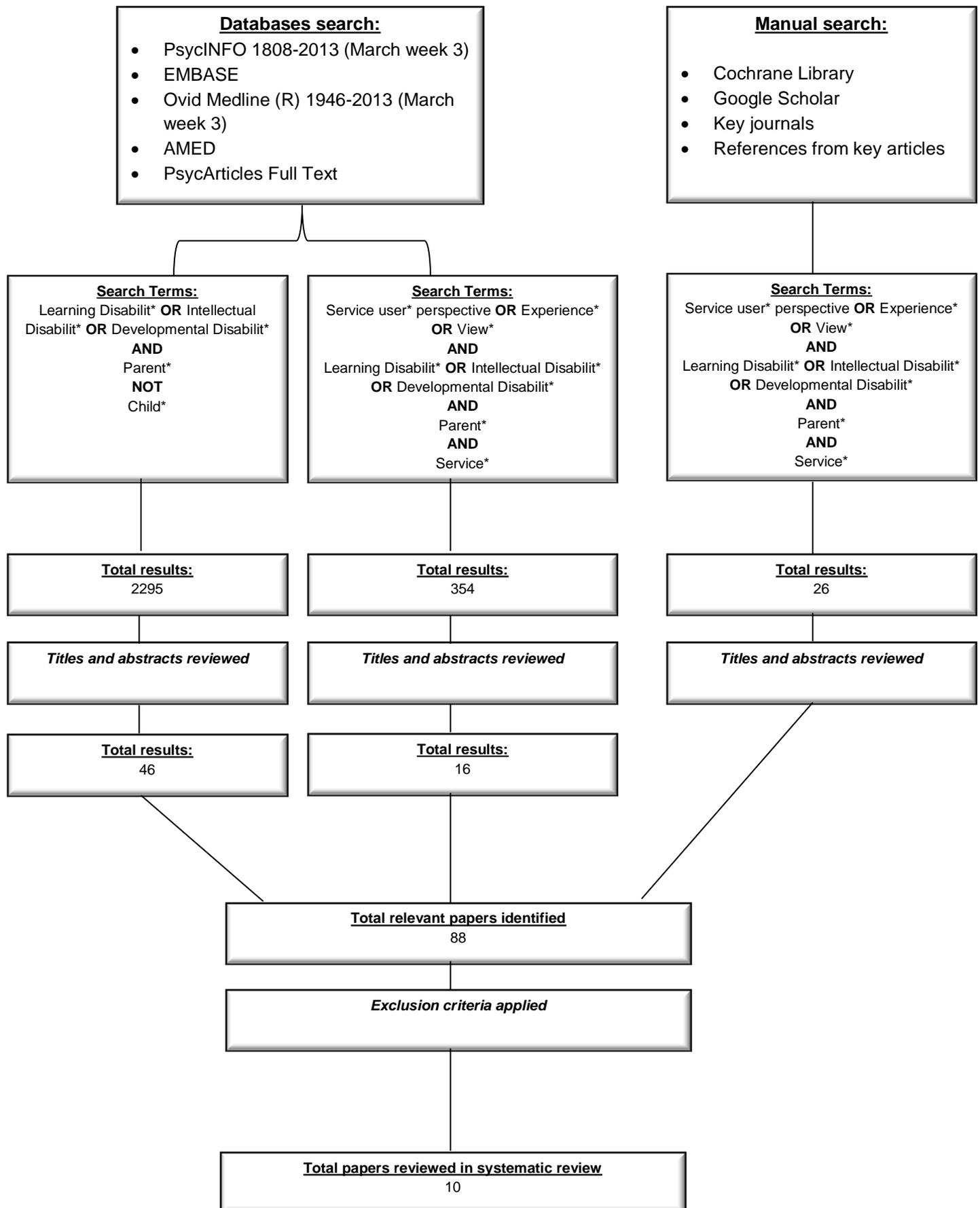
Appendices

- | | |
|-------|--|
| I | Summary of The Systematic Review Search |
| II | Quality Framework for The Systematic Review |
| III | The Systematic Review Table |
| IV | Extracts from Reflective Log |
| V | Extracts from 'Bracketing Interview' |
| VI | Data Analysis Procedure: Table of Integrated Themes |
| VII | Ethics Committee Approval Letter |
| VIII | NHS Research and Development Committee Approval Letter |
| IX | Statement of Approval from Third Sector Organisation |
| X | Participant Information Sheet |
| XI | Consent form |
| XII | Professional Information Sheet |
| XIII | Semi-Structured Interview Schedule |
| XIV | Examples of Images to Supplement Interview Schedule |
| XV | Data Analysis Procedure: Extracts from Transcript |
| XVI | Data Analysis Procedure: Example of Clustered themes |
| XVII | Data Analysis Procedure: Table of Clustered Themes with Quotes |
| XVIII | Research Design Dilemma |
-

Appendix I

SUMMARY OF THE SYSTEMATIC REVIEW SEARCH

SUMMARY OF THE SYSTEMATIC REVIEW SEARCH



Appendix II

QUALITY FRAMEWORK FOR THE SYSTEMATIC REVIEW

QUALITY FRAMEWORK FOR THE SYSTEMATIC REVIEW

To provide a measure of reliability, the studies in the systematic review were assessed using Tracy's (2010, p840): "*Eight 'Big-Tent' criteria for excellent qualitative research*", and in conjunction with the frameworks of Law *et al.*, (1998) and Spencer *et al.*, (2003). Table 1 outlines the quality framework used in the current study and provides some examples of quality indicators for the specific quality criteria. Based on Chenail (2011) a simple ranking scale ranging from 0-2 was used to assess the quality criteria in relation to the specific components of each study: aims and design; sample; data collection and data analysis, and findings and discussion of findings. A total ranking of less than 50% rendered the study unreliable and, therefore, excluded from the analysis. The Systematic Review Table (in Appendix III) provides the detailed analysis and quality rankings for each study identified through the systematic review search strategy.

Table 1: Quality Framework

Quality criteria	Examples of quality indicators
Worthy topic	<ul style="list-style-type: none"> • Clear statement of study purpose, aims and objectives. • Previous literature is reviewed and a rationale provided for the study.
Rigour	<ul style="list-style-type: none"> • Strategies for data collection and analysis are comprehensive. • Rigorous data analysis is marked by transparency regarding the transformation of data into codes. • Steps are taken to ensure that the data analysis is inductive.
Sincerity	<ul style="list-style-type: none"> • The researcher is self-reflexive about their position and context. • The researcher is transparent about methods of data collection and data analysis.
Credibility	<ul style="list-style-type: none"> • The study is trustworthy: the results are supported by quotes and steps are taken to ensure triangulation. • The researcher used different methods or data sources to support and refine findings.
Resonance	<ul style="list-style-type: none"> • The findings are generalisable and transferable. • The study is valuable across a number of different settings and contexts.
Significant contribution	<ul style="list-style-type: none"> • The conclusions are theoretically and (or) conceptually significant. • The study adds to existing knowledge and practice.
Ethical	<ul style="list-style-type: none"> • The researcher gained informed consent. • The researcher was mindful of how their involvement may have impacted on the participants.
Meaningful coherence	<ul style="list-style-type: none"> • The study address original aims and achieves what it set out to achieve. • The study hangs together well and is clearly and coherently reported. • The presentation style matches the aims and philosophy of the project.

Appendix III

THE SYSTEMATIC REVIEW TABLE

THE SYSTEMATIC REVIEW TABLE

1. Reference: Starke (2010)

	Study aims and design	Sample	Data collection & data analysis	Findings and discussion of findings	Quality ranking	
Quality criteria	Worthy topic	Purpose clearly defined: -To obtain views of mothers with Intellectual Disability (ID) in Sweden regarding their interaction with health and social care practitioners.			2	
	Rigour	- Previous literature reviewed. -Concepts and process of support for parents with ID clearly defined.	- 7 parents with ID, purposefully selected provides enough data to support claims and is consistent with methodology. - All women sample, aged between 24 and 42 years. - Children age range of 2-15 years. - Homogeneity of sample quite large.	-Data collection strategies clearly defined and appropriate for research objectives. -Semi structured interviews used, but measure not included. -Method for analysing data specified as textual analysis.	-Limited integration findings with of theory and conceptual context. Concepts referenced include: empowerment, paternalism and autonomy.	2
	Sincerity	-Lack of self-reflection about rationale for study or subjective values, other than length of time working in ID field.		Lack of self-reflexivity and transparency about methods and challenges		0
	Credibility		-Minimum description of participants given with no rationale behind this.	-Evidence of triangulation: -Detailed description of data analysis given. -Two researchers were used in data collection. -Clear strategy for transforming data into themes. -No multivocality and collaboration with participants.	- Three main themes reported with quotes to support. Themes included: the nature of the interaction; a sense of being supported in a meaningful way, and the recognition of needing help. -Themes largely descriptive rather than interpretive.	1
	Resonance		-No clear definition of ID which limits transferability of findings.	-Good ecological validity.	Findings specific to cultural and service context with limited transferability.	1
	Significant contribution	-Study topic was identified as a gap in Swedish research	- All female sample does not address gap in literature regarding the absence of fathers views. -Adding to research with parents with older children.		- Lack of recommendations for clinical practice or further research.	1
	Ethical			- Good procedural ethics clearly stated. -Informed consent gained. -No mention of relational ethics.		2
	Meaningful coherence			-Use of methods and procedures (i.e. semi-structured interviews) fit with aims.	-The study address original aims and achieves what it set out to achieve.	2
Total					11/16	

2. Reference: Llewellyn (1995)

	Study aims and design	Sample	Data collection & data analysis	Findings and discussion of findings	Quality ranking	
Quality criteria	Worthy topic	Purpose clearly defined: - To explore views of parents with Intellectual Disability (ID) in Australia about their relationships and social support for their parenting.			2	
	Rigour	-Previous literature reviewed. -Concepts of support clearly defined.	-6 couples with ID, purposely sampled provides ample data to support claims. -Age range of children was 18months to 14 years. -No age range for parents. -Researcher embedded self in the contexts of participants, including attending outings and observing interactions in different relationships.	- Data collection strategies clearly defined and appropriate for research objectives. Parents were interviewed and observed multiple times over a period of 2 years. -Minimum involvement included, 2 in-depth interviews, 6 informal visits, and bi-weekly phone calls. -Clear structure for interviews defined as having a loose structure with examples of questions given. -Data analysis process specified as Grounded Theory.	-Study uses sufficient amounts of theoretical concepts, and considers findings in relation to existing literature. -The Social Constructionist model was used to understand findings. -Other concepts drawn on included, "negative" self-questioning, isolation, being ignored.	2
	Sincerity	-A self-reflexive account is given that describes a drive for the service user perspective to be equally valued.		-A self-reflexive account of the researcher's position is given. -Transparency about the data collection and analysis	-Limitations of findings recognised in relation to time restraints	2
	Credibility		- Rich description of participants given with sample case studies.	-Evidence of triangulation and crystallisation, through different methods of data collection (interviews and observations). - One researcher only, but clear strategies employed for measuring data credibility, including consistency checks.	-Themes presented with quotes to support. Themes included: Partnership, Family Support, Friendship ties and Professional Support. -A preferred sequence of helping was identified.	2
	Resonance		-Definition of ID clearly stated. -Parents recruited from a range of agencies, increasing transferability.	-Good ecological validity.	-Transferable findings -An evocative representation through detailed description and case studies.	1
	Significant contribution	-Design to readdress oversight in research regarding exploration of parents views and experiences of parenting. -Timely study.	-Interviewing couples is relatively novel in this area. -Research included fathers and a large age range of children, both of which adds significantly to literature.	-Study provides a significant contribution in using qualitative methodology in and interviewing service users. -Longitudinal research of 2 years adds significantly to literature.	-Generation of a sequence of help seeking -Recommendations made for longitudinal work and for policy and practice.	2
	Ethical		-Detailed description of participants risks exposure and identification.	-Stringent procedural ethical stated. -Informed consent gained. -Relational ethics stated, attention to rapport and trust building.		2
	Meaningful coherence		-Social systems perspective used to determine sample, consistent with theory used to understand findings.	-Data collection procedures consistent with aim of enabling parents to tell their own story.	-Meaningfully interconnects literature, research and findings.	2
Total					15/16	

