The postnatal support needs of mothers with an intellectual disability

Abstract

Objective: There is growing evidence that many parents with intellectual disabilities can parent successfully when given adequate support. This paper aims to explore the postnatal care experiences of mothers with an intellectual disability.

Design: A qualitative design was used and data were collected using a semi-structured interview format and analysed using Interpretative Phenomenological Analysis.

Setting: The study took place in community settings in Scotland.

Participants: Six mothers with intellectual disabilities were interviewed about their experiences.

Measurements and findings: Two super-ordinate themes are discussed with accompanying subthemes: challenges of providing support and how support was delivered.

Key conclusions: The mothers valued formal postnatal care, but this was secondary to informal support. How mothers perceived the support impacted on its effectiveness and building effective relationships with professionals presented challenges.

Implications for practice: The study suggests the structure and quality of the wider support networks of mothers with an intellectual disability are central and should be taken account of by professionals. Providing information and advice in ways that validates the mother's role is also important, particularly as the mother's perception of how help is given can impact on the degree to which mothers engage with professionals.

Keywords: intellectual disability, mothers, postnatal care

Introduction

Parents with an intellectual disability (ID) are more likely than any other group of parents to have their children permanently removed by child protection services and placed in care (Booth and Booth, 2005) and a UK survey found that 48% no longer had their children living with them (Emerson et al., 2005). Whilst there is no robust evidence to indicate why some parents with ID struggle and others succeed in providing "good enough" parenting, it has been identified that having access to formal or informal social supports may be an advantage for parents (International Association for the Scientific Study of Intellectual Disabilities: IASSID, 2008). Murphy and Feldman (2002) propose that, when given adequate support, parents with ID can effectively parent.

Research, however, suggests that mainstream parenting support services may be perceived as inaccessible or irrelevant to the needs of groups such as parents with ID (Tarleton et al., 2006). As a result there are limited social support networks for parents with ID, and those that are available typically involve family members (Guinea, 2001; Kroese et al., 2002). Mothers with ID were found to rely on informal support networks for help in areas such as shopping and transport to hospital in times of emergency. Mothers also considered support with childcare as one of the most helpful aspects of informal support (Kroese et al., 2002). Expectant mothers with ID have been found to recognise the need for practical assistance following the birth of their child and to proactively negotiate a support network around them prior to their infants' births. Furthermore, they were careful to ensure they included people who were likely to recognise the central importance of the mother's role in the infant's life. Despite this, many of these parents managed the responsibility of child-rearing with limited external support (Mayes et al., 2008).

Research consistently shows that the ways in which parents perceive the support offered to them is central to whether the support is experienced as being helpful or not (Tucker and Johnson, 1989; Aunos et al., 2004). Indeed, Llewellyn (1995) found that some parents were reluctant to seek professional support because they felt that the staff did not acknowledge the comprehension difficulties that were associated with having an intellectual disability. Tucker and Johnson (1989) outline a distinction between support that is "competence-promoting" and "competence-inhibiting". The latter seeks to enhance the parent's self-reliance and sense of competence in their role, while the former, in contrast, reflects a critical or domineering approach which disempowers parents.

This work has contributed to developments in the concept and definition of parenting, such that it goes beyond the responsibility of the individual parents and instead is viewed as a social responsibility or 'distributed' task (Booth and Booth, 1998) with support being available from a range of individuals, organisations and social structures (Booth and Booth, 2000). Midwives play a central role, as part of this 'distributed' care network, as formal providers of expert support and advice in the ante and post natal periods (Magill-Cuerden, 2006; Hodnett et al., 2007).

Childbirth is a significant life event and support at both the antenatal and postnatal periods is important. Support during the former period helps lay the foundations for future parenting success (Nelson, 2003), while postnatal care is important in facilitating a positive transition to motherhood (Demott et al., 2006). This is also the time when parents first learn to nurture and care for their child. Support at this time is likely to be particularly important for parents with ID, as research suggests that many experience difficulties in childcare (Kroese et al., 2002; Tarleton and Ward, 2007). This difficulty may be exacerbated for mothers by the experience of undiagnosed mental health problems (Cotson et al., 2001;

O'Keefe and O'Hara, 2008), such as postnatal depression, particularly because screening tools may not be as reliable when used in this population (Gaskin and James, 2006).

