

Midwives experiences of caring for women with learning disabilities – A qualitative study

Castell, Emma; Stenfert Kroese, Biza

DOI:

[10.1016/j.midw.2016.02.001](https://doi.org/10.1016/j.midw.2016.02.001)

License:

Creative Commons: Attribution-NonCommercial-NoDerivs (CC BY-NC-ND)

Document Version

Peer reviewed version

Citation for published version (Harvard):

Castell, E & Stenfert Kroese, B 2016, 'Midwives experiences of caring for women with learning disabilities – A qualitative study', *Midwifery*, vol. 36, pp. 35-42. <https://doi.org/10.1016/j.midw.2016.02.001>

[Link to publication on Research at Birmingham portal](#)

Publisher Rights Statement:

Eligibility for repository checked: 19/04/16

General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.

Author's Accepted Manuscript

Midwives' experiences of caring for women with learning disabilities—A qualitative study

Emma Castell, Biza Stenfert Kroese



PII: S0266-6138(16)00039-5
DOI: <http://dx.doi.org/10.1016/j.midw.2016.02.001>
Reference: YMIDW1807

To appear in: *Midwifery*

Received date: 9 July 2015
Revised date: 31 January 2016
Accepted date: 1 February 2016

Cite this article as: Emma Castell and Biza Stenfert Kroese, Midwives experiences of caring for women with learning disabilities—A qualitative study *Midwifery*, <http://dx.doi.org/10.1016/j.midw.2016.02.001>

This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting galley proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Title:

Midwives' experiences of caring for women with learning disabilities – A qualitative study.

Author Names:

Dr Emma Castell (University of Birmingham, Department of Clinical Psychology, Edgbaston, Birmingham, B15 2TT; dr.emma.castell@gmail.com)

Biza Stenfert Kroese (University of Birmingham, Department of Clinical Psychology, Edgbaston, Birmingham, B15 2TT)

Corresponding Author:

Dr Emma Castell

emma_castell@hotmail.com

Revive, Mount Gould Hospital, Plymouth, PL4 7QD

07989 557040

(Corresponding Author's contact details NOT to be shared with agencies outside of Midwifery Journal without permission)

Abstract*Background and Objective*

People with learning disabilities (LD) are increasingly likely to become parents and are entitled to have access to the right support to be able to be suitable parents. However, access to such support is affected by limited resources, attitudes towards people with LD becoming parents, and lack of training regarding caring for parents with learning disabilities for midwives. A learning disability (LD) is defined as a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), reduced skills to cope independently with everyday life, has an impact on most areas of a person's life and the difficulties started in early childhood. Little research has explored health professionals' experiences of their support of people with LD during their journey to become parents. Midwives are often the first professionals pregnant women come into contact with and therefore are key professionals in the support system for parents with LD. The principle objective of the current research is to develop an understanding of midwives' experiences of caring for women with a LD.

Design

The study explored midwives' experiences of caring for women with LD using an Interpretative Phenomenological Approach (IPA).

Participants

Nine qualified midwives employed by a single NHS trust participated in the study.

Measurements and findings

A semi-structured interview schedule was utilised during one-to-one interviews with the midwives. The interview transcripts were analysed using IPA stages. Four superordinate themes were identified.

Key conclusions

The midwives reported receiving a lack of LD training and faced significant time constraints, which left them feeling that they could not spend the necessary time with the women to meet their pregnancy needs. The midwives felt unsupported in their attempts to deliver adequate midwifery care, speaking about a lack of accessible support for pregnant women with LD. They were left feeling responsible to fill the gaps in service provision. The midwives were dedicated in delivering adequate care to help give women with LD a positive experience of childbearing. They felt a safeguarding process (child protection) was an inevitable part of women with LD's pregnancy experience yet were aware that the right support at the right time could improve parenting capacity.

Implications for practice

It is recommended that training on working with and providing services for people with LD is made available to qualified and student midwives as well as accessible resources, professional support and supervision.

Highlights

- Midwives face a number of significant barriers in providing care for women with LD.
- Midwives reported a lack of LD training for both qualified and student midwives.
- Barriers to accessing support for women with LD impacted upon midwifery care.
- Midwives were dedicated in delivering adequate midwifery care to women with LD.

Key words: Parenting, Learning Disabilities, midwives, Interpretative Phenomenological Analysis.

Introduction

Over recent decades, there has been a significant change in the design of services for people with learning disabilities (LD). A Learning Disability is defined as a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), reduced skills to cope independently with everyday life, has an impact on most areas of a person's life and the difficulties started in early childhood. Services are progressively supporting people with LD to live in the community and promoting their rights for community inclusion. As part of this movement, adults with LD are increasingly likely to form relationships and want to create their own families (Working Together with Parent Networks, 2008). The UK government White Papers, 'Valuing People' and 'Valuing People Now' (DoH, 2001;

DoH, 2009) support this movement, advocating that people with LD should have the same rights and choices as other people, including the right to have a family.

