

**VOLUME I : RESEARCH COMPONENT**

**PARENTS WITH LEARNING DISABILITIES: A PSYCHOLOGICAL PERSPECTIVE**

by

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**A thesis submitted to:**

**The University of Birmingham**

**For the partial fulfilment of the degree of**

**DOCTORATE IN CLINICAL PSYCHOLOGY**

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**The University of Birmingham**

**March 2010**

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## **OVERVIEW**

The thesis comprises of both research and clinical components and is submitted as partial fulfilment of a doctorate degree in Clinical Psychology.

Volume I, the research component, includes a literature review, an empirical paper and a public domain paper. The systematic literature review investigates evidence investigating parents' with Learning Disabilities psychological wellbeing and social support. The empirical paper explores the journey of parenthood from the perspective of parents with Learning Disabilities. Finally, the public domain paper provides a summary of the empirical paper.

Volume II, the clinical component, includes clinical practice reports conducted within clinical placements from child, learning disabilities, adult and older adult specialties. The first report contains an attachment and systemic formulation of a young girl and her family. The second report is a small scale service related project investigating the usefulness of an opt-in procedure and reasons for non-attendance in a STAR clinic in a child and family service. The third report is a single case experimental design with a young man with Autistic Spectrum Disorder. The fourth is a case study of a woman seen in a systemic service experiencing low mood. Finally an abstract is provided for a clinical presentation about an older man with Alzheimer's disease who refused to wash.

## **ACKNOWLEDGEMENTS**

Firstly, I would like to thank the mothers and fathers who took part in the study. I was moved by their stories and grateful to them for sharing their personal and emotional experiences. Thank you also to the staff that supported these parents and put them in touch with me.

Although, at times I felt that I would never complete the research the encouragement and support from my supervisor, Biza, kept me motivated. I would also like to thank Mike and Fran for their support at different stages during the research process.

I don't think that I would have got through the course without the weekly chats with my parents and I thank them for listening to my moans and groans and for supporting me. I am especially thankful to my husband, who I love dearly and whose 'chilled-out' personality makes the perfect balance in our relationship. Last, but by no means least, I want to thank our beautiful son, whose arrival during the course was the greatest gift. I know that he does not realise how much he has helped me by just being the amusing, cute toad that he is.

## VOLUME I

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**LITERATURE REVIEW**

**Title: Parents' with learning disabilities psychological wellbeing\* and social support: risk factors and interventions**



Prepared for submission to;

***British Journal of Developmental Psychology (BJDP)***



## **1.0 Abstract**

In this review a brief overview of Belsky's (1984) determinants of parenting model and Sterling's (1998) model adapted for parents with learning disabilities (LD) will be outlined prior to addressing the three review aims:

1. Are psychological wellbeing and social support poorer in parents with LD in comparison to the general population?
2. Is there a relationship between parents' with LD psychological wellbeing and social support?
3. What interventions are most effective in improving parents' with LD psychological wellbeing and social support?

A systematic search of electronic databases was carried out. Nine studies met the inclusion criteria and were reviewed and the overall quality of the studies was identified. The results suggest that parents with LD experience poorer psychological wellbeing than the general parenting population and a relationship was found between psychological wellbeing and social support. Two of the intervention studies found that by improving social support psychological wellbeing was improved. A number of recommendations are suggested for future research with regards to methodology. Finally, Sterling's (1998) model will be discussed in the context of the evidence so far and recommendations for clinicians working in LD services will be outlined.

**Keywords:** *Parents, Mothers, Fathers, Learning Disabilities, Psychological wellbeing, Social support*

**\*Psychological wellbeing and mental health will be used interchangeably**

## **2.0 Introduction**

### **2.1 Parents with LD**

There are no reliable estimates of the number of parents with LD who reside in the UK (Booth and Booth, 1998). However, the Department of Health (2007) estimate numbers of between 23,000 to 250,000. Recent policy documents highlight the importance of adequately supporting parents with LD to care for their children (e.g. Valuing People Now, 2009). Underlying principles of these documents include the right of individuals with LD to have intimate relationships, become parents and to be supported to continue to be parents. Good Practice Guidance on Working with Parents with a LD (2007) provides information on how professionals can support parents with LD adequately. The importance of children and adult services working together is highlighted to ensure both parents with LD and their children are provided with a well-coordinated, consistent service.

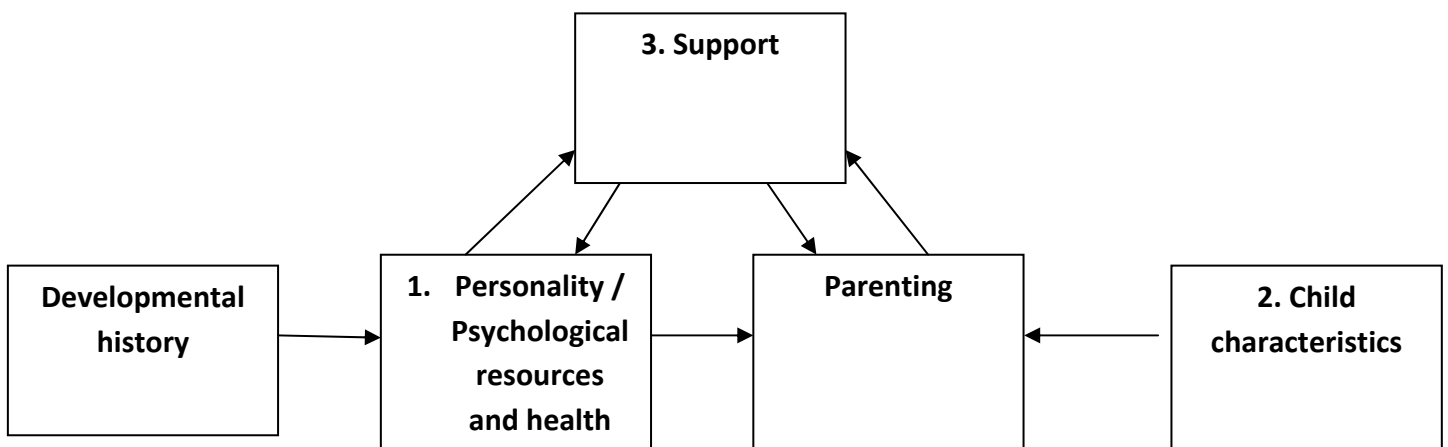
Despite these recent policies and guidelines there is an over-representation of parents with LD in child protection services in the UK. Goodinge (2000) found that less than 20% of parents with other disabilities (which included progressive and chronic illnesses, visual and hearing impairments and physical disability) were involved in child protection procedures. For parents with LD, over 60% of families with one parent with a LD received services for child protection issues. Many parents with LD are at risk of losing custody of their children at an early age, often before the age of three (Booth and Booth, 1994).

## 2.2 Determinants of adequate parenting

Legally, a parent is expected to be able to meet the physical, emotional and health needs of a child (Sheerin, 1998). The absence of a universal definition of 'good' parenting can often lead to professionals making subjective decisions about whether an individual's parenting is good enough (Young & Hawkins, 2005). Belsky's (1984) 'multiple determinants of parenting' model (Figure 1) suggests a number of factors that may impact of how 'good' a parent is.

## 2.3 The process model of the determinants of parenting

**Figure 1:** *Model of multiple determinants of parenting (Belsky, 1984)*



Belsky (1984) clusters determinants of parenting into three subsystems that are within the parent, within the child and within the broader social context in which the parent /child relationship functions. It is important to note that many of the components of Belsky's (1984) model remain subjective concepts.

The first subsystem is a parent's personality and psychological resources and health which is connected to their developmental history. Belsky (1984) suggests that a supportive developmental experience contributes to a 'healthy personality'.

This in turn influences an individual's capacity to parent effectively. The second subsystem contains the child's characteristics. This includes a child's temperament which can shape how easy or difficult a child is to care for and in turn can determine the quality of parental care received. The third contextual subsystem is support which includes marital relations, work and social support. This subsystem may have a negative or positive impact on psychological wellbeing which in turn impacts on parenting capacity. The model proposes that each subsystem acts as a buffer to enable an individual to parent appropriately during times of stress. Belsky (1984) suggests that the personality and psychological resources and health subsystem is the most predictive of adequate parenting during times of stress.

### **2.3.1 \*Parents' psychological wellbeing and social support**

Two subsystems in Belsky's (1984) model that have been well documented in the general parenting literature are a mother's psychological wellbeing and the social support available to her (for a definition of social support see p. 9).

For mothers, being provided with emotional support has been identified as being important from pregnancy onwards. Mothers reported experiencing a more positive birth when they felt the midwife had emotionally supported them (Tarkka, 1996). Although the prevalence of mental health difficulties among mothers is not well documented (Barlow et al., 2007). Stevenson et al. (1989) suggested it to be as high as 45%.

\* In practice most of this data refers to mothers with LD

It has been recognised that women with low socioeconomic status caring for a child at home are four times more at risk of developing depression than mothers with higher socioeconomic status (Brown and Harris, 1978) and single mothers appear to be more at risk of having poor psychological wellbeing and low social support than mothers with a partner (Hope et al., 1999; Cairney et al., 2003). Cairney et al. (2003) found that single mothers reported higher levels of stress, lower levels of perceived social support and infrequent contact with family and friends in comparison to mothers with a partner. It has been suggested that single mothers' financial difficulties may contribute to their risk of poor psychological wellbeing, leading to their risk of depression doubling (Brown and Moran, 1997).

### **2.3.2 Individuals' with LD psychological wellbeing and social support**

In the LD literature it has been recognised that individuals with LD are at risk of encountering high levels of health and social problems (e.g. Dagnan, 2008), leading them to be at risk of poor psychological wellbeing and social support. Although estimates are unclear, Cooper et al. (2007) suggest that the prevalence of mental health problems in individuals with LD is higher in comparison to the general population.

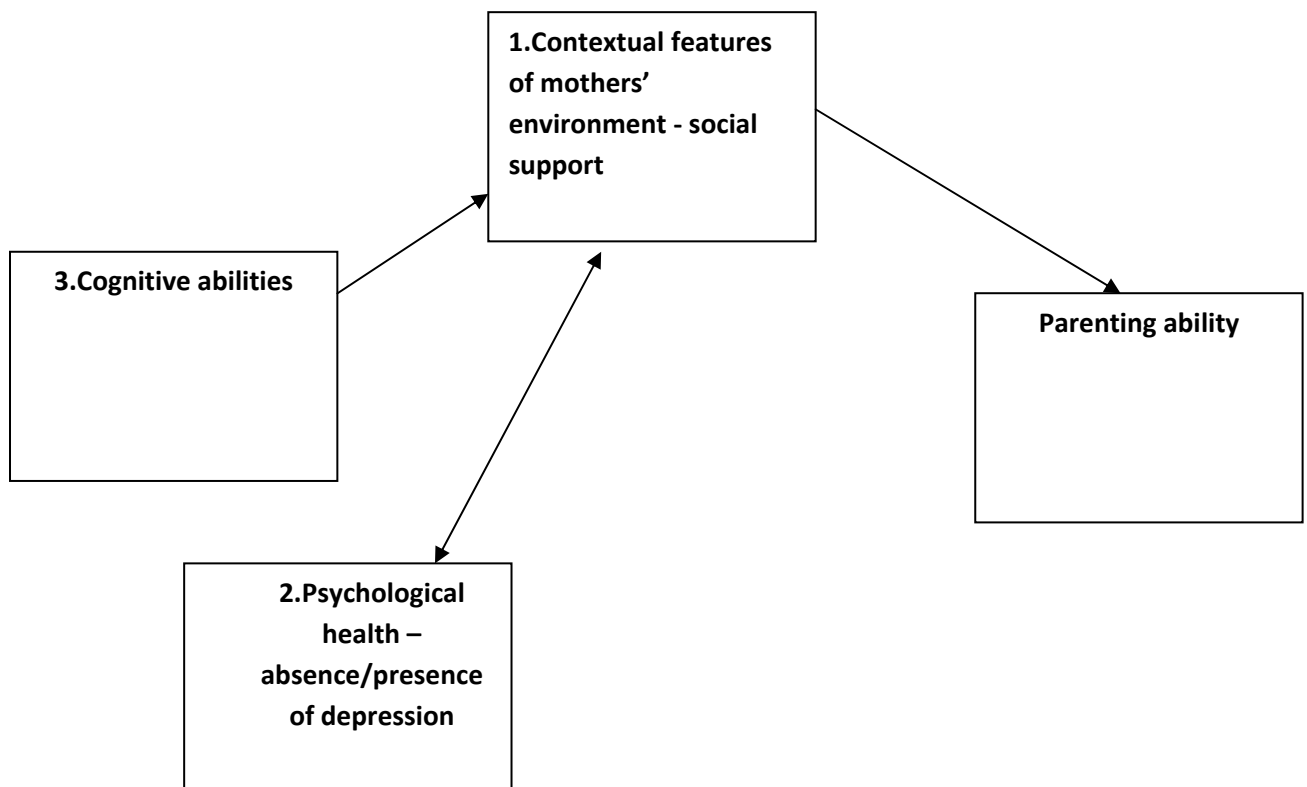
People with LD are often socially excluded (Myers et al., 1998) and express wanting to have more friends and be involved in more community activities (Froese et al., 1999; O'Rourke et al., 2004). Abbott and McConkey (2006) interviewed individuals with LD who identified various barriers that they perceived to lead to social exclusion. The barriers include lack of necessary knowledge and skills, lack of

involvement of support staff, location of house, and community factors such as attitudes towards individuals with LD.

### 2.3.3 Determinants of parenting model for parents with LD (Sterling, 1998)

Sterling (1998) adapted Belsky's (1984) model for parents with LD. Similar to Belsky (1984), she includes three subsystems but adapts the model by substituting cognitive functioning for the child characteristics subsystem (Figure 2). Sterling (1998) does not include the child characteristics subsystem as it is not viewed as a primary determinant of parenting in Belsky's (1984) model.

**Figure 2:** *Determinants of parenting model for parents with LD (Sterling, 1998).*



The first subsystem includes the characteristics of a mother's environment, specifically social support. This subsystem is viewed as the most significant

determinant of parenting. The social support subsystem is the mediator for the relationship between cognitive abilities, psychological health and parenting performance. Unlike Belsky (1984), Sterling (1998) did not view a marital relationship as the primary source of support for parents with LD. Sterling proposed that social support includes any systems capable of providing support to a parent and environmental stimulation to children including a spouse, a family member, a professional or a friend.

The second subsystem is psychological health which includes absence / presence of depression. This subsystem has the strongest direct relationship with social support and an indirect relationship with parenting ability. Sterling (1998) suggests that the relationship between depression and social support is bi-directional (see Figure 2). Thus when a mother experiences symptoms of depression this can keep her from accessing available support and in reverse a mother's lack of social support can increase symptoms of depression.

The final subsystem consists of cognitive abilities. This subsystem has less of an influence on social support and parenting ability than the psychological health subsystem. Sterling (1998) includes this subsystem based on studies that suggest that deficits in speech and language, decision-making, control and interpersonal skills are related to parenting behaviours that can place a child at risk (Bakken et al., 1993; Budd & Greenspan, 1985). Sterling (1998) found that mothers with high cognitive abilities reported having more social support than mothers with low cognitive abilities.

Sterling (1998) tested the relationships between the determinants of parenting in her model empirically and statistically. Therefore her study will be included in the current literature review and discussed in more detail in the Results section.

## **2.4 Parents' with LD psychological wellbeing and social support**

Recently there has been an increase in research exploring parents' with LD poor psychological wellbeing and social support. McGaw (2007) highlighted that it is not only parents' LD that leads to an increased risk of losing custody of their child/ren; a combination of unrecognised mental health disorders and isolation can also contribute.

