**VOLUME I**

**RESEARCH COMPONENT**

**HOW DO WOMEN WITH A LEARNING DISABILITY**

**EXPERIENCE THE SUPPORT OF A DOULA DURING THEIR**

**PREGNANCY, CHILDBIRTH AND AFTER THE BIRTH OF**

**THEIR CHILD?**

**by**

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OVERVIEW

This thesis which comprises of both a research and a clinical volume is submitted in partial fulfilment of the degree of Doctorate of Clinical Psychology (ClinPsyD) at the University of Birmingham.

Volume I, the research component, contains a literature review, empirical paper and a public domain briefing paper. The systematic literature review investigates the impact of maternal childhood sexual abuse on parenting. The empirical paper explores how women with a learning disability experience the support of a doula during their pregnancy, childbirth and after the birth of their child. It also explores the experiences of the doulas who provided the support. The public domain paper provides an accessible overview of the empirical paper.

Volume II, the clinical component, contains five clinical practice reports relating to clinical work conducted whilst on placement in a learning disability service, child, adult and an older adult speciality. The first report details a 32 year old woman with a learning disability presenting with hypochondriasis which is formulated from a psychodynamic and a cognitive behavioural perspective. Secondly an evaluation of a training package is presented alongside professionals views on the use of e-learning for delivery of the training package. The third report is a single case experimental design to evaluate a cognitive behavioural intervention of a ten year old boy presenting with anxiety. The fourth report details a cognitive behavioural intervention with a woman experiencing depression. Finally, an abstract of a case study of a 93 year old man experiencing depression alongside a number of physical health difficulties, in an acute hospital setting is included.

ACKNOWLEDGEMENTS

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# LITERATURE REVIEW

# WHAT IS THE IMPACT OF MATERNAL CHILDHOOD SEXUAL ABUSE ON PARENTING?

ABSTRACT

**Objectives:**

This review examines the influence of maternal child sexual abuse (CSA) on later parenting. The three assumptions proposed by Rumstein-McKean and Hunsley (2001) are outlined and the assumptions used to review the literature regarding maternal CSA. The assumptions are:

1. Mothers who have experienced CSA will have different parental attitudes than mothers who have not experienced CSA.
2. CSA can affect maternal functioning and how mothers who have experienced CSA parent their own children.
3. The children of mothers who have experienced CSA are also at risk of experiencing CSA themselves.

**Methods:**

To address these aims a systemic search of papers regarding CSA and maternal parenting published after Rumstein-McKean and Hunsley (2001) was conducted. Seven papers were identified and were subjected to a quality review using the guidelines published by the National Institute for Clinical Excellence (NICE) (NICE, 2004)

**Results:**

Results suggest support for the first two assumptions and provide evidence that mothers who have experienced CSA are more negative in their parenting attitudes than mothers who have not experienced CSA. There is also support for the second

assumption that CSA can affect maternal functioning and how mothers who have experienced CSA parent their own children. No evidence for the third assumption was identified from the papers, but this was discussed in the introduction of a number of papers.

**Conclusions:**

The results of the review are discussed in terms of the Rumstein-McKean and Hunsley (2001) model. Suggestions for further research in this area and a number of clinical implications are provided.

*Key words***:** Child sexual abuse, mothers, parents, maternal parenting.

*Prepared for the journal: Child Abuse & Neglect*

INTRODUCTION

**What is adequate parenting?**

From a parent's point of view the birth of a child is a significant life event and can

have emotional and physical consequences (McCauley, Kern & Kolodner, 1997). The

role of parent is a key adult role that can place significant demands on an individual

(Barnard & Martell, 1995). Newcomb and Loeb (1999) highlight how the role of a

parent is dependent upon the context in which it occurs, and the characteristics of the

individual parent and of the child involved.

Parenting is said to be the process of promoting and supporting the physical,

emotional, social, and intellectual development of a child from infancy to adulthood

(Alvy, 2007)  It refers to the aspects of raising a child aside from the biological

relationship. Alvy (2007) stressed that parenting is complex and includes a wide

range of responsibilities, as does Steinberg (1990):

*"Good parenting is parenting that helps children succeed. It promotes the*

*development of intellectual curiosity, motivation to learn and desire to achieve. And*

*good parenting is parenting that helps protect children against the development of*

*anxiety, depression, eating disorders and other types of psychological distress."*

(Steinberg, 1990, p82)

The concept of adequate parenting has been difficult to define due to a number of

different variables included in the parent-child relationship such as child age,

temperament, context, home environment and cultural variability. Long, McCarney,

Smyth, Magorrian and Dillon (2001) stated that parenting is part of a complex system in which the behaviour of one person in the system can directly influence the behaviour of another. This influence is bi-directional, each member of the family system can influence behaviour and also be influenced by other members of the system.

Belsky (1984) proposed a bi-directional model of parenting which attempts to take in to account many of the factors that impact upon parenting. This model outlines the determinants of parenting and proposes that parental functioning is determined by three factors or domains which relate to the individual differences inherent in the parenting role. The three domains are 1/ the personal and psychological resources of the parents, 2/ the individual characteristics of the child, and 3/ the levels of stress/ support available.

Belsky proposed that the personal and psychological resources the parents have at their disposal influences their parenting style. Belsky described how a parent who lacks such resources and experiences depression may parent in a way that is less sensitive and less responsive than other parents (Belsky, 1997). This may lead children to experience emotional, behavioural and developmental disorders (Cox et al, 1987). Blegen et al (2010) described how mothers who have experienced mental health difficulties may find it difficult to balance their role as a mother with their identity as a woman with a mental health difficulty. They may experience guilt or anxiety due to this imbalance, which can render a parent less able to cope with the parenting role (McClean, 1976) as personal resources are used up to cope with the mental health difficulty. This can affect the parenting and subsequently the behaviour of the child (McClean, 1976).

The individual characteristics of the child are another determinant that can affect parenting. Belsky (1984) outlined how children who are more challenging or more demanding are harder to parent than children who are more positive in their behaviour or less demanding in their interactions with others. McBride et al (2002) also identified that children with a 'difficult temperament' are parented with less maternal responsiveness than children with a more even temperament. Belsky concluded that children who are more difficult to parent will increase the stress of parents and this led to a more demanding experience of parenting.

The third determinant proposed by Belsky (1984) relates to the levels of stress/ support experienced by the parent. McLanaghan, Wedemeyer and Adelberg (1981) discussed the importance of social support on the parent-child relationship and how parents who have a good support network of family and friends describe their experiences of parenting with greater enjoyment than mothers who do not have this support. Kim, Trickett & Putnam (2010) described how through social support mothers develop an awareness of the parenting strategies of other mothers. The social environment provides guidelines for appropriate and inappropriate parenting strategies, through which positive parenting can develop (Kim et al, 2010). Kim et al (2010) also identified that parents who have higher levels of social support are more nurturing in their parenting, more consistent in their approach, and use less punitive approaches to discipline, and do not ridicule or scold their child for their behaviour.

Belsky concluded that the three determinants of parenting are bi-directional in nature. Stress and support can have an impact upon parenting through psychological well-being. Individual characteristics of both the parent and the child can also influence

the parenting relationship. Belsky prioritised the influence of the three determinants upon parenting. The most influential determinant is psychological well-being which can act as a buffer to stress and the characteristics of the child. Strengths or a weakness in any determinant can influence parenting practices and no one single factor alone is responsible for the quality of the parenting provided. Thus, parenting is dependent on many factors: on the parent and the child and the relationship between them, on contextual and environmental factors such the quality of social support received. As such, parenting can be viewed as a system, able to compensate for weaknesses in one area by having strengths in another (Belsky, 1984).

Parenting styles can be transferred between generations as when children become parents they may model the parenting styles of their own parents (Barrett & Fleming, 2011). Kim et al (2011) described the continuity of parenting across generations whereby specific behaviours are learnt and passed on through the child modelling the behaviour of the parent. This behaviour then becomes part of the child's parenting format and is utilised when they have their own children, either consciously or unconsciously.

**What is abuse?**

Abuse in childhood can take many forms, some of which are more easily identified than others (Sneddon, Iwaniec & Stewart, 2010). Abuse which occurs during childhood can have negative effects both short term and long term (Sneddon et al, 2010). Various forms of abuse may occur at the same time, or at different times during childhood (Sneddon et al, 2010).

Sneddon et al stated that if abuse occurs when a child is young, they might not distinguish it from other behaviours and fail to classify it as abuse (Goodman, Quas & Ogle, 2010). The classification of abuse may happen later in adulthood when the individual is more aware of what constitutes abuse.

Abuse in childhood has been identified as having various negative effects, these include difficulties in mental, emotional and physical health, and social relationships (Mapp, 2006). Teicher, Samson, Polcari and McGreenery (2006) examined the cognitive effects of CSA and whether CSA could affect the developing brain and in agreement with earlier research by DeBellis (2001) concluded that maltreatment in childhood results in alterations in biological stress systems that can adversely influence the development of the brain and can have long-lasting effects so that experiences in childhood can determine both the organisational structure and functional status of a mature brain (Perez & Wisdom, 1994).

**How has childhood sexual abuse been defined?**

Child sexual abuse (CSA) is an 'umbrella term', including many definitions (Hulme & Agrawal, 2004). Marcenko, Kemp and Larson (2000) defined CSA as any sexual act inclusive of genital exposure with or without physical contact or penetration. Browne and Finkelhore (1986) defined CSA as any forced or coerced sexual behaviour upon a child, or sexual activity between a child and a person five or more years older, whether this involves coercion or not. Schuetze and Das Eiden (2005) identify two categories of CSA on the basis of whether it involves physical contact or not. Contact CSA includes at least one form of physical contact, such as intercourse or genital contact. Non-contact CSA includes sexual invitations or exhibitionism either from a family member or another adult before the child is 18. They highlighted that CSA may or may not include the use of violence or physical force.

Sneddon et al (2010) defined sexual abuse as children and adolescents being involved in sexual activities which they do not understand or are unable to consent to. These may or may not involve physical contact.

Thus, there are a number of definitions of CSA. What they have in common is that it is said to occur with or without physical contact, it may or may not include coercion, the perpetrator can be a family member or a non-family member or peer, and it may or may not include the use of physical force or violence.

**What is the incidence of CSA in women?**

Although it is difficult to identify the numbers of women who have experienced CSA, Bolen and Sannapieco (1999) in their US study estimate that between 30-40% of women have experienced a form of CSA. Oates et al (1998) provided a broader estimate of the prevalence of CSA in women in the US of between 7% and 62%. They reflected upon the wide range which was dependent upon the response rate achieved, how broad/ narrow the definition used by the authors was, and how the individual themselves defined the abuse. Sneddon et al, (2010) concluded that 20% of women in their UK prevalence study had experienced CSA either as a single form of abuse or alongside other forms of maltreatment.

Kelly, Regan and Burton (1991) conducted an exploratory study to examine the rates of CSA in a sample of 16-21 year olds. It was identified that one in two girls and one in five boys in the UK could identify an unwanted experience of CSA before they were 18 years old. May-Chahal and Cawson (2005) in their UK study identified that 16% of children/ young people under the age of 21 described themselves as having experienced CSA.

Thus, due to variation in definition, prevalence of CSA varies widely although there is a consensus that a significant minority of females have experienced this type of abuse.

**What is the impact of CSA?**

The experience of CSA and the impact it has varies between individuals (Simpson, 2010). However, long-term effects of CSA have been found to include a broad range of psychological difficulties combined with cognitive and social difficulties (Fergusson & Mullen, 1999; Yampolsky, Lev-Wiesel & Ben-Zion, 2010) in addition to physical health difficulties (Kendall-Tackett, 2002). Kendall-Tackett (2002) identified that CSA survivors were physically unwell more often and are at increased risk of a chronic pain syndrome, and a wide range of other long-term conditions such as ischaemic heart disease, cancer, stroke, bronchitis and diabetes (Kendall-Tackett, 2002). Kendall-Tackett (2002) concluded that CSA was related to physical health difficulties through a complicated process inclusive of four pathways: emotional, social, behavioural and cognitive pathways.

The emotional pathway highlights the negative emotions that may be experienced as a result of CSA. These include PTSD and depression, both of which can significantly affect physical health. Briere and Elliot (1994) identified that those with a history of CSA are four times more likely to develop depression. In relation to PTSD Kendall-Tackett (2002) concluded that although the majority of people who experienced CSA do not meet the clinical criteria for PTSD, they experience symptoms of PTSD such as flashbacks, intrusive thoughts and hyper-vigilance.

