How Do Women with an Intellectual Disability Experience the Support of a Doula During Their Pregnancy, Childbirth and After the Birth of Their Child?

Alison McGarry*, Biza Stenfert Kroese* and Rachel Cox†

*The University of Birmingham, Edgbaston, Birmingham, UK; †Developmental Neurosciences and Learning Disabilities, Mytton Oak Unit, Royal Shrewsbury Hospital (North), Shrewsbury, UK

Accepted for publication 30 December 2013

Background With increasing numbers of people with an intellectual disability choosing to become parents, the right support is imperative for effective parenting (Macintyre & Stewart 2011). The aim of this study was to gain insight into the experiences of parents who received support from Doulas during pregnancy, birth and following the birth of their child. In addition, the experiences of the Doulas who provided the support were investigated.

Materials and Methods Four women with an intellectual disability who received Doula support were interviewed before and after the birth of their child. Three Doulas were interviewed after the birth about their experiences of supporting women with an intellectual disability.

Results Interview transcripts were analysed using Interpretive Phenomenological Analysis (IPA). Themes were identified from each interview, before an overall analysis of themes from each support phase was undertaken.

Conclusions Pre-natally, the Doula was considered helpful and a reliable source of information about pregnancy. Each mother perceived Doula support as a means of keeping her child in her care. Post-natally, mothers described a trusting relationship with their Doula, who enabled them to make informed choices. Doulas described how they adapted their work to meet the needs of parents with intellectual disability. Being involved in Child Protection procedures was perceived as stressful and challenging.

Keywords: Doula, intellectual disability, parenting, pregnancy, support

Introduction

Social support during pregnancy has been identified as a key component in the health of mothers and in the health of their babies after birth (Oakley 1988). Good social support during pregnancy such as good antenatal care can lower a mother’s pre-natal anxiety (Rini et al. 2006), can increase mothers’ confidence in caring for their new baby (Warren 2005), and can lower the risk of post-partum depression (Collins et al. 1993). Continuous psycho-social support during labour has been associated with positive benefits such as a shorter labour and less need for medical intervention and caesarean sections (Zhang et al. 1996; Hodnett et al. 2003; Lantz et al. 2005).

Lantz et al. (2005) reported results of fourteen randomized trials and concluded that all women should have access to continuous support during labour, over and above medical services.

For parents with an intellectual disability support is considered to be essential for parenting. However, mothers with an intellectual disability are more likely to be socially isolated (Mayes et al. 2008) and have limited access to appropriate support. Llewellyn & McConnell (2002) highlight that whilst much attention has focussed upon the assessment of parenting skills for people with intellectual disability, there has been less attention given to the support parents may receive from their families, friends and professionals.
The importance of the quality of the support offered to parents with an intellectual disability was highlighted by Tucker & Johnson as early as 1989. These 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 does not improve (and may reduce) her sense of self-efficacy and tends to assume that the mother is incompetent. Tarleton et al. (2006) highlighted more recently that support needs to be flexible enough to meet parents’ on-going and changing needs especially as their children grow and develop. Moreover, support needs to incorporate a range of strategies such as early assessment during pregnancy, help at home, access to parenting groups and help to engage with other local services.

Despite these recommendations, many services remain inaccessible for parents with intellectual disability (Porter et al. 2012) and not only the amount but also the type of support offered may not always be what is required. Traditionally, most parents received practical and emotional support from family members (Mayes et al. 2008). However, the extended family has become less prevalent and these informal support systems have diminished. Moreover, mothers with an intellectual disability are likely to have smaller social networks in comparison to other mothers and experience lower levels of social support (Stenfert Kroese et al. 2002). This ‘social disconnection’ is associated with high levels of stress and poor mental health (McConnell et al. 2008), further compounded by high rates of abuse of women with intellectual disability from partners and/or family (McConnell et al. 2008; O’Keeffe & O’Hara 2008).

It is therefore not surprising that Aunos et al. (2008) identified that mothers with an intellectual disability reported both poorer mental and physical health compared to other mothers. Sterling’s (1998) model of parenting outlines how social support and mental health are closely related in a reciprocal manner for mothers with intellectual disability and that both social support and mental health are strong predictors of parenting ability (and more predictive of parenting ability than IQ).

Early intervention during pregnancy including information about pregnancy, birth and childcare in an accessible format and opportunities to learn and practice new skills has been found to have positive consequences for parenting ability in families where one parent has an intellectual disability (Tarleton et al. 2006; Llewellyn et al. 2008).