### **2.4.1 Parents' with LD social support**

Llewellyn and McConnell (2002) acknowledged the difficulty in defining social support. However, a definition that seems to depict this concept is 'those who provide help and who someone can turn to for help' (Llewellyn, 1999).

Research into support provided by professionals has found that parents with LD in the UK value support from advocacy agencies (Tarleton, 2007). Advocacy agencies were viewed as 'hearing the voices' of mothers and providing emotional and practical support. There was a sense that this support was provided too late as parents were often already at risk of losing their children and involved in court and child protection procedures. This is further supported by a study of parents with LD who had lost custody of their children. One mother stated that support was '*Too little, too late. Not there when I need it*' (participant A, p. 9, Baum and Burns, 2007).



Mothers with LD find friendships formed in groups for parents with LD helpful, as they often share similar experiences (Tarleton & Ward, 2007). Booth and Booth (2002) reported that women with LD often described their partners as supportive. Interestingly, this was not as the traditional 'bread winner' but when partners added to the families' coping resources e.g. knowledge and skills, especially when these skills complimented the mother's skills. Some mothers also reported that having a partner gave them a role in the community and enabled them to access a wider social network.

Despite these findings, research in both the UK and Australia has found that mothers with LD are often single, lead socially isolated lives and struggle to identify any friendships they have formed (e.g. Llewellyn & McConnell, 2002; Baum & Burns, 2007). In addition, parents with LD are often socially disadvantaged, live in poverty, reside in poor housing and are unemployed (Feldman, 1997), adding to the risk factors associated with depression (see p. 6).

Although quantity of support is deemed important, the nature of the support must not be overlooked. Tucker and Johnson (1989) investigated competency-promoting and competency-inhibiting support. They found that mothers with LD were more effective in their parenting role when they were supported by someone who believed they could become more competent and provided more training rather than someone who belittled their efforts and did not attempt to develop their skills. Several studies have been conducted in Australia investigating the type of support received by parents with LD. Wade et al (2005) found that parents with LD valued

competency-promoting support which is family-centred rather than professional-centred.

#### **2.4.2 Parents' with LD psychological wellbeing**

Psychological wellbeing has been defined as internal, individual dimensions of mental health and is concerned with an individual's feelings and other areas of psychological functioning (Petersen and Kellam, 1977). Recently, in the UK there has been an acknowledgement that individuals in adult mental health services may require support in their parenting roles (O'Keeffe and O'Hara, 2008). However, surprisingly little is known about the mental health needs of parents with LD (Bouras, 2008).

Studies in the UK, Canada and Australia, have found high levels of mental health difficulties in parents with LD in comparison to parents in the general population (McGaw et al., 2007; Feldman et al., 2002; Llewellyn et al., 2003). High rates have also been found in pregnant women with LD. McConnell et al. (2008) found higher levels of stress, depression and anxiety in pregnant women with LD in comparison to pregnant women without LD. However, assessments used for the general population such as the Edinburgh Postnatal Depression Scale (Cox et al., 1987) do not appear appropriate for mothers with LD. Gaskin and James (2006) found that the scale overestimated or did not detect particular symptoms in mothers with LD.

As already highlighted, losing custody of children is a likely event for parents with LD. It is important to consider the impact this may have on an individual's psychological wellbeing. Baum and Burns (2007) interviewed mothers who had lost custody of their children and reported a lack of subsequent emotional support. Many

mothers were still struggling with the loss of their child seven years on, which, the authors suggest, had resulted in long-term psychological vulnerability and distress.

### **2.3 The relationship between psychological wellbeing and social support and interventions to support parents with LD**

Belsky's (1984) 'determinants of parenting' model suggest that there is a relationship between psychological wellbeing and social support within the general parent population as did Brown and Harris (1978). Sterling's (1998) adaption of Belsky's (1984) model for parents with LD also suggests that there is a relationship between social support and psychological wellbeing.

Parenting programmes are one way to offer support to individuals who might be struggling to parent effectively. However, parenting programmes provided for the general population appear to have overlooked the importance of parents' social support network (McConnell et al., 2009). Barlow et al. (2007) conducted a Cochrane review of the effects of parenting programmes on maternal psychosocial health. Social support/ relationships and maternal psychological wellbeing were measured separately as dependant variables. Parenting programmes had a medium effect on psychological wellbeing (stress, anxiety and depression). However, there was no evidence for the effectiveness of parenting programmes on social support.

Parents with LD are frequently offered parenting programmes. A recent literature review on the effectiveness of these programmes found that they do not include measures for either psychological wellbeing or social support. Wade et al., (2008) found that outcome measures for parenting programmes tended to only focus on

child, not parent variables. Despite strong evidence that parents' wellbeing and social support are predictors of parenting capacity, influencing the child's wellbeing.

### **3.0 Aims of literature review**

This review aims to systematically evaluate the empirical evidence relating to parents' with LD psychological wellbeing and social support. In order to establish the evidence of Sterling's (1998) theoretical model three questions will be explored:

1. Are there lower rates of psychological wellbeing and social support in parents with LD in comparison to the general population?
2. Is there a relationship between parents' with LD psychological wellbeing and social support?
3. What interventions are most effective in improving parents' with LD psychological wellbeing and social support?

The studies will be described and a methodological evaluation conducted in order to identify recommendations for future research and clinical practice.

### **3.1 Method**

#### **3.1.1 Definitions**

For the purpose of this review social support was defined as any type of support offered to or accessed by a parent from a professional, friend or family member. Psychological wellbeing was defined by the absence of a psychological or mental health difficulty (including depression, anxiety and stress).

### **3.1.2 Inclusion / exclusion criteria**

The current review covers quantitative studies from January 1989 to July 2009. Articles were included if they were primary research reports investigating factors that impact on adults' with LD ability to parent and they include both measures of parents' psychological wellbeing as well as their social support networks. Articles were excluded if they employed a qualitative method only.

### **3.1.3 Search strategy**

Searches were completed between February and July 2009. The databases included PsycInfo, MEDLINE, CINAHL and Web of Science. Within these searches four main areas were covered: 1. Parents, 2. Learning disabilities, 3. Psychological wellbeing and 4. Social support. Combinations of the following words were executed: *parents, mothers, fathers, learning disabilities, learning difficulties, intellectual disabilities, intellectual difficulties, mental retardation, developmental disabilities, developmental difficulties, learning disorders, mental health, depression, anxiety, wellbeing, psychological wellbeing, self concepts, stress, social support, support network, support and help giving* (see Appendix 1 for full list of search criteria used).

### **3.1.4 Search findings**

A total of 48 articles were obtained from the search of electronic databases. The abstracts of these articles were read and 42 articles were discarded because either they were replicates of articles already selected (3), were about parents with a child with a LD (30), were in a foreign language with no translation (1), or focused on either social support or psychological wellbeing but not both (8).

Accordingly, six papers met the criteria for inclusion. The reference section of each of these articles and of relevant articles that did not meet the inclusion criteria were scrutinised and a further three articles were obtained. Thus, the total number of articles included in this review is nine.

### **3.1.5 Quality criteria for evaluation**

To assist the evaluation of the articles reviewed, a quality assurance checklist was obtained and adapted from National Institute of Health and Clinical Excellence guidelines (NICE 2007; 2009). Quality assurance checklists are applied to reduce bias, ensuring each study is reviewed in a systematic manner and the process can be replicated. Each checklist was scored on a scale of 0-2; a score of '0' indicated no evidence, '1' indicated unclear evidence and '2' indicated definite evidence. An overall rating of each study was then calculated to establish the quality of each article. The cohort checklist was used for two of the studies. There was no checklist available for cross-sectional studies so one was developed using criteria from the other quality assurance checklists (Appendix 2).

## **4.0 Results**

A description of the nine studies will be provided, followed by the systematic assessment of the methodology quality of the articles. The three review aims (see p.13) will then be addressed with reference to the relevant articles. Most articles address more than one review aim, therefore they may be discussed more than once. Tables 1 to 3 each contain the articles relevant to each of the three review aims.

#### **4.1 Description of the studies**

Of the nine studies three were completed in Canada, three in USA, two in UK and one in Australia. Seven of the studies reported using a cross-sectional design and two used a cohort design. All of the studies recruited participants who were involved in services who support individuals with LD. One study recruited both fathers and mothers and the remaining eight only recruited mothers with LD. All of the studies administered questionnaires and conducted face-to-face interviews.

A variety of questionnaires were used to measure psychological wellbeing and social support. For psychological wellbeing some studies administered more than one measure and all were standardised. Two studies administered measures for depression, three for self-concept/esteem, three for general physical and mental health, one for depression and anxiety and one for stress. Only four of the nine studies administered standardised social support measures. Three of the studies used their own un-standardised questionnaires. Two measured various variables which included five topics related to social support and one recorded the amount of social support alongside its helpfulness and recency. Two used non-standardised questionnaires that had been used before in studies with parents with LD.

#### **4.2 Methodology quality**

The level of evidence provided by each study was classified using the NICE guidelines (2007; 2009). One of three classifications were applied. One cohort study received (-) indicating few or no criteria had been fulfilled, one cohort and five cross-sectional studies received (+) indicating some criteria had been fulfilled and two cross-sectional studies received (++) indicating most criteria had been fulfilled.

It was found to be difficult to recruit an adequate number of parents with LD in the community to participate in research (Aunos et al., 2000) which is reflected in the sample sizes of the nine studies under review. Robson (2002) suggests that studies which include cross sectional and cohort designs, should recruit 15 participants per variable measured in the study. Eight of the studies did not comply with Robson's suggestion and had sample size between 15 and 47 (  $n = 30$ ).

#### **4.3 Do parents with LD have poorer psychological wellbeing and social support compared to the general population?**

Six of the studies provided data to explore this question. Five studies made comparisons between reported psychological wellbeing of parents with LD and that of the general population (studies 2, 3, 4, 8, 9 in Table 1). Four of these studies were cross-sectional designs three with quality ratings of (+) and one with quality ratings of (++) and one was a cohort design with a quality rating of (-). The final study compared mothers with LD who had custody with those who did not have custody of their children (study 1 in Table 1). Aunos et al., (2003) used a cross-sectional design to investigate reports of psychological wellbeing and social support between the two groups. This study received a quality rating of (+).



**Table 1.** Summary of articles comparing parents with learning disabilities to the general population

Author, year and origin	Sample size	Parents IQ	Study aims	Study type and quality rating	Psychological wellbeing and social support measures	Other outcome measures	Results relevant to review
Aunos et al. (2003) Canada	47 mothers with LD  30 = custody 17 = lost custody	No measure  All receiving support from LD services	To identify how parents with LD who have custody of their children differ from those who do not	Cross-sectional  <b>+ some criteria fulfilled</b>	<ul style="list-style-type: none"> <li>➤ Community Involvement scale (Gibbins, 2000)</li> <li>➤ Supports and services questionnaire (Llewellyn and McConnell, 1998)</li> <li>➤ SF-36 (Ware et al., 2000)</li> </ul>	<ul style="list-style-type: none"> <li>➤ Family information questionnaire (Feldman et al., 1993)</li> <li>➤ Scales of independent behaviour revised (Bruininks et al., 1996)</li> <li>➤ Child behaviour checklist (Achenbach, 1988)</li> </ul>	Mothers who had custody of their children had more community involvement and greater satisfaction with services received than mothers without custody of their children
Aunos et al. (2008) Canada	32 mothers with LD  1412 Normative sample	No measure  All receiving support from LD services	<p>To identify whether there is a relationship between social support, parenting style, quality of home environment and if it is mediated by psychological wellbeing.</p> <p>To identify if there is a relationship between psychological wellbeing and child problem behaviour and if it is mediated by parenting style</p>	Cross-sectional  <b>+ some criteria fulfilled</b>	<ul style="list-style-type: none"> <li>➤ Support and services questionnaire (Llewellyn and McConnell, 1998)</li> <li>➤ SF-36 (Measure of physical and mental health; Ware et al., 2000)</li> <li>➤ Parenting stress index (Abidin, 1990)</li> </ul>	<ul style="list-style-type: none"> <li>➤ Family information questionnaire (Feldman et al., 1993)</li> <li>➤ Canadian national longitudinal study on children and youth parenting questionnaire (Wilms, 2002)</li> <li>➤ Caldwell HOME inventory (Caldwell and Bradley, 1984)</li> <li>➤ Child behaviour checklist (Achenbach, 1988)</li> </ul>	Mothers reported poor physical and mental health compared to general population

Parents' with LD psychological wellbeing and social support

Feldman (2002) Canada	33 mothers with LD  600 normative sample	No measure  Involved in LD social services	To identify the relationship between social support stress and mother-child interactions	Cross-sectional  <b>++ most criteria fulfilled</b>	<ul style="list-style-type: none"> <li>➤ Parenting stress index (PSI) (Abidin, 1990)</li> <li>➤ Telleen parenting social support index (TPSSI) (Telleen, 1985)</li> <li>➤ Interpersonal support evaluation list (ISEL) (Cohen and Hoberman, 1983)</li> </ul>	➤ Parent-child interactions checklist (PCIC) (Feldman et al., 1986)	Mothers reported significantly higher stress levels than general population
McConnell et al. (2009) Australia	32 parents with LD  Normative sample not reported	No measure  Diagnoses of LD, receiving services from LD services	To determine whether participation in an Australian Supported Learning Program (ASLP) improves psychological wellbeing and strengthens social relationships	Cohort  <b>- Few criteria fulfilled</b>	<ul style="list-style-type: none"> <li>➤ Tilden interpersonal relationships inventory (IPRI) (Tilden et al., 1990)</li> <li>➤ Depression, anxiety, stress (DASS-22) (Lovibond and Lovibond, 1995)</li> <li>➤ Scales of mastery and constraint (Lachman and Weaver, 1998)</li> </ul>	<ul style="list-style-type: none"> <li>➤ Personal goal attainment scale (McConnell et al., 2009)</li> <li>➤ ASLP program goal achievement scale (McConnell et al., 2009)</li> </ul>	Mothers reported significantly lower levels of psychological wellbeing in comparison to general population
8Tymchuk (1991) USA	27 mothers with LD  95 mothers	Special education  Diagnosed with LD	To investigate whether self concepts differ between mothers with and without LD and whether personal, family, child and other factors are associated with	Cross-sectional  <b>+ some criteria fulfilled</b>	<ul style="list-style-type: none"> <li>➤ Tennessee self concept scale (Fitts, 1965)</li> <li>➤ Questionnaire with 12 factors</li> </ul>	N/A	Mothers with LD have significantly less positive self concepts than mothers without LD

Parents' with LD psychological wellbeing and social support

	without LD		high or low self concepts				
Tymchuk (1994)	33 mothers with LD	Special education	To investigate whether mothers with LD have more depressive symptoms compared to mothers without LD and the relationship between symptoms of depression and personality, child, familiar and other characteristics.	Cross-sectional	➤ Beck Depression Inventory (Beck et al., 1961)	N/A	Mothers with LD reported significantly more depressive symptoms than mothers without LD
USA	97 mothers without LD	Diagnosed with LD		<b>+ some criteria fulfilled</b>	➤ Questionnaire		

All of the studies comparing parents with LD with the general population found parents with LD reported poorer psychological wellbeing in comparison to the general population. Aunos et al., (2003) found no difference between mothers who did and did not have custody of their children with relation to their reports of psychological wellbeing. However, mothers who had custody of their children reported more community involvement and greater satisfaction with the services they received in comparison to those mothers who did not have custody of their children.

In most incidents the studies recruited less than 15 participants per variable (Robson, 2002). Aunos et al. (2002) recruited the highest number of participants (N=47). However, this number decreased as they were further divided into two groups (N=30 and N=17). When selecting participants for their research all of the authors recruited through agencies supporting individuals with LD. This may lead to a bias towards individuals with higher support needs and not represent the general population of parents with LD. Only McConnell et al. (2009) included fathers, results obtained from the other five articles are only relevant to mothers.