Despite the recognition of the need for appropriate support for mothers with ID and the recent emphasis that parents with intellectual disabilities should be supported to access generic postnatal support services (e.g. Tarleton et al., 2006; Department of Health, 2007), there is only a limited evidence base which focuses on parental experiences of formal support. This highlights the importance of being listened to and receiving practical support with parenting skills (Tarleton and Ward, 2007), as well as receiving appropriate and accessible information in a non-judgemental context (Starke, 2010). Walsh-Gallagher et al. (2011) explored the parenting experiences of disabled women and the participants included some women with an intellectual disability. While the experience of formal support was not the sole focus of research, the participants reported a number of negative experiences during pregnancy and childbirth, in their interactions with a range of professionals, including GPs, social workers and health visitors, The women reported feeling scrutinised, judged and discriminated against. The limited research into the postnatal period (McKellar et al., 2009), however, means it remains unclear to what extent the support needs of mothers with ID are being met. The present study, therefore, aims to explore how mothers with an intellectual disability experience postnatal care.

Method

Design

As the study aimed to achieve an understanding of individual participant's lived experiences, phenomenological methodology using Interpretative Phenomenological Analysis (IPA) (Smith, 1996) was chosen for the study. This methodology has been adopted by a number of studies of adults with ID (e.g. Baum and Burns, 2007; Mayes et al., 2008).

Participants

Six mothers with ID participated in the study. The mothers were aged between 20 and 55 years. All mothers were known to a community learning disability team (CLDT) comprising social care and health professional staff based within a rural population in Scotland. No formal measure of intellectual or adaptive functioning was completed as part of the study, however all of the mothers were considered to have a mild intellectual disability. Two mothers were single and four mothers, one of whom was married, currently lived with a partner. All of the mothers had experienced one or more of their children being removed by child protection agencies. For two of the participants, this was the only child they had. The other participants had between 2 and 8 children. The ages of the participants' youngest children ranged from 10 weeks to 15 years. All potentially identifying information was removed or altered to protect the anonymity and confidentiality of the participants.

Procedure

Ethics and recruitment

Permission for the study was obtained from the authors' educational institution and National Health Service ethical committees. Following approval, potential participants were recruited via CLDT members. All the mothers who were recruited had an intellectual disability and had previous or current contact with the CLDT. It is recognised that individuals with ID may be vulnerable to acquiescence (Finlay & Lyons, 2002) and in order to ensure that potential participants possessed the capacity to consent to the study a number of steps were taken. Firstly, potential participants were initially approached by a member of the CLDT, who was familiar to them and who described the study. If the mother was interested in participating, her consent was sought to provide her contact details to the first author, who then arranged an initial screening interview. During this, the mothers were provided with an

accessible participant information sheet, which was read to them, where necessary, and subsequently discussed with them. This provided information about the study and the associated limits of confidentiality (for example if child neglect or abuse was disclosed). Following this discussion, the first author asked the potential participants about their understanding of what taking part in the study would involve, the potential benefits and burdens in taking part and that they understood that they could choose not to take part and could withdraw at any point. The mothers were given 24 hours to decide whether they wished to participate. If so, a second interview was arranged, at the beginning of which the first author again checked that the participant understood what the study was about, the implications of taking part and that she still wished to be involved. Written consent was obtained before the interview began.

Data collection and analysis

Data were collected by the first author using a semi-structured interview schedule. The questions and prompts covered areas which were highlighted from previous research as being potentially important. An assessment of content validity was also provided by obtaining feedback from three professionals who worked in the field of intellectual disability. The researcher adopted a "self-developing" technique (Booth & Booth, 1996), and adapted communication as required as the interview progressed in response to any comprehension difficulties that arose. This included employing prompts to probe participants' responses and asking more questions. The interviews lasted for between 57 and 69 minutes. Four of the interviews were conducted in the participants' homes and two in a health centre.