Porter et al. (2012) designed a Pregnancy Support Pack (PSP) for women with an intellectual disability as an accessible resource to enable them to make informed choices about pregnancy. They found that PSP was effective in supporting women with an intellectual disability during pregnancy, allowing them to make informed decisions about their pregnancy (e.g. whether to have a routine blood test or a scan).

Thus, there is evidence that early intervention and social support during pregnancy, birth and post-natally has a beneficial impact on parents’ well-being and parenting capacity whether they have an intellectual disability or not.

**Doula support**

Doulas are practitioners who can provide such support for parents. A Doula is a woman who provides consistent support to another woman and her partner pre-natally and post-natally, and is present during the birth. She can offer a wide variety of flexible support (Pascali-Bonaro & Kroeger 2004) and although the role of a Doula varies with every pregnancy as the needs of every woman are different, the key components of Doula support fall into four categories (Kayne et al. 2001): (i) emotional support through the Doula’s presence, reassurance and praise; (ii) advice and information provision, ensuring the woman understands and is prepared for each stage of pregnancy and labour; (iii) tangible assistance, supporting the family by helping around the house and empowering parents by offering encouragement and suggestions and (iv) advocacy for the woman, encouraging others to respect her decisions and ensuring the woman’s voice is central during her labour.

To become a recognized Doula an individual is required to undertake training and a mentoring programme (www.DoulaTraining.org; Accessed on 17th August 2012). Training focuses on practical and emotional support such as massage techniques, breastfeeding skills and skills pertinent to prenatal, birth and post-natal support. Following completion of the training course a Doula is required to work alongside a mentor for a period between 6 months and 2 years and attend a minimum of four births. This training requirement is supplemented with written documentation and reflective practice and culminates with a formal assessment interview with the mentor. The Doula can then register with one of the Doula organizations and become a recognized Doula.

As an independent practitioner a Doula agrees a contract with the mother/parents regarding the type of
support that will be provided. She is on call around the due date so that she can attend the birth.

Kennell et al. (1991) investigated the effect of Doula support on labour through a randomized controlled trial. Six hundred women were randomly assigned to one of three groups: a group that received Doula support, an observed group where the woman was monitored but not supported, or a control group that did not receive any additional support/observers. The results of this trial indicate that continuous Doula support significantly reduces 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 mean 7 h, observer group mean 8 h and control group mean 9 h). The authors conclude that Doula support has significant and positive effects on labour, and on the experience of birth for the mothers.

The benefits of such support may be especially relevant for women with an intellectual disability who, due to insufficient or inappropriate services and social isolation, often face the challenges of pregnancy and birth without suitable support except standard medical care. Doula support may address their physical, social and emotional needs and improve outcomes for the mother with intellectual disability, her child(ren) and the wider family.

To pilot this as yet untried approach, a small project was launched in an English rural county to provide pregnant women with intellectual disability with the services of a Doula who had received specialist training in working with adults with intellectual disability. The women were subsequently interviewed to gain an insight into how they experienced Doula support. The experiences of the Doulas were also considered to inform future services about the practicalities of adapting Doula practice to this population.

**Method**

**Design**

Interpretive Phenomenological Analysis (IPA; Smith & Osborn 2003) was the chosen qualitative methodology as it facilitates a richness of understanding in a relatively new area of enquiry and allows detailed analysis of the accounts of a small number of participants. It focuses upon an individual’s lived experiences and aims to gain an understanding of these experiences (in this case of having or providing Doula support) and their attributed meaning.

As a methodology, IPA is both interpretive and phenomenological. The analysis looks for shared experiences across a group of participants as well as differences. It does not test a hypothesis and due to the interpretative nature of IPA, researchers reflect upon their own role within the research process (Smith et al. 2009).

**Ethics**

Ethical approval for this study was granted by (name omitted for blind review) Ethics Committee (Ref number: ERN_10-0733).

**Procedure**

To participate in the study participants had to have an intellectual disability, to be pregnant at the time of the study and to have been offered Doula support. No formal assessments of intellectual disability were carried out but all participants were receiving local intellectual disability services, known to have stringent eligibility criteria.

Participants were provided with accessible information about the research. Those who did not want to participate were still able to access Doula support. Withdrawal of interview data from the study was possible until data analysis.

Doulas were recruited through word of mouth and a website (www.Doula.org.uk; Accessed on 11th June 2012). They had all experienced childbirth themselves and had completed a recognized Doula training programme and in addition attended a training day on working with parents with intellectual disability. They also received regular supervision from one of the two experienced intellectual disability practitioners (second and third authors) and attended monthly peer support meetings.