3. Reference: MacIntyre and Stewart (2011)

	Study aims and design	Sample	Data collection & data analysis	Findings and discussion of findings	Quality ranking	
Quality indicator	Worthy topic	Purpose clearly defined: To explore the lived experiences of parents with Learning Disability (LD) living in Scotland. -Focusing particularly on the role of advocacy in supporting parents.			1	
	Rigour	-Literature reviewed. -Concepts such as, advocacy, clearly defined.	-5 mothers with LD randomly selected. -Mothers aged between 24 and 45 years. -Children aged between 2 years and 18years. - 5 advocates & 4 stakeholders, provides minimum data to support claims.	- Use of semi structured interviews with parents, advocates and stakeholders and a short survey sent to local organisations concerning provision. -No method of data analysis specified, stated as both an inductive and deductive process. -No method of interviewing identified and no examples given.	-Limited integration of theory or concepts. Those considered included power, and stigma and early intervention	1
	Sincerity	-Lack of self-reflexive account about rationale for topic area and subjective values.		- Minimal reflection on challenges associated with small study.		0
	Credibility			-Mixed method approach to assist with triangulation of themes. -No multivocality and collaboration with participants. -Evidence of crystallisation with multiple types of data.	-Themes presented were largely descriptive rather than interpretive, and it was not always clear the origin of the results (i.e. source of data). - Limited use of quotes to support themes. -Examples of themes: service demand, complexity of individual situations, support for the individual, appropriate assessment, joint working, and advocacy.	1
	Resonance	- Scottish perspective only, thereby, limiting transferability.	- Sample of parents and advocates from one organisation, limiting transferability. - No clear definition of LD, limiting transferability of findings.	-Good ecological validity.		1
	Significant contribution	- Little prior research on topic in Scotland and therefore difficult to identify parent's needs. -Timely topic in relation to current Scottish policy	- All female sample does not address gap in literature around underrepresentation of fathers. -Big age range of children adds significantly to the literature.		-Findings support existing UK research. -Clinical implications are addressed and recommendations made.	2
	Ethical		-The limited description of participants is consistent with procedure aims of anonymity, due to small sample size and specific geographical area.	-Procedural ethics stated, with approval from ethics committee stated. This included, a process for withdrawing from study, and informed consent gained at multiple stages of study.		2
	Meaningful coherence			- Data collection strategies, such as adapting material was consistent with aims and objectives of study. -Mixed methodology not consistent with aims of giving service users a voice.	-Study achieves what it purports to be about.	1
Total					9/16	

4. Reference: Booth and Booth (2005)

	Study aims and design	Sample	Data collection & data analysis	Findings and discussion of findings	Quality ranking	
Quality criteria	Worthy topic	Purpose clearly defined: -To explore the experiences of mothers and fathers with Learning Disabilities (LD), in England, who are going through care and court proceedings. In particular their experiences of assessment, support, case conferences and court proceedings and the aftermath of the court proceedings.			2	
	Rigour	-Limited literature reviewed. -Concepts, e.g. case conferences, clearly defined.	-25 participants: 18 mothers, 4 fathers, provides an abundance of data to support claims. -No clear description of the age ranges of the parents or children.	-Interviews were conducted as 'guided conversations', examples of questions not provided. -Not very clear whether parents of a couple, where both had learning difficulties, were interviewed together or separately. -No method of data analysis stated.	-Integration of findings with previous research and theoretical concepts such as power, a sense of being treated unfairly and advocacy.	1
	Sincerity	-Lack of self-reflexivity about rationale for study and subjective values.		-Lack of self-reflexivity about subject values and biases	-Discussion reflects authors' emotive experience without reference to implications of this.	1
	Credibility		-Minimum description of participants given with no rationale behind this.	-Evidence of triangulation and crystallisation as multiple researchers were used.	-Themes presented but inconsistently supported by quotes. -Themes were also descriptive rather than interpretive. -Within experiences of assessment, support, case conference and court proceedings, themes emerged around: a readiness to listen; not being bossy; being helpful; feeling put down; not understanding what was said.	1
	Resonance		-Participants were recruited from a large geographical area in England, increasing transferability. -Classification of LD not clearly defined limiting transferability.	-Good ecological validity.	-Evocatively written, promoting empathy.	1
	Significant contribution	-Parents' views of court / care proceedings identified as a gap in research. - Timely due to the current high proportion of parents in the court system.	- Inclusion of fathers and sample size increased the contribution the study made to research.		-Recommendations made for policy implementation	2
	Ethical			-Relational ethics clearly stated: Participants aware of potentially distressing nature of interviews and strategies and procedures in place for data collection, such as use of a 'go-between'. -No procedures for informed consent explicated stated.		1
	Meaningful coherence			-Data collection methods were consistent with aims of accessibility, i.e. plain language used.	-The study achieves what it purports to be about	2
Total					11/16	

5. Tarleton and Ward (2007)

	Study aims, and design	Sample	Data collection & data analysis	Findings and discussion of findings	Quality ranking	
Quality criteria	Worthy topic	Purpose clearly defined: - To describe examples of positive practice in supporting parents with Intellectual Disabilities (ID) as part of a wider research project in the UK. - To explore the parents views on types of support received. - To empower parents, raise awareness about support needs, develop multi-professional and multi-agency support.			2	
	Rigour	-Previous literature and theory reviewed. -Relevant policy identified and reviewed.	-30 parents with ID: 25 mothers and 5 fathers, purposefully sampled, provides an abundance of data to support claims. -However, sample was biased, as only parents with 'good' experiences were recruited, in accordance with aims. -Children were mainly school aged. -Parents aged between 20-50 years old.	- Mixed method of data collection, both semi-structured interviews and focus groups were used, but some open-ended questions were used. Examples of questions given. - Data analysed using a "Constant Comparative Approach", clear procedures outlined.	-Study integrates findings with sufficient amounts of theory / constructs, including: empowerment, normalising, joined up working etc.	1
	Sincerity	-Lack of self-reflexivity regarding subjective values and biases in design.		-Some reflection on design given, researchers wanted to avoid repeating extensive questioning and assessment procedures. - Transparency in data analysis procedure.	-Minimum reflections on impact of sample bias.	1
	Credibility		-Minimum description of participants is consistent with statements re: anonymity.	- Mixed method of data collection was used as a credibility check also. -Themes were cross-checked between the two researchers. -Themes were triangulated with findings from other aspect of wider study (i.e. professionals). -Evidence of multivocality and collaboration with participants.	10 themes around the different kinds of support that enabled parents to be 'good enough' are presented with quotes to support themes. Examples include: support to get voices heard, support to keep children, and support to be good enough parents.	2
	Resonance		-Parents were recruited across 5 geographical areas in the UK, with a rural and urban and metropolitan spread, increasing the transferability of findings. - However, sample was very specific and may not be representative widely. -Classification of LD not clearly stated, limiting transferability.	-Resonance was checked with a sample of parents which was consistent with aims. -Good ecological validity.	-The write up was evocative and mirrored the themes around empowerment – it left the reader with a sense of how to make change in practice.	2
	Significant contribution	-Clinically relevant research - Research was one part of a larger study.	-Age range of children, inclusion of fathers and size of sample significantly increases the contribution of the study to wider literature.		-Many recommendations made for clinical practice, including, training, but no recommendations for future research.	2
	Ethical		-Description of participants consistent with ethics.	-Stringent procedural and relational ethical strategies were employed, but no statement about informed consent.		1
	Meaningful coherence			-Collaboration and consultation from parents is consistent with the study aims.	-The study achieves what it purports to be about. Aims are addressed.	2
Total					13/16	

6. Reference: Wilson (2011) Unpublished Doctoral Dissertation

	Study aims and design	Sample	Data collection & data analysis	Findings and discussion of findings	Quality ranking	
Quality Criteria	Worthy topic	Purpose clearly defined: To explore how mothers with Intellectual Disabilities (ID) experience postnatal care. -To explore mothers' experiences of formal support in the UK.			2	
	Rigour	-Literature reviewed, including a systematic review. -'Postnatal' period not clearly defined.	- 6 mothers with ID, which provides appropriate amounts of data to support claims. -Homogeneity of sample quite large, including mixture of first time mothers and mothers with other children. -Ages of children ranged from 10 weeks to 15 years. -Ages of mothers ranged from 20 – 55 years.	-Semi structured interviews used following a schedule , example given. -IPA stated as method of data collection and analysis. -Clear process outlined regarding the emergence of themes, including example tables.	-Findings integrated with theory and concepts such as power, trust and collaboration.	1
	Sincerity	-Significant self-reflection around researcher's position given.		-Self-reflexivity around how themes reflected participants experience and researcher's interpretation. -Transparency of methods.	-Limitations of study addressed.	2
	Credibility		-Lack of demographic data given to protect anonymity.	-Evidence of credibility checks, the researcher checked themes with supervisors.	-Four themes are presented with quotes to support: Challenges of providing support / how support was delivered / learning how to cope / challenges of providing support.	2
	Resonance	-Specific service context of postnatal care limits generalisability of findings.	-Sample selected from one small and rural geographical area, limiting transferability of findings. -LD clearly defined.	-Lots of different professional relationships reflected on, which could increase transferability. -Ecologically valid.		1
	Significant contribution	- Researcher stated that there was no research at the time that explored mothers with ID experience postnatal care.	-Sample is all female, which limits significance of findings. -Age range of children adds significantly to the literature.		-Clinical implications made and recommendations for future research made.	1
	Ethical		-Limited demographic data is consistent with ethics.	-Procedural ethics stated: Ethical approval from a committee and informed consent gained.		2
	Meaningful coherence			-Use of IPA is consistent with the study's aims of understanding the experiences of mothers. -Materials were adapted and made accessible, again consistent with aims.	-Study achieves what it set out to achieve.	2
Total					13/16	