Support for parents with LD

The Disability Discrimination Act (1995) and the Equality Act (2010) state that all people should have an equitable service. Accessible information on pregnancy, consent, childbirth and childcare is vital in supporting people with LD to have equal access to services and facilitate their abilities to meet their children's needs (NHS Executive, 1998; DoH Dfes, 2007; SCLD, 2009; RCN, 2007). The White Papers 'Valuing People' and 'Valuing People Now' (2001, 2009) also advocate access to adequate support for people with LD to be able to be suitable parents. Yet this is an area where there is significant shortfall in services. Parish & Huh (2006) report poor access to maternity services for women with LD, which is concerning given their additional needs, in particular their need for specialist social support and health provision. Access to such support is negatively affected by limited resources, attitudes towards people with LD becoming parents, and lack of specialist training (Booth & Booth 1993; Cooke 2005; Culley & Genders 1999). A high percentage of parents with LD face the prospect of having their child removed, often because of concerns about their capacity to parent effectively (Champion, 1995).

Crozier et al (2013) reports that parents with LD may require support from a range of services to meet both their health and social needs. Variations in policies across services in terms of their eligibility criteria for supporting people with LD may affect the consistency and support available to meet their needs. This document also reported that multi-agency working is scarce with professionals having limited

awareness of other services available to support to parents, not enough sharing of assessment information and no consistent approach in the assessment of parenting skills of people with LD.

Midwifery services for people with LD

Guidance is available for midwifery care for women with LD within guidelines for caring for women with disabilities ('Pregnancy and Disability', RCN, 2007) which aims to provide guidance for midwives to enable them to deliver high quality, person-centred care for disabled women during their pregnancy, birth and postnatal. Specific LD guidance on a national level is limited although some health trusts have produced their own local guidance (e.g. NHS Highlands, 2011; NHS Greater Glasgow and Clyde, 2006).

There is a distinct lack of research into women with LD's pregnancy experiences, from both the women's (Mayes, 2005; Mayes, Llewellyn & McConnell, 2006) and midwives' view (Hoglund, Lindgren & Larsson, 2013). Begley et al's (2009) review concludes that provision of maternity services for women with LD is under-researched, with little known about women's experiences of midwifery care and a gap in the literature on knowledge, attitudes and behaviours of healthcare professionals towards women with LD.

Support available for midwives

It is estimated that only 7% of people with LD are parents (MENCAP, 2011). Thus parents with LD form a small percentage of a midwife's caseload. However the number of women with LD presenting to maternity services is increasing (Mayes, Llewellyn & McConnell, 2006). Leaviss et al (2011) report that since the early 1990s,

people with LD becoming parents has increased by more than 40%. It is therefore important to ensure that midwives receive appropriate training and feel supported to work with this client group. Brown (2005) suggests a lack of awareness amongst midwives of parents with LD and their support needs, which has an impact on the services these parents receive. Moreover, women with mild LD's needs may go unrecognised within the context of a busy healthcare setting where finding the time to check women's understanding of information given is challenging and professionals, including midwives, have limited understanding of the communication needs of the LD population.

There appears to be limited literature exploring midwives' understandings and experiences of working with parents with LD with the exception of a MENCAP report (2011) which suggests a significant deficit in the knowledge base of midwives caring for women with LD, highlighting the need for further training.

Available midwifery guidance (RCM, 2008; RCN, 2007) recommends that sharing good practice, alongside LD training and multi-agency working is essential when attempting to achieve equal access and efficient maternity services for parents with LD. Given the scarce literature regarding midwives' experiences, research into this area is needed to understand the psychological processes which determine the quality and thus outcomes of maternity services. This information could contribute to the promotion of good practice when working with prospective parents with LD.

Research aims

Researching midwives' subjective experiences and understanding may contribute to what is known currently about supporting parents with LD during

pregnancy, birth and the post-natal period; and throw light on how current guidance and training are impacting on midwives' abilities to provide care for this client group.

Midwives are often the first professionals a woman with LD comes into contact with during her pregnancy. They are therefore likely to have key experiences and insight. This may inform future care pathways and service development. Their knowledge gained from such experiences could contribute to relevant staff training in a drive to provide appropriate access to and support by midwifery services for people with LD.

The principle aim of the current research is to develop an understanding of midwives' experiences of caring for women with a LD. The second aim is to explore how midwives describe the way they work with women with LD in order to understand how midwives make sense of their experiences with this client group. A third aim is to explore midwives' experiences and attitudes to the role of LD training in determining the quality of service delivery for this client group.