Mothers and Doulas were matched to take account of geographical location and personal preferences. Each Doula arranged a preliminary visit with the mother during which they introduced themselves and discussed support requirements. Subsequently, the frequency of the contact between mothers and Doulas averaged twice weekly. Duration of visits ranged from between 30 and 180 min, depending on the mother’s attention span and cognitive abilities. In addition, the mothers and Doulas kept in touch by SMS text messages. The latter was used by the Doulas to remind the mothers of appointments and other commitments whereas the mothers often texted to ask for advice. Doulas
accompanied the mothers to antenatal appointments and child protection meetings and conferences, and were present at the birth.

Data collection

Mothers

Referrals were received from health and social services professionals. During an initial meeting the research and what would happen if the woman gave her informed consent to participate was explained. Accessible leaflets were utilized to aid informed consent. If the woman agreed to participate she was asked to sign an accessible consent form.

The same interview schedule was used for each participant during pre- and post-birth interviews. 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 by discussions with professionals experienced in working with parents with intellectual disability. 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 post-natal period (interview 2).

Doulas

Interviews with the Doulas were carried out towards the end of the post-natal support phase (approx. 6–8 weeks after the birth). A semi-structured interview was used which consisted of five open-ended questions and associated prompts. Interview questions were informed by existing literature regarding the role of a Doula and the types of support provided. The first interview question concerned previous Doula experience and was followed by questions regarding the experiences of supporting a woman with an intellectual disability.

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

Participants

All four women who were referred and asked if they would participate in the research gave their consent. 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 participants and a summary of their background can be seen in Table 1. Table 2 provides information regarding the provision of Doula support. Names have been changed to protect confidentiality. Ages and other identifying features are not specified or have been omitted for the same reason.

Support was provided by three Doulas who had received specialist training to work with women with an intellectual disability. Two Doulas supported two mothers during their pregnancy, childbirth and post-natal period. They each gave separate interviews regarding their experiences of supporting each mother.

Table 1 Information about participants’ background and summary of personal circumstances at time of post-birth interview

<table>
<thead>
<tr>
<th>Name (not real name)</th>
<th>Approx. age</th>
<th>Previous children</th>
<th>Background</th>
</tr>
</thead>
<tbody>
<tr>
<td>Charlotte</td>
<td>20’s</td>
<td></td>
<td>Lives with her husband and her maternal grandparents. Supported by an advocate and community nurse from the local intellectual disability service.</td>
</tr>
<tr>
<td>Sally</td>
<td>30’s</td>
<td>Three children in local authority care</td>
<td>Lives with her partner. Supported by an advocate from the local intellectual disability service.</td>
</tr>
<tr>
<td>Leah</td>
<td>30’s</td>
<td></td>
<td>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 intellectual disability service.</td>
</tr>
<tr>
<td>Katie</td>
<td>30’s</td>
<td>Daughter in local authority care</td>
<td>Lives with her husband in a flat. Both are supported by a psychologist from the local intellectual disability service.</td>
</tr>
</tbody>
</table>
Data analysis

The qualitative methodology employed in the current study was Interpretive Phenomenological Analysis, IPA, which is described in detail by Smith et al. (2009).

The first author analysed the data. This involved reading and re-reading the transcripts several times to become familiar with the content. During the reading of each transcript, the author noted any significant themes of interest and a list of emerging themes was identified for each participant. Connections between the themes were sought, which were then clustered and labelled to denote super-ordinate and sub-ordinate themes across all interviews.

The process of analysing and interpreting qualitative data is highly subjective. An important criterion against which the quality of IPA research is measured is to verify the credibility of the categories and themes that are pulled out of the data. Therefore, to provide an appropriate credibility check, the author consulted the second author at different stages of the analysis to discuss emerging themes and interpretations and the processes through which they had been developed. An example of interview transcript coding can be seen in Table 3.

Results

The themes that were identified from the interviews with the mothers, pre- and post-birth, and with the Doulas can be seen in Table 4.