The social pathway relates to how an adult survivor of CSA forms and maintains social relationships with others. Adult survivors of CSA often form relationships that are exploitative or victimising (Fleming, Mullen, Sibthorpe & Bammer, 1999), they tend to be less satisfied with relationships and describe themselves as socially isolated (Teegen, 1999). In addition, they experience a higher rate of abuse than the general population (Felitti, 1991; Fleming et al, 1999).

Kendall-Tackett outlined the behavioural pathway as the likelihood of adult CSA survivors to engage in behaviours that are harmful to their health such as substance abuse, eating disorders, suicide and high-risk sexual behaviour. They are also more likely to experience sleep difficulties.

The cognitive pathway includes the beliefs, values and attitudes that adult survivors of CSA hold, and that can have an influence on their health. Briere and Elliot (1984) described how CSA can influence an individual's working model of the world. They highlight how an experience of CSA can lead to the development of a negative inner working model that includes a chronic perception of helplessness, powerlessness and danger.

Yampolsky et al (2010) examined whether women who had experienced CSA were more at risk of distress during pregnancy, as both CSA and pregnancy are connected to sexuality, although they can occur at different times in a woman's life. Yampolsky et al concluded that during pregnancy women who had experienced CSA reported higher levels of stress than those without a history of trauma and heightened probability of having a high-risk pregnancy and possible gynaecological problems.

The relationship between CSA and adverse long-term effects may not be clear-cut (Yampolsky et al, 2010). There is a distinct difference between individuals who experience CSA and appear to be resilient to adverse long-term effects and those survivors who experience psychological ill health such as post-traumatic stress symptoms, depression or anxiety in later life (Yampolsky et al, 2010). Fleming et al (1999) identified that the impact of CSA is ameliorated by a supportive and nurturing

family that can provide a safe environment where a child can 'recover' from the effects of the CSA and can experience the stability necessary for more normal development. Bhandari, Winter, Messer and Metcalfe (2011) also concluded that the impact of the abuse is affected by the family environment.

Thus, not all women who have experienced CSA will respond in the same manner nor will their parenting be affected in the same way (Brekenridge, 2006). Moreover, the effects of CSA can fluctuate across the life span of the individual and have various effects at different points during a person's lifespan (Briere, 1992).

## How does CSA affect parenting?

Weissmann Wind and Silvern (1991) identified parenting to be influenced by CSA. Cohen (1995) found that females who experienced CSA scored significantly lower on scales of general parenting measures than non-abused women (Cole & Putnam, 1992). It has also been identified that those who experienced CSA are more likely to report a negative view of themselves and their own parenting abilities (Cohen, 1995).

Research has also identified CSA to have longer-term repercussions for adult mental health, parenting relationships and child adjustment in the following generation (Kendall-Tackett, 2002; Noll, 2008). Dubowitz et al (2001) identified that abuse which happened to mothers in early childhood and early adolescence had 'poorer outcomes' than for mothers who were abused during a later period in their lives. Poorer outcomes included maternal depressive symptoms, harsher parenting and also more externalising and internalising behaviour problems in their own children.

Adults who have experienced CSA and become parents are said to base their parenting behaviours on what they learned as children (Muller, Gragtmans & Baker, 1995), creating an inter-generational cycle of maltreatment and dysfunction (Zuravin & Fontanella, 1999).

CSA has been associated with disruption in the relationship between parent survivors and their children and with a large range of effects upon parenting style and ability (Vasconcelos, 2007). Such disruptions have been termed as 'ripple effects' of CSA (DiLillo & Damashek, 2003) describing the risk factor for 'inter-generational abuse' (Leifer, Kilbane & Kalick, 2004).

**The Rumstein-McKean and Hunsley (2001) Review**
This review aimed to identify existing empirical research addressing secondary trauma resulting from CSA in women. The authors critically examined the empirical literature published between 1996 and 1999 on females who had experienced CSA and their interpersonal functioning.

A computerised search of databases was carried out and ten empirical studies from peer reviewed journals were identified for the review which indicated that women who had experienced CSA experienced 'problems' in maternal attitudes and maternal functioning. Moreover, intergenerational patterns of CSA were highlighted.

**The Rumstein-McKean and Hunsley (2001) Model of CSA on Parenting**
The model of Rumstein-McKean and Hunsley (2001) was developed following a review of the literature which examined the impact of CSA on parenting. They identified three mediating factors as addressed by research studies prior to 2001.

Rumstein-McKean and Hunsley (2001) stated that these three factors can each have an independent effect upon the parenting of mothers who have experienced CSA. This model is presented below:

*Figure 1: Rumstein-McKean & Hunsley's (2001) Model of the Impact of CSA on Parenting.*
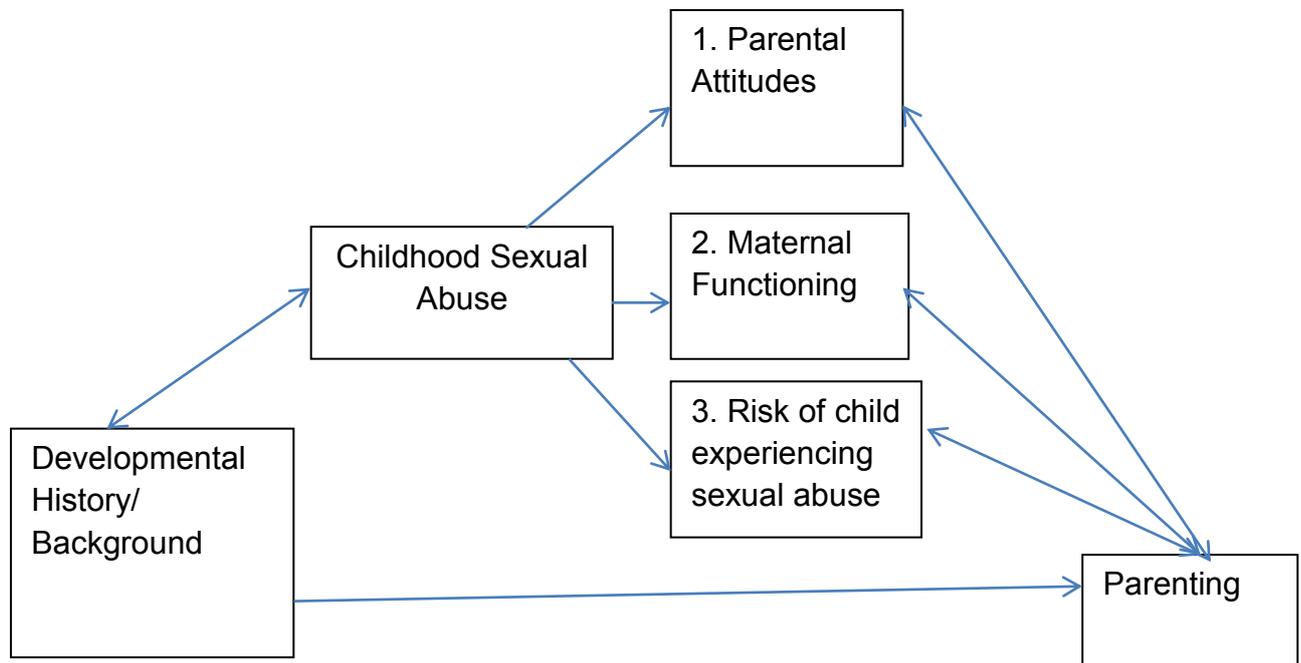


**Description of the model**

The Rumstein-McKean and Hunsley model illustrates how parenting is influenced by the developmental history and background of the parent. The model proposes three main notions of how CSA can influence parenting and family functioning. Due to the prevalence of CSA in women, this review will focus upon how CSA affects mothers.

The first of these influences is through parental attitudes such as through more permissive parenting and the model suggests that these parental attitudes are different from the attitudes of women who have not experienced CSA. Rumstein-McKean and Hunsley (2001) postulated that mothers who had experienced CSA would be less accepting of their children than those mothers who had not. They proposed that this may be due to difficulties in forming relationships with others (Flemming et al, 1999; Felitti, 1991).

The second factor is that CSA can affect maternal functioning and how mothers who have experienced CSA parent their own children. From their review of the available research Rumstein-McKean and Hunsley (2001) concluded that mothers who have experienced CSA are more likely to be harsh and detached in their style of responding to their children.

In addition, the authors reported that the children of mothers who have experienced CSA are also at risk of experiencing CSA themselves, It is argued that being a child of a mother who has herself experienced CSA makes a child more likely to experience CSA due to family culture, the wider environment in which a child grows up, or due to the nature or style of parenting.

AIMS OF LITERATURE REVIEW

The aim of this review is to systematically evaluate the evidence relating to the impact of maternal childhood sexual abuse on parenting. This review will use the three notions of Rumstein-McKean and Hunsley (2001) as a guide to establish what evidence has been published since the Rumstein-McKean and Hunsley (2001) paper relevant to the following hypotheses:

1. Mothers who have experienced CSA will have different parental attitudes than mothers who have not experienced CSA.

2. CSA may affect maternal functioning and as such may affect how mothers who have experienced CSA parent their own children.

3. The children of mothers who have experienced CSA are at risk of experiencing CSA themselves.

**Definitions**

As this literature review focusses on parenting and CSA, these terms will be defined. Throughout this review the following definitions will be used,

Parenting: The rearing of a child or children, especially the care, love, and guidance given by a parent (www.thefreedictionary.com/parenting).

CSA: At least one sexual contact or noncontact such as sexual invitations or exhibitionism either from a family member or another adult before the child is 18 of which they do not understand or are unable to consent to.

METHOD

Following the Rumstein-McKean and Hunsley (2001) paper which proposed three main notions of how CSA can affect family functioning, the literature regarding CSA and parenting was reviewed to examine whether literature published since this date supported these three factors.

This paper reviews the literature from 2001 onwards including to May 2012. A systematic search of electronic databases was carried out. Computerised searches of databases were undertaken between August 2011 and May 2012. The databases used were:

1. OVID
2. Psycinfo
3. Medline
4. Cinahl
5. Web of Science
6. EMBASE

**Search strategy**

The following search terms used were:

- sexual abuse
- childhood
- children
- parenting
- parent

- mothers

- abuse

- childhood sexual abuse

- adolescent

- maternal

With a focus on the review selection/ inclusion criteria the electronic databases were searched to identify relevant peer reviewed papers to review.

**Selection/ Inclusion Criteria**
- Published in or after 2001

- Written in English

- Inclusion of child sexual abuse (CSA) in parents' own childhood

- A focus on the impact of CSA on parenting

The search strategy and the numbers of papers identified are presented in Tables 1 and 2.

*Table 1: The initial search strategy.*

| Search Term | Number of papers identified |
|---|---|
| Sexual abuse | 23644 |
| Childhood sexual abuse | 3936 |
| Childhood | 259688 |
| Children | 825427 |
| Adolescents | 18503 |
| Mother/ Mothers | 121716 |
| Maternal | 215811 |
| Parent | 165274 |
| Parenting | 31759 |

*Table 2: The combinations of search terms and search strategy used.*

| Search Term Combinations using 'And' | Number of papers identified |
|---|---|
| **Search strategy Combination 1** | |
| Sexual abuse | 2807 |
| Child sexual abuse | |
| Children | |
| Childhood | |
| Adolescent | |
| **Search strategy combination 2** | |
| Parents | 31759 |
| Parenting | |
| Mother | |
| Maternal | |
| **Search Strategy combination 3** | |
| Combination 1 | 1332 |
| Combination 2 | |
| **Search Strategy combination 4** | |
| Combination 3 | 432 |
| Without studies regarding pregnancy | |
| **Search Strategy combination 5** | |
| Combination 4 | 139 |
| Only studies with CSA | |
| | |
| Remove duplicates | 91 |

**Search Findings**

Initial searches from the databases yielded 91 articles. Following reading of the

abstracts of these papers 84 were discarded. This process is presented in Table 3

below.

*Table 3: Articles discarded*

| Number of Papers | Number Discarded | Reason for Discarding |
|---|---|---|
| 91 | 38 | Not linking CSA and parenting |
| 53 | 11 | Review papers |
| 42 | 10 | About adolescents aged over 18 years |
| 32 | 5 | Family relationships, not parenting relationships |
| 27 | 13 | About biology |
| 14 | 7 | About teaching/ coping strategies |

Following this process, seven papers met the inclusion criteria and are included in

this review.

RESULTS

This section will include a description of each of the seven articles included. This will be followed by a systematic assessment of each paper that will be based on the quality of the paper. Each article can relate to more than one of the three research questions/ assumptions made and so may be included and discussed within more than one of the assumption sections.