Materials and Method

Design

Interpretive Phenomenological Analysis (IPA) was chosen as the study aims is to explore the experiences and understanding of midwives who have cared for women with LD. IPA is an idiographic approach, offering insight into how an individual, in a specific context, makes sense of a specific phenomenon (Smith, Flowers & Larkin, 2009). For this reason, it does not require a large number (ten or below) of participants as, as long as the sample is sufficiently homogeneous, the data soon becomes 'saturated'.

IPA facilitates an experiential and 'rich' account of a participant's experiences. Working with small samples sizes allows detailed analysis of the data and identification of common themes. A method of data collection adequate for this purpose is individual semi-structured interviewing (Smith, Flowers & Larkin, 2009). To ensure the data collected were from a homogenous sample and provided a rich account of the midwives' experiences, interviews were conducted with a small sample of midwives. The interview schedule is discussed within the Materials section.

Ethical approval

Ethical approval for this study was granted from the University of Birmingham. Subsequently, approval was sought and granted from the NHS Research and Development (R&D) department of four NHS Trusts identified for recruitment.

Materials

A semi-structured interview schedule was developed by the researcher in consultation with a qualified midwife. The midwife was consulted to ensure the language used throughout the schedule was meaningful and appropriate for the participants and the questions asked would allow the participants to discuss their experiences openly. The midwife highlighted the importance of reassuring the participants that there was no right or wrong answer and how the aim of the interview was to explore their experiences, not to judge them or their skills as a midwife. The schedule comprised of five main questions to facilitate discussion with the participant about their experiences of providing maternity services for women with LD.

At the onset of the interview, the researcher used a screening tool to clarify the definition of LD for the participant in order to ensure they were aware of the specific

population the researcher was interested in. This tool was designed by a local LD community health team to support professionals to identify people who may have a learning disability and is currently unpublished. The tool also acted as an introduction to the interview and an opportunity for the midwife to seek clarification regarding the aims of the research.

The initial questions were designed to encourage the participant to think about their clinical work with women with LD and reflect upon their experiences. The remainder of the questions were focused on training and resources the participant had experience of. Hoglund, Lindgren & Larsson (2013), Leaviss et al (2011) and Ward & Tarleton (2007) concluded that there is a distinct need for further LD training for midwives, which was why it was deemed important to collect data regarding midwives' experiences of LD specific training. Additional prompts were included in the schedule to enrich the midwives' responses and to ensure sufficient data were collected for the purpose of IPA methodology. The midwife was asked to describe a clinical case example at the beginning of each interview after the screening tool was discussed. The remainder of the schedule was used flexibly, although the researcher ensured that all topics were covered.

Procedure

An opportunity sampling method was used to recruit participants. A multi-site strategy was employed for recruitment. Four NHS Trusts were identified and contacted and a poster describing the project and inviting midwives to participate was emailed to practice development midwives of each of the Trusts. An information sheet with more details of the project was also included. The poster was then advertised in 'staff only' areas within the maternity services. Interested midwives

subsequently contacted the researcher to discuss the project. Recruitment was closed when the target sample size was achieved, which was nine participants.

If the participant verbally consented to being interviewed at point of initial contact, a mutually convenient date and place was arranged. The participant was contacted via email before the interview to ensure they still wanted to attend. Upon meeting with the participant on the agreed date, they were asked to sign a consent form and the interview took place. A £10 gift voucher of the participant's choice was given to compensate for their time. Interviews lasted between 29 and 62 minutes (mean 42 minutes) and were audio-recorded.

Participants

Nine female midwives were recruited from one of the four NHS trusts included in the study. Seven participants worked as community midwives. Two midwives worked at the hospital, one held a supervisory role, as well as working clinically; the other was a specialist midwife for safeguarding (child protection) children and vulnerable adults. All participants had examples of caring for women with LD during pregnancy or childbirth and were able to discuss their experiences of providing maternity services for those women. Participants varied in terms of the number of years they had been working as a qualified midwife. All participants had a minimum of three years experience, with two having twenty years plus. Participant details are provided in Table 1.

Table 1: Participant information.

Pseudo-name	Current area of work	Approx. age	Approx. years of experience
Jo	Community	40s	10+
Jess	Community (previously hospital based)	20s	≤ 5
Helen	Hospital	40s	10+
Lisa	Community	50s	15+
Judy	Hospital	50s	15+
Kerry	Community	40s	10+
Charlotte	Community	30s	5 - 10
Dawn	Community	40s	10+
Sarah	Community	30s	5 - 10

Data analysis

The audio-recordings of the interviews were transcribed. These data were analysed using the stages identified by Smith, Flowers, & Larkin (2009). All transcripts were read and re-read, with initial notes and researcher reflections made. Notes and exploratory comments were made. These comprised descriptive comments, notes on the use of the participant's language and interpretative, conceptual comments. Emergent themes were then identified. These emergent themes were grouped together. Once all transcripts had been analysed as described above, they were reviewed as a whole to identify patterns across the transcripts. This enabled final themes to be established.