The definition of psychological wellbeing varied across the studies and so did the measures administered. All of the measures were reliable and valid but not all of them were appropriate to use with individuals with LD. However, all of the studies did ensure that the measures were administered face-to-face with the individuals with LD to ensure the questions were understood. Tymchuk (1991) used the Tennessee Self Concept Scale (Fitts, 1965) and Tymchuk (1994) used the Beck Depression Inventory (BDI; Beck et al., 1961). Although the author reported that they were both 'easy-to-read', they had not been standardised to use with individuals with LD. The

SF-36 (Wade et al., 2000) was administered in both studies by Aunos et al. (2003; 2008). Llewellyn et al. (2002) adapted the SF-36 for individuals with LD and found that the sample was normally distributed. Feldman et al., (2002) administered the Parenting Stress Index (PSI; Abidin, 1990) which was adapted for use with individuals with LD. However, the PSI has not been standardised to use for this population. McConnell et al., (2009) administered the DASS-22 (Louibond & Louibond, 1995) to measure depression, anxiety and stress. This is a reliable measure which has been used by the authors in previous research with mothers with LD. However, no reference was provided.

Potential confounding variables were investigated in some of the studies which included IQ, income and number of children. Tymchuk's (1991; 1994) were the only two studies that reported participants' IQ score from a standardised intelligence test. Tymchuk (1991; 1994) provided the mean IQ score for mothers with LD but did not identify whether there were any IQ scores that were particularly low or high in comparison to the rest of the group. The other four studies did not record the IQ of the parents.

Two of the six studies made comparisons between the demographic characteristics of parents with LD and a normative sample. Tymchuk (1991) recorded self-concept scores of mothers with LD and mothers without LD whose children attended a playgroup. He provided demographic characteristics of both groups but did not make any reference to the differences found between the two groups.

Two of the remaining studies compared parents with LD to normative data provided by the questionnaires they administered and McConnell et al. (2009) used a normative sample obtained from parent and family support programmes (Layzer et al., 2001; Barlow et al., 2007).

Aunos et al., (2003) was the only study to focus on social support. The support and services questionnaire (Llewellyn & McConnell, 1998) had been used before with individuals with LD. However, it is not possible to identify the quality of this questionnaire as the relevant data remains unpublished. The questionnaire also relied on mothers recalling support received in the past and their satisfaction with it which may have resulted in the information collected being inaccurate. Aunos et al. (2003) administered the Community Involvement Scale (Gibbins, 2000) but no official norms are available. It is important to note that Aunos et al. (2003) did not identify whether mothers who did not have custody of their children were rating their satisfaction with services before or after they lost custody of their children. Making it impossible to identify how satisfaction with support relates to a mother's parenting ability.

The findings can be summarised as follows: Five of the studies reported parents' with LD psychological wellbeing to be poorer in comparison to the general population and one reported mothers with LD with custody of their children reporting more community involvement and better satisfaction with services received in comparison to mothers without custody. However, no information about causality was provided.

McConnell et al. (2009) was the only study to score (-) mainly due to the authors not providing a suitable control group. Although four of the studies scored (+) they differed in quality on particular aspects. Both Tymchuk (1991; 1994) studies recorded IQ scores and made comparisons between mothers with LD and mothers without LD. However, the questionnaires used to measure psychological wellbeing were of poorer quality in comparison to those used by Aunos et al. (2003; 2008). Feldman et al. (2002) also administered a valid and reliable psychological wellbeing measure and scored the highest quality rating. However, all of the studies did not recruit enough participants for the number of variables they measured and it is questionable if the samples were representative of parents with LD.

In relation to Sterling's (1998) model for determinants of parenting for parents with LD, the current evidence highlights the heightened risk parents with LD have of developing psychological difficulties in comparison to the general parent population which may in turn impact on their ability to parent.

#### **4.4 Is there a relationship between parents' with learning disabilities reports of psychological wellbeing and social support?**

Six of the studies investigated whether there is a relationship between parents' with LD psychological wellbeing and social support (studies 2, 3, 6, 7, 8, 9 in Table 2). They were all cross-sectional design and had quality ratings (+) and (++).

**Table 2.** Summary of articles investigating whether there is a relationship between parents' with learning disabilities reports of psychological wellbeing and social support.

Author, year and origin	Sample size	Parents IQ	Study aims	Study type and quality rating	Psychological wellbeing and social support measures	Other outcome measures	Results relevant to review
Aunos et al. (2008) Canada	32 mothers with LD	No measure  All receiving support from LD services	To identify whether there is a relationship between social support, parenting style, quality of home environment and if it is mediated by psychological wellbeing.  To identify if there is a relationship between psychological wellbeing and child problem behaviour and if it is mediated by parenting style	Cross-sectional  <b>+ some criteria fulfilled</b>	<ul style="list-style-type: none"> <li>➤ Support and services questionnaire (Llewellyn and McConnell, 1998)</li> <li>➤ SF-36 (Physical and mental health measure; Ware et al., 2000)</li> <li>➤ Parenting stress index (Abidin, 1990)</li> </ul>	<ul style="list-style-type: none"> <li>➤ Family information questionnaire (Feldman et al., 1993)</li> <li>➤ Canadian national longitudinal study on children and youth parenting questionnaire (Wilms, 2002)</li> <li>➤ Caldwell HOME inventory (Caldwell and Bradley, 1984)</li> <li>➤ Child behaviour checklist (Achenbach, 1988)</li> </ul>	<p>No relationship between social support, parenting and quality of home environment</p> <p>Relationship between parents' psychological wellbeing and child problem behaviours</p>
Feldman	33 mothers with LD	No measure  Involved	To identify the relationship between social support stress and mother-child interactions	Cross-sectional	<ul style="list-style-type: none"> <li>➤ Parenting stress index (PSI) (Abidin, 1990)</li> <li>➤ Telleen parenting</li> </ul>	<ul style="list-style-type: none"> <li>➤ Parent-child interactions checklist (PCIC) (Feldman et al.,</li> </ul>	<p>Social support (excluding support size) negatively correlated with stress</p>



Parents' with LD psychological wellbeing and social support

(2002) Canada		in LD social services		<b>++ Most criteria fulfilled</b>	social support index (TPSSI) (Telleen, 1985) ➤ Interpersonal support evaluation list (ISEL) (Cohen and Hoberman, 1983)	1986	Support need positively correlated with stress  Social support satisfaction positively correlated with positive maternal interactions
6. Stenfert Kroese et al.  (2002) UK	15 mothers with LD	Not provided	To investigate the relationship between social support, psychological wellbeing and parental attitudes	Cross-sectional  <b>+ Some criteria fulfilled</b>	➤ Affect balance scale (Bradburn, 1969) ➤ Self esteem questionnaire (Rosenberg, 1965) ➤ Interview: - No. of statutory services, friends and family come in contact with - Recency, helpfulness, burdens, benefits and expectations (Stenfert Kroese et al., 2002)	➤ Assertiveness questionnaire (Gambrill and Richey, 1975)	Significant relationship between: 1. Self esteem and burden scores (negative) 2. Affect balance and number of contacts (positive) 3. Self esteem scores and how recent support occurred (positive)
7. Sterling  (1998)	74 mothers with LD	Identified by service as having LD	To determine the relationship between multiple determinants of parenting and parenting performance to build an explanatory model of parenting adequacy in	Cross-sectional  <b>++ Most criteria fulfilled</b>	➤ Center for epidemiological studies depression scale (CES-D) (Radloff, 1977) ➤ Interpersonal	➤ HOME inventory (Caldwell and Bradley, 1984) ➤ Staford-Binet intelligence scale (Thorndike et al., 1986)	Age and marital status related to social support (positive) Depression related to living arrangements (negative)  Significant negative

Parents' with LD psychological wellbeing and social support

USA			mothers with learning disabilities		support evaluation list (Cohen et al., 1985)	➤ Rotter internal external locus of control (Rotter, 1966)	relationship between depression and parenting ability Significant positive relationship between social support and parenting Depression negatively related to social support  Cognition and parenting, and depression and parenting are mediated through social support
8. Tymchuk (1991) USA	27 mothers with LD	Special educatio n Diagnos ed with LD	To investigate whether self concepts differ between mothers with and without LD and whether personal, family, child and other factors are associated with high or low self concepts	Cross-sectional  <b>+ some criteria fulfilled</b>	➤ Tennessee self concept scale (Fitts, 1965) ➤ Questionnaire with 12 factors	N/A	Significant positive relationship between negative self concepts and age at birth of first child, education, work history, child abuse, child neglect, and grandparents approval of marriage/relationship.
9. Tymchuk (1994) USA	33 Mothers with LD	Special educatio n Diagnos ed with LD	To investigate whether mothers with LD have more depressive symptoms compared to mothers without LD and the relationship between symptoms of depression and personality, child, familiar and other characteristics.	Cross-sectional  <b>+ some criteria fulfilled</b>	➤ Beck Depression Inventory (Beck et al., 1961) ➤ Questionnaire	N/A	Significant positive relationship between depression scores and maternal reports of abuse  Mother's history of abuse and neglect predicted depression scores

All of the studies recruited mothers with LD, therefore fathers are not represented. Tymchuk (1994) and Aunos et al. (2008) found no relationship between parents' with LD psychological wellbeing and social support. Sterling (1998) found depression to be negatively related to social support and Feldman et al. (2002) found a negative relationship between social support and stress. Stenfert Kroese et al. (2002) found significant correlations between self esteem and perceived burden of parenting, affect balance scores (a measure of depression) and number of contacts supports, and self esteem and how recent support was received. Tymchuk (1991) found a significant positive relationship between negative self concepts and grandparental approval of marriage / relationship.

As already discussed, the present articles also differ in the definitions of psychological wellbeing. Two that were not included in the previous section were Sterling (1998) and Stenfert Kroese et al. (2002). Sterling (1998) measured depression and Stenfert Kroese et al. (2002) measured affect and self-esteem. Although both had been adapted to use with individuals with LD neither had been standardised to use for this population.

The social support measures administered also vary across the studies. Tymchuk (1991; 1994) used similar questionnaires in both articles. In 1991 a 10 item questionnaire was applied which included personal, child, family and other items. Five items appeared to measure social support: marital status, living arrangements, involvement with public agencies, current provision of grandparental support and grandparental approval of relationship/ marriage. The latter is a tentative measure of social support assuming that if grandparents approved of the parents' relationship

they are more likely to be supportive. The same social support factors were included in Tymchuk's (1994) study. Although the author noted that the factors listed above were important, no evidence was provided to determine how this was decided. Aunos et al. (2008) administered the Social Support and Services Questionnaire (Llewellyn and McConnell, 1998) which had been used with mothers with LD in previous research. However, the data were unpublished and the questionnaire relies on mothers' accurate recall of their satisfaction with services they had received in the past and present. Both Sterling (1998) and Feldman et al. (2002) administered standardised questionnaires. The ISEL (Cohen et al., 1985) and TPSS (Tellegen et al., 1985) have internal reliability and validity. However, neither had been normed for individuals with LD. Feldman et al. (2002) administered both of these social support questionnaires to ensure concurrent validity. Of the two questionnaires the TPSS measured support received in relation to a participants' role as a parent rather than general support. Stenfert Kroese et al., (2002) used a semi-structured interview to identify mothers' with LD social support. Information from the interview was then categorised using content analysis to provide quantitative data. The information was reliant on mothers' recall of the support they had or were currently receiving. The mothers then had to rate each support on how recently it had occurred and its helpfulness.

As discussed in the previous section there are various potential confounding variables when conducting research in this area. Sterling (1998) found that living arrangements impacted on psychological wellbeing, with those mothers living alone reporting higher depression levels than those living with a spouse. She also found lower rates of social support among single and older mothers.

The majority of the studies used a correlational design to investigate the relationship between parents' with LD psychological wellbeing and social support. The drawback to this design is that it does not identify causality. Sterling (1998) applied a structural equation analysis to investigate the associations between the various determinants to parenting in mothers with LD. She found that social support explained 33% of variance for parenting ability and cognitive abilities and psychological health accounted for 39% of the total variance in social support. Sterling (1998) suggested that psychological health is indirectly related to parenting through social support with a strong association between depression and social support (path coefficient = -0.59). The relationship between psychological health and social support was bi-directional. This indicates that mothers experiencing depression receive less social support and, in turn, lack of social support facilitates depression. However, it must be noted that although Sterling (1998) recruited the largest number of participants the sample was not large enough to cross validate her statistical findings.

In summary, four studies did and two studies did not find a relationship between parents' with LD psychological wellbeing and social support. None of the studies used a representative sample or administered questionnaires that were standardised for use with individuals with LD. Although in Tymchuk's (1991) study grandparental approval of relationship/marriage was positively correlated with positive self concept it must be noted that this is a tentative measure of social support. Sterling's (1998) findings provide support for her model of determinants of parenting for parents with LD and the study is of the highest quality however her sample size is not large enough for the statistical analysis administered. Feldman et

al. (2002) and Stenfert Kroese et al. (2002) also found a relationship between psychological wellbeing and social support but do not provide any evidence for the direction of this relationship.

#### **4.5 What interventions are most effective at improving parents' with LD psychological wellbeing and social support?**

Two of the studies explored what can be done to improve parents' with LD psychological wellbeing and social support (studies 4, 5 in Table 3). Both studies were cohort designs with a quality rating of (+) and (-).

**Table 3.** Summary of articles investigating what interventions are most effective in improving parents' with learning disabilities psychological wellbeing and social support

Author, year and origin	Sample size	Parents IQ	Study aims	Study type and quality rating	Psychological wellbeing and social support measures	Other outcome measures	Results relevant to review
McConnell et al. (2009) Australia	32 mothers	No measure  Diagnosis of LD, receiving services from LD services	To determine whether participation in an Australian Supported Learning Program (ASLP) improves psychological wellbeing and strengthens social relationships	Cohort study  <b>-Few criteria fulfilled</b>	<ul style="list-style-type: none"> <li>➤ Tilden interpersonal relationships inventory (IPRI) (Tilden et al., 1990)</li> <li>➤ Depression, anxiety, stress (DASS-22) (Lovibond and Lovibond, 1995)</li> </ul>	<ul style="list-style-type: none"> <li>➤ Personal goal attainment scale (McConnell et al., 2009)</li> <li>➤ ASLP program goal achievement scale (McConnell et al., 2009)</li> <li>➤ Scales of mastery and constraint (Lachman and Weaver, 1998)</li> </ul>	<p>A large experimental effect for pre and post measures of depression, anxiety and stress</p> <p>A medium experimental effect for pre and post measures of social support</p>
McGaw et al. (2002) UK	22 parents  12 = EPG  10 = CPG	No measure  Receiving services from LD services	To determine what effect participation in a group for parents with learning disabilities has on their relationships with their children, significant others, self-concept and social networks	Cohort Between subjects EPG = experimental CPG = control  <b>+ some criteria fulfilled</b>	<ul style="list-style-type: none"> <li>➤ Judson self-rating scale (Judson and Burden, 1980)</li> <li>➤ Social changes questionnaire (Ball, 1995)</li> </ul>	<ul style="list-style-type: none"> <li>➤ Behaviour problem index (Cunningham et al., 1986)</li> <li>➤ Malaise inventory (Rutter et al., 1970)</li> </ul>	<p>Self concept increased for EPG</p> <p>64% positive changes in parental support for EPG in comparison to 0% in CPG</p> <p>Single parents had low self concepts, and negative view of child capabilities, feelings and interactions in comparison to those in relationship</p>

McGaw et al. (2002) and McConnell et al. (2009) both investigated whether participation in a group intervention can increase parents' with LD reports of psychological wellbeing and social support. McGaw et al.'s (2002) intervention sought to improve parents' with LD social awareness and their ability to maintain personal relationships. McConnell et al.'s (2009) intervention, the 'Australian Supported Learning Program (ASLP), consisted of a twelve week programme, two hours per week including homework tasks. The aims of the intervention were to increase confidence and awareness through social integration, reflecting on past and present experiences and setting and achieving parent-centred goals. Both studies found that parents with LD reported an improvement in psychological wellbeing and social support when they attended the group. However, the quality of both studies differed on a number of dimensions.