**Description of the studies**

The majority of the studies (5) were carried out in the US, one was completed in the UK and one in Canada. The research studies were carried out either by interview alone (Schuetze & Das Eiden, (2005), by questionnaire and interview (Kim, 2010; Roberts, O'Connor, Dunn & Golding, 2004; Barrett, 2009; Libby, Orton, Beals, Buhwald & Manson, 2008; Banyard, Williams & Siegel, 2003) or by questionnaire alone (Ruscio, 2004). In the studies that used both questionnaires and interviews, the interviews were semi-structured.

Four of the studies can be classed as case-control studies. These are studies that employ a between-groups comparison design, in this instance between mothers who have experienced CSA and those who have not. Three studies report use of a cohort design which is a form of longitudinal study which compares a cohort, a group of people who all share a characteristic or an experience, to a population which has a limited exposure to the area being studied, but is otherwise similar (Robson, 2002)

Only one study recruited both mothers and fathers, the other six recruited only mothers. Four studies involved participants already involved in longitudinal studies, one study recruited mothers who were using outpatient clinics and one study had only one recruitment criteria, that participants were parents of a child. Two of the

studies collected data via postal questionnaire, the other five conducted face-to-face interviews with participants.

A range of questionnaires were used to measure parenting. Each study administered at least one standardised measure of parenting which assessed parenting stress or parenting satisfaction, four studies reported on their reliability and validity.  Two studies report the use of two measures of parenting.

Two studies report the use of measures designed for use in the study. One of these presents measures of the validity and reliability for their questionnaire (Libby et al, 1998). However, Ruscio (2001) does not present statistical evidence for validity or reliability for the questionnaire designed for and used in their study, and so the properties of this measure are unknown. In summary, six of the studies used standardised measures of parenting, only one study used a measure of parenting that was not standardised (Roberts et al, 2004).

Each study reported the use of a measure of CSA, three of these measures were standardised. In addition, two studies asked participants about their experience of CSA in a semi-structured interview format. Four studies provided a definition of CSA.

Each study described how participants had been identified as having experienced CSA. Three studies, which formed part of on-going longitudinal studies outlined how participants had been identified as having experienced CSA at the start of the research, and had been selected for the present study. Four studies assessed CSA experiences during the research, either at the time of enrolment for the study or during the first research interview.

Each of the papers reviewed had obtained a large sample size of participants. It was noted by Robson (2002) that studies of a cross sectional or cohort design should allocate at least 15 participants to each variable being investigated. The sample sizes in the articles being reviewed range from 45 to 8292 and so are well over the minimum sample size proposed by Robson.

With regard to ethical considerations and informed consent, three studies gained informed consent from participants and two studies gained both consent and briefly described other ethical considerations. Two studies did not provide a description of ethical considerations or informed consent.

**Quality criteria for this evaluation**
To assess the methodological criteria for the papers used in this study a quality criteria framework was used. This checklist was provided by the National Institute for Clinical Excellence (NICE, 2004) and provides criteria for the evaluation of the quality of research (see Appendix 1). This framework provides a rating of a paper which can range from a ++ rating which identifies that most criteria have been fulfilled, a + rating identifying that some of the criteria have been fulfilled and a – rating which highlights that only a few, or none, of the criteria have been met.

*Table 4: Summary of articles selected for review*

| Author, year and origin | Sample size | Study Aims | Study type and quality rating | CSA and parenting measures | Other outcome measures | Results relevant to review |
|---|---|---|---|---|---|---|
| Ruscio (2001) USA | 45 mothers receiving outpatient mental health services | ~To determine whether parenting practices employed by CSA survivors differed from those of mothers in the community. ~To determine whether CSA was a unique predictor of parenting practices above and beyond other experiences commonly | Case-control **2+** **Some criteria fulfilled** | ~Childhood Experiences Survey (Ruscio, 2001) ~The Parenting Attitude Questionnaire (Ruscio et al., 2001) ~Parenting Practices Questionnaire (Robinson et al., 1995) | ~Social Support Questionnaire (Sarason et al., 1983) ~Socioeconomic Status (Nock and Rossi, 1979) | ~Abuse survivors reported more permissive child rearing practices than the community sample mothers. ~CSA was not a predictor of parenting attitudes, an interaction between CSA and SES was found to predict parenting attitudes. |

| | | associated with CSA.<br><br>~To determine whether the severity of the abuse moderated the relationship between CSA and parenting.<br><br>~To examine aspects of survivors' psychological adjustment through which CSA might indirectly affect parenting. | | | | ~CSA severity was associated with diminished social support satisfaction and social support satisfaction was positively linked to authoritative parenting. |
|---|---|---|---|---|---|---|
| Kim et al. (2010)<br><br>USA | 127 in total including 123 biological mothers and 4 adoptive mothers | ~To explore the relationship between CSA and parenting practices among non-offending mothers of sexually abused girls.<br><br>~To examine the extent | Cohort-study<br><br>**2++**<br><br>**Most criteria** | ~Mother's Developmental History Questionnaire (Trickett and Everett, 1988)<br><br>~The Dissociative | ~Interview to gain ratings of the frequency of discipline, satisfaction with social support. | ~CSA was a significant predictor of mother's parenting practices. It predicted less positive structure in parenting relationships and practice, but more |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | to which mother's childhood experiences and social support contribute to their parenting practices. | **fulfilled** | Experience Scale (Bernstein and Putnam, 1986)<br><br>~Interview to gain ratings of parenting practices on a likert scale. | | punitive discipline. |
| Roberts et al. (2004) UK | 8292 families, a subsample of a longitudinal study | ~To investigate the links between CSA, later mental health, family organisation, parenting behaviours and adjustment in offspring. | Cohort-study<br><br>**2+**<br><br>**Some criteria fulfilled** | ~A detailed history was gained including<br><br>~A self-report measure of CSA with a 5 point likert scale.<br><br>~A series of eight statements concerning parent-child relationships were rated. | ~The Strengths and Difficulties Questionnaire (Goodman, 1987).<br><br>~The Edinburgh Post-Natal Depression Scale (Cox et al, 1987)<br><br>~The Crown-Crisp | ~The presence of CSA combined with poor psychological well-being lowers maternal enjoyment of parenting. |

| | | | | ~Measure of Maternal Bonding (Parker, 1988) | Experimental Index (Crown and Crisp, 1979).<br><br>~Backman Self Esteem Scale (Medora et al., 1993) | |
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| Barrett<br>(2009)<br>Canada | 483 mothers in a sample of predominantly African-Asian women receiving public assistance | ~Investigated the link between CSA and adulthood parental stress, parental warmth, use of non-violent discipline strategies, psychological aggression and the use of physical punishment. | Cohort-study<br><br>**2+**<br><br>**Some criteria fulfilled** | ~CSA: was identified through a 'two-part' indicator to determine the presence and severity of CSA.<br><br>~The Parenting Stress Index (Abidin, 1995) | ~Home Observation for Measurement of the Environment Scale (Caldwell and Bradley, 1984).<br><br>~The Parent-Child Conflict Tactics Scale | ~CSA survivors were found to have significantly lower rates of parental warmth, higher rates of psychological aggression and more frequently used corporal punishment than mothers who had not |

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| | | | | | Revised (Strauss et al., 1998) | experienced CSA. |
| Schuetze and Das Eiden (2005) USA | 263 primiparous women  107 with a history of CSA  156 comparison mothers | ~To examine whether the association between CSA and parenting outcomes was direct or indirect, through a mediational role of maternal depression or experiences with partner violence. | Case-control  **2++**  **Most criteria fulfilled** | ~CSA (Russell, 1983)  ~The Parenting Stress Index (Abidin, 1995)  ~The Parenting Sense of Competence Scale (Gibaud- Wallston and Wandersman, 1978) | ~Center for Epidemiological Studies Depression Scale (Radloff, 1977)  ~The Conflict Tactics Violence Scale (Straus, 1979; Straus and Gelles, 1989) | ~CSA is significantly associated with parenting outcomes (p=.05) and with punitive parental discipline (p<.05)  ~Mothers with a history of CSA were more likely to have negative parental perceptions and were also more likely to be punitive with their children.  ~The effects of CSA on parenting are indirect. |

| Banyard et al. (2003) USA | 152 women, 76 had experienced CSA, 76 were a matched comparison group with no documented history of CSA.<br><br>(from a sample of 174 women interviewed in the third wave of a longitudinal study) | ~To begin to examine both unique and common contributions of a variety of types of childhood and adult trauma on parenting outcomes. | Case-control<br><br>**2+**<br><br>**Some criteria fulfilled** | ~The Parenting Stress Index (Abidin, 1995)<br><br>~CSA (Russell, 1983)<br><br>~Trauma Composite (based on Turner and Lloyd, 1995)<br><br>~A structured interview was also carried out which included questions regarding 'witnessing harm or violence as a child', 'Social support', 'Spirituality', 'Parenting satisfaction' and 'reporting of child | ~The Conflict Tactics Scale (Straus, 1990)<br><br>~The Trauma Symptom Inventory (Briere, 1985)<br><br>CTSPC Neglect Scale (Strauss et al., 1998)<br><br>~Conflict Tactics Scale (Trauma) (Straus, 1990) | ~The experience of a trauma such as CSA was related to problems in parenting children.<br><br>~CSA did not on its own directly relate to any of the parenting outcome measures, except if it was experienced as a trauma. |
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| | | | | abuse'. | | |
| Libby et al. (2008) USA | 2221 parents from two different tribes. | ~To explore the relationship of CSA and CPA with reported levels of parenting satisfaction and parenting role impairment later in life among American Indians. | Case-Control **2+** **Some criteria fulfilled** | ~Parenting Satisfaction Index (Libby, 2008) ~AI-SUPERPFP trauma section of questionnaire (Libby et al., 2005; Libby et al., 2004) | ~Psychiatric Disorders assessed using items from the University of Michigan version of the Composite International Diagnostic Interview (WHO, 1990). ~Physical and Sexual victimization: was identified through a 'two-part' indicator to | ~CSA significantly decreased parenting satisfaction in one tribe, The Southwest Tribe (p=<0.01), but not in The Northern Plains Tribe. |

| | | | | | determine the presence and severity. | |
| --- | --- | --- | --- | --- | --- | --- |
| | | | | | ~Through a semi structured interview respondents were also asked about level of 'social support' and 'family of origin problems'. | |

DO THE STUDIES SUPPORT THE THREE MAIN NOTIONS PROPOSED BY RUMSTEIN-MCKEAN AND HUNSLEY (2001) OF HOW CSA CAN AFFECT MATERNAL PARENTING?

The three notions will be presented individually and support for each presented and discussed. A number of the studies present evidence for more than one assumption and so may be discussed with regard to more than one assumption.

**Assumption 1**
*Do mothers who have experienced CSA have different parental attitudes?*

Three studies examined whether mothers who have experienced CSA had differing parental attitudes to those mothers who had not experienced CSA (studies 1, 2 and 5 in Table 4). Two of these studies were case-control studies which both received a quality rating of (2++), the third study was a cohort study which also received a quality rating of (2++). Each of the three studies that presented information with regard to CSA and parental attitudes described CSA as having a negative impact upon parenting and parental attitudes.

Kim et al (2010) described how CSA was a significant predictor of mothers parenting practices, it predicted less positive structure in parenting relationships and in parenting practice and also that discipline of the child would be punitive. Schuetze and Das Eiden (2005) also identified that parents who experienced CSA were more likely to be punitive towards their children, in addition to holding negative perceptions about them. This study also provided statistical evidence that CSA is significantly associated punitive parental discipline.

Ruscio (2001) also identified a relationship between CSA and parental attitudes in that mothers who had experienced CSA reported more permissive child rearing practices that the mothers in the community sample who had not experienced CSA.

The three studies utilised a range of measures, Ruscio (2001) designed her own measures which had yet to be standardised, although had been designed to be used with mothers who had experienced CSA. Kim et al (2010) used two standardised measures and also interviewed participants to ask directly about their parenting practices. This study described the use of trained interviewers who were able to ask sensitively about experiences of CSA and were able to identify information about the onset, severity and duration of the abuse the mother had experienced, and also whether anyone else in the family had experienced CSA. Schuetze and Das Eiden (2005) used two standardised measures to assess parenting stress and parenting competence, and a questionnaire specifically designed and standardised to identify experiences of CSA in mothers.

There are a number of confounding variables which may have affected the research in this area. CSA can cause psychological difficulties such as depression, anxiety or PTSD which is said to indirectly affect parenting. Only one of the studies (Schuetze & Das Eiden, 2005) included a depression scale. The other studies did not include any measure of psychological well-being. Another factor identified to have an influence upon parenting practice is social support. Only Ruscio (2001) and Kim et al (2010) included a measure of social support in their study.