7. Reference: Howarth (2009)

	Study aims and design	Sample	Data collection & data analysis	Findings and discussion of findings	Quality ranking	
Quality criteria	Worthy Topic	<ul style="list-style-type: none"> - Purpose clearly defined: -To find examples of 'good support' for parents who live with their children by asking the parents themselves, the professionals who support them and senior managers. The Welsh perspective. - To report the approximate number of parents with LD in Wales using questionnaires and short assessment tool sent to services 			2	
	Rigour	<ul style="list-style-type: none"> -Literature reviewed. -Policy and guidance reviewed. -Focused on finding 'good' examples of support rather than a holistic picture. 	<ul style="list-style-type: none"> -11 parents: 8 mothers, 3 fathers, purposefully sampled, provides ample data to support claims. -Children aged between 10 months and 24 years. -Ages of parents not stated. - 16 professionals and 3 managers purposefully recruited. 	<ul style="list-style-type: none"> -Data collection strategies clearly defined. -Semi-structured interviews used. -Mixed method of interviewing, some couples, some individual interviews. -Data analysis procedures defined, but no method of analysis stated. 	<ul style="list-style-type: none"> -Conclusions integrate findings and previously reviewed literature and policy. Theoretical concepts included: power, control, collaboration, professional attitudes and types of support. 	2
	Sincerity	<ul style="list-style-type: none"> -Lack of self-reflection regarding subject area, subjective values and biases. 			<ul style="list-style-type: none"> -Subjective opinion included during reporting of results, with no mention of researcher subjective position. 	0
	Credibility		<ul style="list-style-type: none"> -Demographic data given consistent with rational ethics around anonymity. 	<ul style="list-style-type: none"> -Credibility checks stated, themes checked with supervisors. -Evidence of triangulation and crystallisation as multiple methods of data collection were used. -Evidence of multivocality and collaboration with participants. 	<ul style="list-style-type: none"> -Themes presented with an abundance of quotes to support. Themes presented around what is "good support": being listened to; being reliable; sorting out problems; choice and control; peer support groups; advice. 	2
	Resonance		<ul style="list-style-type: none"> - Questions over transferability as sample specific to wales, but were recruited across wales. -Classification of LD not clear. 	<ul style="list-style-type: none"> -Good ecological validity. 	<ul style="list-style-type: none"> -Evocative description of parent's lives and experiences. 	1
	Significant contribution	<ul style="list-style-type: none"> - Few studies have sought parents' views on the topic, - No previous researcher aimed to report figures, number of parents in Wales. 	<ul style="list-style-type: none"> -Age range of children and inclusion of fathers adds significantly to research literature. 		<ul style="list-style-type: none"> -Recommendations made for clinical practice, policy, research amongst others. -First study to report figures on number of parents with LD in Wales. 	2
	Ethical			<ul style="list-style-type: none"> -Stringent procedural ethics clearly stated. -Clear relational ethics stated, researcher went to great efforts to ensure informed consent, and in building relationship with participants. 		2
	Meaningful coherence			<ul style="list-style-type: none"> - Materials were adapted for accessibility, which is consistent with research aims and philosophy. -Methodology consistent with aims of hearing parent's views. 	<ul style="list-style-type: none"> -Findings presented with accessible summaries, consistent with aims and philosophy. 	2
Total					13/16	

8. Reference: Wade et al., (2007)

	Study aims, purpose and design	Sample	Data collection & data analysis	Findings and discussion of findings	Quality ranking	
Quality criteria	Worthy topic	Purpose clearly defined: To explore the views of parents with Intellectual Disability (ID) on the helpfulness of service delivery by exploring characteristics of services that parents regard helpful. Australian context. -Research question: to what extent do parents' perceptions of what are helpful and inhibiting aspects of service delivery fit with conceptualisations of family-centred and professional-centred practice?			2	
	Rigour	-Significant amount of data reviewed. -Concepts and theory, such as, types of practice, clearly defined.	-Large sample size of 32 parents with ID, giving ample data to support claims. -Proportion of mothers and fathers is unknown. Assumed to be largely mothers. -Ages of children and parents unknown.	-Interviews asked parents to reflect on relationship with current practitioners, which may have biased findings. -Clearly defined structure for interview. -Clearly defined process of data analysis identified. Participants responses were written down verbatim and coding processes outlined. -Chi-squared analysis completed on statements and relationships analysed.	-Study used an abundance of theoretical constructs. The two main theories of family centred and professional centred practice are integrated throughout.	2
	Sincerity	-Lack of self-reflexivity about subjective values.		-Process of data analysis was transparent.		1
	Credibility		-Clear rationale for lack of demographic data.	-Evidence of triangulation through use of two trained independent raters at data analysis and included a 0.90 quotient for inter-rater reliability.	-Examples of parents' comments are listed and categorised into family centred or professionally centred help giving. -Limitations about the sample group are considered and recommendations made for future research.	2
	Resonance		-Large sample size increases transferability of findings. -Specific criteria for ID identified increasing transferability.	-Good ecological validity.	-Evocatively written.	1
	Significant contribution	-First study to explore concepts of family-centred and professional-centred practice with population group.	- Composition was mainly mothers, so limited contribution to literature.		-First published data on how parents with ID find family centred help giving styles more helpful.	2
	Ethical		-To protect anonymity no demographic information was given.	-Good relational ethics. -Awareness of impact of interview on relationships with practitioner. - Clear procedural ethics, as ethics committee approval stated with clear procedures for informed consent.		2
	Meaningful coherence			-Methods of data collection were designed with service user involvement, which was consistent with the studies aims.	- Study achieves its aims.	2
Total					14/16	

9. Reference: Ehlers-Flint (2002)

	Study aims and design	Sample	Data collection & data analysis	Findings and discussion of findings	Quality ranking	
Quality Criteria	Worthy topic	Purpose clearly defined :To explore the experiences of mothers with Intellectual Disability (ID), and to explore the factors and challenges mothers with ID face in America. -To explore what factors, other than ID, pose a challenge to how mothers with ID cope with parenting. -To explore the relationship between parents' perceptions and family support, community support and therapeutic support.			2	
	Rigour	-Previous literature reviewed. -Concepts of support clearly defined.	- 20 mothers with ID were purposefully selected, which provides an abundance of data to support claims. -Mothers aged between 21-43 years. -Ages of children not specified.	- Data collection procedures clearly defined. -3 questionnaires were used, including one open-ended parenting questionnaire, and one inventory was used. -Quantitative data analysis and qualitative data analysis was conducted. -Process for identifying themes was clearly stated, but no qualitative data analysis method stated.	-Discussion integrates findings, literature and ideas, such as, empathetic and non-judgemental attitudes and types of support, such as, emotional support.	2
	Sincerity	-Limited self-reflection around subjective values.		-Clear transparency about methods and challenges.		1
	Credibility			-Evidence of triangulation and crystallisation, as two professionals were trained to rate the questionnaires and inter-rater agreement was 95%. -Different methods of data collection and analysis triangulated the findings. Information from the open-ended questionnaire was used to confirm findings in the inventory.	-3 main themes around rewarding aspects of parenting, criticism of parenting abilities and view of childhood emerged. -Quotes from the open-ended questionnaire thickened the findings in the inventory.	2
	Resonance		-Parents were recruited from one agency in California which limits transferability of findings.	-Parents reflected on their relationship with therapists from a specific service ,who on average had been involved for 4 years. The speciality of service limits transferability of findings. -Good ecological validity.		1
	Significant contribution	- Few studies have explored the perceptions of mothers with ID when investigating their parenting practice.	-Mother only sample, limits contribution to literature.		-First finding to highlight the importance of therapeutic intervention for parental attitudes. -Ideas for future research presented.	2
	Ethical			-No reference to procedural ethics.		0
	Meaningful coherence			-Measures were adapted to increase accessibility, which is consistent with the study aims.	-The study achieves what it purports to be about.	2
Total					12/16	

10. Tymchuk (1999)

	Study aims, and design	Sample	Data collection & data analysis	Findings and discussion of findings	Quality ranking	
Quality Criteria	Worthy topic	Purpose clearly defined: To gain professionals' and parents' views on the possibility of an integration of services for parents with Intellectual Disabilities (ID) in America, to ensure 'evenness' of support. - To generate parents views about support needs, - To generate possible solutions to perceived challenges with service provision.			2	
	Rigour	-Significant amounts of literature reviewed. -Concepts, such as types of support needs clearly defined.	-No statement of number of participants given so unable to make judgements about amount of data to support claims. -Sample purposefully selected by 'known' professionals	- Parent focus groups used with loose procedure, examples of questions given. -Delphi method of data collection named. -No statement of data analysis procedure.	-Does draw on literature and policy, but not integrated with parents accounts.	1
	Sincerity	-Lack of self-reflexivity about subjective values.		-Some transparency in process of data collection. -Lack of reflection on challenges with using focus groups.	-No discussion of limitations.	1
	Credibility		-No description of participants, with no rationale behind this.	-No evidence of credibility checks.	-Statements presented, with no quotes to support.	0
	Resonance	-To add to the international research on topic .	-Parents were recruited across 2 cities in California. -Sample not defined, limiting transferability.	-Good ecological validity.	-Findings not evocatively presented.	1
	Significant contribution	-No previous research into ways of integrating services	-Unable to make claims due to lack of detail about sample given.		-Makes recommendations for future practice.	1
	Ethical			-No mention of ethical procedures followed.		0
	Meaningful coherence			-Recruiting parents is consistent with aims around making services more accessible.	-Some interconnection with literature and findings.	1
Total					7/16	

Appendix IV

EXTRACTS FROM THE REFLECTIVE LOG

EXTRACTS FROM THE REFLECTIVE LOG

May 2011: Coming up with a research topic

“With the thought of having to present to the cohort our initial ideas for research in July I need to start brainstorm the different topics. This is somewhat overwhelming, especially given my limited research experience. I notice that I am drawn to the area of Learning Disabilities, perhaps because this is what I have most experience of working in, and due to my personal knowledge of the gaps in service provision, the service philosophy and service design. I am trying to hold different ideas and perspective in mind, but am aware that I do not feel as comfortable using quantitative design.”

February 2012: Finalising ideas around the design

“I am feeling overwhelmed by the number of meetings I’m attending around my research, and how I seem to come away with more questions than answers. It feels like I have had to do a lot of fighting to get this research project off the ground, which has made me more determined to do it! However, I am torn over how to design the interviews, what to include in my inclusion and exclusion criteria and how to shape my semi-structured interview. I’ve been advised to contact Jonathon Smith directly, which is a bit daunting. I’m also being redirected to look at examples of other research projects, but it feels like I’m doing a lot of thinking (I’m holding too much information in my head) and I’m not doing enough ‘do-ing’. I’m really keen to have my rationale clear for what I am doing so that I’m prepared for the ethic’s panel, and also to be able to provide some answers to the questions I’m being asked in my research meetings. I’m also noticing my desire to include service users in the research, but am not quite sure how best to go about this yet!”

September 2012: Start of data collection

“I’m feeling frustrated and worried about recruitment, I’m relying on other people to source my participants, which is out of my control. I’ve had a mixture of responses from the people who are recruiting. On the one hand the advocate has been so enthusiastic and proactive in supporting the research and has lined up four parents

for me. On the other hand I have been met with resistance from many. Again, I feel like I am having to fight really hard to make this research viable. I am noticing that this is a theme across the different stages of the research and am left wondering what this is about?