McConnell et al. (2009) scored low in quality due to the absence of a control group. In comparison, McGaw et al. (2002) provided a control group. Although the selection and treatment of the control and experimental group presented various biases in this study. Parents were not randomly allocated to the experimental (EPG) and control (CPG) parent group. Instead they were given a choice of which group they would like to be assigned to on a 'first-come-first-serve-basis' (McGaw et al., 2002, pp.356). It is possible that parents in the EPG may be more motivated and committed to the group intervention, thus potentially biasing the results. It is unclear whether the two groups were comparable on all characteristics at baseline as no analysis was performed. The number of children a parent had on the child protection register and previous children removed appeared to differ between groups and could have confounded the results. Both the EPG and CPG received a home-based



treatment programme. However, the content of the home treatment for each group is not highlighted. These details would provide more clarity on how the interventions differed. Participants and the researchers were not blind to the treatment allocation. Both groups were followed up 14 weeks after the group ended. It is questionable whether this is long enough to ensure that improvements in parents' psychological wellbeing and new social support networks were monitored in the long-term.

McConnell et al. (2009) used psychological wellbeing and social support questionnaires that had been applied to mothers with LD in previous research, however no references were provided. The IPRI (Tilden et al., 1996) and DASS-22 (Lovibond and Lovibond, 1995) both have high internal consistency and test-retest reliability. McGaw et al. (2002) questionnaires had not been used before with parents with LD. The Judson Self-rating scale (Judson and Burden, 1980) has high internal consistency, however the reliability of the Social Changes questionnaire (Ball, 1995) is not known. The scale is reliant on mothers' reports of changes that had occurred in their social lives over the past 27 weeks, a challenging test for individuals with LD.

In summary, the McGaw et al. (2002) and McConnell et al. (2009) studies suggest that increasing parents' social networks and improving their skills to maintain relationships can improve parents' psychological wellbeing. However, to be more confident in these findings, various methodological improvements need to be applied. Using a comparison group is vital when investigating the effectiveness of interventions, differences between the groups need to be controlled and an adequate follow-up is required. In relation to Sterling's (1998) model both studies suggest that social support and psychological wellbeing are related.

## **5.0 Discussion**

### **5.1. The evidence so far**

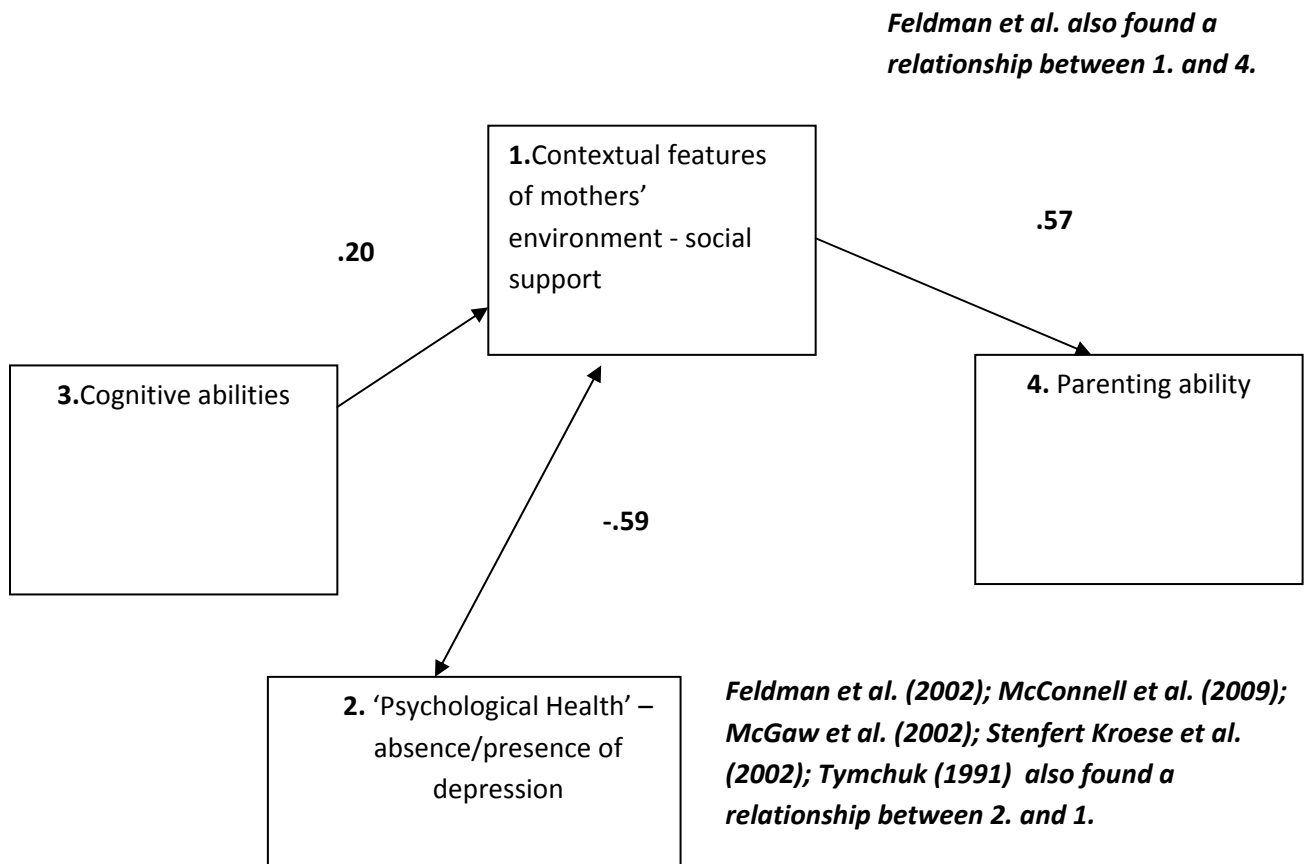
Two of the nine articles fulfilled most of the criteria, six fulfilled some of the criteria and one article was of poorer quality fulfilling very few criteria for cross sectional or cohort designs. These nine articles have addressed three review aims and although flawed in some respects, nevertheless contribute to our knowledge about parents' with LD psychological wellbeing and social support:

1. The evidence suggests that parents with LD experience poorer psychological wellbeing than the general parenting population.
2. A relationship was found between psychological wellbeing and social support although the direction of this relationship is unclear in most studies due to correlational designs being used to analyse the results. Sterling (1998) used more sophisticated statistical analyses which indicate a bi-directional relationship between parents' with LD psychological wellbeing and social support. However, cross validation of the findings were not possible due to the limited sample size.
3. The two intervention studies found that by improving social support parents' with LD psychological wellbeing was improved.

### **5.2 Support for the Determinants of parenting model**

Sterling's (1998) model (see Figure 3) has been discussed throughout the current review in relation to the three review aims and will now be described in the context of the evidence.

**Figure 3:** The path coefficients and the relationships between the factors in the determinants of parenting model for parents with LD (Sterling, 1998) with other studies providing supporting evidence included.



Overall, Sterling (1998) found that her model fitted the data well ( $\chi^2 = .926, df = 3$ ). There was a strong association between psychological health and social support (-.59) and social support had a strong association with parenting ability (.57).

- A positive correlation between cognitive abilities and social support was supported by Sterling (1998) however the association between cognitive abilities and social support was weak (.20).
- The relationship between psychological health and social support was supported by most of the studies reviewed (see Figure 3). Sterling (1998) identified a bi-directional relationship the other four studies did not identify the causality.
- The relationship between social support and parenting ability was supported by Feldman et al. (2002) and Sterling (1998) that both scored (++). Feldman et al. (2002) found a positive relationship between satisfaction with social support and positive maternal reactions but the causality of this relationship was not identified. Sterling (1998) found social support to positively influence parenting ability.

Of the studies that support Sterling's (1998) model, Aunos et al. (2003; 2008) administered the most appropriate psychological wellbeing measure. Feldman et al. (2002) and Sterling (1998) studies were of the highest quality and the former used the most appropriate social support measure.

### **5.3 Recommendations for future research**

None of the nine studies fulfilled all of the criteria from the NICE (2007; 2009) quality assurance checklists for cohort and cross sectional designs. Therefore, a number of recommendations for future research will now be discussed.

#### **5.3.1 Measuring psychological wellbeing and social support**

In the studies reviewed a range of different questionnaires were administered to measure psychological wellbeing and social support. These questionnaires differed in their quality and suitability for use with individuals with LD. Identifying an appropriate measure is essential in ensuring reliability and validity.

Psychological wellbeing incorporates a number of components including an individual's mental health. A number of studies described included reliable and valid questionnaires but they did not measure all of the components of psychological wellbeing and/or were not standardised for individuals with LD. Aunos et al.'s (2003; 2008) studies both administered the SF-36 (Wade, 2000) which measures psychological wellbeing on eight subscales. In the current review it is the only questionnaire that provided a reference for the adaptations applied to use with individuals with LD (Llewellyn et al., 2002).

Further studies need to be conducted to test Sterling's (1998) model. Psychological health was only measured as absence or presence of depression. Future research could administer a general psychological wellbeing measure adapted for people with LD (e.g. SF-36) to ensure the psychological health determinant is measured in a valid and reliable manner.

Social support can be measured on a number of different levels, for instance an individual's satisfaction with support, the amount and how recently support was received. None of the studies administered questionnaires that were standardised to use with individuals with LD. However, Feldman et al. (2002), Sterling (1998) and McConnell et al. (2009) administered social support questionnaires standardised for use with the general population. Of the three, the TPSSI used by Feldman (2002) is

the only support measure specifically related to the role of parent. It measures resource size, satisfaction with and need for each support. The TPSSI would be an appropriate questionnaire to use if adapted for and standardised to use with parents with LD.

### **5.3.2 Generalisability**

Sterling (1998) has the largest sample size, the remaining eight studies recruited smaller numbers of participants. Future research needs to recruit a higher number of parents with LD and access more fathers in order to comply with statistical requirements and to be relevant to all parents. McConnell et al. (2009) is the only study to recruit both mothers and fathers. All nine studies used parents with LD who were involved in services offering support to individuals. These parents are more likely to have more complex needs than parents with LD not receiving services. Although identifying parents with LD who are not involved in services is a more challenging task, such recruitment is needed if findings are to be relevant to all parents with LD.

### **5.3.3 Confounding variables**

Due to the difficulties in recruiting parents with LD to participate in research (Feldman et al., 2002), many researchers included all participants they were able to recruit without controlling for variables that could influence the results. Parental factors that could potentially influence the results include marital status, age of child and parent, language, and socioeconomic status. However, only Sterling (1998) investigated confounding variables and controlled for the age and marital status of

the mothers in her study. Future research in this area needs to consider the influence of age and marital status of parents with LD may have.

McConnell et al. (2009) and McGaw et al. (2002) both investigated the effectiveness of group interventions to improve psychological wellbeing and social support. However, future research needs to randomly allocate or match participants in the control and intervention groups to control for confounding variables.

#### **5.4 Recommendations for clinicians**

Clinicians working in LD services need to be aware of the risks parents with LD face as most individuals with LD can become parents in the future. A number of recommendations based on the evidence reviewed above are outlined below:

- Care packages for and assessments with individuals and parents with LD need to include measures of psychological wellbeing and social support. Clinicians need to be mindful that they use a questionnaire that is reliable, valid and suitable to use with individuals with LD.
- Interventions to teach and improve social skills should be offered to individuals with LD regardless of their parenting status. Such an intervention could support individuals with LD to access social support networks and in turn have a positive impact on their psychological wellbeing.
- Pre-natal and parenting programmes for parents with LD should specifically include topics on psychological wellbeing and social support. Pre and post measures would identify whether these topics have enabled parents to transfer the skills to their own lives.

## 5.5 Conclusions

Individuals with LD are more likely to be socially isolated and at risk of poor psychological wellbeing. The added pressure of becoming a parent may magnify these risks, impacting on both parent and child. The current review sought to address three aims and identify how the evidence supports Sterling's (1998) model. Parents with LD have been found to be at more risk of poor psychological wellbeing than the general population. A bi-directional relationship between parents' with LD psychological wellbeing and social support has been found, suggesting that parents who are depressed may not access available social support and in reverse parents who are socially isolated may become depressed. Intervention studies have further supported that social support is a predictor of psychological health.

On the basis of these findings various recommendations have been suggested. These include future research taking into account confounding variables, providing an adequate sample size, and administering consistent measures of psychological wellbeing and social support. A number of recommendations have also been suggested for clinicians working with individuals with LD. Clinicians should be mindful that adults and in particular parents with LD are more at risk of poor psychological wellbeing than the general population and of the relationship between psychological wellbeing and social support. Interventions and support aimed at strengthening and expanding social networks need to be offered to both parents and all young adults with LD, as the latter may become parents in the future.



## 6.0 References

- Abbott, S. & McConkey, R. (2006). The barriers to social inclusion perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities*, 10, 275-287.
- Abidin, R.R. (1990). *Parenting Stress Index – Manual*. Pediatric Psychology Press, Charlottesville.
- Achenbach, T.M. (1988). *Child Behaviour Checklist*. University of Vermont, VT.
- Aunos, M., Goupil, G., & Feldman, M.A. (2003). Mothers with intellectual disabilities who do and do not have custody of their children. *Journal of Developmental Disabilities*, 10, 65-79.
- Aunos, M., Feldman, M.A., & Goupil, G. (2008). Mothering with intellectual disabilities: Relationship between social support, health and well-being, parenting and child behaviours outcomes. *Journal of Applied Research in Intellectual Disabilities*, 21, 320-330.
- Ball, K. (1995). *The Social Changes Questionnaire*. Special Parenting Service, Cornwall Partnership Trust, Cornwall.
- Bakken, J., Miltenberger, R.G., & Schauss, S. (1993). Teaching parents with

mental retardation: Knowledge versus skills. *American Journal of Mental Deficiency*, 405-417.

Barlow, J., Coran, E., & Stewart-Brown, S.S.E. (2007). Parent-training programmes for improving maternal psychosocial health. *Cochrane Database of Systematic Reviews*, 4, 1-105.

Baum, S. & Burns, J. (2007). Mothers with learning disabilities: Experiences and meanings of losing custody of their children. *Learning Disability Review*, 12, 3-14.

Beck, A., Ward, C., Mendelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry*, 4, 53-63.

Belsky, J. (1984). The determinants of parenting: a process model. *Child Development*, 55, 83-96.

Bouras, N. (2008). Mental health of people with intellectual difficulties. *Current Opinion in Psychiatry*, 21, 439-440.

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

Booth, T. & Booth, W. (2002). Men in the lives of mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 187-199.

Bradburn, N.W. (1969). *The Structure of Psychological Well-being*. Aldine, Chicago.

Brown, G.W. & Harris, T.O. (1978a). *Social Origins of Depression: A Study of Psychiatric Disorder in Women*, Free Press, New York.

Brown, G.W., & Moran, P.M. (1997). Single mothers, poverty and depression. *Psychological Medicine*, 27, 21-33.

Bruininks, R.H., Woodcock, R.W., Weatherman, R.F., & Hill, B.K. (1996). *Scales of Independent Behavior - Revised*. Riverside Publishing, Itasca, IL.