In summary, three out of the seven studies reviewed identified that mothers who had experienced CSA had different parental attitudes to mothers who had not experienced CSA. Ruscio (2001) identified that mothers who had experienced CSA were more permissive in their parenting. This contrasts to the conclusions of Kim et al (2010) and Schuetze and Das Eiden (2005) who identified that mothers who had experienced CSA used punitive parenting strategies.

Punitive attitudes to parenting use punishment as a way to teach children the difference between appropriate and inappropriate behaviour, and as a way to extinguish inappropriate negative behaviour (Woodward, Fergusson, Chesney & Horwood, 2007). With this style of parenting the child learns how to avoid punishment, not about appropriate behaviour (Woodward et al, 2007). Woodward et al (2007) state that extremely punitive parenting can be classed as abuse. Within this study Woodward defines punishment in terms of a parent using 'physical force' to discipline their child. The use of physical force forms a continuum with smacking on the hand or bottom at the lower end actions that can cause injury to a child at the top of the continuum regardless of the parents' actual intentions.

Permissive parenting stems from the failure to define, explain and enforce appropriate rules and boundaries (Maccoby, 1992). Any rules that are in place tend to be inconsistent and there are very few standards of behaviour in place (Baumrind, 1967). Permissive parents are undemanding of children and try to avoid conflict with them (Baumrind, 1967).

These two styles of parenting appear to be opposites. However, the consequences of these styles are similar (Baumrind, 1967). Both permissive and punitive parenting place little emphasis on teaching the child new skills, there is no focus upon modelling appropriate behaviour to the child, and the child is rarely praised (Neal & Frick-Horbury, 2001) with negative consequences for the child's social, emotional and cognitive development.

**Assumption 2**
*Does CSA affect maternal functioning and how they parent their own children*

Six of the seven studies provided information regarding this assumption. However, there was considerable variety as to how much information was presented in support. Three of the studies were case control studies, of these one received a quality rating of (2++) and two received a quality rating of (2+). Three of the studies were cohort studies, of these one received a quality rating of (2++) and two received a quality rating of (2+).

Kim et al (2010) and Barrett (2009) both identified that CSA had a significant impact upon maternal functioning and the parenting role. The study of Kim et al (2010) also examined the role of social support and the contribution this could make to parenting practices. It was identified that social support was able to buffer the effect of the CSA and lessen the negative impact on the parenting role.

Schuetze and Das Eiden (2005) also concluded that the relationship between CSA and parenting was indirect. They identified that the relationship between CSA and

parenting was mediated through the mother's experiences of depression and partner violence, which they suggested women with a history of CSA are more likely to experience depression than mothers without a history of CSA.

Banyard et al (2003) also identified that the link between CSA and parenting practice was indirect. This included neglectful behaviours, lowered parental satisfaction and increased levels of physical punishment. In both the Banyard et al (2003) and the Schuetze and Das Eiden (2005) studies the link between CSA and parenting is an indirect relationship mediated by other variables: an experience of a childhood trauma, other than CSA, depression and partner violence.

Parenting satisfaction was included in three studies. Schuetze and Das Eiden (2005) identified that CSA significantly decreased parenting satisfaction. Libby et al (2008) identified CSA decreased parenting satisfaction in one tribe, The Southwest Tribe, but not in the other tribe known as The Northern Plains Tribe. Roberts et al (2004) also identified a link between CSA and parenting satisfaction, but this was an indirect link mediated by the presence of poor psychological well-being. Roberts et al discussed how mental health difficulties such as anxiety or depression with the presence of CSA could lower maternal enjoyment of parenting.

In summary, all of the six papers identified a link between CSA and maternal functioning. Three of the papers also provided evidence that CSA is associated with lower maternal satisfaction with the parenting role. The presence of a mediating factor such as the experience of a childhood trauma, mental health difficulties and partner violence between CSA and maternal functioning was highlighted.

**Assumption 3**
*The third notion is that the children of those who experienced CSA are themselves at*

*risk of CSA.*

None of the seven studies selected for this review provided direct evidence that the

children of those who experienced CSA were themselves at risk of CSA. The

assumption of Rumstein-McKean and Hunsley (2001) could not be supported.

Two of the papers selected for review provided tentative support to the

intergenerational cycle of CSA. Banyard et al (2003) and Kim et al (2010) discussed

intergenerational effects of CSA in the introduction of their paper but this notion was

not empirically tested.

DISCUSSION

The articles included in this review address the link between CSA and parenting capacity in women. Although none of the studies provided evidence to support all three of the notions, they provided robust evidence to contribute towards the growing body of literature regarding the effects of CSA on maternal parenting.

This literature review suggests that there is empirical support for the first assumption that mothers who have experienced CSA are more negative in their parenting attitudes and more punitive towards their children than mothers who have not experienced CSA. There is also support for the second assumption that CSA can negatively affect maternal functioning. No evidence for the third assumption was identified in any of the papers.

**Limitations to Quality Framework**

The quality framework used to assess the methodological criteria of papers was provided by The National Institute of Clinical Excellence (NICE, 2004). This framework was selected for the review as the framework provided a method of evaluating both types of methodology (case-control and cohort-study) used by the papers selected for review. However, there are limitations to this framework; both case-control and cohort-study are evaluated using the same framework and therefore the methodological criteria used in the evaluation are very broad. This led to a 'ceiling effect' for the ratings, allowing little differentiation between the quality of the various papers and thus the quality of the paper was

determined more by the judgement of the author of the review than as a result of a systematic assessment.

**Recommendations for future research**
The review did not find support for the third assumption proposed by Rumstein-McKean and Hunsley (2001). That is, the children of mothers who have experienced CSA are at risk of CSA themselves. This concept, known as inter-generational abuse, was discussed in two studies but did not form part of the research. Further research could be conducted to examine whether this assumption is valid or not.

Factors mediating the link between CSA and maternal parental functioning were highlighted. These included the experience of CSA as a trauma, mental health difficulties and the presence/absence of social support and a 'safe' home environment. Future research could further investigate the factors that mediate between CSA and maternal parenting in order to develop evidence-based interventions to help the mother to have a more positive experience of parenting and improve her parenting capacity.

Each study examined how CSA affects the parenting role. Future research could develop a standardised questionnaire to measure CSA experiences in terms of frequency, intensity and long-term impact. A standardised tool would ensure reliability and validity, presently lacking in the studies reviewed here.

An alternative method of collecting data on CSA would be to take a qualitative approach and collect information through semi-structured interviews with open-ended questions. One of the studies reviewed (Banyard et al, 2003) trained interviewers to

ask questions in a sensitive, non-blaming manner that encouraged participants to talk about difficult past experiences. Qualitative methodologies such as Interpretive Phenomenological Analysis (IPA) which focuses upon an individual's lived experience (Johnson, Burrows & Williamson, 2004) and aims to gain an understanding of the experiences of participants, in this case of experiencing CSA, and the interpretation of these experiences. The use of IPA following interviews with women who have experienced CSA may help provide more in-depth information about the way women have experienced and have been affected by CSA and how they experience the parenting role and their mental health problems.

Only one of the studies reviewed here (Libby et al, 2008) focussed upon CSA and potential effects upon fathers in addition to mothers. Future research could examine fathers who have experienced CSA and how CSA could affect their parenting.

Finally CSA is one form of childhood trauma. Many others exist such as child physical abuse, neglect and emotional abuse. CSA may occur as one part of other forms of abuse, or alongside other forms of abuse (Barrett, 2009). It can be difficult to take one of the forms of abuse and look at the effects it has without examining the effect of the other forms of abuse, which can occur during childhood and have an influence upon later parenting.

**Recommendations for clinical work**
The experience of CSA has been identified to affect parenting and clinicians need to be aware of this when working with a parent who has experienced CSA. Not every

parent who has experienced CSA will develop difficulties in their parenting. This can make identification of those who are having difficulties parenting more difficult.

One recommendation for clinicians is the use of reliable, standardised measures to help in the identification of CSA. Parenting support could then be offered at an early stage and encouragement and appropriate teaching (e.g. on attachment) provided.

Another recommendation is to provide support groups for parents who have experienced CSA and have difficulties with parenting. This could provide parents with a form of social support that as a mediating factor can ameliorate the negative impact of CSA on parental functioning.

Finally, clinicians may be able provide more effective services if they can identify and provide therapy for parents' mental health difficulties (such as anxiety, depression and PTSD) resulting from the experience of CSA and affecting parenting capacity. Cognitive Behaviour Therapy (CBT) could provide a useful framework for therapeutic intervention with parents who experienced CSA. CBT could provide a 'safe' environment for exposure to the memories of the experience and to address feelings which stem from the abuse whilst learning new coping skills (King et al, 1999). CBT could also offer techniques such as cognitive reframing, thought stopping and the use of positive imagery to aid therapeutic change (Ramchandni & Jones, 2003)

## CONCLUSIONS

It has been identified that mothers who experience CSA have different parental attitudes than mothers who have not experienced CSA. The review also identified that CSA could have an impact upon maternal functioning and parenting capacity. A further literature could focus specifically upon investigating the evidence for an intergenerational impact of CSA.

A number of suggestions for further research have been proposed which have focussed mainly on the need for further developing knowledge of how CSA affects parenting. The need to identifying positive factors which mediate between CSA and parenting has been highlighted in order to equip clinicians with preventative interventions, including individual therapy as well as peer social support.

CSA can have significant effects upon the parenting role and early identification and intervention is essential to prevent or lessen the impact of CSA upon the parenting role.

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**EMPIRICAL PAPER**

**HOW DO WOMEN WITH A LEARNING DISABILITY EXPERIENCE THE SUPPORT OF A DOULA DURING THEIR PREGNANCY, CHILDBIRTH AND AFTER THE BIRTH OF THEIR CHILD?**

# ABSTRACT

**Background:** With increasing numbers of people with a learning disability (LD) choosing to become parents (Booth & Booth, 1994) it is important the right support is provided to enable them to parent effectively (Macintyre & Stewart, 2011).

**Materials and Methods:** This study used semi-structured interviews with four women with a LD who received doula support prenatally, during labour and postnatally. The women were interviewed during prenatal and postnatal support periods. The doulas were interviewed about their experience of supporting a woman with a LD towards the end of the postnatal support period.

**Results:** Interview transcripts were analysed using Interpretive Phenomenological Analysis (IPA). Themes were identified from each of the ten interviews, before analysis of themes for the same support phase were analysed together for mothers and doulas, allowing discussion of similarities and differences.

**Conclusions:** The findings show that prenatally the women considered the doula to be a reliable source of information about pregnancy and birth. Each mother perceived doula support as a means of keeping her child in her care. Postnatally, mothers described a trusting relationship with their doula, which enabled them to make informed choices.

Doulas described the need to adapt their work to meet the needs of parents with LD. The experience of working alongside statutory agencies was perceived as potentially challenging, and an important area for supervision.

## INTRODUCTION

Increasing numbers of people with a learning disability (LD) are deciding to live an 'ordinary life' (Booth & Booth, 1994) and choose to become parents (Booth & Booth, 1994). There is evidence that people with a LD are able to parent effectively if they have the right support to do so (Macintyre & Stewart, 2011). The need for support for parents with an LD was highlighted by Tarleton, Ward and Howarth (2006) who stated that parents with a LD need effective support, flexible enough to meet their on-going and changing needs especially as their child grows and develops. Such support needs to incorporate a broad range of different strategies such as the assessment of support needs during pregnancy, help at home, access to parenting groups and help to engage with professional services.

However, parents with a LD may have to negotiate many hurdles to ensure they receive the support they need (Ward & Tarleton, 2007). Aunos and Feldman (2002) stated that negative attitudes towards parents with a LD may adversely influence the levels of both offered and received support. Tarleton et al (2006) highlighted that parents with a LD may not feel able to access services due to the fear that their children will be taken away from them. There may also be a 'mismatch' between the support provided for parents and the amount of support parents would like to receive (Guinea, 2001).

The importance of the quality of the support offered to parents with a LD was highlighted by Tucker and Johnson (1989). The authors identified competence promoting support as a positive intervention which enhances a mother's sense of competence and appreciates the role she has in her child's life. Competence inhibiting support on the other hand tends to assume that the mother is incompetent

and does not improve (or may even reduce) her sense of self-efficacy (Tucker &

Johnson, 1989).

Thus, not only the amount of support but also the *type* of support provided may not

always be what is required by a parent with a LD. Traditionally, parents have gained

both practical and emotional support from family members (Mayes, Llewellyn &

McConnell, 2008). However over recent years the extended family has become less

prevalent and these informal support systems have diminished. Moreover, mothers

with a LD are likely to have smaller support networks in comparison with other

mothers and experience lower levels of social support (Stenfert Kroese, Hussein,

Clifford & Ahmed, 2002). This 'social disconnection' is associated with greater levels

of stress and poor mental health. This is further compounded by higher rates of

abuse of these vulnerable women from their partners or family (McConnell, Dalziel,

Llewellyn, Laidlaw & Hindmarsh, 2009; O'Keeffe & O'Hara, 2008).