The analysis of the data adhered to the process outlined by Smith et al. (2009). Each interview was transcribed verbatim with the mothers being allocated a pseudonym. Reading and re-reading of the data was carried out, which facilitated the process of taking exploratory

notes and identifying emerging themes. Possible connections between themes were then explored to produce clusters of themes. The emergent themes were intended to reflect, not only the participant's experience, but also the researcher's interpretation in order to capture and reflect an understanding of the participant's experience. In accordance with IPA, the emergent themes captured similarities across mothers' narratives, as well as including idiosyncrasies within the data (Reid et al., 2005). Subsequent transcripts were analysed with a table developed for each transcript. A final master table of super-ordinate and subthemes was produced. The researcher also conducted a credibility check (Elliot et al., 1999) using an independent assessor to evaluate the themes.

Results

Two super-ordinate themes: 'challenges of providing support' and 'how support was delivered' emerged from the data. These, and the accompanying sub themes are outlined below.

Super-ordinate theme 1- Challenges of providing support: overview

The main aim of the study was to explore mothers' experiences of formal postnatal care, however family members emerged as the key form of support during this period. All of the mothers spontaneously referred to family or significant others as providers of support in their lives, even when the support given was at times unsatisfactory. It seemed, from the mothers' narratives that input from professionals was valued, however, it was generally considered secondary to that received from family members and its value seemed limited to the care typically received from the mid-wife and health visitor post-birth. There was the suggestion that providing more intensive input could present challenges.

Sub theme 1: Significance of family support

The support provided to the participants by loved ones, particularly their partners or mothers was clearly significant during the postnatal period. A range of types of support were experienced, however most participants focused on the value of practical support.

If he's there we have turns about feeding. Em, if I'm eating my breakfast John (partner) will take over, like with everything like I'm having my lunch and even at tea time, he'll do stuff as well like he'll put the dinner on and I'll see to Fraser and things like that. It's much easier with John being there. (Fiona)

She (her mother) came and helped us and dressed him, looked after him and like. (Betty)

For two of the mothers, family members also played a role in providing instrumental support. Here the provision of baby clothes was appreciated.

She (her sister) helps me out quite a lot with clothes for Fraser. She helps me out quite a lot with them. (Fiona)

Family members also provided emotional support. This was most salient during the participants' time in hospital, perhaps due to the strange hospital environment or the need for help during the initial stages of transition to motherhood.

It was nice to have two close people (mother & partner) there that mean so much to me there and to support me so that was really nice. (Ruth)

But at the hospital he (partner) was great. He was holding my hand and stuff like that. (Donna)

Overall, the participants described relying heavily on family to provide support during the postnatal period. This was predominantly received from mothers and partners and mainly took the form of assisting with practical childcare tasks.

Sub theme 2: Feeling supported by professionals

Despite a strong emphasis on the value of informal support, the role and benefits of professional support was also recognised by all the mothers.

Cause if you ever asked a question, they would tell you what to do and show you what to do but that was it. They wouldnae say you're doing wrong or that. (Jean)

Being shown what to do featured in many of the mothers' accounts, suggesting it was important in facilitating the learning of childcare tasks.

One of the midwives, one of the nurses, she gave me a hand and showed me what to do, like bath her. (Jacinta)

Cause it was my first kid you know, you want to learn and what you learnt was by watching you know, seeing what she did. (Betty)

Well before I had Lucy she would show us the birthing pool and things like that around the hospital, and talk to us about when it came to the weaning and that as well and just things like that. She was brilliant. (Fiona)

Two of the mothers had attended groups for parents and described practical and emotional benefits, including increased self-confidence:

So we talk about weaning, what's good for them what's bad for them and things like that. We do some cooking and things like that, general discussion if we've got any worries about the baby, cause obviously there's a midwife there and you can ask questions and things like that. (Ruth)

Em I'm not as shy now, I can em, like if I don't know someone, I've got more confidence to actually speak to them rather than shy away from that person and try and engage wi' them. Whereas before, if I didnae ken someone I wouldnae talk to them and I would sit in the corner and things. (Ruth)

The need for emotional support, particularly someone to listen to them, was emphasised by a number of the mothers. In many cases the midwife, who was most involved in their care, took on this role.