Mothers

Interview 1: Pre-birth

Theme 1 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 was 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 get as she wanted to keep her child:

People with disabilities means a lot of support especially support with social services because they
Table 3 Example of interview transcript and coding

<table>
<thead>
<tr>
<th>Emergent theme</th>
<th>Original transcript</th>
<th>Exploratory comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unknown as first child, first, new experiences, not knowing, expectations</td>
<td>I: So, lots of different types of support</td>
<td>Emphasis on new experience of being pregnant and preparing to have a baby</td>
</tr>
<tr>
<td>Planning, sharing worries and concerns</td>
<td>P: Hmmm. I know, some but yeah, cos when you, 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 going do a birth plan and send me leaflets and that what they do.</td>
<td>Expressing concern around not knowing what happens</td>
</tr>
<tr>
<td>Not knowing, learning about Doula role</td>
<td>I: So she’s going to write the birth plan with you?</td>
<td></td>
</tr>
<tr>
<td>Power, learning from the Doula, lack of support from medical, expectations</td>
<td>P: Yeah, cos like she said midwives don’t listen much when you’re in labour do they? And that’ll tell what’s going on.</td>
<td>Acknowledgement of the role of a Doula and how she can help with planning and ways of having Doula support</td>
</tr>
<tr>
<td>Relationship anticipated as problematic</td>
<td>I: Ummm</td>
<td></td>
</tr>
<tr>
<td>Process of gaining knowledge, different sources of information.</td>
<td>I: Oh</td>
<td></td>
</tr>
<tr>
<td>Self as being able to ask questions, confidence,</td>
<td>P: And I got things to ask the midwife as well questions if I’ve got any, erm that’s it really I think.</td>
<td>Not knowing, emphasis on knowledge as a struggle</td>
</tr>
<tr>
<td>View of self as similar to Doula</td>
<td>View of self as comparable with Doula, development of a relationship</td>
<td></td>
</tr>
<tr>
<td>View of self as lone parent, anticipation of difficulty of role.</td>
<td>View of self as questioning</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Able to learn from someone who has had children, been through the process</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The initial development of a personal relationship with the Doula</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Thinking about self</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Anticipation of role of self as single mother, over thinking? Sharing of concerns over the change in self identity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Preparation of change in self after pregnancy</td>
<td></td>
</tr>
</tbody>
</table>

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 intellectual disability:

I didn’t know much about it actually, but they, a Doula’s for people who ain’t got intellectual disability but they have got, now they do people with intellectual disability. 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:
Table 4 Themes identified from the research interviews

<table>
<thead>
<tr>
<th>Theme Identified</th>
<th>Title of Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-birth</td>
<td>Not knowing Doulas can meet our needs</td>
</tr>
<tr>
<td></td>
<td>Support with hopes and dreams</td>
</tr>
<tr>
<td></td>
<td>Preparing for and coping with pregnancy changes</td>
</tr>
<tr>
<td>Post-birth</td>
<td>Support received during labour</td>
</tr>
<tr>
<td></td>
<td>A trusting relationship</td>
</tr>
<tr>
<td></td>
<td>Learning and having an informed choice</td>
</tr>
<tr>
<td>Doula</td>
<td>Changing and adapting with intellectual disability in mind</td>
</tr>
<tr>
<td></td>
<td>Reflecting on the personal and emotional impact</td>
</tr>
<tr>
<td></td>
<td>Being accepted and making a difference</td>
</tr>
</tbody>
</table>

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 fear of being perceived as ignorant.

Theme 3 Support with hopes and dreams

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 their goal was that their child remains 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, emphasizing 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 reported that she was able to use new ideas and techniques in practice.

Each mother emphasized the importance of engaging with their Doula to learn about childcare, with a focus upon meeting the requirements of statutory services and Sally in particular:

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 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 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’ 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, aware of their cognitive deficits, experienced the Doula as a reliable and safe source of information about pregnancy, birth and the neonatal period. Further, they perceived Doula support as a means to achieving the goal which was shared by all four mothers, namely not to have their child removed from their care.

Interview 2: Post birth

Theme 1 Support received during labour
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 5 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 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 the stages of labour 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 to about anything, 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 now 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 is] 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. ... (line: 106)

Katie summarized 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 individualized support allowed women to make informed choices during the birthing process and feeling more knowledgeable about what to expect.

**Doulas**

**Theme 1 Changing and adapting with intellectual disability in mind**

Each Doula spoke of changes and adaptations in their normal practice whilst working with women with an intellectual disability. 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 intellectual disability. 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 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 intellectual disability 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.

**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 that she experienced 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 intellectual disability 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 intellectual disability 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 intellectual disability]. 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] 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 an intellectual disability. The experience of working alongside statutory agencies in child protection cases was perceived as 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 Doula support they received. They acknowledged the impact of their intellectual disability upon their ability to learn and to parent effectively and experienced the Doula service as effective and pleasant.