The themes identified were discussed with two midwives, independent to the study. Both midwives reviewed a draft version of the result section and were invited to comment upon the themes identified. The aim of this process was to help validate the researcher's interpretation of the midwives' experiences and to reflect upon the

themes identified and if they were an accurate representation of midwives' experiences of caring for women with LD. The midwives' comments are considered during the discussion of the results.

Results

Four superordinate themes were identified following analysis (see Table 2). The first theme, 'Not being able to do my job' identifies the challenges the midwives faced in delivering care. The second theme, 'Delivering the best care' details how the midwives strived to deliver adequate care. The third theme 'Support for midwife' concerns the lack of support available as well as detailing the midwives' experiences where they felt supported in their care of the women with LD. The final theme, 'Safeguarding process' describes the midwives' view that this process was an inevitable part of a woman with LD's pregnancy experience. Although it was acknowledged that support in terms of social care (housing, finances), activities of daily living, pregnancy education and parenting could make a difference.

Most midwives discussed similar experiences during their care for women with LD, regardless of their role (hospital or community based), age or length of time as a qualified midwife.

Table 2: Summary of themes identified.

Super-ordinate theme	Sub-ordinate themes (number of midwives who contributed to each theme)
1. Not being able to do my job	1. Support available but not accessible (9)
	2. Having to do other people's jobs (9)
	3. Not skilled enough – out of my depth (9)
	4. Not enough time to do everything (8)
	5. Lack of LD training (9)
2. Delivering the best care	6. Wanting to do your best (9)
	7. Gaining a woman's trust (9)
3. Support for midwife	8. Feeling alone and unsupported (9)
	9. We need to work together (5)
4. Safeguarding process (child protection)	10. Inevitable (9)
	11. Support can make a difference (9)

Not being able to do my job

This super-ordinate theme appeared throughout the midwives' narratives as they talked about their experiences. A number of barriers were identified with the midwives being concerned that they were not delivering the care the woman should be receiving as a consequence. They felt frustrated that they were not meeting the women's needs as a result of the barriers, many of which were out of their control.

1. *Support available but not accessible*

All the midwives felt that the women required additional support to meet their varied needs during pregnancy, as part of their human right to have children. They all talked about how there was an apparent lack of services available for the woman and when they tried to access support, they faced many barriers.

'I felt like I was banging my head up against a brick wall, to try and find the help and support, the appropriate help and support for her.' (Jo)

Jo and Charlotte spoke about how they had a lack of awareness of services available for women with LD, which was an extra obstacle in accessing support for the women. This experience left the midwives feeling that they did not have the knowledge in order to deliver the care the woman needed as well as frustrated that they were not given the information or support they needed.

'it's very difficult to try find out what other agencies are around locally that can help her and support her, so I did struggle, I found it really difficult.' (Jo)

'I didn't realise.. that there's actually an advocate that can actually help ... if I'd had known that, I would have tried... having one of those for her as well.' (Charlotte)

Several participants spoke about the benefit, in terms of accessing support, that the diagnosis of LD brings.

'I think the most difficult thing is because there isn't any diagnosis or she hasn't had any type of assessment ... then its very difficult to go to ... places becausethey want a diagnosis.' (Jo)

'If it's documented and it's diagnosed, it's easier to refer them... To get the extra support.' (Charlotte)

The midwives suggested that the women fell between existing services and there was a sense of frustration because they saw the benefit of specialist support for other women with additional needs (e.g. young mothers), yet they were aware of the gap in services for women with LD.

'we get family nurses but they'll take 20 and under... Family support workers, they didn't want to look after her because they felt she was way over their heads and she wasn't going to be able to take in anything they told them, she... she fell down this huge hole... that was really frustrating.' (Sarah)

2. *Having to do other people's jobs – can't focus on midwifery care*

The midwives stated they were not able to focus on their role due to the lack of support in place for the woman, which left many feeling responsible and pressured to pick up the extra care needs, as they were aware they would otherwise go unmet.

'it's just frustrating because we still have to do what we have to do plus more... as carers you can't just say 'well that's not my job' and ignore that aspect you just have to get on and do it' (Lisa)

3. *Not skilled enough – out of my depth*

All the participants talked about how they didn't feel skilled enough to care for women with LD. This meant they couldn't deliver care to an adequate standard. They questioned their own skills, knowledge and experiences and did not feel confident.