Aunos, Feldman and Goupil (2008) identified that mothers with a LD reported both

poor mental and physical health. They asked 32 mothers with a LD who had custody

of at least one child to complete a number of questionnaires. These included a

demographic and social support questionnaire, a health measure, and a measure of

parenting stress and of child behaviour. An assessment of the home environment

provided for the children along with an assessment of the quality of the parenting

provided was conducted. Results indicated that on average the sample of mothers

with LD gained significantly lower scores on the physical health and mental health

component scales indicating they experienced lower levels of physical and mental

health than mothers in the general population.

Poor mental and physical health for mothers with a LD was also highlighted in the model of parenting defined by Sterling (1998). This model outlined how social support and psychological well-being are closely related in a reciprocal manner. Sterling's model defined three subsystems of parenting ability. Included in the first subsystem are the characteristics of a mother's environment. This includes social support which can come from anyone who is capable of providing such support. The second subsystem is psychological health. Sterling describes the link between social support and depression, and reports that if a mother is depressed the symptoms she experiences can prevent her from accessing social support. This relationship is bi-directional indicating that a mother's lack of social support can intensify depressive symptomatology. The third subsystem described is cognitive abilities, as deficits in abilities such as speech and language, decision making, and interpersonal skills can be linked to parenting and other behaviours that can endanger a child. Sterling concluded that both social support and psychological well-being are strong predictors of parenting ability, and are much more predictive of parenting ability than IQ level or intellectual functioning (a finding also reported by Llewellyn, Mayes & McConnell, 2008).

Early intervention such as support during pregnancy has also been found to have positive consequences for parenting ability of parents with a LD (Llewellyn et al, 2008). Women with a LD need information about pregnancy, birth and childcare in an accessible format and presented in various ways, such as through the use of visual aids (Tarleton et al, 2006). Women with a LD who are pregnant should also be given time to learn, along with opportunities to practice new skills (Tarleton et al, 2006).

However, Porter et al (2012) identified a lack of accessible information about pregnancy for women with a LD, who are often expected to rely upon mainstream services which may not be experienced in supporting women with a LD, especially during pregnancy. Porter et al (2012) designed a Pregnancy Support Pack (PSP) for women with a LD as an accessible resource to support them in making informed choices about pregnancy. The package was used by community midwives to support five women with a LD during pregnancy. Both the mothers and the midwives were interviewed about their experiences of using the pack. It was concluded that the PSP was effective in supporting women with a LD during pregnancy, identifying that with accessible information parents with a LD are able to understand relevant information and make informed decisions about their pregnancy (e.g. whether to have a routine blood test or a scan) and the consequences of their decisions.

The PSP, although comprehensive, does not include support during labour when accessible support and information has been shown to be beneficial. Continuous psychosocial support during labour has been associated with positive benefits for women such as a shorter labour, a decreased need for medical intervention and a lower number of caesarean sections (Lantz, Low, Varkey & Watson, 2005; Hodnett, Gates, Hofmeyr & Sakala, 2003; Zhang, Bernasko, Fahs & Hatch, 1996). Lantz et al (2003) reported the results of fourteen randomised trials and concluded, on the basis of their findings, that all women should have access to continuous (over and above medical) support during labour (Lantz et al, 2005).

A doula is a woman who provides consistent support to another woman prenatally,

postnatally, and constant support during the birth. The word doula is taken from the Greek, meaning 'a woman who accompanies another woman' (Campero et al, 1998). The term 'doula' was first used in its current context in 1973 by an anthropologist Dana Raphael (Kennell & Klaus, 1991) who noted the widespread practice in many cultures of having an female family member or friend experienced in birth present to provide support. A doula is able to support both the woman and her partner and offer a variety of techniques in addition to information giving, such as massage, encouragement and coping strategies (Pascali-Bonaro & Kroeger, 2004). The role of a doula can vary as every pregnancy and the needs of every woman/ couple are different.

The key components of doula support can be placed into four broad categories (Kayne, Greulich & Albers, 2001). The first of these is emotional support which includes the doulas continuous presence, reassurance and praise. The second category contains the advice and information provision aspect of the doula role, ensuring the woman understands and is prepared for each stage of labour. The third category includes the tangible 'hands on' assistance, empowering a family to take care of itself by helping around the house and offering encouragement and suggestions. In order to be responsive to the specific needs of each family, the doula works flexible hours. The fourth category is advocacy for the woman and support for the woman's decisions, encouraging others to respect them and ensures the woman's voice is central during her labour.

To become a 'Recognised Doula' an individual is required to undertake training which includes a mentoring programme. There is no one specified training route and

dependent upon prior experience initial training can last between two and five days (www.doulatraining.org). However each training course will include a focus upon practical and emotional support such as massage techniques, breastfeeding skills and skills pertinent to prenatal, birth and postnatal support. Following completion of the training course a doula is required to work alongside a personal doula mentor for a period of between six months and 2 years to enable her to gain additional experience, and attendance at a minimum of four births. This training requirement is supplemented with written documentation and reflective practice and culminates with a formal assessment interview with their doula mentor. This interview also includes a formal review of the births attended and the written documentation kept. Having undergone a recognised training programme, the doula can register with one of the doula organisations and become a 'Recognised Doula' (www.doula.org.uk). As an independent practitioner a doula agrees a contract with the mother/ parents they provide support to regarding their payment. They are paid an additional fee for being on call at the time around the birth of the baby. The amount of support provided by a doula is agreed with each mother/parent but tends to be on a part-time basis, for example a doula may visit once every two weeks with additional visits at the mother/parents request.

Kennell, Klaus, McGrath, Robson & Hinkley (1991) investigated the effect of doula support for women in labour by means of a randomised controlled trial. Six hundred women were randomly assigned to one of three groups, a group who received doula support, an observed group where the woman was monitored but not supported, or a control group who did not receive any additional support or observers. In this study the doula met with the women assigned to the doula group for the first time after

hospital admission. She remained at the woman's bedside throughout labour and birth providing support and encouragement, explaining the process of labour, and medical terminology. To assess efficacy, information about labour and the new born were gained from hospital records. The results of this trial indicate that continuous doula support significantly reduced the rate of caesarean deliveries (doula group 8%, observer group 13% and control group 18%). In addition, labour was found to be shorter in the doula group (doula group 7 hours, observer group 8 hours and control group 9 hours). The authors conclude continuous doula support during labour has significant and positive effects upon labour, and on the experience of birth for women.

A further area where doula support has been identified as beneficial is with regard to pregnant women in prison. Typically, pregnant women in prison have few choices with regard to pregnancy and birth. They are separate from their support systems of family and friends and can face long periods of separation from their new-born child. These are conditions that are likely to increase the chances of a stressful birth experience especially as mothers tend to labour alone (Hufft, 1992; Wilson and Leasure, 1991). Schroeder and Bell (2005) interviewed eighteen women in prison who received continuous doula birth support. The doulas met with the women on three occasions, the first occasion when the woman was in labour. In addition to providing continuous support each doula took photographs of the birth and used these to prepare a short birth story for the second visit. The third visit usually took place within three days of birth during which the doula reviewed the birth experience and presented the birth story and photographs.

All of the women interviewed about their experiences provided positive feedback

about doula support, and stated that they would recommend this service to other women. One woman commented that she would have been "petrified" if she had been by herself during labour and birth, another that the doula enabled her to have a positive experience of birth whilst in prison. It was concluded that doula support provided a more positive experience of birth for women in custody, even with the inherent constraints.  This research highlights the positive effect of support provided by a doula for women who do not have access to the support of more experienced family, friends or their partner.

The importance of support prenatally, during childbirth and postnatally has been identified as vitally important. This is especially for women with a LD who due to insufficient or inappropriate services and social isolation may face many of the challenges of pregnancy and birth alone, without support over and above medical care. Providing continuous doula support during pregnancy, birth and postnatally could help reduce this isolation, with a range of other benefits such as the provision of accessible information, reassurance and encouragement, tangible assistance and the advocacy role taken by a doula. Research into the experiences of women with LD and their doula may provide an insight into how mothers with a LD experience consistent support prenatally, during labour and postnatally.

**Research Aim**
The aim of this research is, therefore, to investigate the experiences of women with a LD who have been provided with a perinatal, birth and postnatal doula support. The experiences of the doulas will also be considered with regard to providing support to a woman with a LD.

METHOD

**Design**

This research used Interpretive Phenomenological Analysis (IPA; Smith & Osborn,

2003) as it focuses upon an individual's lived experience (Johnson, Burrows &

Williamson, 2004) and aims to gain an understanding of the experiences of

participants, in this case of having or providing doula support, and the interpretation

of these experiences.

As a methodology, IPA is both interpretive and phenomenological. Participants are

recruited due to their experience in the phenomenon. IPA focusses upon the

participants' lived experience combined with an interpretative analysis which looks for

shared experiences across a group of participants. It does not test a hypothesis

(Reid, Flowers & Larkin, 2005). Due to the interpretative nature of IPA, it is inherent

that the researchers reflect upon their own role within the research process, and are

aware of any relationship developed with data collection or analysis (Reid et al,

2005).

**Personal preconceptions and reflections**

My interest in this area of research developed through my background in working

with women with a LD. My experience is broadly professional, rather than personal

as I have not yet experienced pregnancy, or what it is like to become a parent.

My experience whilst carrying out this research was one of being accepted by the

people I interviewed, who were willing to share very personal experiences of

pregnancy and birth, of previous children being taken into care, and their hopes and

dreams for the future. Powerful experiences of personal challenges were shared by the mothers and the doulas throughout the research process.

**Ethics**

Ethical approval for this study was granted by The University of Birmingham School Ethics (Appendix 3) and throughout the study professional practice guidelines were adhered to (British Psychological Society, 2004).

Two accessible leaflets were designed. The first described what a doula is and the service offered by a doula prenatally, during labour and postnatally. The second leaflet described the aim of the study, and provided the information necessary to allow potential participants to give informed consent (see Appendix 4 and 5). The consent form consisted of a number of 'tick boxes' (see Appendix 6).

**Procedure**

To participate in the study participants had to have a LD and to be pregnant at the time of the study. No formal assessments of LD were carried out but all participants were receiving local LD services that are known to have stringent eligibility criteria.

Participants were provided with accessible information. Those who did not want to participate were still able to access doula support. Withdrawal from the study was possible up to data analysis. If withdrawal from the research occurred women could still receive doula support.

**Data collection**
*Mothers*

Referrals were received from professionals involved in the care of the pregnant woman with a LD. Once the referral had been made the woman was offered a meeting with the clinical research supervisor who is a Consultant Clinical Psychologist currently working within a local adult LD service.

During the initial meeting with the clinical research supervisor the role of a doula was described to the woman. The research project was also explained, and what would happen if the woman provided her informed consent to participate in the research. Accessible leaflets describing the role of a doula and the current research were utilised to aid informed consent (Appendix 4 and 5). If the woman agreed to participate she was asked to sign an accessible consent form (Appendix 6). Women could have doula support without participating in the research.

Women who consented to participate in the research also consented to their contact details being passed on to the researcher, who contacted them by telephone to arrange to meet with them to interview them about their experience of doula support during and after their pregnancy.

Mother participants were either interviewed individually or in the presence of a partner or family member. A semi-structured interview schedule was used (see Appendix 7). The same interview schedule was used for each participant for both the pre-birth and post-birth interview. The interview schedule for the mother participants comprised of six questions with prompts that asked about their experiences of doula support. The questions were informed by existing literature on the provision of doula

support and through discussions with other professionals with regard to the various types of support which a woman with a LD might require during pregnancy. The interview questions were initially focussed upon the mother's experience of pregnancy before leading into more specific questions with regard to how they had experienced the support of a doula during their pregnancy so far (interview 1) and during the birth and the postnatal period (interview 2).

At the end of the first meeting permission was sought to meet again after the birth of the baby for a further interview. Each woman who participated consented to the post birth interview.

*Doulas*

Interviews were also conducted with the doula participants. These interviews were carried out towards the end of the postnatal support phase. Helen was interviewed one month after the birth, Millie was interviewed three months after the birth and Joanna six months after the birth of the baby. A semi-structured interview was used which consisted of five open-ended questions and associated prompts (see Appendix 8). Interview questions were informed through existing literature regarding the role of a doula and the types of support provided. Discussions with other professionals also informed interview questions with regard to the types of support which may be beneficial for women with a LD during pregnancy. Interview questions were initially general questions about previous doula experience, before leading into more specific questions with regard to experiences of supporting a woman with a LD during pregnancy.