If you were upset like, Emma (midwife) was there to talk to. (Fiona)

I got a bit tearful and things like that and one of the midwives took me away to another room, spoke to me, gave me a shoulder to cry on. And things like that, so it was really good. It was nice that they actually did that and listened to me, let me get it all out basically. (Ruth)

..cause she (midwife) knew what I was going through cause it was my first kid you know. (Betty)

Professionals were seen as offering both practical support, in terms of advice and guidance, but also emotional support. The mothers valued feeling cared for emotionally and having a professional who was accessible and empathetic to their situation. This tended to be the midwife, as someone who had most regular contact with the mother and was more familiar.

Sub theme 3: Professional input as an intrusion

Despite the positive benefits of professional support, four of the participants who had experienced intensive input after the birth of a child, perceived this negatively, as excessive and intrusive.

They were in and out like yoyo's (Fiona)

Yeah, every five minutes, they (staff) were always interfering, I says "get out", I know what I'm doing (Jacinta)

The continued presence of professionals appeared to lower some mothers' perceptions of their own capabilities and, at times, was resisted.

..It wouldnae have bothered me to have them there as long as they didnae crowd me too much, cos that's what they done.....there in my face all the time, and I couldnae cope with it (Fiona)

So basically that's why I came back here early (to her own house) to get away from them all (Donna)

For one mother, the continued involvement of social work staff was identified as particularly unhelpful, especially as it did not produce anything tangible. The visits were

regarded as an unwelcome intrusion which induced a sense of disempowerment rather than support.

> *They don't really do anything, I don't ken if it's support to be honest wi you cosall they do is come in saying "Hi-ya, how's you? How is the baby? How are things between yourselves?" things like that I don't see that as a support, cost that's just normal chitchat (pause) cos like for me, if we were stuck with money or something and they could like give us a loan of money something, that's supporting us, not actually just saying "hi-ya how's you?" I don't think that's support at all (Ruth)*

Overall, more intensive support that exceeded that provided as part of a standard care pathway was seen by some mothers as negative, intrusive and disempowering.

Sub theme 4: Managing unhelpful supports

Several participants continued to turn to informal supports during the postnatal period, despite experiencing them as unhelpful either because of a lack of effort...

> *...cause he (her partner) wasnae helping us ken he was just sitting watching telly and everything. He wouldnae feed the bairn or change the bairn, he would just sit and watch sport all the time. (Jean)*

...or because the quality of the support was poor:

> *...cause I wouldnae let (partner) bath her cause when (partner) bathed her one time, he made the water far too hot, and when he pulled the bairn out of the bath she was all red and he burnt her. So I had to buy some cream for the burns and stuff and then*

I still, for quite a bit I wouldnae let him do nought with the bairn cause of that. (Donna)

Despite stating that she would not accept any further help from her partner, it appeared that he remained actively involved in the care of their new infant. This need for support similarly extended to her brother on whom she continued to rely even when she was unable to supervise him.

...he went, he took my bairn to the pub, and I wasnae happy wi' it cause she was only a couple of weeks old and em so, what I done was I wouldnae let him take her anywhere unless I was wi him. (Donna)

The reliance on, at times, unsatisfactory informal support may indicate how much some of the participants needed help to fulfil the mothering role and suggests a gap in formal support networks. .

Super-ordinate theme 2 - How support was delivered: Overview

All of the mothers highlighted the importance of the ways in which professionals delivered support. They identified both positive and negative professional practices during the postnatal period which appeared central to their experiences of care.