Budd, K. & Greenspan, S. (1985). Parameters for successful and unsuccessful interventions for parents who are mentally retarded. *Mental Retardation*, 23, 269-273.

Cairney, J., Boyle, M., Offord, D.R., & Racine, Y. (2003). Stress, social support and depression in single and married mothers. *Social Psychiatry and Psychiatric Epidemiology*, 38, 442-449.

Caldwell, B.M., & Bradley, R.H. (1984). *Home Observations for Measurement of Environment*. University of Arkansas, Little Rock, AK.

Cohen, S., & Hoberman, H.M. (1983). Positive events and social supports as buffers of life change stress. *Journal of Applied Social Psychology*, 13, 99-125.

Cohen, S., Mermelstein, R., Kamarck, R., & Hoberman, H.M. (1985). Measuring the functional components of social support. In: *Social Support: Theory, Research and Applications*, (Eds I.G. Sarason & B. R. Sarason ), pp. 794. Martinus Nijhoff, The Netherlands.

Cooper, S., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill health in adults with intellectual disabilities: prevalence and associated factors. *The British Journal of Psychiatry*, 190, 27-35.

Cox, J., Holden, J.M. & Sagovsky, R. (1987). Detection of postnatal depression: development of the 10-item Edinburgh Postnatal Depression Scale. *British Journal of Psychiatry*, 150, 782-786.

Cunningham, C., Sloper, T., Rangelcroft, A., Knussen, C., Lennings, C., Dixon, I., & Reeves, D. (1986). *The Effects of Early Intervention on the Occurrence and Nature of Behaviour Problems in Children with Down's Syndrome*. Final report to DHSS. Hester Adrian Research Centre, University of Manchester.

Dagnan, D. (2008). Psychological and emotional health and well-being of people with intellectual disabilities, *Tizard Learning Disability Review*, 13, 3-9.

Department of Health (2007). *Good Practice guidance on Working with Parents with a Learning Disability*. Department of Health, UK.

Department of Health (2009). *Valuing People Now: a new three year strategy for*

*people with learning disabilities*. Department of Health, UK.

Feldman, M.A., Towns, F., Betel, J., Case, L., Rincover, A., & Rubino, C.A. (1986).

Parent Education II: increasing stimulating interactions of developmentally handicapped mothers. *Journal of Applied Behavior Analysis*, 19, 23-37.

Feldman, M.A., Sparks, B., & Case, L. (1993). Effectiveness of home-based early

intervention on the language development of children of mothers with mental retardation. *Research in Developmental Disabilities*, 14, 387-408.

Feldman, M.A., Leger, M., & Walton-Allen, N. (1997). Stress in mothers with

intellectual disabilities. *Journal of Child and Family studies*, 6, 471-485.

Feldman, M.A., Varghese, J., Ramsay, J., & Rajska, D. (2002). Relationships

between social support, stress, mother-child interactions in mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 314-323.

Fitts, W. (1965). *Tennessee Self-concepts Scale*. Counselor Recordings Test, TN,

Nashville.

Froese, P., Richardson, M., Romer, L. & Swank, M. (1999) Comparing

Opinions of People with Developmental Disabilities and Significant People in Their Lives Using the Individual Supports Identification System (ISIS). *Disability and Society*, 14: 831-43.

Gambrill, E.D., & Richey, C.A. (1975). An assertion inventory for use in assessment

and research. *Behavior Therapy*, 6, 550-556.

Gaskin, K. & James, H. Using the Edinburgh postnatal depression scale with learning disabled mothers. *Community Practitioner*, 79, 392-396.

Gibbins, C. (2000). Factors affecting the development of externalizing behaviour problems from birth to 48 months. *Unpublished Doctoral Dissertation*. Queen's University, Kingston. ON.

Goodinge, S. (2000). *A Jigsaw of Services. Inspection of services to support disabled adults in their parenting roles*. Department of Health: UK.

Hope, S., Power, C., & Rodgers, B. (1999). Does financial hardship account for elevated psychological distress in lone mothers? *Social Science and Medicine*, 49, 1637-1649.

Judson, S., & Burden, R. (1980). Towards a tailored measure of parental attitudes: an approach to the evaluation of one aspect of intervention projects with parents with mental retardation. *Child Care, Health and Development*, 6, 47-55.

Lachman, M.E., & Weaver, S.L. (1998). The sense of control as a moderator of social class differences in health and wellbeing. *Journal of Personality and Social Psychology*, 74, 763-773.

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., McConnell, D., & Mayes, R. (2003). Health of mothers with intellectual limitations. *Australian and New Zealand Journal of Public Health*, 27, 17-19.

Lovibond, S.H., & Lovibond, P.F. (1995). *Manual for the Depression Anxiety Stress Scale (2<sup>nd</sup> ed.)*. The Psychology Foundation of Australia Inc, Sydney.

McConnell, D., Mayes, R., & Llewellyn, G. (2008). Pre partum distress in women with intellectual disabilities. *Journal of Intellectual and Developmental Disability*, 33, 117-183.

McConnell, D., Dalziel, A., Llewellyn, G., Laidlaw., & Hindmarsh, G. (2009). Strengthening the social relationships of mothers with learning disabilities. *British Journal of Learning Disabilities*, 37, 66-75.

McGaw, S., Ball, K., & Clark, A. (2002). The effect of a group intervention on the relationships of parents with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 354-366.

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.

Myers, F., Ager, A., Kerr, P. & Myles, S. (1998). Outside looking in? Studies of the community integration of people with learning disabilities. *Disability and Society*, 13, 389-413.

National Institute of Health and Clinical Excellence. (2007 & 2009). *The Guidelines Manual*. Retrieved July 18 2009, from NICE website Access: <http://www.nice.org.uk/guidelinesmanual>.

O'Keeffe, N., & O'Hara, J. (2008). Mental health needs of parents with intellectual disabilities. *Current Opinion in Psychiatry*, 21, 463-468.

O'Rourke, A., Grey, I.M., Fuller, R. & McClean, B. (2004). Satisfaction of living arrangements of older adults with intellectual disability. *The Journal of Intellectual Disabilities*, 8, 12-29.

Petersen, A. C., & Kellam, S. G. (1977). Measurement of the psychological wellbeing of adolescents: The psychometric properties and assessment procedures of the How I Feel. *Journal of Youth and Adolescence*, 6, 229-247.

Radloff, L.S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385-401.

Robson, C. (2002). *Real World Research*, 2<sup>nd</sup> Ed. Blackwell Publishing, UK.

Rosenberg, G. (1965). *Society and Adolescent Self-Image*. Princeton University,



Princeton, NJ.

Rotter, J.B. (1966). Generalized expectancies for internal versus external control for reinforcement. *Psychological Monographs*, 80, 1-28.

Rutter, M., Tizard, J., & Whitmore, L. (1970). Malaise Inventory. In: *Education, Health and Behaviour*. Longmans: London.

Sheerin, F. (1998). Parents with learning disabilities: a review of the literature. *Journal of Advanced Nursing*, 28, 126-133.

Stenfert Kroese, B., 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.

Sterling, J.D. (1999). *Determinants of parenting in women with mental retardation*. The Fielding Institute, Ann Arbor: MI.

Tarkka, M.T. & Paunonen, M. (1996). Social support and its impact on mothers' experience of childbirth. *Journal of Advanced Nursing*, 23, 70-75.

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.

Telleen, S. (1985). *Parenting Social Support Index: Reliability and Validity*.

(Technical report no.1). University of Illinois at Chicago School of Public Health, Chicago, IL, USA.

Thorndike, R.L., Hagen, E.P., & Sattler, J.M. (1986). *The Stanford-Binet Intelligence Scale, fourth edition: Guide for administering and scoring*. Riverside, Chicago.

Tilden, V.P., Nelson, C.A., & May, B.A. (1990). The IPI Inventory developmental and psychometric characteristics. *Nursing Research*, 39, 337-343.

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

Tymchuk, A.J. (1991). Self-concepts of mothers who show mental retardation. *Psychological Reports*, 68, 503-510.

Tymchuk, A.J. (1993). Depression symptomology in mothers with mental retardation. *Australian and New Zealand Journal of Developmental Disabilities*, 19, 111-119.

Wade, C.M., Mildon, R.L., & Matthews, J.M. (2005). Service delivery to parents with an intellectual disability: Family –centred or professionally centres? *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.

Ware, J.E., Snow, K.K., & Kosinski, M. (2000). *SF-36 Health Survey: Manual and Interpretation Guide*, Quality Metric Incorporated, Lincoln.

Wilms, J.D. (2002). *Vulnerable Children*. University of Alberta Press: Edmonton, AB.

Young, S. & Hawkins, T. (2005). Special parenting and the combined skills model.

*Journal of Applied Research in Intellectual Disabilities*, 19, 346-355.



**EMPIRICAL PAPER**

**Title: Exploring the journey of parenthood from the perspective of parents with learning disabilities**

**WORDS: 7539**

Prepared for submission to;

***Journal of Applied Research in Intellectual Disabilities (JARID)***

## **1.0 Abstract**

Parenthood is a life changing event which is often accompanied with an array of emotions as an individual tries to be a 'good enough' parent. For parents with learning disabilities (LD) parenthood can often be a difficult experience with their parenting coming under scrutiny. Following from Booth and Booth (1994) exploration of parents' with LD experience of parenthood, the current study applied in-depth analysis to explore mothers' and fathers' experiences of the journey of parenthood.

Semi-structured interviews were conducted with nine parents and the findings were analysed using Interpretive Phenomenological Analysis (IPA). Five superordinate themes were identified along with accompanying sub themes; 1. 'the developing relationship between parent and child', 2. 'feeling at the mercy of professionals', 3. 'LD overshadowing other problems', 4. 'the struggle between being cared for vs. autonomy', 5. 'adjustment to change after losing custody of children'.

Although the parents' experiences of parenthood had similarities, there were also distinct differences in their stories. These similar and different experiences were explained using 'reciprocal roles' from Cognitive Analytical Therapy (CAT; Ryle, 1975) and the 'determinants of parenting' model for parents with LD (Sterling, 1998). Recommendations for researchers and clinicians working with parents with LD are outlined.

**Key words:** *Parents, Mothers, Fathers, IPA, Learning Disabilities, Child Protection*

## **2.0 Introduction**

Parenthood is a significant life event which is often accompanied by a mixture of excitement and uncertainty about how to be a 'good' parent. Parents are not born into the world knowing how to care for a child but have to learn these skills through an array of experiences from the past and present (Llewellyn and McConnell, 2003). There are variations across different cultures as to what aspects of parenting are important (e.g. Xiong et al., 2005) which makes identifying 'good' parenting even more difficult. Hymes (1990) suggests that parents worry too much about parenting skills and children do not need 'experts' as parents. However, the reality for some parents is that their parenting skills are under scrutiny and with the absence of a universal definition of 'good' parenting, professionals make subjective decisions about whether an individual's parenting is 'good' enough (Young & Hawkins, 2005).

For parents with LD parenthood is often not an enjoyable experience. Sometimes the fact that a parent has a LD can be enough for them to be deemed unfit (Booth and Booth, 1995) despite intellectual functioning being a poor predictor of parenting (Booth, 1993). Parents with LD often live in deprived areas (Booth & Booth, 1996) and are at risk of poor psychological wellbeing and a lack of social support (for review see Darbyshire, this volume) which can lead to parenting being more challenging. Professionals may become involved with parents with LD and their children, assessing whether they are 'good enough' parents. Such assessments can lead to parents with LD being at risk of losing custody of their children and they have been found to be over-represented in child care proceedings (Goodinge, 2000; Booth & Booth, 1995). When considering these challenges, it seems important to discover how parents with LD actually experience parenthood.

Research with parents with LD has been conducted since the 1940s. Llewellyn et al. (2008) highlighted three different phases of research: the first two being the hereditary of LD and usefulness of parenting programmes. The current phase of research is focusing on the exploration of parenthood in different contexts such as within the family and community, drawing on parents' with LD own experiences.

Booth and Booth (1994) pioneered this current phase of research. They interviewed 33 parents, 25 of whom had LD and applied a life story approach and systematic thematic analysis to analyse the interviews. Through 126 interviews the 'downside' and 'rewards' of parenthood were identified. Stenfert Kroese et al., (2002) used content analysis and interviewed mothers with LD with and without custody of their children. Five categories were explored; helpful and unhelpful support, burdens and joys of parenthood and hopes for the future.

Edmond (2000) applied a more in-depth approach to explore the psychological consequences of being a mother with LD using Grounded Theory (Glaser & Strauss, 1967). She interviewed eight mothers who had at least one child living with them; from her findings she described how having an identity as a mother influenced the mothers' psychological wellbeing and feelings about having a LD. Edmond (2000) highlighted that her findings were not representative of parents with LD as a whole (e.g. mothers and fathers with LD with and without custody experiences of parenthood).

Although more recently studies have applied in-depth analyses to explore parents' with LD experiences of losing custody of children (Mayes et al., 2008) and of social support networks (e.g. Traustadottir & Sigurjonsdottir, 2008; Tarleton &



Ward, 2007), the general experience of parenthood has not been investigated since Booth and Booth (1994). Using an in-depth analysis and including both mothers and fathers with LD with and without custody of their children, will contribute to the body of literature about parents with LD. This may reveal more about how both mothers and fathers with LD experience the journey of parenthood.

## **2.1 Research aims**

This study aims to explore parents with LD journey of parenthood from pregnancy to their current relationship with their children. This includes their experiences with their children, family, community and society, exploring the meaning they give to these experiences.

## **3.0 Method**

### **3.1 Design**

The current research used Interpretive Phenomenological Analysis (IPA; Smith & Osborn, 2003). IPA was used to understand the parents' with LD first-hand experiences of parenthood and interpret these experiences using a range of theoretical perspectives (Reid et al., 2005). There are two central components of IPA, it is both phenomenological and interpretive.

A phenomenon is a particular experience or state that an individual experiences which in the current study is parenthood. IPA is interested in how an individual makes sense of, and the meanings they assign to, a particular phenomenon. Therefore a participant is viewed as the expert with the researcher

interpreting and applying psychological theories to a participant's first hand experiences.

For a researcher to be able to ground themselves in a participant's experiences it is important for them to think about their own relationship with the research project and be mindful of any assumptions they have made about the potential findings of the research. Reflexivity refers to the monitoring of thoughts, feelings and reactions which a researcher should try to 'bracket' off when applying IPA. Although it is questionable how possible it is to 'bracket' off one's feelings, it is a useful skill in IPA. If applied successfully by the researcher, the interpretations they make are more likely to be from a participant's experience rather than their own feelings influencing their interpretations.

### **3.1.1 Own preconceptions and reflections**

My preconceptions about the research seemed to alter as the research progressed. Therefore it seems important for me to reflect on my own journey of parenthood. When I began the research project I was not a parent but interested in the research topic from my clinical experience of working with looked-after children and individuals with LD. However, when interviewing the parents I was pregnant and when analysing the data I had recently given birth to my son. As a first time mother I experienced many difficult emotions and feelings, unsure about what I was doing and scared of doing things wrong. I became mindful of the different position I was in compared to parents with LD. I was the one who was putting pressure on me to be a 'perfect' parent and I didn't have the added pressure of feeling that I was being judged by professionals and at risk of losing my baby. I empathised more with the

parents I was interviewing and felt that they were subjected to unrealistic expectations from professionals to be 'perfect' parents. I ensured that I was mindful of my own preconceptions and experiences which was further helped by completing an analytic diary in which I recorded thoughts and feelings throughout the research process.