Having done the first interview I feel a real sense of relief. Going into it I was filled with anticipation around whether or not I would get enough rich data, (one of the worries presented to me by others at the early stages of the research design). Rather ridiculously I feel pleased that the interview lasted over an hour! Perhaps this is evidence of its worthy topic? Having checked out with the parent how she found the experience, I felt so relieved to hear that it was a validating experience. Despite my relief, new anxieties have arisen around the procedure of conducting the interview, and thoughts around homogeneity. It felt a lot like a clinical interview, except, I was aware of my need to stay more 'neutral'. I have also come away with a sadness surrounding the life and experiences of the parent.”

December 2012: End of data collection

“Yes! I have done all 10 interviews! I feel a mixture of exhaustion, happiness, relief and anticipation for what is to come! It felt like I had to work a lot harder in this last interview, the responses were not as detailed or elaborate as some of the others. I also felt like the parent was a little suspicious of me, despite me explaining the purpose of the interview, and checking in with him around how he was feeling.

Looking back across all interviews, I'm really struck by the amount of adversity that the parents in the study have faced, and indeed, their strength in overcoming these adversities. Looking back at my previous worries around the richness of data, I feel cross that I was made to doubt this; I have got a wealth of information, if not in the number of words in quotes, but in the quality and power behind those words. I've been left thinking about the epistemology of the approach, the focus on idiography, and how my drive for richness in data led me to pursue quantity; number of participants. As a result I am keen to adequately reflect the idiography of each parent in the write-up.”

Appendix V

EXTRACTS FROM 'BRACKETING INTERVIEW'

EXTRACTS FROM 'BRACKETING INTERVIEW'

Using a 'bracketing interview' (Rolls & Relf, 2006) with fellow trainees I was able to explore how my own assumptions and experiences may be influencing the construction of the research project. This interview took place after the completion of the semi-structured interviews with participants and lasted approximately 40 minutes.

Interviewer: What were your expectations going into the project?

Researcher: "The project came out of my experience as an Assistant Psychologist with parents with learning disabilities and a role of assessing whether their skills were 'good enough', which fed into child protection etc. I felt frustrated at how the parents were judged. I also had an insight into the number of appointments they attended. I remember at the time an urge to align myself with the parents, trying to empower them wherever possible and work with the system, but because of the service set up I was only able to do the assessment..."

Interviewer: What might cause you to be judgemental or halo the experiences of others?

Researcher: "A big bugbear for me is the inadequacy of service provision, and the fact that often services are not 'good enough' in the support they provide to parents. Which mirrors the judgement frequently placed on parents about not being 'good enough' parents. I am also really encouraged to hear when parents have the support from advocates, because in my experience the focus is on the parents' strengths..."

Interviewer: Any particular triggers or things hard to listen to / poignant points?

Researcher: "The theme around being treated differently was hard, given my personal experience of becoming an aunty for the first time during the completion of the research project. I kept finding myself wanting to check out with my brother what his experiences of being a parent were, to see if what the parents' were reporting were similar. This was not to validate points, or 'test out' parents' accounts, as I was not trying to find the 'truth', but instead what the parents' perception of events were,

it was because I did not have a reference point. I was also very aware of power differences, I guess based on my experiences of being one of the professional's that assessed parents. I think I used this experience in a helpful way as I made every effort to make information accessible, and to be really clear about my role as a researcher in an attempt to minimise any power differential. For me, not being an expert is really important, which was another reason that led me to the approach of IPA. **Interviewer:** You are now in a more powerful position as you have more information about parents' experiences, but you are using this power in a more positive way..."

Appendix VI

DATA ANALYSIS PROCEDURE: TABLE OF INTEGRATED THEMES

DATA ANALYSIS PROCEDURE: TABLE OF INTEGRATED THEMES

Superordinate Theme 1: "Stepping up: Expectations

THEME	Helen	Rebecca	Angela	Simon	Zara	Karen	Paul	Jane	Amy	Jeremy
"Extra" Expectations	External: 206-208 , 680-689 , 198-202, 206-208	Internal: 358-368 , 377-379 , 759-761, 776-779, 841-845, 1054-1056, 407, 386	External: 397-398, 617-623	External 55-56, 80, 405-406, 498-499, 803-805 , 811, 913 , 1060-1061, 1219-1226, 1259-1260 , 1280-1283 , 1306-1307 750-757 internal: 913, 897,	External: 896-910, 914-917 , 947-950 Internal: 87-97, 606- 610, 880- 886, 1020- 1021,	External: 197-198, 713-716, 723-725, 894, 900- 901, 1280-1282, 1299-1301 , Internal: 1219-1224 ,	External: 626-641 , 621-625 Internal: 100-104, 174-176, 229-230, 281-290 , 553-554, 587- 590 , 650-651,	External 803-805	External 166-171 , 364-372, 423-425, 491-494, 809-815,	External 209-222, 231-244, 549-557, Internal 448-449 ,
Presumption of Incompetence	220-227		137-138, 162-163, 769-773 ,	186, 195- 201, 419- 422 , 633- 637,	148-154, 818-821	96-98, 259-260 , 345-346 , 625-627, 917, 1102-1103 , 1180 , 1247, 1564- 1566 , 1782-1783		970-984 , 662-665 , 986-988,	15-22, 286- 289 ,	364-366 ,
Awareness of difference	503-515 , 388-389, 802, 419, 1226-1228, 1237-1245, , 464	392-398, 978-981, 369-375 , 410-411		31, 40, 547- 553 ,	73-75, 103- 105, 351- 364, 574- 579, 716- 729, 735- 742 , 753- 759, 761- 764, 863- 873,	951-953, 1597- 1601, 1679-1684 , 1694-1701 , 1705- 1706, 1710-1712, 1762, 1785,1789- 1792 , 154, 623, 1112-1114 , 1176, 1180 ,	593-610, 612-614, ,	301-303, 729-734	33-41, 712- 722, 729- 741,	296-297, 334-336,

KEY:

Red = Negative experience / Black = positive experience

Superordinate Theme 2: Partnership and perceived experience of support

THEME		Helen	Rebecca	Angela	Simon	Zara	Karen	Paul	Jane	Amy	Jeremy
Dimensions of helping	Scaffolding	782-799, 805-813, 894-895, 925-935, 1311-1321,	26-27, 36-41, 68-71, 240-241 , 343, 602-603, 619-622, 796-798, 807-812,	802, 265, 344, 457, 581, 629, 650, 281, 824-826, 138, 163, 271, 452, 97-98, 502-503, 141-142, 234-240, 345-350, 371	764-767, 950-957, 18-19, 47, 179-180. 748-749	117-132, 171-173, 302, 304-311, 367, 389-391, 480-502, 925-929,	236-250, 665-673, 741-750, 802-818, 1555-1580 , 1769-1772, 222-225	120, 132, 146, 164-167, 335, 97-99, 352, 377, 303, 549-550, 687	65-67, 385-388, 16, 186-188, 916-922, 455-457, 390-404, 49, 77-78, 175-176, 545-546, 19-21, 43-46, 875-879, 195-197, 328-331, 939-956, 1057-1058	251-255, 392-394, 542-546, 727-729, 757-758	127, 272-281, 300-305, 320-323, 314-316
	Validation	136-150, 441-449,	86-88, 132, 142-144, 197-200, 548, 557-566, 724, 867, 925-928	603-604,	427, 839-840,	145-147, 272-279, 338-349 , 528-530, 954-955,	1688-1691 ,	241, 664-666, 185-186	364-365	378-381, 381, 612-617	393
	Practical support		110-114, 140-142,	326, 600-603				172-173, 207, 267-268, 306-312, 272	127-130, 886-887, 497-500, 339-343, 821-829 ,	346-349, 559-560, 743	94-95, 122
Professional's Qualities		<u>Helpful:</u> 428-429, 453-454, 469-478, 1053-1055, 696, 478, 472, <u>Unhelpful:</u> 1278-1282, 267-279	<u>Helpful:</u> 93-94, 96, 129, 123-124, 134, 135, 207-208, 221, 227, 331, 1048,	<u>Unhelpful:</u> 82-83, 146, 296-298, 833-834, 608-612, 277-278, 419-420, 483, 492, 590, 655, 860	<u>Helpful:</u> 1035-1037, 1070-1071, <u>Unhelpful:</u> 784, 787-791, 203-207, 586-587, 398-400, 942-948, 1213-1219, 392, 813-818	<u>Helpful:</u> 160-163, 373-374, 393, 393, 393, 470-471, 962, 986-987,	<u>Unhelpful:</u> 830-831, 576-577, 651-656, 448 -461, 332-348, 1284-1285, 1483, 1603,	<u>Helpful:</u> 150-151, 222-225	<u>Helpful:</u> 966, 11-12, 421-424, 460-462, 1046-1047, <u>Unhelpful:</u> 581, 585-591, 598-600, 526-527, 753, 603-608, 613	<u>Helpful:</u> 191, 264, 269-274, 286-288, 335, 349-354, 370-372, 183-185 <u>Unhelpful:</u> 529-535, 186, 193-198, 182	<u>Helpful:</u> 86, 271, 284 <u>Unhelpful:</u> 129-130

Degrees of empowerment	The Expert approach	230, 408-413 , 1278-1280 , 160-182 , 670, 974-985, 423-425 , 1086-1097 , 254-255, 593-596, 345-346, 292-309 , 341-348, 336-337, 354-368 , 523-527 , 535-544, 339-340, 476, 553-559, 560-580, 1282-1291, 685-686		871-874, 540, 542-544, 357-358, 374-381, 499-500 , 502, 100, 639-641 413-416 , 467-468, 579, 645	919-928, 90-92, 512, 182-183, 405-408, 441-442, 540-541, 825-827, 987-988, 1058, 1277-1278, 1285, 1310, 204-205, 215-217, 591, 813, 24-25, 56, 58, 69-70, 201, 219-220, 242-244, 643-646 , 650-652 , 656, 889-891 , 995-996, 1230-1233, 1302-1304, 201, 491 , 660-663, 680-681, 1267-1268, 1318-1320, 732, 833-835, 1042-1044, 1111-1114, 1084-113, 416-417, 618-620		749, 1174, 1579-1581, 216-217, 386, 389, 350-351, 781, 1507, 1613, 1615-1616, 1652, 1484-1486, 356-358, 1269, 1042-1043, 1000-1001, 1014, 696-697, 1688-1691,		8-9, 939-941, 1052-1053, 1061-1065 , 51-52 , 456-468 , 555-556, 562-563, 107-109, 427, 572-573, 137-138, 479-481, 962-964	12-13, 771-775 , 794, 26-31, 201-203, 47-51, 638-644, 808-809, 777-781. 437, 16-19, 21-22, 40-41 623-630 , 594-597,	207-212, 194-196, 169, 485-490, 146-147, 154, 100-101, 182
	Collaboration	857,429-493,	153-154, 642-645, 157-165, 264-274, 352-353, 1028-1029, 291, 591-594, 88, 1456, 151-152, 104-107, 57-53, 167		600, 779 , 1004-1007, 1035, 1354-1357, 797-798, 496-497,	165-168, 266-267, 373-376, 258-261, 461-475 , 579-522, 1004-1014 ,	1554-1556	454-462, 474-477, 593, 617-619, 437, 261-264 , 157, 447-457, 211-225	109, 359-364 , 619-621 , 801-802 , 510-513, 282-283, 462-466, 185-190	170-171, 191-192, 435, 541-542, 546, 547, 466, 482,	