'I would always go away thinking, worrying about that situation... I suppose it only comes with experience of looking after them ladies that you'd ever.. gain that confidence' (Jess)

'I felt completely out of my depth..' (Lisa)

'I had no idea and I'm not unexperienced, I'm experienced in my job... But I'm not experienced with this ... 'cause we don't get loads and loads of people with learning disabilities...' (Sarah)

The midwives felt they were not doing enough, that they did not have the time, support or training to develop their practice to meet the needs of women with LD. This did not sit easy; they wanted to adapt their practice and felt frustrated they had a lack of training, resources and support.

'I did wonder whether or not my care of her was possibly not.... what I'd given the other women ... it made me feel really guilty' (Helen)

'you just feel overwhelmed.. and guilty that you're not providing, something because you don't know about it, you don't know what's out there... you find out maybe too late that all of this might have been useful.' (Lisa)

4. *Not enough time to do everything*

The majority of the participants' narratives focused on the lack of time and how this is an issue in any pregnancy but presents as a particularly significant problem when caring for women with LD.

'we didn't have the time to get everything that we needed in place that we wanted to get in place... Which goes to show that if, as soon as you know there are any issues with learning disabilities, let us know and we can try to get things in place... As soon as possible... And I think that's just hugely important...'. (Judy)

'I try to do it early enough, getting it all... Up and running, is the problem that I find that's obstructive to making sure that she gets the level of care... That she deserves'. (Kerry)

'I think it gets lost, I think that women with learning disabilities probably still do lose the care they should have when they come to the hospital because we are too busy...'. (Helen)

Lisa and Charlotte talked about having to make adjustments to their routine practice to ensure women received the extra time they needed.

'I had to.. give some of my work to other people... because it would take a long time. So I had to, protect time to go and visit her'. (Lisa)

'I always tried to put her kind of at the end of the day or maybe try and see her at home... So I'd have a bit more time to spend with her.' (Charlotte)

5. Lack of LD training

An evident theme throughout all the midwives' experiences was that they had a significant lack of LD training and information. None of the midwives could remember having any specific LD training during their midwifery training. Charlotte and Dawn noted that it was still not a part of student midwives' training today.

'as a student, we don't have training in it really. I've been qualified five years now, but they still haven't got any specific training at the university.' (Charlotte)

The midwives not only felt that training would be helpful but were keen to develop their skills and knowledge as they wanted to enhance the level of care they provide for women with LD.

'develop my knowledge and my skills so that it would enable me to manage things better.. so I can look after these ladies and give them the appropriate care....' (Jo)

'what would have helped me? ... a better understanding because there's so many.. learning disabilities, you'll never be able to have all the information in the world but.... a bit more specific to each.. learning.. disability as to.. what is good and what is bad practice.' (Jess)

The participants who had received recent LD training thought that others could benefit from such training.

'it was very useful... And I'd recommend anyone to go on it... from a practical point of view and an emotional point of view, so practically, seeing the visual aid that they used to explain things... And emotionally, realising the impact Children's Services' involvement has with... families.' (Judy)

Delivering the best care

The midwives wanted to deliver the best care they could despite the countless barriers they faced. The midwives were focused on building a relationship with the women, as they felt it was essential to gain their trust to facilitate the midwifery care.

There was a covert assumption throughout the narratives that women with LD had the human right to become parents. The midwives never questioned the fact that the women were pregnant or that they were going to become parents. Although it was acknowledged that these women had additional needs that required support, there was a positive attitude towards the women and a sense that the midwives strived to deliver the 'best' care they could within the circumstances.

6. Wanting to do your best

The participants in this study spoke of how they strived to deliver the best midwifery care they could despite the challenges they faced. It was apparent they felt responsible

for the shortfall in the care provision and frustrated that they could not change the situation due to the challenges they faced in regards to time, resources and skills.

'we should all just try and do our best, for anybody ... it doesn't matter who they are what their circumstances are, I think that is part of our job To try and get the best for people'. (Jo)

'you try to do the job... the best way you can and if you feel in your heart that you have done as much as you possibly can to actually help that person... I don't think you can do any more really.' (Judy)

7. Gaining a woman's trust

The importance of continuity of care and how it is vital to build a relationship to gain trust was mentioned by all participants.

'continuity of care in any given area was really important to her. It is to most women but certainly.. when you've got a disability I think it's pretty essential really.' (Lisa)

'they get to trust you and they open up to you more if they know your face.' (Charlotte)

'if you ask any woman, they prefer to see one face really... Than lots of different faces... for ladies who have got learning disabilities, I think it is important... for them to try and be able to see that same... person... So it's just, it doesn't make her feel uncomfortable then.' (Dawn)

Support for midwife

The midwives reflected how the right support, for both the woman and the midwife, can make a significant difference in terms of the quality of care delivered and the woman's and the midwife's experiences. All the participants felt that working in partnership with other services was key.