### **3.2 Ethical issues**

Ethical approval was sought and gained from an NHS research ethics committee (Appendix 4). The importance of ensuring individuals with LD are knowledgeable about their participation in research has been highlighted (Arscott et al., 1998). Therefore, firstly parents were informed about the research by professionals who were currently or use to be involved in their care. These professionals were knowledgeable about the research and provided parents with written and verbal information about the details of the research project. If parents were still interested in participating in the research an appointment was arranged for them to meet with the researcher to provide further information about the research project. To further ensure that the parents understood what the research entailed they were asked a number of questions about the research before they were asked to provide written informed consent (Appendix 5). All of the participants were able to answer the questions correctly and appeared to understand what the research entailed. Participants were also aware that they could withdraw from the research up until the debrief session.

Many parents with LD are at risk of or lose custody of their children. Therefore, discussing experiences of parenthood can be an emotionally arousing

and sensitive topic. Interviews were conducted with this in mind and terminated if a participant found the process too emotionally distressing. This happened with one participant (see 3.4). The interviewer received supervision from a Clinical Psychologist and offered all participants a debrief session ensuring they received appropriate support if required. The participants were also reassured that all information used in the study would be anonymous.

### **3.3 Procedure**

#### **3.3.1 Inclusion criteria and sampling method**

The inclusion criteria for the study were parents with LD over the age of 18. No formal assessment of their level of ability was conducted but all participants had attended special schools, special education classes within mainstream schools or were involved with LD services. Potential participants were identified through professionals working with parents with LD. Professionals were briefed about the research and asked to approach individuals who they thought would be suitable. An information sheet (Appendix 6) was then given to the individuals and they were asked if they would be willing for a researcher to contact them to arrange a meeting to discuss the research in more detail.

#### **3.3.2 Data collection**

Individuals were contacted once their details had been provided by a professional involved in their care. Three meetings were then arranged; the first to explain the research in more detail and gain informed consent, the second to conduct a semi-structured interview and the final meeting was to debrief participants.

Participants were individually interviewed, using a semi-structured interview format (Appendix 8). The interviews were conducted in private rooms in advocacy agencies or LD community team premises. Nine key questions were asked and accompanying prompts were used when needed. The interviews applied a 'funnel' approach and began by asking participants general questions about their decision to have a baby leading into more specific questions about what happened and who was involved in their journey of parenthood. All nine interviews were tape-recorded and transcribed verbatim.

### 3.4 Participants

Sixteen individuals requested to take part in the research after they had been given an information sheet. Of these sixteen, six did not attend the first meeting to gain consent and one consented but was later identified as being unsuitable as she believed being interviewed would help her to get contact with her children. She was offered support from her manager and advocate following this. Information about the nine remaining participants is provided in Table 1.

**Table 1.** Demographic details and summary of participants' situation at time of interviewing (no real names are used).

Name	Age	Ethnicity	Summary of context
Sophie	30's	White British	Sophie lived on her own and had six children all of whom she had lost custody of. She was actively involved in an advocacy organisation for individuals with LD.
Jane	40's	White	Jane lived on her own and had one child who was in foster

		British	care. She had a close relationship with her mother. She had been supported by several professionals from a community LD team.
Salina	20's	Asian British	Salina lived with her husband. They had one son who she had contact with but was being looked after by a member of their family. She was supported by an advocate to gain custody of her son.
Cassie	20's	White British	Cassie lived with her husband and had two children who had been adopted. She had 'post box' contact with them. Cassie was involved in an advocacy organisation for people with LD and was being supported by a Clinical Psychologist.
Jenny	30's	White British	Jenny lived with her fiancé. She had lost custody of her two children. She was involved in a women's group for mothers with LD.
Charlene	20's	Asian British	Charlene lived with her daughter and son. She had contact with the children's' father and was supported by her mother who was in another country for a few months. She had involvement with a community LD team.
Tanya	20's	White British	Tanya had five children all of whom she had lost custody of. She was actively involved in an advocacy organisation for individuals with LD.
Tom	20's	White British	Tom lived with his partner and their son. He had a close relationship with and support from both of their families. He had recently ended work with a Clinical Psychologist

Ryan	20's	White British	Ryan lived with his wife and youngest daughter. They had four children in foster care who they had contact with. They were being supported by an advocate to gain custody.
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Although the participants ranged in age, gender, ethnicity and custody status it was felt that they all had a position of expertise to offer an insight into parents with LD experiences of parenthood.

### 3.5 Data analysis

In IPA there are a number of stages of analysis which are applied to each transcript before moving on to the next.

The first stage of the analysis involved reading and re-reading the transcript and making notes of any observations in the data. More detailed line-by-line coding was then used with the codes being consistent with the participant's own words (see Appendix 8, left hand column). From the line-by-line coding a number of themes were identified which were more interpretive (see Appendix 8, right hand column). Finally, all of the themes were listed and relationships between the themes were identified and clustered together to create superordinate themes. Certain themes were excluded if they did not fit in the emerging data or were not of rich data. A table was created to present a 'trail' of the data from the participant's verbatim accounts (see Appendix 9).

### 3.6 Validity

Findings from qualitative studies are rarely replicable. However, results in one area of research can be useful in influencing other similar areas (Yardley, 2009). Triangulation was used throughout the analysis to try and ensure that the results were valid. This involved discussing the analysis with two supervisors involved in the research to ensure the themes linked to the participants' own words. I was also involved in a peer support group where samples of the transcripts were shared with peers external to the research to identify whether they found similar themes.

## **4.0 Results**

Before the results are discussed in detail it is important to note that the parents were asked to explore their journey of parenthood. The superordinate themes are ordered in relation to this journey: from pregnancy to their current relationships with their children. Five superordinate themes were identified and will be discussed with their accompanying subthemes; 1. 'the developing relationship between parent and child', 2. 'feeling at the mercy of professionals', 3. 'LD overshadowing other problems', 4. 'the struggle between being cared for vs. autonomy', 5. 'adjustment to change after losing custody of children'.

### **4.1. The developing relationship between parent and child**

All of the parents spoke about their relationships with their children. The relationships were perceived to develop and alter as their children went through various developmental stages. This led to some of the parents experiencing difficulties and struggling to cope with parenthood.

#### **4.1.1. *Finding out about forthcoming pregnancy***



None of the mothers explicitly stated that they had planned their first pregnancy and for many it was unexpected. Cassie was one mother who expressed being shocked:

*"No it was kind of like a bad shock really. Because I didn't know how my husband was going to take it....He took it well actually".* (line: 9)

Cassie's uncertainty about motherhood appeared to centre on how her partner would react to the news that she was pregnant. Tom felt that his partner was also unsure about how he would react to the news but he stood by her and was clearly excited:

*'She was scared what I'd, because all the blokes yeah, when they find their partner's pregnant, they leave them don't they?... Some blokes do but I'm not like that. And she, she told me she was pregnant and I went, I went, go and see to the doctor first, so she went to the doctor and the next day she told me and I was, I was shocked but I was like shocked but happy..'* (line: 9)

The other parents also appeared uncertain about how other people might react, which included partners and family members. Salina was certain that her partner would be happy about her pregnancy as she had experienced a miscarriage previously. However, she did not tell anyone else, in particular her mother as she did not think she would be pleased:

*"Erm, I didn't tell no-one. My mum found out when I was five months... she, she wasn't happy at first because I was with an older guy".* (line: 29)

Although Salina was happy about her pregnancy she had her uncertainties about the labour and birth of her unborn child:

*"I was very, very scared I was scared but got use to it [the birth] didn't really hurt"*

(line: 50)

In contrast, Tanya was uncertain about motherhood and questioned whether it was the right time in her life to become a mother:

*"I felt not ready for kids. I weren't ready for children. I was only like 24. I weren't really wanting kids, I weren't ready for them.."* (line: 19)

#### **4.1.2. Need to express love and be understood**

Salina, Tanya, Jenny, Jane, Cassie, Tom and Ryan reminisced about their experiences of bringing up their children. They described their interactions with their children and seemed to have experienced a close bond, understanding their child's needs and communications. Ryan experienced this when spending time with his youngest daughter:

*"It's like you talk to her and she's like she looks at me like "yeah I know what you're on about dad". I'm talking to her like I talk to a child so they'll understand"* (line: 920)

Jane experienced that the people taking care of her son thought he was more difficult to manage than what she felt he was:

*"That's what they said and that hurt me a lot and I said, and I thought 'well he isn't that bad when I had him'. I mean I might have had a few problems but he was never as bad as what they said he was".* (line: 667)

The unconditional love that Jane seemed to experience towards her son was expressed in some of the others parents' stories. For Tanya, her children

understanding that she loved them and why she couldn't take care of them was of great importance when they were taken into care:

*"And he says that Mummy loved...me and [daughter's name] but I know that Mummy couldn't look after us as well as she wanted to, and I love my Mummy". (line: 302)*

#### **4.1.3. Struggling to cope and assert control**

During the first few months of their children's lives many of the parents described the challenge of learning to carry out various tasks needed to care for a newborn such as feeding and changing a nappy. However, as their babies developed Tanya, Cassie, Charlene, Jane and Sophie experienced different struggles as they tried to discipline their children.

Jane's partner had different ideas to her about how to care for and discipline a child:

*"Well he was going in the fridges and things like..I mean I knew what to do but he didn't got a clue. I mean I used to say "no" and he knew he couldn't go in the fridge when I was there but his dad worked different to me". (line: 151)*

The inconsistencies in their child-rearing practices seemed to result in Jane experiencing difficulties, leaving her feeling she had no control over her son:

*"I had a right game. Sometimes, in town screaming and everything, it was a bloody nightmare". (line: 206)*

Charlene also found it difficult to control her children. Although she received helpful advice on how to use various coping strategies with her children's behaviours, she felt that they were ineffective when she tried them:

*"This lady is telling me what to do with him if he's really naughty put him outside for two minutes, that is what they do in the nursery... that is helpful but he doesn't stay there".* (line: 316)

Sophie reflected on her own experiences of discipline as a child:

*"I didn't really know how to discipline my children, because I have never been disciplined myself, as a child".* (line: 192)

Sophie seemed to know that she needed to discipline her children but did not have any experiences she could draw on which resulted in her feeling uncertain about how to discipline them.

#### **4.1.4. Recognising the importance of putting a child's needs before your own**

All of the parents experienced difficult feelings during their journeys of parenthood. Tanya, Cassie, Salina, Jenny, Tom and Ryan mentioned the importance of placing their own feelings to one side to focus on the needs of their children.

Salina did not have the support from her own mother and experienced feelings of anxiety about how to care for her 'tiny baby'. Despite these uncertainties Salina recognised that she had to cope and respond to the needs of her son:

*"I was scared myself but I have got to put his needs before my own so I've got to do it for my son".* (line: 159)

Ryan discussed how he had to control his own feelings during contact with four of his children:

*“Obviously I love all them to bits. It is just difficult at the moment because I only see them in contact for a few hours. And when you’ve got to say ‘tara’ to them it is really upsetting inside, but I don’t want them getting upset and if they get upset, I’ve got to comfort them and say don’t worry, everything will be alright”* (line: 928)

Ryan seemed to be clear about his role as a father and the importance of protecting his children from his own emotions.

#### **4.1.5. The desire to do the right thing and protect my child**

For Sophie, Salina, Jane, Charlene, Tom and Ryan there was an overriding sense that they needed to protect their children from danger and to try and do the ‘right thing’ as a parent.

Throughout her story Charlene expressed a need to protect her children from risks inside and outside of the home and ensure they knew ‘right from wrong’:

*“I just told her, I told my daughter, I said ‘don’t talk to strangers, if you don’t know them, don’t talk to them and don’t have anything off them’”*. (line:377)

Charlene had experienced being let down by professionals as they had not supported her to make her house safe for her children:

*“I don’t know they could have just put locks or something to make it safe. But they didn’t”*. (line: 155)

Jane, Tom and Sophie's desires to protect their children led to them contacting professionals for support. Jane felt that her son was at risk due to her partner's behaviour and expressed a need to do the right thing despite the consequences:

*"Yeah I went because I think I did the right thing going because his dad was letting him use the tools, erm things he shouldn't have been using, like the toaster and cookers and everything and I got really a bit worried about it and I went to social services and I said "it can't go on" and he didn't like me going because the social services come out and seen what was going on but they said I did the right thing about it at the time". (line: 135)*

For Tom he was aware that he was struggling to control the angry feelings he experienced and requested support from social services, acknowledging that his son could be at risk if he is unable to manage his feelings:

*"Yeah. Because if you don't talk about problems because it is just going to build and build, build up inside you. It's like a volcano ready to erupt...and then if you've got a little child and your child it's going to like erupt and that poor little kid is going to get hurt". (line: 369)*

Tom also made other changes in his life to ensure that his son was protected which included socialising with friends who he felt were more responsible and were in a similar situation with a young family.

## **4.2 Feeling at the mercy of professionals**

All of the parents had encountered difficulties with some of the professionals involved with them and their children. Social workers, solicitors and judges were the

professional that parents experienced the most difficulties with. However, it is important to note that some parents also had positive experiences with these professionals.

#### **4.2.1. *Belief that professionals are working against me***

All of the parents apart from Cassie experienced professionals working against, not with them. The relationships between the parents and professionals appeared to be surrounded by suspicion. This included parents doubting what professionals were saying, feeling deceived by them and sometimes feeling that all they wanted was to take children away from their biological parents.

Salina's mistrust of professionals was based on past experiences. She described whilst she was in hospital how her husband had been told to sign a form to hand over temporary custody of their son. After he did this they struggled to regain custody although they were told it would be easy:

*"Not at all because he was told that if he signed [son's name] over he could have it any time back but what he wasn't told then was once he wrote it, once he signed he couldn't go back on it unless he went to court".(line: 293)*

Sophie's experiences seemed to be that professionals, in particular social workers, were focused on taking children away from parents with LD. She had lost custody of all seven of her children:

*"Yeah. Yeah. But I just don't understand with social services, they are there to try and help everybody, parents keep their children, but they don't. They just take them and I am fed up with everywhere I go, all I see is adopt a child, everywhere I go. It is*

*all in social services on the wall, adopt a child. On the bus it has got "do you want to adopt a child?" And I feel like ripping it down on the bus I do". (line: 1008)*

Sophie's scepticism about professionals' priorities when working with parents and their children was evident throughout her story. Charlene and Jenny also seemed to question the motives of professionals, similar to Sophie's experiences they felt the priority was to take children and not work with parents to help them to keep custody of them.

#### ***4.2.2. Feeling that professionals are detached from my reality and expect perfection***

Cassie, Sophie, Tanya, Jane, Charlene and Ryan all felt that some professionals' expectations were too high, often expecting parents to be 'perfect'. This seemed to be a particular frustration to Cassie who felt that perfection was impossible to attain:

*"Yeah and they expect me to be the most perfect parent in the world and I know for a fact that you, that there is no way you can be perfect". (line: 728)*

This expectation of perfection seemed to lead to the parents feeling detached from some professionals and experiencing negative feelings towards them. Tanya described a heated conversation with a social worker after she had visited her children for the last time when they were adopted:

*"Yeah and erm, when they went up for adoption I had, I had... an hour to say 'tara' to them and the social worker turned around and said "how are you feeling? And I said "Well how do you think I am feeling you stupid cow?" I said "Well how would you*



*react if your kids was taken away from you?" and she said "I wouldn't cope" I said "well there you go then" What do you expect me to say? She said "you have to", "yeah right whatever". (line: 485)*

Tanya seemed to be frustrated that the social worker was unable to empathise with her situation and seemed to need the social worker to see things from her perspective, but when she did it was no comfort.