“Understanding what I’m going through”: Connectedness	379-387, 1072-1077, 1010-1014, 1322-1330, 614-615 1301-1306, 590, 437-439, 501-502, 1062-1063, 1311-1313, 1043-1052	123, 169-170 482, 488-489, 459-461, 256, 282, 101-102	261, 369, 357, 486, 530, 575, 593, 392-393, 537, 738, 880, 489-490 595-596	78-79, 573-581, 831-833, 1318-1320, 1334-1336, 142-150	947-950, 815-816, 970-980, 414-420, 397-420, 457-458, 378-382, 1033-1039, 1057,	100, 1457-1459, 1284-1285, 1089-1090, 1100-1102, 1078- 1079, 1014, 696-697, 376, 382, 529-530, 570-572, 579 , 908-909, 1120-1135, 1152-1153, 1159-1160 1633-1634, 1638-1639, 1440-1450, 1603, 421-422	535-543, 154-157,	406-410, 433, 569-570 64-65, 493-495, 583, 191-192,	69-73, 181-183, 330-332, 278-280, 326-328, 323-326, 337-342, 103-107,	461, 178-181, 184-187, 537-538, 496-501, 511-517 439-440, 172-176, 96-98, 84, 560
--	---	--	--	---	--	--	----------------------	---	---	--

KEY:

Red = Negative experience

Black = positive experience

Superordinate Theme 3: “Getting through it”: Coping

THEME		Helen	Rebecca	Angela	Simon	Zara	Karen	Paul	Jane	Amy	Jeremy
Sense of coping		399, 847-857 950-993, 999, 1021, 1008-1014, 1208-1210, 1197-189, 758, 1153-1154, 1199,	512-513, 880, 236-239, 284, 297-303, 734-735, 815-816,	339, 510-512, 525, 672, 810-811, 269, 267, 384	452-454, 514-515, 870-971, 906-907, 1119-1121, 1167-1169, 501-502, 512-515, 912, 977, 1195, 645-646, 978-979, 1235-1238	888, 914-917, 672-678, 589-594, 655, 666-668, 783-786, 851, 775-779,	1575-1576, 477-483, 532, 190-191, 477-478, 480-483, 967-969, 1380, 1390, 1382, 861, 985-986, 1341, 1382,	303, 356-361, 510-511, 632-646, 685-699	167-170, 393-397, 756-760, 795, 996-999, 167-170, 343-345, 364	212-218, 568-570, 581, 436-438, 733-735, 242, 571, 381, 69-70,	503-506, 448-449
Strategies for coping	Practical	357, 862, -867, 885-892, 1019- 1024, 1333-1335,	894, 1028	339-341, 520, 523-525, 670	813, 831,		778, 1505,		384-385, 548-550	583-584	
	Emotional	187, 283-285, 462, 636, 657-659, 1167,	1029	859-860	238, 245, 494, 529-531, 750, 729,		103-106, 266-267, 400-404, 586-590, 826-828, 997-998, 1046-1048, 1548-1551, 1568-1581,		395, 554-555, 578, 183-185, 594, 616-617, 680-685, 792		524-530,
Emotional impact	Positive	938,	305, 642, 660-661, 880, 915		1182,	529, 648-651, 838, 936		340, 386-388, 528-530		69	432,
	Negative	131, 193, 203, 214, 252, 324, 416-417, 515, 544, 609, 995, 999-1000, 1036, 1091, 1115-1117,	470, 586, 767, 784, 892, 908,	277, 312-314, 660, 667,	90-92, 539, 628, 658, 663, 825-827, 894, 995, 1055, 1174, 1178, 1267,	83, 93, 811-813, 834, 1026-1027,	377, 440, 471, 602-603, 718, 771, 1056, 1207-1209, 1332,	301,	352, 524, 530-531, 533, 786, 800, 806, 831, 863, 898	12, 46, 54, 73, 410, 440, 456-457, 636,	100, 146, 156, 166, 286, 354, 364-366, 420, 426, 522, 549,

KEY:

Red = Negative experience

Black = positive experience

Superordinate Theme 4: “Who is the parent here?” : Identity

Theme		Helen	Rebecca	Angela	Simon	Zara	Karen	Paul	Jane	Amy	Jeremy
Beliefs about parental ability and skill		88-96, 150, 316, 379-383, 712-718, 720-733, 782-783, 1132, 1145, 1157, 1159, 1215-1219, 754-756, 741	499-507, 518-529, 878-880, 1012-1016, 313-316, 538, 748	716-718, 441-443, 255, 257, 561	524-527, 862-865, 888-889,	84-85, 559-561, 678-680, 709-714, 807-808, 943-944, 1020-1021, 248-253, 287-290, 324-334, 565-579, 749-750,	356-358, 723-726, 731-738, 1159-1160, 1236-1240, 1258,1311, 1620,	106- 117, 137-139, 315-316, 329, 480-481, 517, 579, 668, 569	21-24, 658-660, 662-670, 679-680, 725, 817-818, 839-840,	50, , 808-809, 40-41, 402-412 396-399	443, 449, 294-295
The importance of time		160-175, 211-213, 332-334, 350-355, 365-368, 405-408, 441-448, 663-664,			44-45, 498-499, 543-544, 555-562,	77-81, 87-92, 121, 182-187, 426-453, 540-546, 683-695, 716, 765-773				33-40	100-101, 140-141,
Dependent position	On family and professional	206-208	473-477 324-325, 697, 676, 962-968, 655	162-163, 583-584 362-366, 703-704	914-918, 424-425, 429-430, 890-891,	857-859, 914-917, 982-985, 1063-1070	106-117, 162, 285, 1069, 1190 555-557, 588-590, 594-596, 960-963,	380-384	56-58, 69, 103, 179-181, 448-450, 868-871, 1023-1024, 1064-1065, 159-161, 173-176 35-37, 166-170, 905-906, 1001	260-261, 382-383 507-508 442-444	140-143,
	Self agency	225-227, 831-832, 1202, 1177-1186	591-594, 645-648, 655, 291	639-641	875-877, 1200-1201,			167-168	620-623,	41-42	347, 350-351

KEY:

Red = Negative experience

Black = positive experience

Appendix VII

ETHICS COMMITTEE APPROVAL LETTER

Appendix VIII

NHS RESEARCH AND DEVELOPMENT COMMITTEE APPROVAL LETTER

Appendix IX

STATEMENT OF APPROVAL FROM THIRD SECTOR ORGANISATION

Appendix X

PARTICIPANT INFORMATION SHEET



**SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL**

VERSION 2: 03.08.2012

Information Sheet

“The Experiences of Parents with a Learning Disability who have support to be a Mum or Dad”

My Name is Hannah Moore. I am training to be a Clinical Psychologist.



As part of my training I am doing a research study. In this study I am interested in hearing from parents with learning disabilities who have support to be a mum or dad from professionals.

I would like to invite you to take part in my study.

This leaflet will tell you about my study. You can talk to a family member, support worker and social worker about this study if you want to.

Please ask questions if you do not understand anything in this letter.



What is research?

Research is one way of trying to find out answers to questions.

Research gives people the chance to tell others about their lives and about their views.



Why is this research project being done?

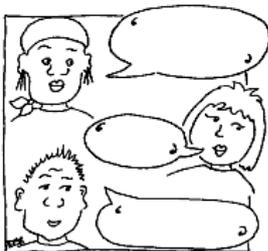
Lots of parents with learning disabilities have support from professionals to help them to be a mum or dad. Professionals are Social Workers, Nurses, Advocates, Support Workers and other people whose job it is to help you to be a mum or dad.



Some parents find this help good and other parents don't like it when professionals try to help them.



I would like to talk to parents with learning disabilities about what it is like to have support to be a mum or dad from a professional.

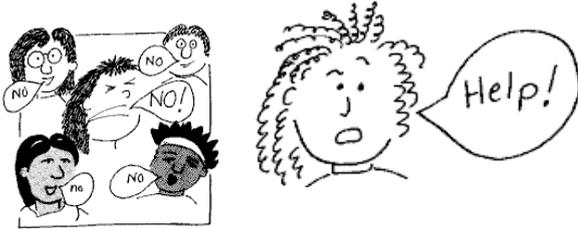


I think it is really important that people with learning disabilities have a chance to tell others about their lives and their views.



Why have I been asked to take part?

You have been chosen because you are a parent with a learning disability and you have support from a professional to look after your child(ren).



You do not have to take part. If you are not sure, you can ask your family, friends and anyone else to help you to decide if you want to take part.



Who else will take part?

Other parents with learning disabilities will be asked to take part in the study.



Do I have to take part in the study?

No. You can change your mind about taking part at any time. This will not change the support you get from anyone.

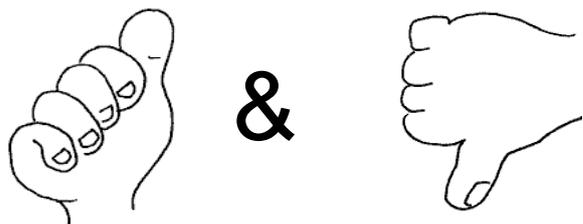
What will happen if I agree to take part?



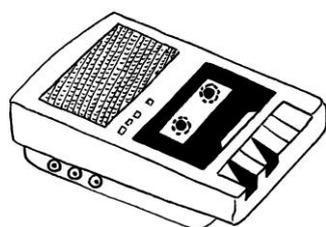
If you agree to take part then I will meet with you once for about an hour and a half. I am happy to meet you at home or somewhere you feel comfortable. You can choose to have someone with you at the meeting.



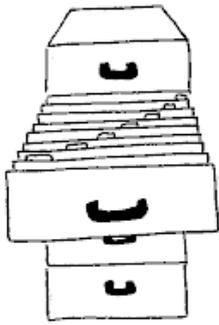
I will ask you to think about one professional who helps you with being a mum or dad.



I will ask you what is good about working with that professional and what is hard about working with that professional.



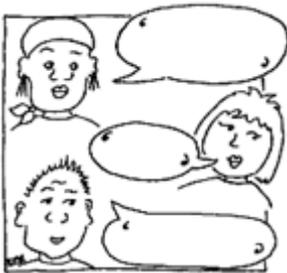
I will record what you tell me. I will also type it up at a later date. I will not use your name when I type it up so only I will know who said those things. The tape will be destroyed at the end of the study, by May 2013.



The recording and the write up will be kept in a locked cabinet in my office in the University Health Board. I will be the only one who can see it.



I may want to meet you again, to check that I have understood what you told me.