Most support for parents with intellectual disability tends to be crisis driven, provided by mainstream services whose workers may not be experienced in supporting women with an intellectual disability. In contrast, the support provided to parents in this study was individually tailored to parents, taking their learning needs into account. The mothers/couples in this study were aware of this and spoke appreciatively about the accessibility of the Doula support, including being given ‘easy read’ versions of information and having complex issues explained without jargon.

Tucker & 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 patronized or demotivated, indicating that the support had been experienced as competence promoting.

Each woman who participated also spoke about the trusting relationship they developed with their Doula. 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 an intellectual disability 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’Keeffe & 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 positively influences the experiences of pregnancy and parenting and thus parenting capacity.

One of the limitations of this study is the small number of women who participated and only two of the four gave both pre- and post-birth interviews. More extensive research is therefore required to establish efficacy of this type of intervention as measured by outcomes for parents and their children in the short and long term.

The Doulas identified that supervision from two experienced intellectual disability practitioners and support from other Doulas was helpful. However, two of the Doulas who had experienced particularly difficult child protection procedures described how they were not able or willing to go through with this process again. Their descriptions suggest that they were experiencing something close to ‘burnout’. As this was a qualitative study, no formal measures of burnout were applied and no firm conclusions regarding the Doulas responses to the work-related stressors can be made. However, the authors consider the Doulas’ accounts to have important implications for the delivery of future services and have therefore included a brief discussion in the context of the burnout literature.

Duffy et al. (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 & 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 the person, but on the people they support and on colleagues, as prolonged experience of burnout can lead
to the professional interacting in a detached and impersonal manner.

Duffy et al. (2009) identified that a combination of support, both practical and emotional is beneficial in preventing burnout. They found that training, including role-play, didactic methods and discussion, can raise levels of self-efficacy and decrease 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 were made for future clinical work. Although this was perceived as helpful and supportive, it did not ameliorate the stress experienced by the Doulas who were involved with childcare proceedings. They had received training to support their work with parents with an intellectual disability, but not specifically with regard to child protection procedures. Our findings indicate that future training must incorporate this, in addition to supervision from an experienced intellectual disability professional, to lower the risk of burnout and increase the Doulas’ self-efficacy.

Each Doula received regular supervision, the value of which was highlighted by the Doula participants, as was peer support and knowing that there is always someone to call on. These comments echo those of Collins (2008) who highlighted the importance of support from within the work setting to lessen the impact of occupational stress, such as mutual group support and support from colleagues. Gibbs (2001) suggested that supervision lowers the rates of attrition among child protection workers if supervisors ensure workers are aware of their value to the organization as this can increase self-esteem and self-efficacy and lower job-related stress. Boyass & Wind (2010) have also highlighted the importance of supervision and support for those working in child welfare or child protection services.

As mother participants were identified through a local intellectual disability service, they were in receipt of other services such as support from an advocate, community nurse or clinical psychologist. None of the mothers interviewed were without some form of other specialist intellectual disability support, although this support was not directly linked to their pregnancy. To establish the effectiveness of Doula support without the added interventions from others, one would have to provide Doula support to mothers with intellectual disability not known to services. These mothers are more likely to be socially isolated and vulnerable and may benefit from Doula support even more than the present sample of women.

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 support 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.

Conclusions

The findings of this qualitative research indicate that mothers with intellectual disability experience Doula support as positive, helpful and informative. Their descriptions of the intervention indicate it was perceived as competence enhancing and parents reported to be supported in learning new skills and routines and in making decisions for themselves and their babies. They had developed trusting relationships with their Doulas and did not feel patronized. Although further research needs to be conducted, these initial results suggest that the doula model of support during pregnancy, birth and the post-natal period can be beneficial for mothers with intellectual disability.

The Doulas reported to have had positive experiences in their work with the mothers but found being part of a child protection procedure challenging and stressful. Although they appreciated supervision and peer support, future training should emphasize the impact of this component of their work so as to prepare them more effectively, increase self efficacy and reduce work-related stress.

Acknowledgments

Thank you to the parents and doulas who took part in this study. Also thank you to Dr Fran Taylor and Amanda Hilton for their very helpful comments on earlier drafts of this paper.

Correspondence

Any correspondence should be directed to Alison McGarry, Community Learning Disability Team, Whitnash Lodge, RLSRH, Heathcote Lane, Warwick. CV34 6SR Email: Alison.mcgarry@Covwarkpt.nhs.uk).
References