#### **4.2.3. Experiencing assessment centres as stressful places**

Sophie, Tanya, Cassie and Ryan had experienced being in residential assessment centres with their children. All of them described assessment centres as stressful places for a number of reasons. Ryan experienced the assessment centre as being very different from a family home:

*"It's difficult one to answer really because erm it was really a stressful environment being there it's not normal living being watched 24/7 and you can't and you can only go out for one hour a day, I mean how are you meant to do your shopping and get what you gotta get you can't take the kids out to the park because you are rushing back again and you haven't got no time, it's not normal living". (line: 544)*

He also commented on the difficulties of living with other families and being restricted.

Many of the parents also described staff members at the assessment centres not doing their job properly or not appearing to have the knowledge or experience of working with individuals with LD or with a mental health difficulty. Cassie described

her experiences of not being supported when in an assessment centre and having to struggle to cope with symptoms of postnatal depression (PND) on her own:

*“And the staff, I don’t think they got the message I had postnatal depression at all. And they were very, they weren’t sympathetic at all over it. They didn’t try and support me with it or anything”.* (line: 256)

### **4.3. LD overshadowing other problems**

All of the parents apart from Ryan, Tom and Charlene contributed towards this superordinate theme. Additional difficulties that parents had experienced such as abusive childhood experiences, mental health difficulties, domestic violence and attachment difficulties were all discussed. There was a sense that these difficulties were neglected or ignored, with the label of a LD stigmatising parents.

#### **4.3.1. Loss of identity as LD overrides who I am**

Some mothers described being identified and judged based on having a LD and that their qualities and abilities as a parent were not being recognised.

Cassie described feeling overlooked in meetings as though she was not important despite being the mother of the children that were being discussed:

*“I felt they treated me, not like an individual, I thought they treated me as though I was stupid”.* (line: 273)

The loss of identity that Cassie spoke about was also experienced by the other mothers. Jane described being able to assert herself with someone who she felt was judging her for having a LD:

*"I said to him, I said to..I said to them a LD isn't an illness, it's just what people have got". (line: 437)*

Being labelled with an LD led parents to feel that professionals made various assumptions about them. One thing that Sophie appeared particularly frustrated about was the assumption that individuals with LD cannot parent properly:

*"I don't know, I just feel as if they think, oh because we have got LD, we can't parent properly, children. What...how social services know what we can and can't do, if they don't even see us [parents with LD] with children". (line: 588)*

Sophie's experience of being a mother seemed to be that others judged her as an unfit parent without giving her an opportunity to demonstrate her parenting skills.

#### **4.3.2. Feeling insignificant – why didn't anyone notice?**

Not only did some of the parents feel that they were stigmatised by the label of having a LD, also that other difficulties were overlooked because of this. In Salina, Cassie and Sophie's stories there was sense of them feeling that other individuals did not notice the psychological difficulties they were experiencing and struggling with. Cassie described having a difficult childhood with professionals with social services being involved in her care from an early age:

*"It made me feel angry and hurt, especially when social services, I was under them, they should have noticed more than anybody else, especially when I got older, they*

*should have noticed that emotional pain. And then they would have actually erm realised that something was wrong and done something at that point". (line: 437)*

For Cassie the "emotional pain" she experienced as a child had not been addressed resulting in it impacting on her when she became a mother. Cassie felt that her childhood problems were overlooked by professionals possibly leading to her feeling that they were insignificant. Salina also described struggling with psychological difficulties with no one noticing that she needed support:

*"They just said that erm I wasn't capable of looking after my child. But how did they know, they didn't give me a chance. I was suffering from postnatal depression. They should have known that". (line: 222)*

For both Cassie and Salina there is a sense that things might have been better and losing custody of their children could have been avoided if professionals had recognised the psychological difficulties they were struggling with. Their expressions of frustration, hurt and anger seem to highlight the belief that their difficulties were insignificant to and not a priority for some professionals.

#### **4.3.3. Being 'on another planet' and losing sense of reality**

Salina, Jane, Tanya and Cassie described times when they felt they were behaving out of character during motherhood. They made sense of these experiences by relating them to the impact of stressful situations and being diagnosed with PND.

Tanya recalled an uncertain time where she couldn't remember what she had done during the day in relation to caring for her children:

*"I didn't know if I was here or on another planet...I couldn't remember if I had took my medication. Erm, I couldn't remember if I had fed [daughter's name]. And they said 'well what did you give [daughter's name]?' Don't know. 'What did you give [son's name]?' Don't know. When did you give her a bath? "I don't know" because I just couldn't remember nothing". (line: 137)*

Some of the other mothers described behaving in ways they had not before such as hitting or shouting at professionals. For Cassie things felt so out of control that she tried to cope by using alcohol:

*"I think all the stress I was going to in that place. I think I needed, I knew I need a drink. Oh all I was thinking was 'I need a drink'. (line: 318)*

None of the mothers seemed to be educated about the causes and symptoms of PND. Salina expressed several times during her story a feeling that she could have somehow stopped herself from becoming depressed:

*"...but when I got postnatal depression I just couldn't but I wish I could help mothers more, they should put their kids first, and try not to get ill". (line: 132)*

#### **4.3.4. Unable to stop pushing baby away**

Jane and Cassie both experienced PND and struggled to bond with their newborns. Cassie appeared to make sense of why she was 'pushing away' her daughter by being diagnosed with PND:

*"And then eventually I started I wasn't bonding started pushing away from her for a bit because I was diagnosed with post natal depression". (line: 87)*

Jane recalled a frightening experience when she was attacked by a stranger and reflects on how this impacted on her relationship with her son:

*“And I was going to this scheme one morning and this bloke come out and I had never seen him before in my life and he wanted me to go out with him and then he attacked me and all this and it was a nightmare and I had to, we had to leave. I couldn't go out for six months, I couldn't face, I had to give up my scheme in and everything. So that was a nightmare and then I had [son's name]. They noticed I wasn't giving him the love and attention I should have given him. I think [son's name] knew there was something wrong but I couldn't tell a kid of that age can you, what's up.” (line: 773)*

Both mothers seem to have made sense of why they struggled to attach to their children.

#### **4.3.5. Need to escape a destructive relationship**

Sophie, Tanya and Jane experienced abusive relationships with the fathers of their children. Jane described how her relationship with her partner gradually escalated into violence:

*“It was only for a bit. It wasn't always, it was only when we had...started having [son's name] and things got a bit out of control and I was trying to explain to his dad about things, but you could never explain it to him, he wouldn't listen and things like that. And then things got worse after, think it was 12 months or something that he started hitting me and I tried to get out of the relationship, I couldn't. He said he was*

*going to change and the social said "you are going to have to leave the relationship because of [son's name]" but I couldn't do it. I couldn't do it". (line: 844)*

The three mothers appeared to be holding onto the hope their partner would change and that that things would improve. Tanya described having to build up the strength to be able to leave her partner and ensure that she and her children were safe:

*"Erm, in the end he set the house on fire so we had, had to live separated for about six months. I was going to divorce him but then I backed out. I backed out, I was a chicken. Erm, in 2003 I finished, I told him to get out and I think I was 28, I had [daughter's name] and I told him he was a loser". (line: 53)*

#### **4.4 The struggle between being cared for vs. autonomy**

All of the parents expressed the battle between two competing needs. The first was the need to be in control of their parenting by asserting their independence and the second was the need to be supported by other people. The equilibrium of the two needs seemed to be achieved when the parent knew someone was there for them if and when they needed support.

##### **4.4.1. Needing the strength of a partner**

Although some of the mothers had experienced abusive relationships, all of the parents apart from Tanya recognised the need for a supportive partner when bringing up children. Jane expressed the loneliness of having to give birth without her partner being with her:

*"Bit hard because I wanted the father to stop but he wouldn't do it, he said he didn't want to be there..I don't know, it was strange, I don't know, I wanted him to be there but he just didn't want to be there so I had to do it all myself". (line: 42)*

Although Jane tried to communicate to her partner that she needed his support she felt that he did not respond to her needs. Charlene's husband was there however, she did not experience his presence as beneficial:

*"He wasn't... he was here but he wasn't that helpful". (line: 215)*

Ryan also experienced a number of difficult times with his wife as they did not communicate with one another. He described how their relationship evolved into a partnership where they learnt to communicate openly to one another:

*"I'd speak to people you know, speak to [advocate's name], speak to all the professionals involved with us but you know me and [wife's name] get on bet, a lot better now, we talk more, we never used to talk, we always used to have stupid rows, now we don't, we just talk more, decide what the best way to, you know working through any problems". (line: 754)*

Ryan described his own and his wife's ability to make changes in their relationship to ensure that they supported one another adequately. For Ryan having someone there to talk to and depend on was especially important during childcare proceedings. Tom also experienced his relationship with his partner as teamwork, both of them having roles and complementing one another:

*"Like I help with, I get her things because I can't like change his nappy because he was first born and that it was easy to change his nappy because they don't move*



*around, now he's wiggling, so she changes his nappy and I just pass what she needs... yeah we work as a team".*

He also described learning skills from his partner so that he could be more involved with the care of their son.

#### **4.4.2. Need for control and independence**

Jenny, Jane, Sophie, Tom and Cassie expressed a need to be in control of their lives. When Jane had her son she was encouraged to live with her parents but she felt that it was important to have her own home and be in control of what she did:

*"I don't know, when I was 20..I'd probably been about 26 when I had [my son] so I felt like I wanted to be independent and things. And then when you live with your parent, like your parents, you haven't got that space have you, to do anything".* (line: 166)

The need for independence appeared particularly important for the parents when caring for their children. Sophie described wanting to try out things on her own first and trusting herself to ask for help when she needed it:

*"Because I want to do it myself. ((laughs)) But I do ask for help".* (line: 732)

#### **4.4.3. Reassurance that someone is there for me**

Despite wanting to be independent, all of the parents said to be reassured by knowing that someone would be there for them. Many of the parents were supported by advocates and the parents experienced advocates as being able to balance offering their support with respecting the parents' independence. Cassie appeared to be reassured that her advocate enabled her to take control of things but was by her side if things got too difficult:

*"She's the advocate at [agency's name], she was around. And she was supporting me in the background". (line: 48)*

For many of the parents the advocate's support was useful in informing them about their rights and procedures to have contact and/or custody of their children. Salina described feeling misguided and let down by professionals in the past. She expressed the importance of someone empathising with her situation:

*"She, she can, I find she is very helpful. She makes, she tries to make me understand how bad things can be and she does help so..I am grateful that I have her support I don't know where I would be now". (line: 412)*

Salina's gratitude for the support she received from her advocate is clear. She expressed being uncertain how she would have coped and what she would have done without this support. The lack of support appeared especially noticeable for some parents when they lost custody of their children. Jenny described social workers being there for the child but not for the parent. It seemed important to Jenny that she had a social worker who was thinking about her needs:

*“Well me and [advocate’s name] was talking about that, I should have had a social worker involved in, with me...I should have had one..For myself, yeah”.* (line: 340)

#### **4.5. Adjustment to change after losing custody of child/ren**

All of the parents except for Charlene and Tom had experienced losing temporary or permanent custody of their children. This experience appeared to initially cause most of them intense emotional suffering with some of the parents later being able to reflect on what happened and how to improve their parental skills. All of the parents experienced a hope that they would be reunited with their children in the future.

##### **4.5.1. *Unbearable pain of my child being taken away***

All of the mothers spoke about the unbearable pain of having their children taken away from them. Without their children many of these mothers expressed that life was not worth living. Salina experienced losing part of herself when her son was taken into care and her feelings of desperation were expressed as she recalls contemplating ending her life if she could not be with her son:

*“Erm no. I just...really, really upset when my baby was taken off me and I didn’t want to live I thought there was no point of living if my baby wasn’t with me”.* (line: 214)

Jane expressed similar feelings to Salina, as she was also devastated by losing custody of her son:

*“Because it was like everything ended when my son went away, like I give everything in, I didn’t care like myself anymore, I didn’t care about myself or nothing”.* (line: 226)

#### **4.5.2. Gaining the strength to change**

Ryan, Jenny, Cassie, Salina and Sophie described the changes that they had made since losing their children.

From Ryan's story it is clear that he was determined to educate himself about the legal system so that he was knowledgeable about his rights as a parent. Reflecting on these changes Ryan seems to recognise his progression over the past two years and how his maturity has grown through this process:

*"Because I've learnt a lot in two years. And I grew up a hell of a lot in two years".*  
(line: 355)

Sophie has also experienced personal changes and discovered qualities that she didn't realise she had, such being assertive:

*"But I am going to fight all the way. That is another thing I thought I never had in me. Fighting. And I feel because of [advocate's name] and advocacy I have got, I can fight, I have got the strength now to fight and to get things changed and that is what I want to do. I want to help other parents with LD".* (line: 985)

Not only has Sophie gained the strength to change and "*fight*" for what she wants but she feels that she has the capacity to support other parents in similar situations.

#### **4.5.3. Reflecting on what went wrong and sorting myself out**

All of the parents apart from Salina reflected on what happened before they lost custody of their children and attempted to put changes into place for themselves and their children.

Ryan recognised how his actions impacted on his family and made several changes. These included accessing support for his gambling habit, supporting his wife and ensuring his home was clean and tidy. Ryan is open about the things he did wrong and his determination in changing is clear:

*“No, no. The social workers came out, well we understand why, because our house was a state... Yeah. We had pets and the house was a mess and we neglected the children, we understand that”.* (line:273)

Cassie also seemed to recognise her self-destructive behaviour and expressed an acceptance that she needed support to work through the difficulties she experienced as a child and focus on taking care of herself:

*“I actually... I looked deep centre I thought ‘what am I doing to myself?’”.* (line: 327)

Ryan and Tanya noted that some professionals had acknowledged the changes they had made. Tanya especially seemed to celebrate this:

*“That they think I will cope now that I have sorted my head out and I have sorted all of my problems out. No I have come a long way”.* (line: 572)

Whilst reflecting on their lives some of the parents found completing a life story a beneficial way to process what had happened to them. Jane felt that her son should read it when he is older so that he could understand why he was not with his mother:

*“So I did a life story, I think it was last year and I put it in the life story, what happened. I did a really good life story....and I put in there what happened to me and things so [son's name] will probably be...when he gets a bit older, if he wants to read it, to understand what I'd been through”. (line: 795)*

#### **4.5.4. Holding on and hoping to be reunited with children**

Despite losing temporary or permanent custody of their children all of the parents apart from Jenny described the hope that they will be reunited with their children.

Ryan's determination to be reunited with his four children was evident throughout his story. This hope was what motivated him to keep fighting to get them back:

*“Erm I suppose never give up on you know...if you're kids, if you do end up you know or your children go into care, it's not the end of the road you can actually get them back. I mean I know we haven't got ours back yet but I really and truly believe we will. It's just a matter of time, you know”. (line: 614)*

Tanya, Jane and Cassie seemed to have accepted that they would not get custody of their children. However, there was a sense of hope as with age comes choice. Tanya hoped that her two children will decide to return to her when they are 16 years old when they are legally able to decide for themselves:

*“Hopefully they will come and live with me when they are like 16. Because [son's name] he says “well I want to go and live with Mummy” there is nothing they can do”. (line: 226)*

#### **4.5.5. *Fear that my role of parent is replaceable***

The journey of parenthood for all of the parents who contributed to this final superordinate theme ended with them expressing concern about whether their role as a parent could be replaced by someone else. This seemed to be a particular concern for the mothers who had lost permanent custody of their children. Jane acknowledged that her son was being cared for properly but seemed to hold onto the hope that she would not be forgotten by him:

*"I don't know, the people that's got him because he's with a family now, he's in like is it a care, the people that look after him, it's like...I don't know what they call them, somebody is looking after him at the moment aren't they? And things picking him up and things like that but that's not the same as his mum is it?"* (line: 344)

Jenny described a meeting that she attended with her advocate which was to educate professionals about working with parents with LD:

*"But like I said to them at the meeting, at the end of the day, no-one's going to change who I am."* (line: 433)

It seemed important for Jenny to remind professionals that the role of a mother cannot be replaced, possibly hoping that they would be mindful of this when working with parents with LD.