Sub theme 1: Feeling 'told what to do'

The sense of being 'told what to do' by professionals emerged from all of the mothers' narratives. Being given advice in an authoritarian, direct manner, disempowered them and undermined their confidence in their own abilities to parent. Here, the mother feels her own knowledge and role as mother is being ignored and disrespected:

M: I says you have to leave her herself to wake up and I says you can try her, you wake her up, and you'll find out, so I woke her up and tried but she would nae take that bottle, "that's what I tellt you, you got to leave her and let her wake up herself", they tried to force us. I says "dinnae force me"

Support which was perceived as disempowering was devalued and no longer regarded as helpful.

She was a bit like she would nae so much support, she would be telling you what to do. You should do this with the child and you shouldn't do that with your child. (Ruth)

They were interfering, telling me what to do with Mary the whole time. (Jacinta)

This could also lead to confrontational responses. In the following excerpt the participant discredits the professional on the basis that she had no children of her own.

They were telling me stuff to dae and how to dae it and I was getting quite snappy wi them, cause I was like, have you got kids of your own, no, well don't tell me what to dae then. (Donna)

Being told what to do resulted in some participants avoiding the professional support and instead opting to fulfil the mothering role independently.

I says "get out" I know what I'm doing. (Jacinta)

This is contrasted with professional support that is offered in a collaborative manner which acknowledges the importance of the mother's role. This resulted in the participant being more inclined to follow the professional advice offered.

> She'd more advise you, give you, advise you, you can do it that way, well our way, but em, I would do it that way, or no so much she would do it, just give us advice other ways we can turn, so if what we were doing was nae right, we would take her advice on what she would tell us. (Ruth)

All of the participants provided examples of times when they felt they were being told what to do by the professionals during the postnatal period. This appeared to have a significant disempowering impact and resulted in the mothers resisting the input in a range of ways, from discrediting the professional to actively refusing the support offered.

Sub theme 2: Feeling judged

Many participants described feeling judged and scrutinised by the professionals involved in their care. This occurred throughout the post natal period, including in hospital and at home.

> They were taking notes to feed back to social work on how I was getting on looking after the baby on my own, in hospital, and caring for him and things like that. (Ruth)

> Luke was starting walking and of course, he's going to fall. He's going to have bruises and things like that. They (the health visitor) were asking how he was getting the bruises from and checking my house was tidy and things like that. (Fiona)

Oh you're no changing the baby right, you're no bathing her right and then you're no feeding her right. (Jean)

This scrutiny was resisted by some of the mothers, either by telling the professional to leave in no uncertain terms or by challenging the perceived judgement of themselves as a bad parent.

I was changing her bum there and I put the nappy at the sink cause it was a dirty nappy and I was putting the thingy on and like I left the bairn cause obviously she's not going to move and stuff and I left the bairn lying there and I went and got one of those nappy like things and she went "you never done that right! You shouldnae have left her on the floor" I was like "She aint going to move for crying oot loud" and I chucked her oot my hoose. (Donna)

Yeah, they came in the next day and there was about, there was a load of washing and they was saying that Harry and I never changed Mary and her nappy, I says what's that on the floor there's about 100 dirty nappies, there's a load there, what you trying to do, make me out to be a bad parent? (Jacinta)

Feeling judged had positive as well as negative valences. It offered an opportunity for mothers to receive positive feedback and reassurance that what they were doing was correct, which ultimately had an empowering influence.

She says "Jacinta well done for bathing her. I've never seen you do that before. (Jacinta)

She would come and speak to you. You know. You're doing well, you're feeding her, you're giving him what he needs, she was guid. (Betty)

Feeling judged appeared to be an inevitable occurrence during the period of transition to motherhood and it seemed to evoke both negative and positive emotions on the part of the participants. Those who felt they were being scrutinised and judged badly, described avoiding, challenging or resisting professional support, while being judged positively offered reassurance that they were fulfilling their mothering role.

Sub theme 3: Significance of feeling understood

Related to the sense of feeling judged, was the need to be and feel understood by professionals, especially in terms of having an intellectual disability. This understanding was particularly valued if it resulted in information and support being tailored to the individuals' needs.