8. Feeling alone and unsupported

There was a strong sense that the midwives felt alone and unsupported in their care of women with LD. The midwives felt out of their depth and had limited, if any, guidance to refer to. This led them to feel alone and unsupported by their employing organisation in their attempts to deliver care for women with LD.

'it's like the blind leading the blind I suppose, you literally just find your way through it...' (Jess)

'there's loads of specialist people that deal with people with learning disabilities, help me, please tell me where I'm supposed to go with it, 'cause I didn't know... I tried, loads of times... But it just was falling on deaf ears... .. So it was really frustrating' (Sarah)

All the midwives spoke about an absence in policy and guidance from their employing organisation on working with women with LD.

'I just don't feel there was ever .. anything explicitly said, or support from the trust itself to say ... this is what you should do in this situation ...' (Jess)

9. We need to work together

The midwives talked about their experiences of multi-disciplinary and multi-agency working and how it was vital for services to work together, supporting each other to ensure women were receiving the care and support they needed.

'I can't do everything ... myself... and that's what it's supposed to be, it's multi-disciplinary... So we do need other people on board' (Kerry)

When LD workers had been involved, the midwives stated they were able to focus on the woman's midwifery needs.

'She did have carers... and a learning disabilities nurse... that was easier because she did have that support. ... I felt I could do my job without getting embroiled in trying to set up support networks that clearly weren't there for my other lady.' (Lisa)

'I have to say the family support worker, the health visitor, they've all been really good.. a multi agency approach.. is definitely the way to go because I think if it was just me, I would've struggled and perhaps not given her the.. best care I could've given her so, I think support from other agencies is important as well.' (Jo)

'working with Mencap have been amazing... I was really shocked, I've never had any involvement with them before, so all of that's been so positive and everything with my lady's been just so lovely and positive.' (Dawn)

The participants stated that it was important to share information between community and hospital midwifery teams.

'we filled it all in (my maternity book) and I said, it's there and it makes all the healthcare professionals aware, when you go into hospital... Without you having to explain anything or them having to ask you, what is your difficulties... and I know she might not always speak out very well....' (Dawn)

'I'll let the hospital know... a little bit about you... so at least the midwife that is going to look after you, can make sure they've got a student with them who can support you... And get a little bit of a... insider knowledge...' (Dawn)

Safeguarding

The participants all assumed that safeguarding procedures were part of the pregnancy process for women with LD. They felt under pressure during the process, worrying about how to do the best for the women.

10. Inevitable process

The midwives spoke of the safeguarding process as inevitable in any pregnancy of a woman with LD.

'if there are any concerns at all we have to do a referral and that can be hard as well because That's not the way I want it to go ..for her ... nobody wants to do that ...but ...sometimes its necessary.' (Jo)

'I did refer her to the family support workers, but they felt that it was safeguarding because she had obvious disability... you don't want to necessarily go down the safeguarding route but I had to.' (Sarah)

11. Support can make a difference

It was evident that the midwives felt that support could make a difference in the pregnancy of a woman with LD and could be influential in the outcome of a safeguarding process.

'I think it really hit home for me because that makes you think hang on a minute ... these people deserve a chance and with a bit of help and support .. they can be good parents where as I think before that ... it's quite easy to just think .. social services ... which isn't giving them a chance and that's such a shame really'. (Jo)

'if you can give them enough support, if we do manage to get it right and give them the right support, it'll have a good ending...' (Charlotte)

'Just because they've got learning disabilities doesn't mean they can't be parents. With the support, I think a lot of them can be.' (Charlotte)

Discussion

Summary

The participants' narratives indicate a common underlying assumption that women with LD are entitled to become parents. They highlight gaps in health and social care services and how because of this their own practice falls short in delivering the care these women are entitled to.

Midwives' experiences of working with women with LD

Midwives who worked with women supported by other agencies reflect on the positive difference this made, both in terms of the woman's experience and the midwife's ability to deliver adequate care. There was an apparent lack of such services accessible to pregnant women with LD, frustrating the midwives as they were aware of the benefit specialist support can offer for women with additional needs. This is similar to the experiences reported previously by specialist LD doulas (McGarry, Stenfert Kroese & Cox, 2015) who felt that support appeared to be crisis-driven and provided by inexperienced mainstream services.

The midwives spoke about feeling alone, unsupported and unskilled in delivering care for women with LD. This appears to be a common theme across healthcare professionals (e.g. nurses, GPs) who also feel inadequately skilled and supported to deliver care for people with LD (Melville, Cooper & Morrison, 2006; Sowney & Barr, 2006). McGarry, Stenfert Kroese and Cox (2015) and Hoglund, Lindgren & Larsson (2013) highlight the need for more support for professionals working with women with LD during their pregnancy.