All interviews took place in a private place. Interviews were audio recorded and transcribed for the purpose of analysis.

**Participants**

Four mothers took part, two were single mothers and two had a partner or husband. One woman had her baby earlier than anticipated and was only able to provide a post birth interview. One woman consented to both interviews but disengaged from services following the birth of her child. Two women provided both pre and post birth interviews. Information about the participants and a summary of their background can be seen in Table 1. Table 2 provides information regarding the provision of doula support.

*Table 1: Information about participants' background and summary of personal circumstances at time of post birth interview.*

| Name (not real name) | Approx. age | Previous children | Background |
|---|---|---|---|
| Charlotte | 20's | | Lives with her husband, and her maternal grandparents. Supported by an advocate and community nurse from the local LD service. |
| Sally | 30's | Three children in local authority care | Lives with her partner. Supported by an advocate from the local LD service. |
| Leah | 30's | | Lives alone in flat close to her mother's house. Leah divides her time between her flat and her mother's house. Supported by a psychologist from the local LD service. |
| Katie | 30's | Daughter in local authority care | Lives with her husband in a flat. Both Katie and her husband are supported by a psychologist from the local LD service. |

Names have been changed to protect confidentiality. Ages and other identifying features are not specified for the same reason.

*Table 2: Information about provision of doula support*

| Name (not real name) | Doula/s | Stage of pregnancy at interview 1 | Gender of baby | Age of baby at interview 2 | Partner or relative present during interview |
|---|---|---|---|---|---|
| Charlotte | Joanna | Post natal interview only | Girl | 8 months | Maternal grandmother |
| Sally | Millie | 3 months | Mother disengaged following birth of baby | | Partner |
| Leah | Helen | 6 months | Girl | 3 months | |
| Katie | Millie and Helen | 3 months | Boy | 3 months | Husband |

Doula support was provided by three doulas who had received (at least one full day) specialist training to support their work with women with a LD. One doula supported two mothers during their pregnancy and childbirth. She was interviewed separately regarding her experiences of supporting each mother. The interviews with the doulas lasted for approximately an hour to an hour and a half.

Prior clinical experience with mothers without LD ranged from over five years to being newly qualified. At the time of interview Joanna had five years doula experience and had provided support at ten births and Helen had ten months doula experience and had attended two births. Millie had approximately four years of providing doula

support and had attended five births. For each doula it was their first experience of providing doula support to mother with a LD.

The level of support provided to each woman/ partner with a LD varied between the individual women and their doula. Support provided included face to face meeting time and the time taken to prepare and individually adapt and tailor resources to be accessible to the women with a LD.

Doula visits to the mothers tended to be short sessions ranging between half an hour to an hour and a half, depending on the mother's attention span ad cognitive abilities. The frequency of the contact between mothers and doulas varied but on average each doula visited the mother twice a week with the same amount of time spent on preparation, development and adaptation of resources.

**Data analysis**
*Process of IPA analysis*

IPA data analysis involves the researcher looking for themes in the data whilst bearing in mind the experience/s of the participants. There are a number of stages for this process.

Initially the interview transcripts are read and re-read and annotated, highlighting issues of interest or significance. Following this, the transcript is annotated with emerging theme titles (Smith & Osborn, 2003).

These themes, once identified, are listed and connections identified between them. Once each transcript has been analysed, themes are clustered together to create a superordinate theme.

If a theme does not fit with the emerging themes or is not supported by 'rich data', it is excluded from the analysis.

Each interview was analysed individually using IPA. Following this the interviews were placed into three groups; mothers' pre-birth, mothers' post-birth and doulas interviews.

The themes from the groups of interviews were examined together and themes identified across cases. Themes present across cases were relabelled to define superordinate themes within groups.

This section will focus on the themes relevant to mothers' with LD who received support from a doula, and the experiences of the doulas who provided this support.

## MOTHERS
### *Pre Birth*

### Theme1 Not knowing

All of the women spoke about experiences of not knowing. This related to not knowing what a doula was or how she could help, and to the physical changes that occur in pregnancy.

For Charlotte and Leah this had been their first experience of being pregnant. Leah in particular spoke about not knowing about labour as she had not experienced it before. She spoke about how she was hopeful doula support would be helpful:

*"Yeah cos when it's your first you don't know what's gonna happen in labour do you. You get worried and that's why she's [doula] going to send me a birth plan and send me leaflets"*. (line: 22)

For each mother this was the first time they had doula support. None of the mothers or partners knew what a doula was or how she could support them. For Charlotte the first meeting with the doula had been awaited with anxious anticipation:

*"I thought she would come and tell me how to live my life, I felt nervous, and 'oh no not another one'. It was scary meeting her for the first time".* (line: 92)

Charlotte spoke about how easy it was to get to know her doula:

*"It was different when we got to know her, and it didn't take long to get to know her".* (line: 20)

**Theme 2 Doulas can meet our needs**

Sally spoke of how she did not know what a doula was, but signed herself up for support without hesitation. She spoke about wanting all the support she could have as she wanted to keep her child even though she had a disability:

*"People with disabilities means a lot of support especially support with social services because they think oh because a girl's got moderate learning problems they think can't look after a baby you know".* (line: 19)

Leah was also of the opinion that doula support was particularly suitable for women with LD:

*"I didn't know much about it actually, but they, a doula's for people who ain't got LD but they have got, now they do people with LD. I think it's good because if people who've got learning disabilities and don't understand labour and they're scared to ask questions to a midwife, I think it's really good".* (line: 70)

Other mothers spoke about how important it was that the doula supported them in a way that was meaningful to them. Katie requested the doula provide basic childcare information:

*"Basically talking to us about what routine the baby's going to be in, what time, what needs to be done, like how to change a nappy or do the bottles or sterilising and what the baby's going to be like".* (line: 126)

It was important for the mothers that doula support helped them to understand their pregnancy and enabled them to find out more, without the LD being a barrier and without fear of being perceived as ignorant.

**Theme 3 Support with hopes and dreams**

This was an important perceived aspect of doula support. Each mother identified what their hopes and dreams were. '*To be a good parent'* was identified by Leah which she felt was achievable with the support from her doula. Charlotte, Sally and Katie were facing child protection proceedings and identified their goal was to have their child remain in their care. For example, Sally stated:

*"You know we're a family unit and I well, it'll be a dream come true if the baby, you know, can get to stay with us".* (line: 131)

Doula support was identified by mothers as a way of helping keep their children. Katie described how her doula had provided support tailored to her needs and those of her partner:

*"It was a bit of talk as well as an awful lot of practical, but that's how we find things a lot better, practical with easy read and writing and help with mumble jumble* [jargon]". (line: 139)

Charlotte spoke about how her doula showed her how to do tasks, emphasising the importance of teaching skills through modelling:

*"She showed me how to hold my baby, how to hold her in a sling and then I could do stuff like housework whilst holding her, holding her close to my heart. "* (line: 62)

This allowed Charlotte to combine looking after her baby and making sure necessary tasks were completed. Through doula support Charlotte was able to use new ideas and techniques in practice.

Each mother emphasised the importance of engaging with their doula to learn about childcare, with a focus upon meeting the requirements of statutory services. Sally in particular highlighted the importance of this:

*"Cos you know, the more support I, we have, you know the better chance we have* [of keeping the baby] *so, and now* [doula] *so, yeah, the more support the better". (line: 42)*

The doula was viewed as someone who would be able to provide relevant, tailored support to enable mothers to progress towards their goal of having their baby with them and function as a family.

**Theme 4 Preparing and coping with pregnancy changes**
The mothers identified doula support as beneficial for coping with changes during pregnancy and knowing what changes were likely to happen. These included changes in hormones, 'getting bigger', and feeling tired.

Sally spoke about her body changing as pregnancy progressed and as this happened she decided to try breastfeeding. She spoke about breastfeeding with doula support:

*"I said that I'm going to be breast feeding so she* [doula] *says she'll take me and P up there* [local health centre] *to have a look at breastfeeding"*. (line: 68)

Leah spoke about ruminating on pregnancy changes and how as her pregnancy progressed and she noticed changes, she had many questions to ask:

*"I don't know it's just got you know, different things in your head"*. (line: 159)

She continued to speak about the advice she had been given to ensure that she could remember all the queries which she had:

*"Yeah you can put them down on a piece of paper and ask when your doula's there".* (line: 78)

The doula was viewed as someone who knew about pregnancy and could answer questions and offer advice with regard to areas of concern for mothers.

Sally had noticed '*her hormones changing'* as pregnancy developed and she explained that this affected her memory and how doula support was beneficial in helping her to remember and develop skills:

"*Is good to have support now with changing hormones, helps me remember new things".* (line: 209)

In summary, in the pre-birth period and in the context of having to cope with a host of new and challenging experiences these women, who were aware of their cognitive deficits, experienced the doula as a reliable and safe source of information about pregnancy, birth and the neonatal period and they perceived the doula support as a means to achieving the goal which was shared by all four mothers, namely to not have their child removed from their care.

*Post Birth*

**Theme 1 Support during the birth**

Katie described a long and difficult labour:

"*I was very discomfort*". (line: 32)

Due to the length of labour two doulas provided constant support for her throughout the five days she was in labour:

*"They were always there, always one of them there and they were fantastic, all through the week supporting us*". (line: 50)

The doulas' presence during labour, having someone there to help you understand what is happening and who can explain medical terminology was experienced as reassuring and supportive.

Leah spoke of the value of doula support to prepare her for labour. She was able to identify the start of labour as her doula had explained what the signs were:

*"I was in labour, had a show and I was sick then I was on contractions on bed, and then and then started".* (line: 17)

Leah had learned about labour with her doula to prepare for the birth. However, she required a caesarean section and was unprepared for this:

*"When you have a C-section you don't know what's going on."* (line: 12)

Leah described the caesarean and how her doula and her mother had supported her through this:

*"They keep me calm, talked me through it, when I went into the room [theatre] doula was there cos mum don't like injections and she* [doula] *was there calming and told me everything".* (line: 41)

**Theme 2 A trusting relationship**

None of the four mothers knew what a doula was initially. However, every mother described how she subsequently developed a close relationship with her doula. Charlotte spoke of feeling anxious and unsure of the doula's role. Sally and Katie both described wanting to have support, despite not knowing what a doula was.

Charlotte described how it did not take long to get to know her doula and she spoke of her doula as someone she could relax with and talk about anything with her, even things she could not talk to anyone else about. Katie spoke of how she needed to trust her doula, that this took time but how by the end of support her doula was like a member of their family:

"*They're like family now to us, she's like a mum I never had*". (line: 72)

Leah expressed the importance of the relationship:

"[The best part of doula support] *me and doula actually, we've made a good bond*".
(line: 87)

**Theme 3 Learning and having an informed choice**

Each mother spoke about what they had learnt from their doula. Charlotte spoke

about learning enough to enable her to make informed choices throughout

pregnancy:

*"She talked about labour with me, a normal birth and a caesarean. When she told me*
*about a caesarean I said no way, I wanted a normal birth".* (line: 80)

Katie and partner described the support they received:

*"And she asked for the easy reading books and she was showing us all pictures,*
*what's going to happen next and everything. And it's like teaching us words".* (line:
78)

They described how much the doula had taught them, and how they enjoyed being

supported to learn together:

"*We've learned so much it's because of them* [doulas], *we've learned so much, it's to*
*do with this parenting assessment now*". (line: 106)

Katie summarised their learning experience as:

*"Loads of support you know, the simple things and how to be parents*". (line: 75)

In summary, during the post birth period, the mothers described a trusting relationship with their doula. They experienced doula support as a calming and a reliable source of support during labour and throughout the post birth period. The individualised support allowed women to make informed choices during the birthing process and provided an opportunity for them to focus on achieving the goal of having their child in their care.

**DOULAS**

**Theme 1 Changing and adapting with LD in mind**

Each doula spoke of changes in the way they provided support whilst working with women with a LD. This ranged from slightly changing the role, to the development of tailored resource packages and card games.

Helen described how she changed her working practice only slightly to fit the needs of the mother with LD. This included breaking down information into smaller chunks and recapping information regularly.

*"I don't want to bombard mother with too much information because, well for anyone, it's a bit mind boggling you know if you try and drum too many things into one person at the same time, so it's a case of just spreading it out"*. (line: 119)

Joanna spoke about using a similar system of teaching and recapping:

*"She didn't always remember what she's been told and so it was a case of going over it a lot of times".* (line: 63)

Joanna identified this as the impact of the LD on her work, and the importance of remaining mindful of this during the support period.