What will you do with the information?

I will put the information you told me together with the information that other parents told me. I will write it up in a report.

What would I have to do?

I would like you to tell me about how you get on with a professional who helps you with being a mum or a dad.





What are the pros and cons for taking part?

Nothing different will happen to the support you get. I cannot promise that the study will help you. It might feel good to talk about your views. The results of the study may help to improve support for other parents in the future.



If anything upsets you when you talk to me, you will be able to take a break or stop altogether. If you do not want to answer a question then that is ok.



Will anyone else know what I have said?

No. No one else will know so it will be confidential. It will be kept private.



If I think that you may harm yourself or someone else I will need to tell other people who are supporting you. If you tell me that a professional has hurt you or your child, or has done something to scare or upset you, I will have to tell my supervisor. I will tell you if I need to do this.

What will happen to the results of the study?



After the study is finished I will write the results up into a report. This is because this study is part of my training to become a Psychologist . The report will be read by other Psychologists. Your name will not be in it.



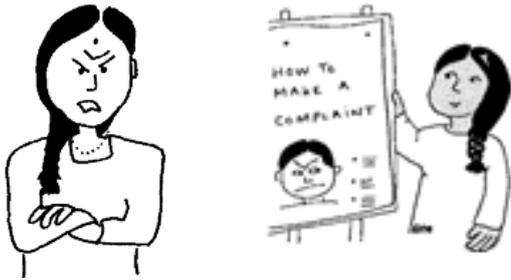
I might then write about it in a magazine called a 'journal'. Your name will not be in it. I may also talk about the research to others. I can tell you about the results if you want me to. I will tell you about the shared experiences of parents with a learning disability.

What can I do if I am unhappy about anything in the study?



If you feel upset or unhappy about something during the study, please talk to me and I will try to help. You can also talk to my supervisor, Rosemary Jenkins, who may also help. Her contact details are at the end of this letter.

What if there is a problem?



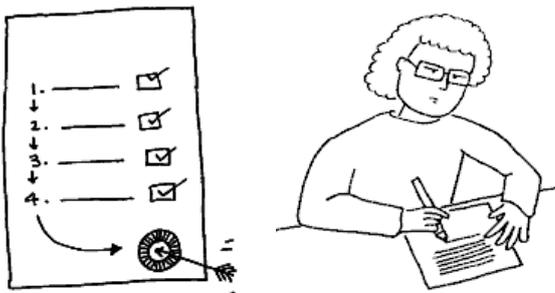
If I say anything that makes you feel unhappy during the interview you can let me know. I will do my best to help you. If you are still unhappy then you can make a complaint. I will give you the name of a person who can help you to make a complaint.

Who has agreed that this study is safe?

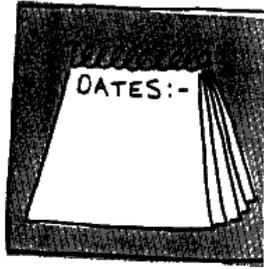


All studies in the NHS are looked at by a group of people called a Research Ethics Committee. The South Wales Research Ethics Committee have agreed that this study is safe.

How do I take part?



If you are interested in taking part in the study, please complete the consent form and give it to the person who went through this letter with you. That person will contact me and send me the consent form.



I will then phone you to arrange to meet. If you do not want to take part in the study, do not complete the consent form and I will not contact you.



What if I have more questions?

If you would like to find out more about my study, you can contact me or my supervisor, Dr Rosemary Jenkins (Consultant Clinical Psychologist). Our details are at the bottom of this letter.



Contact details

You may contact me at any time after we meet if you are worried about something to do with the study, or to ask any questions that you have about the study.

Hannah Moore

Trainee Clinical Psychologist

School of Psychology

11th Floor

Tower Building

70 Park Place

Cardiff, CF10 3AT

Tel: 029 208 70582

E-Mail: Hannah.Moore@wales.nhs.uk

You can also contact my supervisor, Rosemary Jenkins, if you do not want to speak with me.

Dr Rosemary Jenkins

Clinical Psychologist

School of Psychology

11th Floor

Tower Building

70 Park Place

Cardiff, CF10 3AT

Tel: 029 208 70582

Email: Rosemary.Jenkins3@wales.nhs.uk

Appendix XI

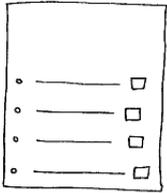
CONSENT FORM: VERSION 2



SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

Version 2: 03/08/2012

Consent Form



“The Experiences of Parents with a Learning Disability who have support to be a Mum or Dad.”

Researcher: Hannah Moore, Trainee Clinical Psychologist

If you agree with the statement please put your initials in the box.



1. I have read the information sheet about the study dated 03.08.2012. I understand what I would have to do if I agree to take part.



2. I have had chance to ask any questions that I had.



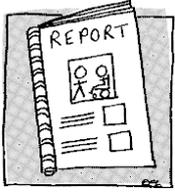
3. I know that I can say no to the project if I don't want to do it. I know that I can stop doing the study at any time. I know this will not change the support I will get in anyway.



4. I agree to allow the tape recording of the sessions.



5. I understand that everything I say will be kept confidential unless Hannah is worried about someone's safety.



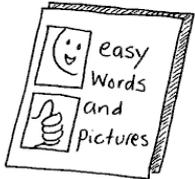
6. I agree for Hannah to type up what I say afterwards and write it in a report. I know that my name will not be in it.



7. I give my permission for Hannah to contact me to arrange a time and date to meet.



8. I agree to take part in the study.



9. I would like a summary of the research findings when it is finished. I understand and agree that if I want her to, Hannah could meet with me again to talk about these results.

Contact number _____

Name:Signature:

Date:

I, the undersigned, confirm that I read through and discussed the information sheet with the participant who has agreed to take part in the study:

Person taking consent (print):

Signature

Date:

Appendix XII

PROFESSIONAL INFORMATION SHEET



SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

VERSION 1: 21/05/2012

Professional Information Sheet

“The Experiences of Parents with a Learning Disability who have support to be a Mum or Dad”

My name is Hannah Moore and I am a Trainee Clinical Psychologist. I would like to inform you of a research study which I am carrying out under the supervision of Dr Rosemary Jenkins, Consultant Clinical Psychologist and Dr Julia Frearson, Clinical Psychologist.

This leaflet will tell you about my study. If you want to ask any questions or would like further information then please feel free to contact me using the details at the bottom of the leaflet.

What is the purpose of this study?

The purpose of the current study is to explore parents' experiences of what it is like to parent with a learning disability who has support from professionals to be a mum or dad. The parent will be asked to think about their relationship with a professional of their choice during the interview.

It is widely recognised that many parents with a learning disability are able to be 'good enough' parents if the right support is provided. Further research is needed to explore the experiences of parents with a learning disability who have regular support with parenting from professionals. Little is known about the development of relationships between parents and professionals, how they work together in parenting and what the impact of having professional involvement is on the parent.

It is hoped that the findings of this study will inform practice in relation to:

- avenues for parents' engagement with services;
- better prevention of relationship breakdown between parents with a learning disability and services;

- better tailoring of interventions;
- raising awareness of parents with a learning disability and their support needs;
- increasing knowledge about the impact of professional involvement on parents with a learning disability;
- promoting a person centred approach, and
- empowering parents with a learning disability.

I think it is really important that people with learning disabilities have a chance to tell others about their lives and their views.

What is expected of me?

You have not been asked to take part in this study. This information sheet is purely to tell you about the research that I will be doing with a parent with a learning disability that you are supporting with parenting. The reason why you are being informed about this research is that it may be the relationship that you have built up with the parent that is talked about in their interview. All professionals working with the parent will be provided with this information sheet.

What are the possible advantages of the study?

It is hoped that the study may help to improve support for other parents and professionals working together in parenting in the future. The parent may also find it good to talk about their views.

What are the possible disadvantages of the study?

There are no known risks involved in taking part in this study. However, some participants could find the topic sensitive. If anything upsets the parent during the interview then the researcher will take a break or stop the interview altogether and provide support. It is also possible for the researcher to arrange for the parent to speak with someone independent of the research, for example, a qualified Clinical Psychologist.

Will the information gained be kept confidential?

Yes. The researcher follows a strict ethical and professional code of conduct that requires that all information must remain confidential and anonymous. The researcher will audio-record the interviews and transcribe the data. Each of the audio-recordings will be given a code and stored safely to maintain anonymity. The parent's name and the name of the professional talked about will be changed during the transcribing and in the write up of the study so that they will not be identifiable. The recordings and the transcript will be stored in a

locked cabinet within the University Health Board, and only the researchers in the study will have access to the data. The audio-recording will be destroyed following its transcription.

In accordance with policy, confidentiality will only be broken if the researcher becomes aware of malpractice, misconduct or possible risk to the parent or another person, including the child. If this occurs, the researcher will discuss this information with Dr Rosemary Jenkins. The researcher will then inform the parent what they will do next.

What will happen to the findings of the study?

The findings of the study will be written up as part of the researcher's doctoral thesis, which forms part of their Doctorate in Clinical Psychology. It will be submitted and assessed by an examination panel. As part of the write up the researcher will use quotes from the interviews, but all information will be kept anonymous. A summary sheet with the main findings will be provided to those participants who request it.

It is also hoped that the findings from the research will be published in an academic journal and presented throughout the NHS and third sector organisations in England and Wales.

What if there is a problem?

If the parent feels upset about something during the study, the researcher will try to help. Dr Rosemary Jenkins will also provide support to the parent if they request it. Her contact details are at the end of this letter.

The researcher will do their best to help the parent, but if they remain unhappy and wish to make a complaint then the researcher will provide them with the contact details of the people who may be able to respond to their concerns.

Who has agreed that this study is safe?

All studies in the NHS are looked at by a group of people called a Research Ethics Committee. This committee ensures the safety and rights of all participants in the study. South East Wales Panel C Research Ethics Committee have agreed that this study is safe.

Further information?

If you would like to find out more about the study, you can contact me (Hannah Moore) or my supervisor, Dr Rosemary Jenkins (Consultant Clinical Psychologist). The details are at the bottom of this letter.

THANK YOU FOR TAKING THE TIME AND READING THIS INFORMATION SHEET

Contact details

You may contact me at any time if you are worried about something to do with the study, or to ask any questions that you have about the study.

Hannah Moore
Trainee Clinical Psychologist
School of Psychology
11th Floor
Tower Building
70 Park Place
Cardiff, CF10 3AT

Tel: 029 208 70582

E-Mail: Hannah.Moore@wales.nhs.uk

You can also contact my supervisor, Rosemary Jenkins, if you do not want to speak with me.