The midwives felt their lack of skills and limited communication with other services negatively influenced the delivery of maternity care. Midwives' experiences

suggest that services were not working together, which parents with LD also have reported to be a barrier to accessing effective services (MacIntyre & Stewart, 2012). McGarry, Stenfert Kroese and Cox (2015) reported individual supervision and peer group support as helpful for doulas working with women with LD. Such support could be beneficial for midwives also.

Despite a difference in roles of the hospital and community midwives, similar themes arose. There was good agreement throughout the narratives, irrespective of the midwives' role, age or time as a qualified midwife.

Midwives' view of their work with women with LD

Lack of time appears to be a frequent challenge midwives face during their clinical practice (Kennedy et al, 2004). Constraints on professionals' time are reported to significantly influence support available for pregnant women with LD (e.g. Tarleton, Ward & Howarth, 2006; Crozier, Morris & Genders, 2013). The midwives participating in the current study also reported they did not have the time to spend with the women to adequately meet their needs. It appeared that the midwives' experiences indicated that women with LD require more intensive support during their pregnancy than other women on their caseloads. This has implications when considered in context with the midwives' other experiences; for example, limited funding and resources, difficulties accessing specialist support and working with other professionals to deliver holistic care for pregnant women with LD.

They all stressed that they want to work towards delivering equitable services for all women (Lavender & Chapple, 2004) and the importance of developing a trusting relationship and of continuity in their work with women with LD.

To achieve this they stated that they went above and beyond their role.

Kennedy et al (2004) also reported that midwives would 'go out on limbs' to deliver tailored care to meet women's needs, which were not part of standard midwifery guidance.

The midwives' narratives indicate that they take pride in their work, wanting to provide adequate care and a positive experience of childbirth. In contrast to previous health professional research (e.g. Hoglund, Lindgren & Larsson, 2013; Lewis & Stenfert Kroese, 2010), all the participants held positive attitudes towards women with LD and it was never questioned that the women should have children. Although they acknowledged support was needed, there was an assumption that the women had a right to have children.

Safeguarding procedures appeared to be an inevitable process for the midwives when working with parents with LD. McGarry, Stenfert Kroese and Cox (2015) found that doulas experienced the safeguarding process as most stressful and regular supervision and peer support did not always prevent 'burn out'.

Midwives' experiences and attitudes towards the role of LD training

Crozier, Morris & Genders (2013) suggest that training can help professionals empathise with parents with LD, facilitating an understanding that people do not choose to be poor parents but require effective support to learn skills to become good parents. Hoglund, Lindgren & Larsson (2013) and Leaviss et al (2011) recommend LD training for midwives.

The midwives in this study held the belief that LD training would be helpful, with some reporting it should be included in mandatory training for qualified midwives. Suggestions for training included information about services for parents

with LD and accessible resources to support women with LD understanding.

However, very limited post-qualification training had been attended. Those midwives who had attended training felt it had been influential in their work, giving them both insight into the women's needs as well as developing their own knowledge and skills.

Midwives could not remember any LD training as students and felt it was important this be made available to both students and qualified midwives. Michael (2008) recommends that LD training and experience features in undergraduate clinical education to develop both students' knowledge and experience of LD. It is suggested that clinical experience with people with LD can facilitate positive attitudes (Gill, Stenfert Kroese & Rose, 2002). Research with student doctors (Ouellette-Kuntz et al., 2012) reported that role models and supervision could foster students' positive attitudes towards people with LD, reinforcing the importance of LD experience during education and on-going skill development for qualified professionals.

In recognising their limited LD experience and knowledge, the midwives appeared motivated to develop their skills. Porter et al (2012) also reported midwives were willing to utilise resources, when available, to support their clinical practice with people with LD.

Possible limitations

The themes identified in this study reflect the experiences of the nine midwives who participated in the study. Due to the idiographic characteristic of the research, the themes may not reflect all midwives' experiences of caring for women with LD and as such it is not possible to generalise the findings of this study accurately to all midwives who have worked with parents with LD. Future research

may wish to consider how additional themes may become evident through the recruitment of a larger sample size.

It is possible that there was a selection bias since participation was voluntary. This may have led to a biased sample of midwives who wanted to discuss their experiences. Those midwives who did not choose to take part may possibly have more negative experiences and attitudes on providing maternity services for women with LD.

Four NHS trusts were included in the study, however all the participants were from one NHS trust. Organisational policies, support systems for midwives and specialist services for parents with LD may vary regionally impacting on the generalisability of the findings.