T: Right ok so that's interesting, you felt you could understand her (midwife)?
M: And she could understand me,
T: So what did she do, do you think, that made you understand her?
M: Plain. Plain how to speak how to talk, and that's what she was there. (Betty)

I was finding it hard to understand cause of my learning disability, so he drew on a piece of paper wi like the pulses. (Ruth)

In contrast, one mother's difficulty in understanding the concept of time meant that she felt abandoned and distressed, but unable to communicate her needs

... you were only supposed to have that in for a couple of hours, minutes or a couple

of hours. I had that in until the next morning and it should have been oot. One of the

nurses, came and went and says did they no come and take that out I says no, I've had

it in all night. (Jean)

This illustrates the importance of professionals having an understanding of the specific needs associated with having an intellectual disability, which are specifically related to having an intellectual disability and tailoring information and interventions to account for these needs.

Discussion

The aim of the study was to explore how mothers with ID experience postnatal care. Two super ordinate themes were outlined: 'challenges to providing support' and 'how support was delivered', with the associated sub themes. The study found that the majority of participants appeared to rely heavily on informal support networks, primarily family members and partners. While emotional support was seen as important, particularly during the stay in hospital (Guinea, 2001), it was the value of practical support during the post natal period which was emphasised. This corresponds with previous research which has explored the wider support networks of parents with intellectual disabilities (Llewellyn, 1995; Aunos et al., 2008) and the type of support provided (Kroese et al., 2002). Not all forms of informal support were, however, helpful and although this was recognised by the participants, this unhelpful support was allowed to continue. Previous researchers have suggested that similar patterns of behaviour may result from a lack of assertiveness skills on the part of the parent (Kroese et al., 2002). While this appears applicable to some extent for the mothers in the

present study, the tolerance of unhelpful supports also seemed to derive from a dependence on practical support from others.

Previous research has highlighted the advantages parents with ID experience when receiving support from professionals (Starke, 2010) and the mothers in the present study also acknowledged the value of professional input. The mothers saw benefits in being offered advice and having questions answered, but particularly emphasised the advantages of receiving assistance with the practical aspects of childcare, in terms of being shown how to do things. This may reflect the concrete learning styles of this parenting group. Indeed, reviews of parental training interventions have emphasised that interventions that adopt a performance based rather than knowledge based approach are associated with more positive outcomes (Feldman, 1994; Wade et al., 2008).

Interestingly, the participants in the present study appeared to turn to professionals, mainly their midwife, for emotional support in relation to parenting, rather than to informal support networks. The midwife was described as being accessible, respectful of the mothers' role and easy to talk to. This is consistent with research that suggests that midwives have a key role in directly providing and facilitating social support (Magill-Cuerden, 2006). The facilitating role of midwives was also apparent in the present study: with two of the participants reporting the positive benefits of attending parenting groups. This is consistent with research from mothers in the general population which has shown that they view sharing their experiences with other mothers as important (Darvill et al., 2010; Wilkins, 2010) and supports calls for increased opportunities for mothers with ID to socialise with other mothers (Booth and Booth, 2003; IASSID, 2008; McKenzie et al., 2010).

While the support that mothers received from professionals was generally viewed favourably, when this exceeded what was viewed as typical postnatal care, it was perceived

less positively. One possible explanation is that the more intensive input may have led participants to make negative self-comparisons with mothers in the general population. Such social comparisons have been found to be associated with poor self-esteem (Dagnan and Sandhu, 1999) and the mothers in the present study certainly portrayed the additional input as disempowering, undermining of their sense of self-esteem and their role as mothers. This may also partly offer an explanation for why mothers appeared to prefer to turn to unhelpful informal supports for the care of their infant, in preference to seeking more intensive involvement from professionals.

Many participants perceived their maternal role as being undermined or dismissed at points during the postnatal period. This is consistent with previous research which has also identified similar unhelpful forms of support from professionals at various stages of parenthood (Tucker and Johnson, 1989; Kroese et al., 2002; Walsh-Gallagher et al., 2011). This clearly had an impact on how the participants viewed and used the professional input and overlapped with the sense of being judged. On the negative side, feeling judged led some participants to feel under scrutiny which elicited confrontational responses and an unwillingness to accept professional input. On the positive side, being judged could also result in the mothers feeling reassured that they were performing their role satisfactorily. Starke (2010) also found that mothers with ID valued positive feedback as it increased confidence in their role, while research with mothers without ID has shown that reassurance, in addition to learning new skills and receiving advice, contributes to emotional well-being (Wilkins, 2010).