Dr Rosemary Jenkins
Clinical Psychologist
School of Psychology
11th Floor
Tower Building
70 Park Place
Cardiff, CF10 3AT

Tel: 029 208 70582

Email: Rosemary.Jenkins3@Wales.nhs.uk



Appendix XIII

SEMI-STRUCTURED INTERVIEW SCHEDULE: VERSION 2



SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

VERSION 2: 03/08/2012

Interview Schedule

PART 1: RAPPORT BUILDING AND 'CIRCLES OF SUPPORT' EXERCISE SEMI-STRUCTURED PROMPTS

1. Introduction

- Go through information leaflet to check understanding
- Reaffirm consent
- Ask for permission to take notes in addition to taping

Prompts:

- Before we start, this is what is going to happen today:
 - I will ask you some questions to learn a bit about you.
 - There are no right or wrong answers to any of the questions
 - Then I will ask you to choose a professional who helps you with being a mum or dad. I have an exercise that can help you to choose which professional to think about.
- Then I will ask you how you get on with that professional.
- Confirm time length and number of breaks

2. Elicit worries / questions

- Any worries or questions before we start?

3. Background information

Prompts:

- It would be useful if I can to get a bit of background information about you.
 - age
 - who lives at home
 - age of child[ren]
 - occupation / education
 - previous work
 - Who looked after you when you were a child?
 - Did your parents have any support from a professional when you were a child?

4. Relationships circles exercise:

Prompts:

- Draw a picture of yourself or write your name in the centre of a piece of paper.
- Make a list of all the different professionals that support you to be a mum or dad. These are people whose job it is to work with parents with learning disabilities to help them to look after their children. This may include, a Social Worker, a Support Worker, a Speech and Language Therapist, an Advocate and a Psychologist, for example.
- Write the name of the person or draw them on the paper.

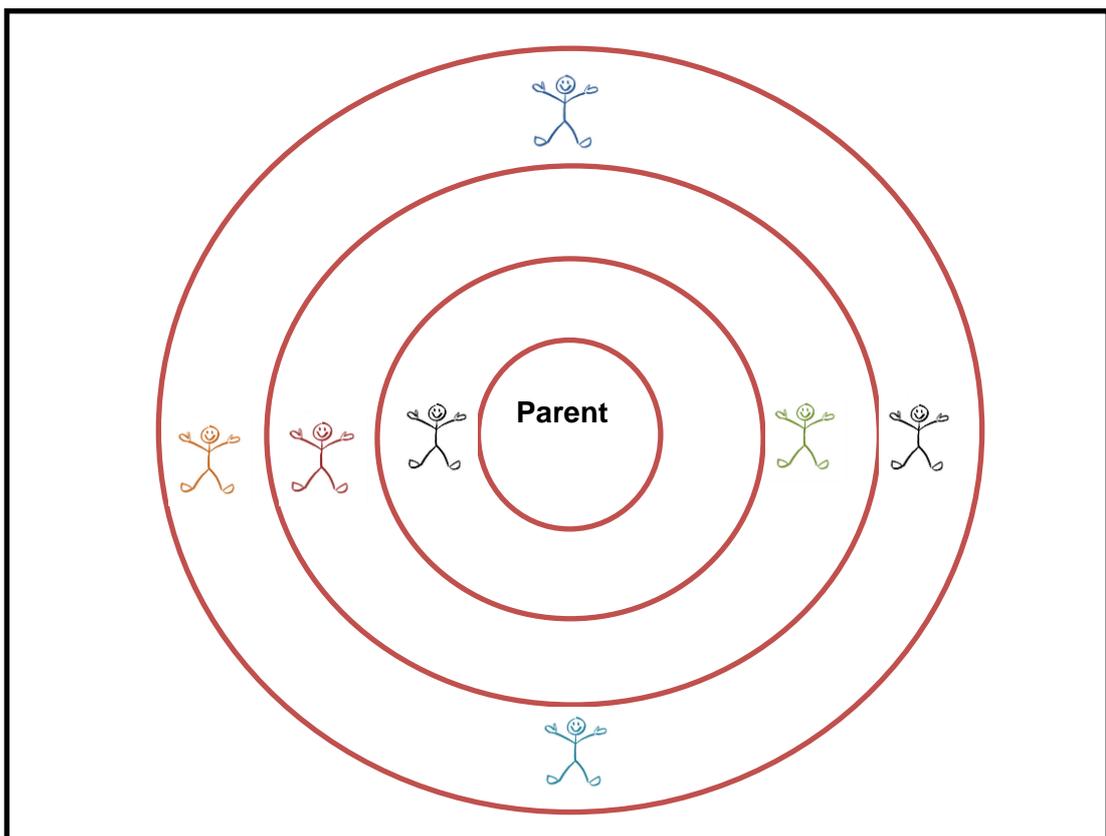
- If you feel close to that person – or if you think that they give you the most support, put them close to you in the centre. If you do not feel close to the person, or think that they do not give you much support then put them further away from you.
- Those professionals that you feel closest to, and those who you think give you the most support, will be close to you in the middle. Those professionals you do not feel as close to, and those who you think give you the least amount of support will be further away from you.

- Questions to ask once professional is chosen:

PROMPTS:

- How long has the professional been working with you?
- What is the professionals role? i.e.. social worker, advocate, etc.
- What kind of support do they give you?

- Here is an example:



PART 2: INTERVIEW

OPEN ENDED QUESTION

1. What is it like having [professional] support you to be a mum or dad?

SEMI-STRUCTURED PROMPTS FOR DISCUSSION

2. Relationship with professional:

Prompts:

- How do you get on with [professional] now?
 - Has it always been like that?
- What are the best things about [professional] supporting you to be a mum / dad?
- What things have helped you to get on with [professional]?

- What is hard or difficult about [professional] supporting you?
- Are there times where you don't agree on something?
 - If so, how do you cope with that situation?

- What are the best ways that you have found to talk to each other?
- How do you tell each other about how you are feeling?

- What is it like when [professional] tells you what to do or gives you support/ help, for example, shows you how to stick to routines, or make food, or set rules?
 - What things make that easier / harder?

3. How has working with [professional] impacted on parent:

Prompts:

- Impact on what they think they are good at as a mum / dad?
 - What did you think you were good at before [professional] started supporting you to be a mum or dad?
 - What do you think you are good at now that [professional] is supporting you to be a mum or dad?
 - What did you think you needed help with before [professional] started supporting you to be a mum or dad?
 - What do you think you need help with now that [professional] is supporting you to be a mum or dad?

- Impact on what they do as a mum/ dad?
 - What things did you do as a mum or dad before [professional] started supporting you to be a mum or dad?
 - What things do you do now that [professional] is supporting you to be a mum or dad?

- Impact on how they cope with your problems?
 - How did you cope/ manage with problems before [professional] started supporting you to be a mum or dad?
 - How do you cope/ manage with problems now that [professional] is supporting you to be a mum or dad?
 - Do you think you would be able to cope/ manage problems if [professional] was not supporting you to be a mum or dad?

- Impact on what support they get from others, such as family and friends?
 - What support did you get from friends and family before you had support from [professional] to be a mum or dad?

- What support do you get now that you have support from [professional] to be a mum or dad?
 - Impact on what other people think they are good at as a mum or dad: Family / friends / other professionals / people in their community?
 - What did your family think you were good at as a mum or dad before [professional] started supporting you to be a mum or dad?
 - What do your family think you are good at as a mum or dad now that [professional] is supporting you to be a mum or dad?
 - What did your friends think you were good at as a mum or dad before [professional] started supporting you to be a mum or dad?
 - What do your friends think you are good at as a mum or dad now that [professional] is supporting you to be a mum or dad?
 - Impact on the worry of having their child[ren] taken away?
 - How much of a worry was having your children taken away before [professional] started supporting you to be a mum or dad?
 - How much of a worry is it now that [professional] is supporting you to be a mum or dad?
 - Impact on how they are feeling each day?
 - How were you feeling each day before [professional] started supporting you to be a mum or dad?
 - How are you feeling each day now that [professional] is supporting you to be a mum or dad?
 - Impact on how they feel about themselves?
 - How did you feel about yourself before [professional] was supporting you to be a mum or dad?
 - How do you feel about yourself now that [professional] is supporting you to be a mum or dad?
4. What changes would you make:
- Prompts:**
- If you could start again, and meet [professional] for the first time, would you do anything differently?
5. Ideas:
- Prompts:**
- Do you have any ideas of things that could help other parents with learning disabilities who have someone like [professional] help them?
6. Other comments:
- Prompts:**
- Is there anything else that you wanted to say about your relationship with [professional]?
7. Closing:
- Prompts:**
- That's all I wanted to ask, thank you for your time in helping me.
 - How has it felt to have that chat?
 - Has it raised any issues / feelings / thoughts that you were not aware of before?
 - Do you have any concerns or questions about what we've been talking about?

Appendix XIV

EXAMPLES OF IMAGES TO SUPPLEMENT INTERVIEW SCHEDULE

EXAMPLES OF IMAGES TO SUPPLEMENT INTERVIEW SCHEDULE



Worried About Child



Support Mum



Show How To Bath Baby

Appendix XV

DATA ANALYSIS PROCEDURE: EXTRACTS FROM TRANSCRIPT: ZARA

Appendix XVI

DATA ANALYSIS PROCEDURE: EXAMPLE OF CLUSTERED THEMES: SIMON

DATA ANALYSIS PROCEDURE: EXAMPLE OF CLUSTERED THEMES: SIMON

Worry (1172-1175)(1178) (1246-1253)

Overdose (454)

Scared (73) (628) (995)

Stressful (826) (1232)

Frightened (894)

Nervous (987)

Crying (87)(1055)

Quite hard (539)

Sadness (825)

Fear (240-242)(795-796) (995-996)

Lonely (1145)

Mood has got better (1182)

Identity (865)

Drive – to keep the boys (503-504) (978-979) (1167-1169) (1172-1175) (1235-1238)

Live and learn the hard way (870)

The value of time (44-46) (405) (560-562) (619-620) (633-637)

Low self-esteem and belief in self (118-124) (844-845)

Confidence (912) (967-971) (977) (1195) (1202-1204)

Limited Self-agency (424) (429-430) (1200)

Disabling (118-124) (186-187) (410-417) (894-896)

Loss of privacy and freedom (189-190)

Negative attribution style (94-96) (101)

Compassion (985-966)

Parent's tolerance (501-502) (512-515)

Pressure (108)

Skill acquisition – learn the hard way (970-871)

Just get on with it (1119) (1113)

Still accepting / wanting help (503-504) (903-906)

Bottle up (452-454)

Secondary handicap and handicapped smile (72)(110)(203) (220) (238) (245) (494) (729)
(750)

Placating (876-877)

Managing conflict (62-63)

Transitory relationships (15)

Fostering dependency (914-915)

Evaluation of skills / progress (90-92) (512) (524-527)

Blame – on parent (182-183) (405-408) (441-442)(446-448) (540-541) (825-827) (987-988)
(1058) (1277-1278) (1285) (1310)

System of power (204-205) (215-217) (591) (813)

Powerless (24-25) (56) (58) (69-70) (201) (219-220) (242-244) (643-646) (650-652) (656)
(889-891) (995-996) (1230-1233) (1302-1304) (1356-1357)

Having a voice (201) (491) (660-663) (680-681) (1267-1268) (1318-1320)

His voice is not enough - Need others to help have a voice - Need confirmation from others –
authorisation (732) (833-835) (1042-1044) (1111-1114)

Collaboration (600) (779) (1004)

Not making allowances for LD (78-79)