## **5.0 Discussion**

Although the nine participants' experiences of parenthood had similarities it should be noted that there were also distinct differences in their stories. Some of their experiences have already been discussed in previous research findings (e.g.

Booth & Booth, 1994; Edmond, 2000) whereas other themes are new and less prominent in the existing literature. The themes in the results section will be discussed in relation to psychological theory that enables further understanding of the parents' experiences.

Llewellyn and McConnell (2003) suggest that mothering a child does not only involve the child's parents but other people involved in a child's life. They refer to this as a mother's 'social milieu'. In the current study experiences of parenthood were shared with other people and relationships with these people appeared particularly pertinent for the parents. For example relationships with children, partners, family and professionals.

Booth and Booth (1994) suggested that there is an assumption in society that parents with LD are unable to put their child's needs before their own because of their LD. This assumption was not confirmed in the current study as parents described taking on a 'caring' role with their children and some highlighted their experiences of putting their children's needs before their own. This 'caring' role has also been described in other studies of parents with LD (Booth & Booth, 1994; Edmond, 2000).

The relationship between parent and child was difficult for some as they struggled to cope and assert control. Baum and Burns (2007) suggest that some parents with LD struggle to cope with their children's difficult behaviour because of the poor parenting role models they experienced in their own childhood. Sophie linked her own childhood to make sense of the difficulties she had with disciplining her own children. The difficulties that some of the parents experienced appeared to worsen



as their child went through different developmental stages. This has been mirrored in the experiences of the mothers in Edmond's (2000) study. A limited understanding about child development and discipline seems common among parents with LD, with some expressing a need for more support in this area (Llewellyn et al., 1998; Stenfert Kroese et al., 2002).

Whitman et al. (1990) has highlighted the importance of professionals working with mothers with LD being aware of the influence male partners can have on mothers' lives. Three of the mothers in the current study had experienced abusive relationships with men, an experience also described in other studies (e.g. Baum & Burns, 2007; Edmond, 2000). However, some of the mothers in the current study were able to break away from their role as the 'victim' and end the relationship.

Eight of the parents in the current study recognised the importance of a supportive partner when bringing up children and some experienced positive relationships. The importance of a loving and supportive relationship has been expressed by other parents with LD (Booth & Booth, 1994; Llewellyn et al., 1995). For some of the parents in the current study relationships were experienced as being particularly supportive when couples complimented one another, for instance one person taking on practical chores and the other being emotionally supportive. Booth and Booth (2002) interviewed 55 mothers with LD and the majority of them were in long standing relationships where their partner was described as bringing personal skills to the relationship which benefited the whole family. Some of the parents in the current study recognised that their relationship with their partner was 'unhealthy' and had made changes to these relationships with the help of psychological interventions.

The relationships between the parents and professionals were experienced both positively and negatively. Some of the professionals were described as rigid, unable to alternate between providing support and allowing autonomy depending on the parents' situation. The importance of professionals providing adaptable support is highlighted in Tucker and Johnson's (1989) 'competence promoting vs. competence inhibiting' model. They suggest that parents with LD who are trained and supported to be self-sufficient are likely to be more competent than parents with LD who are not supported to develop their skills. Wade (2005) also found that parents with LD preferred family-centred rather than professional-centred support. Family-centred support places the needs and views of the parents at the fore front rather than being led by professionals and/or the needs of the child/ren only. For four of the parents unhelpful relationships were experienced between themselves and staff at residential assessment centres. Experiences of these centres have not as yet been documented for parents with LD, with the exception of two studies who makes a brief mention (Baum & Burns, 2007; Edmond, 2000).

Booth and Booth (1994) found that many of the parents with LD were subjected to system abuse because of inadequate advice and no access to an advocate. However, six of the parents in the current study did have support from an advocate. The parents seemed to experience these relationships positively, as the advocate facilitated their independence whilst still being there for them when they needed support. This was unlike their experiences with some professionals. Other mothers with LD have also reported finding advocacy useful and valued being listened to and supported (Tarleton & Ward, 2007; Stenfert Kroese et al., 2002).

The differences and similarities that the parents experienced in their relationships with significant people in their lives can be explained through reciprocal role procedures (RRs). RRs are an aspect of Cognitive Analytical Therapy (CAT; Ryle, 1975). RRs relate to the patterns of how individuals relate to significant people in their lives. RRs develop between a caregiver and infant and continue to develop successfully when an infant is provided with a nurturing environment. However, when there are disruptions in parenting such as trauma, difficulties can occur. To pursue a successful relationship, an individual needs to take up a role in relation to the person they are interacting with and predict the response of the other person. For instance two roles might be 'caring' to 'cared for' and difficulties can occur if an individual who is 'caring' needs to be 'cared for' but this is not reciprocated in the relationship. Some of the parents experienced unhelpful patterns of behaviours in relationships such as 'abuser' to 'abused'. CAT can support individuals to become aware of unhelpful patterns of behaviour and apply more helpful patterns in relationships with others which some of the parents were able to do through psychological support.

Booth and Booth (1994) highlighted that parents with LD do not easily fit into one particular service, often being batted between Child and LD services. Despite the 'Good Practice Guidance on Working with Parents with a LD (Department of Health, 2007) providing guidance on how Child and LD services can work together, some of the parents in the current study did not experience collaboration between services.

The seven parents that had lost permanent or temporary custody of their children mentioned the lack of support from services following the removal of their child. Baum and Burns (2007) found that mothers with LD following the loss of their child

made sense of losing custody through external attributions such as blaming professionals. However, some of the parents in the current study made more internal attributions reflecting on what they did wrong and thinking about changes they needed to make. These parents had experienced psychological interventions as being useful in enabling them to work through their difficulties.

Baum and Burns (2007) highlighted the negative psychological impact that losing custody of a child can have. However, parents' with LD experiences of mental health problems have not been well documented in the literature. The parents in the current study did not all experience psychological distress. Those who did expressed that their difficulties were not recognised by professionals and support was not there when they needed it. O'Keefe and O'Hara (2008) have suggested that services tend to be crisis driven and the mental health needs of parents with LD are often recognised too late.

Sterling's (1998) 'determinants of parenting' model for parents with LD presents the impact three determinants have on parenting capacity; cognitive impairment, social support and depression. The relationship between depression and parenting capacity is indirect through social support. A bi-directional relationship exists between depression and social support suggesting that depression can lead to lack of social support and perceived lack of social support can lead to depression. A positive relationship was found between social support and parenting capacity suggesting that both psychological wellbeing and social support can influence an individual's experience of parenthood. The relationships between limited social support, poor psychological wellbeing and difficulties with parenting were expressed

in many of the parents' experiences of parenthood. Salina describes this relationship when speaking about her experience of PND:

*"They just said that erm I wasn't capable of looking after my child. But how did they know, they didn't give me a chance. I was suffering from postnatal depression. They should have known that". (line: 222)*

## **5.1 Recommendations for further research**

The limitations of the current study will be outlined below along with a number of recommendations for further research with parents with LD.

### **5.1.1 Selection of participants**

The current study only recruited participants who were known to services supporting parents with LD who may have more complex difficulties. Therefore it is important to identify parents with LD who are living in society without professional involvement.

All of the participants shared the experience of being a parent with LD. However, research to date has either interviewed parents with LD (e.g. Booth & Booth, 1994) or mothers with LD (e.g. Baum & Burns, 2007) and not fathers with LD. It would be interesting to investigate experiences of parenthood from the perspective of a father with LD.

### **5.1.2 Other areas of research**

Some parents with LD attend residential assessment centres to determine the adequacy of their parenting. There is limited research investigating the experiences

of both staff and parents with LD who work and live in these centres. It is also unclear how many parents with LD leave these assessment centres with their children. Research has highlighted parents' with LD preference for family-centred and home-based support (e.g. Wade, 2005). Further research is needed to identify how residential assessment centres can become less stressful for both parents with LD and the staff, and evaluate their outcome.

Three participants described experiencing PND. The psychological wellbeing of parents with LD still appears to be a neglected area and investigating mothers' with LD experiences of PND and other mental health difficulties is needed to identify how their mental health needs can best be met.

## **5.2 Clinical implications**

The following recommendations are suggested for clinicians working with parents with LD and their families:

### **5.2.1 Training**

- Providing training for individuals with LD before as well as when they become parents is of great importance. Relevant topics include discipline, psychological wellbeing and child development. Training on helpful and unhelpful relationship patterns could also benefit parents with LD. This could focus on personal relationships as well as those with professionals.
- The relationships between parents with LD and professionals seemed to be more positive when support was balanced with facilitating independence. Training for professionals is required on how to work with individuals with LD, specifically thinking

about the skills advocates use as participants spoke highly of their advocates' ability to provide emotional and practical support.

### **5.2.2 Services working together**

- In accordance to the Department of Health (2007) guidance Child and LD services need to work together. Providing a parent with LD with a social worker may help to ensure both children and parents are supported regardless of whether the child is living with their parents.

- Advocacy appears to be a useful support for parents with LD. However, many parents become involved with an advocate when they are already at risk of losing custody of their children. It is recommended that individuals with LD access advocacy support when they are planning on having children or become pregnant.

### **5.2.3 Psychological wellbeing of individuals with LD**

- Professionals need to be aware that individuals and specifically parents with LD are at risk of poor psychological health and that this is related to a lack of social support. They need to be mindful of this during assessments with support being offered before a psychological crisis arises.

## **5.3 Final personal reflections and conclusions**

Nine parents with LD have provided an insight into their experiences of parenthood. What struck me, was that despite many of them losing custody of their own children, they showed me warmth and appeared comfortable with my pregnancy, offering me advice on how I might prepare for parenthood. They were also able to share some personal and emotionally arousing stories about their

journey of parenthood, which was possibly painful for them and at times difficult for me to hear.

The current study sought to explore the experiences of parenthood from the perspective of parents with LD by applying an in-depth analysis. The parents showed similar experiences and some were echoed in past research. However, no two stories were the same and the similarities and differences between the parents can be understood through differing RRs and the 'determinants of parenting' model for parents with LD (Sterling, 1998). Further recommendations for research and for clinicians working with parents with LD have been suggested. It is hoped that these recommendations will allow us to expand our understanding of parents' with LD lives and ensure professionals working with individuals with LD are adequately trained.



## **6.0 References**

- Arcscott, K., Dagnan, D., & Stenfert Kroese, B. (1998). Assessing the ability of people with learning disability to give informed consent to treatment. *Psychological Medicine*, 29, 1367-1375.
- Aunos, M., Goupil, G., & Feldman, M.A. (2003). Mothers with intellectual disabilities who do and do not have custody of their children. *Journal of Developmental Disabilities*, 10, 65-79.
- Baum, S. & Burns, J. (2007). Mothers with learning disabilities: Experiences and meanings of losing custody of their children. *Learning Disability Review*, 12, 3-14.
- Booth, T. & Booth, W. (1993). Help of hindrance? Practitioners working with parents with learning difficulties. *Disability, Pregnancy and Parenthood International*, 4, 6-7.
- Booth, T. & Booth, W. (1994). *Parenting Under Pressure: Mothers and Fathers with Learning Difficulties*. Open University Press, UK.
- Booth, T. & Booth, W. (1995). Unto us a child is born: The trials and rewards of parenthood for people with learning difficulties. *Australia and New Zealand Journal of Developmental Disabilities*, 20, 25-39.

- Booth, T. & Booth, W. (1996). 'Supported parenting for people with learning difficulties: Lessons from Wisconsin. *Representing Children*, 9, 99-107.
- Booth, T. & Booth, W. (2002). Men in the lives of mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 187-199.
- Darbyshire, L.V. (this volume). Parents' with learning disabilities psychological wellbeing and social support: risk factors and interventions. *[Unpublished]*.
- Department of Health (2007). *Good Practice Guidance on Working with Parents with a Learning Disability*. Department of Health, UK.
- Edmond, J. (2000). On being a mother: a positive identity in the face of adversity. *Clinical Forum*, 21-25.
- Glaser, B.G. & Strauss, A.L. (1967). *The Discovery of Grounded Theory: Strategies of Qualitative Research*. Aldine de Gruyter, USA.
- Gooding, S. (2000). *A Jigsaw of Services. Inspection of Services to Support Disabled Adults in their Parenting Roles*. Department of Health, UK.
- Hymes, J.R. (1990). Notes for parents: It's not easy to be a good parent. *Child Care Information Exchange*, 73, 45-46.

- Llewellyn, G. & Brigden, D. (1995). Factors affecting service provision to parents with intellectual disability: An exploratory study. *Australia and New Zealand Journal of Developmental Disabilities, 20*, 97-112.
- 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. (2003). Experiences of mothers with learning disabilities: Learning from their voice. In: *Mothering, Occupations: Challenge, Agency and Participation* (Eds S.A. Esdaile & J.A. Olson), pp. 193-214. F.A. Davis, Philadelphia.
- Llewellyn, G., Mayes, R., & McConnell, D. (2008). Towards acceptance and inclusion of people with intellectual disability as parents. *Journal of Applied Research in Intellectual Disabilities, 21*, 293-295.
- Llewellyn, G., Mayes, R., & McConnell, D. (2008). Towards acceptance and inclusion of people with intellectual disability as parents. *Journal of Applied Research in Intellectual Disabilities, 21*, 293-295.
- Mayes, R., Llewellyn, G., & McConnell, D. (2008). Active negotiation: mothering with intellectual disabilities creating their social support networks. *Journal of Applied Research in Intellectual Disabilities, 21*, 341-350.

O'Keeffe, N., & O'Hara, J. (2008). Mental health needs of parents with intellectual disabilities. *Current Opinion in Psychiatry*, 21, 463-468.

Reid, K., Flowers, P. & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 18, 20-23.

Ryle, A. (1975). *Frames and Cages*. London: Chatton and Windus. Cited in Heppel, J. & Sutton, L. (2004). *Cognitive Analytic Therapy and Later Life: a new perspective on old age*. Routledge, UK.

Smith, J.A. & Osborn, M. (2003). Interpretive Phenomenological Analysis. In: *Qualitative Psychology: A Practical Guide to Methods* (Ed J.A. Smith), pp. 51-80. Sage, London.

Stenfert Kroese, B., 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.

Sterling, J.D. (1999). *Determinants of Parenting in Women with Mental Retardation*. The Fielding Institute, Ann Arbor: MI.

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.

- Traustadottir, R. & Sigurjonsdottir, H.B. (2008). The mother behind 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, O. (1989). Competence promoting vs. competence inhibiting social support for mentally retarded mothers. *Human Organization*, 48, 95-107.
- Wade, C.M., Mildon, R.L. & Matthews, J.M. (2005). Service delivery to parents with an intellectual disability: Family –centred or professionally centres? *Journal of Applied Research in Intellectual Disabilities*, 20, 87-98.
- Whitman, B., Graves, B. & Accardo, P. (1990). Parents learning together: Parenting skills training for adults with mental retardation. In: *When a Parent is Mentally Retarded*. (Eds B. Whitman & P. Accardo), pp. 51-65. Paul H Brookes, Baltimore.
- Xiong, Z.B., Eliason, P.A., Detzner, D.F. & Cleveland, M.J. (2005). Southeast Asian immigrants' perceptions of good adolescents and good parents. *The Journal of Psychology*, 139, 159-175.
- Yardley, L. (2008). Demonstrating validity in qualitative psychology. Interpretive phenomenological analysis. In: *Qualitative Psychology: A Practical Guide to Methods* (Ed J.A. Smith), pp. 235-252. Sage: London.

Young, S. & Hawkins, T. (2005). Special parenting and the combined skills model.

*Journal of Applied Research in Intellectual Disabilities*, 19, 346-355.