Joanna and Millie both described developing their own teaching resources. Joanna spoke of making up games and using cards to support decision-making. Millie described the resources she developed:

*"I used a whole mixture of learning resources so sort of visual images, photographs, and cartoons, lots of post it notes, lots of role play in certain practical activities, using a doll to practice skills"* (line: 164)

The differences in supporting a woman with LD were highlighted by all three doulas. Helen spoke about how Leah had a smaller support network than most expectant mothers and thus found it difficult to find a safe person to discuss concerns with. Joanna spoke about how she became a support and an advocate for the whole family, not just for the mother. Millie identified how much more time consuming this work was, both the support itself and the preparation of this.

**Theme 2 Reflecting on the personal and emotional impact**

Each doula spoke about the impact of this work on them personally. Helen spoke of her increased confidence and experiencing this as an area of work she wanted to develop:

*"In fact it's almost made me want to push more towards this sort of doula work especially with kind of, Mother hasn't got a partner now, so single ladies, first time mums with LD is more where I'm looking at now which you know I can't pick and choose, I know but I think that's where I feel I'm kind of best really at the minute"* (line: 229)

Joanna and Millie, on the other hand, had experienced their work with mothers with LD as much more challenging. This may have been because the mothers they were supporting were subject to a child protection procedure.

Joanna described how the work affected her emotionally and how this also had an impact upon her family:

*"I wouldn't want to put myself through that again because when I'm so upset I'm unavailable for my family for hours and hours and hours, when I can't, I can't pull myself together".* (line: 423)

The experience of Millie was similar:

*"It's exhausting emotionally, it was exhausting because you know practically I had time and I was doing it and it was intense"* (line: 363)

Both Joanna and Millie spoke of the importance of supervision and Millie added peer support as an important way to cope. Joanna spoke about her supervisor and commented on the value of knowing that there is always someone to call on:

"*She's always at the end of the line*". (line: 327)

Joanna spoke about her supervision and added:

*"It was really good to be able to triangulate that with having contact with* [other professionals involved with the mother with LD]. *And also contact with my own doula community as well to get a bit of input on how I should operate more effectively really".* (line: 71)

The importance of a space for reflection on the work and role of the doula was highlighted especially by Millie:

*"There is that element of you do learn on the job and things come up and you need to reflect to somebody as it's happening almost"*. (line: 463)

She indicated that reflection time was an important part of her work that gave her the opportunity to gain feedback from others when she was confronted with new challenges.

**Theme 3 Being accepted and making a difference**

Joanna and Millie described similar experiences possibly because they both experienced being involved in a child protection procedure for the first time.

Millie described the importance she placed upon developing links with statutory services during this time to enable her to feel accepted:

*"I also thought it was important that the doulas aren't, it's not quite mainstream, and I think a lot of social services are very conservative in their approaches"* (line: 105)

Millie spoke about developing links and how the lack of knowledge about the role of a doula could make this difficult:

*"I mean I'm not coming with the same agenda as a lot of other agencies and yet I just think that a lot of agencies are uncomfortable, well uncertain really because we're* [doulas] *are unknown and that sort of unnerves people. Really will take time to develop links"* (line: 125)

However, having explained her role, Joanna spoke of how she worked alongside other professionals, developing links and promoting choices for the mother she supported:

*"You act as a translator between the many health professionals who may not have seen her* [Mother] *so many times and may not know exactly what she's aiming for in her birth".* (line: 9)

Both Joanna and Millie spoke about how it was their role as a doula to promote the mothers' choices and ensure that mothers' voices were heard:

*"A lot of the doula's role is about empowerment and hearing and responding to the woman's voice".* (line: 118)

Each doula stressed the importance of empowering the mother, especially promoting her birth choices, as this would make a difference to her experience of birth. However, Millie spoke about how difficult this could be:

 *"The* [hospital] *staff were not happy with me explaining it and stating certain things but I felt it was crucial, really crucial that she* [Mother] *had been robbed of making the decision for herself and understanding what was being told to her, properly understood".* (line: 269)

Being accepted and making a difference was highlighted as important by each doula, as a key part of their role to enable them to make a difference for the mother. However, other agencies were often unaware of a doula's role and this meant the doula had to develop meaningful links in a short time frame.

In summary, in the context of providing support in a new, often challenging environment the doulas adapted and changed their working patterns. Practical adaptations were developed to meet the individual needs of each woman with a LD. The experience of working alongside statutory agencies in child protection cases was perceived as extremely challenging and emotionally draining, and an important area for supervision and peer feedback.

## DISCUSSION

The mothers in this study each expressed positive views about the accessibility of the support they experienced. They acknowledged the influence of their LD upon their ability to learn and to parent effectively without support.

Most support for parents with LD tends to be crisis driven and provided by mainstream services that may not be experienced in supporting women with a LD. In contrast, the support provided to the parents in this study was individually tailored to each mother/ couple, taking their learning needs into account. The mother/ couples in this study were aware of this and spoke appreciatively about the accessibility of the doula support, including being given 'easy read' versions and having complex issues explained without jargon.

Tucker and Johnson (1989) highlighted the concept of competence promoting support that enhances a mother's sense of self-efficacy. The parents' accounts in this study indicate that the doulas were successful in providing such support. Charlotte spoke about her doula teaching her skills both related to childcare as well as more general skills, such as household tasks. With their learning needs taken into account,

the parents in the current study were able to learn new skills and take on board new information without feeling patronised or demotivated, indicating that the support had been experienced as competence promoting.

As well as receiving support, each woman who participated spoke about the trusting relationship they developed with their doula and how they were able to develop a good relationship with her. Leah spoke about her relationship with her doula as akin to friendship and Leah, Kate and Charlotte all felt that they could talk to their doula about things other than pregnancy and viewed the doula as a valuable extension to their support network.

Women with a LD tend to be socially isolated and have poor support networks (Stenfert Kroese et al, 2002), which has been found to predict mental health problems and inadequate parenting (Sterling, 1998; O'Keefe & O'Hara, 2008; McConnell et al, 2009). The accounts of the parents in the current study suggest that the practical and social support provided by the doulas appears to mediate psychological well-being and positively influence the experience of pregnancy and parenting and thus parenting capacity. More extensive research is required to establish the efficacy and maintenance of this type of intervention.

Kayne et al (2001) outlined the role of a doula and placed the key components of the role into four broad categories namely emotional support, advice and information, tangible hands on assistance, and advocacy and support for the woman's decisions. Within this study the doulas appeared to have fulfilled these roles as well as the extra role of providing support during child protection procedures. The doulas described

how they successfully adapted resources and the manner in which they provided support to women with a LD, but stressed how they found the experience of being involved in a child protection procedure emotionally demanding and draining.

The doulas identified that supervision from two experienced LD practitioners and support from other doulas was helpful in this context. However, two of the doulas who experienced particularly difficult child protection procedures described how they were not able or willing to go through with this draining process again. Their descriptions suggested that they were experiencing something close to 'burnout'.

Duffy, Oyebode and Allen (2009) argue that burnout occurs in those who work in the helping professions due to their frequent contact with others, often under intense and challenging conditions. Schaufeli and Enzman (1998) describe burnout as an experience including low mood, general fatigue and a loss of motivation and pleasure in work. This can have a negative effect not only upon themselves, but on the people they support, as prolonged experience of burnout can lead to the professional interacting in a detached and impersonal manner.

Duffy et al (2009) investigated coping in care staff working with older adults with dementia and found that the older members of staff reported lower levels of burnout. This may be due to the older members of staff having more experience of the area of work. This concept (that experience can defend against burnout) was highlighted in this study by Millie who spoke about providing doula support and how difficult it was to be one of the first to do so:

*"It's hard when you're pioneering something".* (line: 742)

This research highlights the need for support for the doulas to help prevent burnout. Duffy et al (2009) identified that a combination of support, both practical and emotional is beneficial in preventing burnout. They found that training that includes role play, didactic methods and discussion succeeds in raising the level of self efficacy within team members and decreases levels of burnout.

The doulas in this study were able to access individual supervision in addition to monthly peer group support where cases were discussed confidentially and suggestions proposed for future clinical work. This was perceived as helpful and supportive for the work carried out with the mothers with LD. However, it did not ameliorate the stress experienced by the doulas who were involved with child care proceedings.

Future support could, therefore, include working alongside another doula with more experience of supporting women with LD through child protection procedures. Future training could include a greater emphasis on practical and emotional ways to cope with emotionally demanding work.

As the mother participants were identified through a local LD service, they were previously known to services. Each woman also had support from an advocate, community nurse or clinical psychologist. None of the mothers interviewed were without some form of other specialist LD support, although this support was not directly linked to their pregnancy. In order to establish the effectiveness of doula support without the added interventions from others, one would have to provide doula

support to mothers with LD, living in the community and not previously known to services. These mothers, who are not in receipt of any other services, are likely to be even more socially isolated and vulnerable and may benefit from doula support even more than the present sample of women.

In addition, a small number of women who were eligible to participate were not able to receive doula support as they were living with a violent or abusive partner. Due to the potential risk posed by partners, it was deemed unsafe for a doula to be involved in supporting these women. However, these are the women who are more likely to be socially isolated during their pregnancy, due to potential risks for professionals and family alike. How to provide support for this group remains a challenge for this and other maternity services.

Participants were identified once their pregnancy had been confirmed. This confirmation happened at different stages in the pregnancy for different mothers. The earlier the pregnancy was identified, the more time and opportunity the mother had for doula support. The length of time for pre-birth support differed between participants which may have impacted on the amount of support the doula was able to provide pre-birth.

Each doula in the current study spoke of how she adapted the resources used to provide accessible support for women with a LD providing individually tailored support for each mother/ couple she supported. The doulas were also able to utilise accessible resources from CHANGE (www.changepeople.co.uk), an agency established to promote the human rights of people with a LD and the British Institute

of Learning Disabilities (BILD; www.bild.org.uk). These accessible resources include visual images and resource packs with information presented in an 'easy read' format. They were presented to the doulas during their specialist training and were available for use during the entire support phase. In order to pool these resources and ensure quality and consistency, a 'doula pack' could be developed which doulas could use when supporting a woman with a LD. It could also be used with adults with a LD who are planning on becoming parents to support and enable them to learn about the roles and responsibilities of parenting.

The doulas in the current study provided doula support prenatally, during labour and postnatally. However, the longer-term effects of doula support are not known. Parental support needs to change as the child grows and develops so support provided will need to be adapted and tailored to meet the changing need.

Due to the changing support need of parents, they may no longer need the pregnancy related support provided by a doula, but still require support and advice around childcare and parenting. The service in which the current research took place has now been commissioned to work in partnership with Home-Start, a charitable organisation which is able to provide practical and emotional support to parents in their own homes, as well as supporting the family to use local resources and access their local community (www.home-start.org). After the post-natal doula support phase which may last between one and three months, parents will be 'handed over' to a specially trained Home-Start volunteer who will be able to provide accessible and continuous support until the child reaches school age. Further research could

investigate the efficacy of such long-term support and the type and quantity of support that is required.

One of the roles the doulas took on and spoke of at length was to engage with other services, many of which were not aware of what a doula is, and how a doula provides support. Developing a training package for other professionals including social workers, nurses and general practitioners involved in the support of parents with LD may allow them to make use of doulas most effectively.

The doulas in the current study received training to support their work with a woman with a LD, but not with regard to child protection procedures. Future doula training would need to incorporate specific training on this procedure, followed by mentoring from a more experienced doula. This may potentially lower the risk of burnout and increase the doula's self-efficacy.

## CONCLUSIONS

The current study aimed to consider the experiences of women/ couples with a LD who have the support of a doula during pregnancy, labour and postnatally as well as the experiences of doulas who provided this support.

The parents who participated highlighted the positive benefits of receiving doula support, including the development of a positive relationship throughout the support phase. Despite having a LD this support was experienced as empowering, allowing parents to make informed choices.

The doulas described their first experiences of working with parents with a LD as positive. They felt able to deliver accessible support to parents and develop positive relationships with parents and their extended families. The experiences of child protection procedures presented an emotional challenge.

It is hoped that through further research, training and evidence-based service planning parents with a LD may have increased and improved access to competence enhancing and person centred support from the planning stage of starting a family through to the child's early years of life.

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**PUBLIC DOMAIN BRIEFING PAPER**

**HOW DO WOMEN WITH A LEARNING DISABILITY (LD) EXPERIENCE THE SUPPORT OF A DOULA DURING THEIR PREGNANCY, CHILDBIRTH AND AFTER THE BIRTH OF THEIR CHILD?**

BACKGROUND

When people with a learning disability (LD) choose to become parents (Booth and Booth, 1994) it is important they have the right support to help them to be good parents (Macintyre and Stewart, 2011). However, women with a learning disability often do not get the support they need when they are pregnant. This means that it can be difficult for them to understand the changes that happen during pregnancy.