Not understanding each other's needs (78-83) (142-150) (496-497) (573-581)

Difficult relationship (831-837) (1319-1320)

Rigid approach (813-818)

Rules (764-767)

Practical support (427) (950) (954-957) (748-749)

Poor communication (442) (619-626) (1087-1091) (1219-1223)

Timeliness of support (401-406)

Putting pressure on us (108)

Feedback (839-840)

Battle – 'on our side' (820-821)

Meetings (19) (47) (179-180)

Ambivalent about the effectiveness of the help (392) (748-749) (875) (919-928)

Mutual trust (784) (787-789)

Mutual Honesty (1035-1037)

Vulnerability of professional (205-207) (586-587)

Sorry (1070-1071)

Reliability (398-400) (942-948) (1213-1219) (392)

Presumption of incompetence (86) (195-201) (419-422)(633-637)

Too high Expectation – in an impossible position (498-499) (803-805) (913) (1259-1260)

'Not good enough' (80) (405-406)(811) (1060-1061) (1219-1226) (1280-1283) (1306-1307)

Prescribed way of behaving (55-56)

Awareness of difference – extra needs (31) (40) (547-553)

Judgement/ stigma (751-752)

Appendix XVII

**DATA ANALYSIS PROCEDURE: TABLE OF CLUSTERED THEMES WITH
QUOTES: SIMON**

DATA ANALYSIS PROCEDURE: TABLE OF CLUSTERED THEMES WITH QUOTES: SIMON

Subordinate themes	Clustered themes	Examples of quotes
Emotional impact	<ul style="list-style-type: none"> -Worry (1172-1175)(1178)(1250-1253); -Overdose (454); -Scared (73) (628) (995); -Stressful (824-827) (1232); -Frightened (894-897); -Fear (240-242)(795-796) (995-996); -Lonely (1145); -Nervous (987); -Crying (87)(1055); -Sadness (825); -Quite hard (539); -Mood improved (1182) 	<p><i>"I get frightened sometimes when they do come, if uh, if they think there is something wrong with the house , or something like that, and we think it might be perfect, you mean, the house is so small" (894-897)</i></p> <p><i>"...we had a meeting on, and I was break down and crying see, it was stressful and it was getting harder all the time, and they were trying to blame everything on us..." (824-827)</i></p> <p><i>"I'm just worried, in case she points the finger, you're not doing things what she tells us to do" (1250-1251)</i></p>
Self	<ul style="list-style-type: none"> -Identity (862-865); -Drive: to keep the boys (503-504) (978-979) (1167-1169) (1172-1175) (1235-1238); -Live and learn the hard way (869-871) -The value of time (44-46) (405) (560-562) (619-620) (633-637) -Low self-esteem and belief in self (118-124) (844-845); -Confidence (912) (967-971) (977) (1195) (1202-1204); -Limited Self-agency (424) (429-430) (1200); -Disabling (118-124) (186-187) (410-417) (894-896); -Loss of privacy and freedom (189-190); -Negative attribution style (94-96) (101); -Compassion (985-966) 	<p><i>"I always try and read for them, I always sit down, on the couch with both of them by me, watch Fireman Sam or watch Scooby-Do, oh I, every programme with the children, and sit down with them, being their dad..." (862-865)</i></p> <p><i>"I'm more confident now, going through this, right, I find myself, right I've got to pull on for this, I've got to be strong for my boys, I have got to fight for them, you mean. I know things have never, it's never gone to court or nothing like that". (977-981)</i></p> <p><i>"I didn't have a clue to be a dad, but live and learn the hard way to be a dad" (869-871)</i></p>
Coping	<ul style="list-style-type: none"> -Tolerance (501-502) (512-515); -Pressure (108); -Skill acquisition (970-871); -Just get on with it (1119-1120) (1113); -Accepting / wanting help (503-504) (903-906); -Bottle up (452-454); -It's fine (72)(110)(203) (220) (238) (240-245) (491-494) (729) (750); -Placating (876-877); -Managing conflict (62-63) 	<p><i>"...from the start I felt like calling her everything, but I didn't, if you start calling somebody names, and stuff like that, it will be on your record , something like that, or this guy's not a nice guy to talk to, but everything is fine with us" (491-494)</i></p> <p><i>"before we had her I just, we coped with it, we didn't have nobody" (1119-1120)</i></p>
Interpersonal context	<ul style="list-style-type: none"> -Transitory relationships (15); -Fostering dependency (912-915) 	<p><i>"...just to give me more support to be more confident, uh, doing the perfect thing. In time, they are gonna finish with us. One or two people reckon we don't need them now, but I do need them" (912-915)</i></p>
The expert approach	<ul style="list-style-type: none"> -Evaluation of skills (90-92) (512) (524-527); -Blame on parent (182-183) (405-408) (441-442)(446-448) (540-541) (825-827) (987-988) (1058) (1277-1278) (1285) (1310); -System of power (204-205) (215-217) (591) (813); -Powerless (24-25) (56) (58) (69-70) (201) (219-220) (242-244) (643-646) (650-652) (656) (889-891) (995-996) (1230-1233) (1302-1304) (1356-1357); -Having a voice (201) (491) (660-663) (680-681) 	<p><i>"You'd come to the meetings, and things are fantastic, there's what, about 15 / 20 of us now, it's getting less now, last time it was only about 12, and everybody gets a say , about , about us..." (524-527).</i></p> <p><i>"So she was pointing the finger this , she was pointing the finger that , ah it doesn't matter what we were doing it was wrong" (446-448)</i></p> <p><i>"...that's why at the moment now, we've been</i></p>

	(1267-1268) (1318-1320); -Authorisation (732) (833-835) (1042-1044) (1111-1114); -Collaboration (600) (779) (1004)	<i>through a lot with, with social workers, we've had now we have never had bad things about social workers, we, that's why we still got our boys, the boys are everything to us" (643-645)</i>
The relationship	-Not making allowances for LD (78-79) -Not understanding each other's needs (78-83) (142-150) (496-497) (573-579) -Difficult relationship (831-837) (1319-1320)	<i>"...she needs to come but she can't do it, you know, this, alright if she had, if she has got something on I can, you can't help that anyway, you mean, but I want somebody to cover her to go with me, this is very important for me, to have somebody by my side..." (573-579)</i> <i>"Not swearing, but told her that I absolutely hated her" (1319-1320)</i>
Professional's skills	-Rigid approach (813-818) -Rules (764-767) -Practical support (427) (950) (954-957) (748-749) -Poor communication (442) (619-626) (1087-1091) (1219-1223) -Timeliness of support (401-406) -Putting pressure on us (108) -Feedback (839-840) -Battle: 'on our side' (820-821) -Meetings (19) (47) (179-180) -Ambivalent about the effectiveness of the help (392) (748-749) (875) (919-928)	<i>"Before she was helping a lot of us, when, helping, the solicitors, and everything was involved. She is starting to settle down a bit again now, it's like, things are fine, they don't need this help. We do need it, you mean." (954-957).</i> <i>"With meetings, we've had now it's been good, positive things, in the meetings and things like that" (839-840).</i>
Professional's qualities	-Mutual trust (782-785) (787-789) -Mutual Honesty (1035-1037) -Vulnerability of professional (205-207) (586-587) -Sorry (1070-1071) -Reliability (398-400) (942-948) (1211-1216) (392)	<i>"If they're gunna hide something away from a social worker, you're not gunna gain nothing. But sometimes I have felt sometimes, by telling the truth to a social worker, I felt worse off." (782-785)</i> <i>"Apparently we had a phone call saying somebody has cancelled a meeting, would we like this meeting, and it's like chucking things over to everybody else you mean, and it is very important for us to go, and it's like um, oh I can't, I can't take you, can you ask Tracey, or can you ask somebody else" (1211-1216)</i>
Expectations	-Presumption of incompetence (186) (195-198) (419-422)(633-637) -Too high Expectation (498-499) (803-805) (913) (1259-1260) -'Not good enough' (80) (405-406)(811) (1060-1061) (1219-1226) (1280-1283) (1306-1307) -Prescribed way of behaving (55-56)	<i>"I think her role was making sure that the kids didn't come to harm, the kids have never been to harm". (195-198)</i> <i>"... we each was talking about children, and I thought to myself if we do a mistake, are we gunna lose the boys..." (803-805)</i> <i>"...doesn't matter what else, was like, she was trying to blame anything, she was looking anywhere for any faults, she was going up stairs she was looking, well this is not good enough, that is not good enough," (1280-1283)</i>
Awareness of difference	-Extra needs (31) (40) (547-553) -Judgement/ stigma (751-752)	<i>"The reason I am asking her to come, that's why, I have learning difficulties, you know, if you were my social worker now, or the children's social worker now, I want you to come and the reason I want you to come is, if you were sat down by there, and person was talking to you, I wouldn't be able to explain to you the following day, what he said." (547-553)</i>

Appendix XVIII

RESEARCH DESIGN DILEMMA

RESEARCH DESIGN DILEMMA

	Aim	Pros	Cons
Interview just parent	To elicit parents views on their relationship with a professional, and the impact of that relationship on the parent.	<ul style="list-style-type: none"> • Gives the parent (who is devalued in society and in the research arena) a voice • Less threatening without the professional there. • Person centred • Less time consuming • Recommendation of research would be to interview the professional to get their opinion. 	<ul style="list-style-type: none"> • Query over the richness of data? • Finding enough parents to take part to make the research credible. • Only gaining one perspective on the relationship. However, the relationship is not a tangible thing that resides in one or other person, it is a person's perspective. This design would be focused on the parent's perspective of the relationship with is perfectly legitimate.
Interview dyad	To explore how parents and professionals work together in developing a relationship that seeks to support parenting.	<ul style="list-style-type: none"> • Richness of data • Develop a social constructionist understanding of the formation of the relationship. • Professional could support parent better after the interview as they would have been a part of the process. 	<ul style="list-style-type: none"> • May restrict parent's ability to speak. • Perhaps would be difficult to ascertain whether the parent was acquiescing with the professional. • More of a challenge to transcribe and analyse. – Would not be able to account for process issues / body language using IPA approach.
Interview pair separately	To explore how parents and professionals work together in developing a relationship that seeks to support parenting.	<ul style="list-style-type: none"> • May give richer content? • Could compare responses between parents and professionals. • Less threatening without the professional there. 	<ul style="list-style-type: none"> • Would require 3 visits for each parent pair. • Would take a lot longer to transcribe – twice the amount of interviews altogether. • Ethical consideration: how to maintain anonymity and confidentiality: it may be obvious the source of statements. • Unsure of how to analyse data. <ul style="list-style-type: none"> ○ How to compare responses • Feels like it is two research projects in one?

Advice from Jonathon Smith, dated: 01/05/2012: *"In general, advice would be to interview someone on their own as they may find it difficult to reveal something if the relevant party is also there However there is then a major ethical issue. If you do separate interviews and the parent reveals something that they would not say directly to the support person, how do you handle this in the write up, when it is possible the identity of the participant will become apparent to the other? ... Personally I would also consider just doing interviews with parents- as this overcomes some of the ethical/interpersonal issues".*