The results of the present study also highlighted the importance of ensuring that information, advice and support is consistent with the needs of people with ID. By definition, mothers with ID will have difficulties with a range of cognitive and adaptive skills, such as memory, comprehension and visuo-spatial skills, and professionals should adapt the ways in

which they present information in order to minimise the impact of these difficulties (Williams et al., 2009).

Limitations

One limitation of the study was that it had a sample size of only six participants. This reflected two main factors: that adults with ID represent only 2.2% of the population (DoH, 2007) and that many people with ID may have cognitive and communication difficulties that make participating in research that relies on verbal abilities difficult. For these reasons, they are often excluded from having the opportunity to express their views and, although the numbers are relatively low in this study, it does offer the opportunity for mothers with ID to communicate their feelings and experiences.

A second potential limitation is that while IPA methodology recommends the use of a homogenous sample, the sample in the present study included those who had several children and some who were first time mothers, as well as those who had previously had children removed from their care. It is likely that these individuals will have had qualitatively different experiences as well as shared reflections. It would be helpful for future research to explore the impact of such factors on the lived experiences of mothers with ID.

Clinical implications

The findings of the present study are consistent with previous research indicating that it is not the extent, but the type and quality of support that is important to parents with ID (Aunos et al., 2004). Midwives need, therefore, to ensure that input to this group of parents is competence promoting rather than competence-inhibiting (Tucker and Johnson, 1989) and that it recognises and legitimises the parents in this role (Kroese et al., 2002). The evidence

from the present study suggests that the direct input from midwives is largely achieving this, through respectful interactions which validate the mother' role and take account of their needs. The study, also however, indicates that not all professionals interact with mothers with ID in this positive way and that this can result in hostility and resistance from the mothers. These negative interactions may be the result of a lack of professional confidence, knowledge or expertise in working with this client group (Llewellyn and Bridgen, 1995; Tarleton et al., 2006; Barkby et al., 2009). This suggests that midwives and intellectual disability specialists should consider providing joint training to professionals working with parents with ID, particularly in light of the increasing emphasis on people with ID receiving support from mainstream services (e.g. Department of Health, 2001; Tarleton et al., 2006).

The study also indicates the need to take account of the informal support networks of mothers with ID. Where these are in existence, the midwife may wish to negotiate her own role within this and help facilitate these negotiations on the part of others to allow a smooth transition of support. Where the mother lacks informal social support, or where it is unhelpful or unstable, more intensive formal support may be required. In order for this not to be perceived as intrusive or undermining, this could take the form of an invitation to participate in support groups with other mothers. Such groups have been evaluated positively by mothers with and without an intellectual disability (e.g. McKenzie et al., 2010).

Conclusion

The mothers in the present study described a number of issues in relation to their support needs which were categorised as the two themes of: the challenges of providing support and how support was delivered. The mothers saw the benefits of receiving formal post natal support and care, however this appeared to be perceived as being of less value than informal support. The study suggests that mothers' informal supports play a key role during the early stages of parenthood, particularly in terms of providing practical support in areas

such as sharing the burdens of child care and providing material resources, but also for emotional support. As such, the structure and quality of the wider informal support networks of mothers with ID should be recognised as central and be taken account of by professionals. The results also suggests that professionals need to deliver post natal support in ways that empower parents, such as providing information and advice in ways that validate the mothers' role, to help ensure that they engage with the professional and use the available support to full effect. For example, professional input was valued when delivered according to the typical pathway of care post-birth, but could be seen as intrusive and consequently resented when it was perceived as exceeding these 'typical' levels. This highlights that the way in which mothers perceive support impacts on its effectiveness and the extent to which they build constructive relationships with professionals and suggests that professionals need to be mindful of this relationship.

Conflict of interest: None

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