Mothers with a LD are likely to have smaller support networks in comparison with other mothers and experience lower levels of social support (Stenfert Kroese et al, 2002). This 'social disconnection' is associated with greater levels of stress and poor mental health. Aunos et al (2008) identified that mothers with a LD reported both poor mental and physical health. Results indicated that on average the sample of mothers with LD gained significantly lower scores on physical health and mental health scales indicating they experienced lower levels of physical and mental health than mothers in the general population.

Sterling (1998) describes the link between social support and depression, and reports that if a mother is depressed the symptoms she experiences can prevent her from accessing social support. This relationship is bi-directional indicating that a mother's lack of social support can intensify depressive symptomatology.

A doula is a woman who provides consistent support to another woman during pregnancy and postnatally, and constant support during the birth. A doula can support mothers and their partners in different ways such as helping them to understand medical terms and changes that happen in pregnancy, they can answer questions

and teach mothers about being a parent and support them to learn new skills.

## AIMS OF THE STUDY

The aim of this research was to investigate the experiences of women with a LD who have doula support during pregnancy, labour and after their baby is born. The experiences of the doulas will also be considered with regard to providing support to a woman with a LD.

## METHOD

Women with a LD were interviewed and asked about their experience of having doula support. Each woman was interviewed twice, once before their baby was born and once after their baby was born. The doulas were interviewed once, near the end of the support they were providing and were asked about their experience of supporting a woman with a LD. The interviews were recorded and themes for the same support phase were analysed together for mothers and doulas, allowing discussion of similarities and differences.

## RESULTS

The findings show that prenatally the women considered the doula to be a reliable source of information about pregnancy and birth. Each mother perceived doula support as a means of keeping her child in her care. Postnatally, mothers described a trusting relationship with their doula, which enabled them to make informed choices. Doulas described the need to adapt their work to meet the needs of parents

with LD. The experience of working alongside statutory agencies was perceived as potentially challenging, and an important area for supervision.

## CONCLUSIONS

Parents highlighted the positive benefits of receiving doula support. Support was experienced as empowering, allowing parents to make informed choices. The doulas described experiences of working with parents with a LD as positive. They felt able to deliver accessible support to parents and develop positive relationships with parents and their extended families. The experiences of child protection procedures presented an emotional challenge.

Through further research, training and evidence-based service planning parents with a LD may have increased and improved access to competence enhancing and person centred support from the planning stage of starting a family through to the child's early years of life.

*APPENDIX 1: NICE research quality grading criteria*

The criteria used for the evaluation of research quality, as published by the National Institute of Health and Clinical Excellence (NICE), 2009.

| Level of evidence | Type of evidence |
|---|---|
| **1++** | High-quality meta-analyses, systematic reviews of RCTs or RCTs with a very low risk of bias |
| **1+** | Well-conducted meta-analyses, systematic reviews of RCTs or RCTs with a low risk of bias |
| **1-** | Meta-analyses, systematic reviews of RCTs or RCTs with a high risk of bias |
| **2++** | High-quality systematic reviews of case-control or cohort studies<br><br>High-quality case-control or cohort studies with a very low risk of confounding, bias or chance and a high probability that the relationship is causal |
| **2+** | Well-conducted case-control or cohort studies with a low risk of confounding bias, or chance and a moderate possibility that the relationship is causal |
| **2-** | Case-control or cohort studies with a high risk of confounding bias, or chance and a significant risk that the relationship is causal |
| **3** | Non-analytic studies (for example, case reports, case series |
| **4** | Expert opinion, formal consensus |

If you would like more information about meeting with a doula, please contact,

Rae Cox

(Consultant Clinical Psychologist)



Having Doula
Support

# What is a Doula?

A doula is a woman who supports a woman when they are pregnant, when they give birth and after the birth.

**How does a doula support women and how could she help me?**

A Doula can help with lots of different things around pregnancy, birth and following the birth such as:

**While you are pregnant**

She can meet with you at your home or another place you choose to get to know you.

She can help you think about what happens to your body when you are pregnant.

She can help you find out information and get help from professionals while you are pregnant.

A doula can talk to you and answer questions you have about your pregnancy and your baby.

She can help you think about your "birth plan". That is things like where you want to have your baby and what kind of help and support you like to get, who you want with you at the birth and what kind of pain killers.

She can talk to you about things that are worrying you about being pregnant, giving birth or after the baby is born.

She can speak up for you if you are not confident and help you make choices if you're not sure what people are telling you.

She can make sure that people respect you and listen to what you want.

She can go to meetings with you about you and your baby.

**During the birth**

She can be with you at the birth of your baby if you want her to be.

During the birth she can make sure you get the kind of help and support you want.

**After the birth**

A doula can help support you with things you might find difficult at first such as feeding your baby.

She can be there when you are visited by the midwives and health visitors if you want her to be.

You and your doula can decide together how she can best support you.

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<u>Contact Details</u>
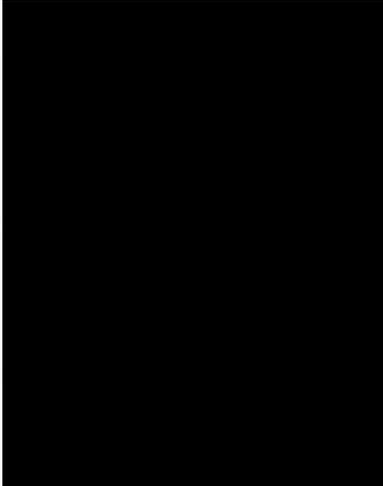
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College of Life & Environmental Sciences,
University of Birmingham.
Edgbaston.
Birmingham.



## The Doula Project

## Meeting with a Doula

### What is a Doula?
A doula is a woman who supports a pregnant woman during their pregnancy, when they give birth and after the birth.

### What is the study about?
We are asking pregnant women with a learning disability about their experiences of having support from a Doula.

## If I choose to take part,

### What will happen?
We will give you **free support from a doula** during your pregnancy, during the birth of your child and after your child is born.

Your doula will visit you and introduce herself. If you continue to take part your doula will meet you again at the times you agree on.

### What will I have to do?
If you choose to take part you will have the support of a doula during your pregnancy, during the birth of your baby and after your baby is born. Your doula can support you to attend appointments and can help with any worries or questions you have about pregnancy, birth or childcare issues.

### What we will ask you to do
In return for the free doula support we will ask you to meet with a member of the research team three times for an interview. We will ask you about your experience of having doula support during your pregnancy, during the birth of your baby and after the birth. Each interview will last for about one hour.

### Are there any risks?
No. Your benefits and services will not change if you take part. You can talk to someone about your feelings after the interviews if you would like to.

### Who else is taking part?
Other women who have a learning disability and who are pregnant have been asked to take part.

### Where will we meet?
We will always meet in a place that is convenient for you.

### Who will find out about what I say?
Everything you say will be private, only the researcher will know what you say. We will ask questions about what it was like to have doula support. We will write a report at the end of the research but will not tell other people what you said. We might use some of the words you said in the report, but your name will not be included. You can choose whether what you have told us goes into the report. The report will also include some of the things other women have told us.

### What if I change my mind?
You can change your mind about taking part, just let us know. You can still have doula support if you want to.

# The Doula Project

## Meeting with a Doula

☐ Doula support has been explained to me and I would like doula support.

☐ I know I can end the doula support whenever I want to

## Meeting with a Doula and Taking Part in the Research

☐ I have had the research explained to me and **I want** to take part.

☐ I have had the research explained to me and **I do not want** to take part.

☐ If I decide to take part I know I can change my mind.

☐ If I change my mind during the research, I know I can still have doula support.

☐ I give my consent for the interviews to be tape recorded.

Name _____

Signed _____

Date _____

*APPENDIX 7: Interview Schedule for the Mother Participants*

Questions relating to being pregnant

1. Can you tell me about your experience of being pregnant?

- When did you find out you were pregnant?

- How did you feel then?

- Have your feelings changed over time?

- What were your expectations?

- Was there anything you were worried about?

Questions about demands

2. What sorts of things have you had to do since you became pregnant?

- Have you had to go anywhere?

- Have you needed to get anything?

- Have you need help with any of them?

- Have you needed company for any of them?

Questions about support during pregnancy

3. Have you needed support from other people during your pregnancy?

- Who has supported you during your pregnancy so far?

- How have they supported you?

- What kinds of support have you needed?

- Has this changed over time?

- Who has been the most helpful?

Questions about meeting with a doula

4. What was it like meeting with your doula?

- Had you heard of a doula before?

- What did you expect would happen?

- What was it like meeting her for the first time?
- Has your experience changed over time?
- Has your experience changed as your pregnancy progresses?
- Have your experiences changed as you have got to know your doula better?

Questions about the type of support offered by the doula.

5. Do you think your doula has supported you?

- How has she supported you?
- What has she supported you with?
- Has she attended meetings or appointments with you?
- Has she given you any information?
- Has she talked with you about pregnancy?
- Has she talked with you about having a baby?

Questions about experiences of doula support

6. How has your experience of doula support been?

- If a friend were pregnant what would you tell them about meeting with a doula?
- Is there anything you would change?
- Is there anything you would do differently?
- Is the support you received the same as you thought it would be?
- Is there any other support you would have liked?
- Is there anything else you think it is important in relation to your experience of doula support?

*APPENDIX 8: Interview Schedule for the Doula Participants*

Questions relating to the role of a doula

1. Can you tell me about being a doula?

- What does your role entail?
- What types of support does a doula offer?
- How is a doula trained?

Questions about meeting with a woman with a learning disability

2. What were your expectations of supporting a woman with a learning disability?

- Were there any differences providing support to a woman with a learning disability?
- Have you previous experience of working with someone with a learning disability?

Questions about supporting a woman with a learning disability

3. How did you support a woman with a learning disability?

- What were your expectations?
- Do you think your role changed?
- What was the best thing about supporting a woman with a learning disability?

Questions about the type of support provided to the woman with a learning disability

4. Can you tell me about your experience of supporting a woman with a learning disability?

- How did you support a woman with a learning disability?
- Were there any differences in the types of support you gave?
- Did you provide one type of support more than other types?
- Did you find some aspects of support more difficult than other aspects?

Questions about experiences of providing doula support to a woman with a LD?

5. Can you tell me about your overall experience of providing doula support to a woman with a learning disability?

- What aspect of the role did you enjoy the most?
- What was the most challenging aspect of the role?
- Is there anything you would do differently?

| Emergent Theme | Original Transcript | Exploratory Comments |
|---|---|---|
| | I: So, lots of different types of support | |
| Unknown as first child, first, new experiences, not knowing, expectations | P: Hmm.I know, some but yeah, cos when you, when it's your | Emphasis on new experience of being pregnant and preparing to have a baby |
| | first you don't know what's gonna happen in labour do you?  You | Expressing concern around not knowing what happens |
| Planning, sharing worries and concerns | get worried and that's why she's going do a birth plan and send | Acknowledgement of the role of a doula and how she can help with planning and ways of having doula support |
| Not knowing, learning about doula role | me leaflets and that what they do. | |
| | I: So she's going to write the birth plan with you? | View that doula will be able to meet her needs for support and preparation for the birth |
| Power, learning from the doula, lack of support from medical, expectations | P: Yeah, cos like she said midwives don't listen much when | |
| Relationship anticipated as problematic | you're in labour do they?  And that'll tell what's going on. | Emphasis on the unknown |

| | | |
|---|---|---|
| Process of gaining knowledge, different sources of information.<br>Self as being able to ask questions, confidence, | I: Ummm<br><br>P: And I got things to ask the midwife as well questions if I've got<br><br>any, erm that's it really I think. | Not knowing, emphasis on knowledge as a struggle<br>Emphasis on questions-overwhelmed? Use of I, sense of self needing to know<br>Self as questioning |
| View of self as similar to doula | I: Do you think she'll be a good person to answer questions?<br><br>P: Yeah cos she's got 2 kids as well | Able to learn from someone who has had children, been through the process |
| View of self as comparable with doula, development of a relationship<br>View of self as lone parent, anticipation of difficulty of role. | I: Oh<br><br>P: And I'm 26 and she's 27 and a good age,  but I'm a single<br><br>mum, it's going to be hard, but, but er, yeah, I'm looking forward<br><br>to it. | The initial development of a personal relationship with the doula<br><br>Thinking about self<br><br>Anticipation of role of self as single mother, over thinking?<br>Sharing of concerns over the change in self identity<br>Preparation of change in self after pregnancy |