Recommendations

Based on the findings, tentative recommendations can be made which may have a positive impact on the experiences of midwives and women with LD during midwifery care. It is recommended that training on working with and providing services for people with LD is made available to all midwives. Training and information on how to adapt clinical practice to cater for women with LD's special needs would be beneficial. Given the increasing likelihood of midwives caring for women with LD, it would be useful to consider including LD teaching and clinical experience for student midwives.

Supervision should be routinely offered to midwives caring for women with LD to support them in developing their skills and reflect upon their experiences. Where there is a lack of local guidance for midwifery provision for women with LD,

it is recommended that guidance is developed and implemented. It would be helpful to invite local midwives to share their experiences of caring for women with LD, in particular the barriers they face, as well as making available specific guidance for midwives and more general guidance (Guidance on Working with Parents with Learning Disabilities, DoH and Dfes, 2007). Joint working, sharing information with colleagues through a specific LD forum and identifying a lead midwife for LD within a service could be ways of improving service delivery.

To foster multi-agency working, liaison with LD nurse specialists, midwifery managers and the safeguarding lead for LD could be a practicable way of distributing information via safeguarding lead midwives.

Conclusion

This study aimed to explore midwives' experiences of caring for women with LD. The midwives, whether community or hospital based, reflected upon not having enough time or skills to deliver the care these women are entitled to. They felt unsupported and alone in their attempts to deliver adequate midwifery care with limited, if any, LD training to support them. The midwives spoke of a lack of accessible support for pregnant women with LD and were left feeling that they were responsible to fill the gaps in service provision. The midwives were dedicated in delivering adequate care to help give women with LD a positive experience of childbearing. The midwives felt safeguarding was an inevitable as part of women with LD's pregnancy experience yet were aware that the right support at the right time could make a positive difference. The midwives requested more training and information on providing midwifery services for women with LD.

References

- Begley, C., Higgins, A., Lalor, J., Sheerin, F., Alexander, J., Nicholl, H., Lawler, D., Kennan, P., Tuohy, T. & Kavanagh, R., 2009. *Women with Disabilities: Barriers and Facilitators to Accessing Services During Pregnancy, Childbirth and Early Motherhood*. School of Nursing and Midwifery, Trinity College, Dublin.
- Retrieved from:
[http://www.nda.ie/cntmgmtnew.nsf/0/419BBFC356BC438A80257705003FA51D/\\$File/literaturereview.pdf](http://www.nda.ie/cntmgmtnew.nsf/0/419BBFC356BC438A80257705003FA51D/$File/literaturereview.pdf)
- Booth T. & Booth W., 1993. Parents with learning difficulties: lessons for practitioners. *British Journal of Social Work*, 23, 459–80.
- Brown, M., 2005. Emergency care for people with learning disabilities: What all nurses and midwives need to know. *Accident and Emergency Nursing*, 13 (4), 224–231.
- Champion M.J., 1995. *Who's fit to be a parent?* London, Routledge.
- Cooke P. 2005., *Acting to support parents with learning disabilities*. Nottingham, Ann Craft Trust.
- Crozier, H., Morris, S., & Genders De, N., 2013. *Good Practice in Parenting Support for Parents with a Learning Disability – Report of the Project Group*. Retrieved from <https://dmuweb.dmu.ac.uk/documents/health-and-life-sciences-documents/nursing-and-midwifery/goodpracticeinparentingsupport2013.pdf>.
- Culley L. & Genders N., 1999. Parenting by people with learning disabilities: the educational needs of the community nurse. *Nurse Education Today*, 19, 502–8.

Department of Health., 2001. *Valuing people: a new strategy for learning disability for the 21st century* (No CM 5086). London: The Stationary Office.

Department of Health., 2009. *Valuing people now: a new three-year strategy for people with learning disabilities*. Norwich: The Stationary Office.

Department of Health and Department for Education and Skills., 2007. *Guidance on Working with Parents with Learning Disabilities*. London: The Stationary Office.

Disability Discrimination Act., 1995. The UK government. Available at: <http://www.legislation.gov.uk> (last accessed on 16th May 2014).

Equality Act., 2010. London, HMSO. Available at: <http://www.legislation.gov.uk> (last accessed on 16th May 2014).

Gill F., Stenfort Kroese B., Rose J., 2002. General practitioners' attitudes to patients who have learning disabilities. *Psychological Medicine*. 32 (8), 1445-1455.

Höglund, B., Lindgren, P., & Larsson, M., 2013. Midwives' knowledge of, attitudes towards and experiences of caring for women with intellectual disability during pregnancy and childbirth: A cross-sectional study in Sweden. *Midwifery*, 29 (8), 950-955.

Kennedy, H. P., Shannon, M. T., Chuahorm, U., & Kravetz, M. K., 2004. The landscape of caring for women: A narrative study of midwifery practice. *Journal of Midwifery & Women's Health*, 49 (1), 14-23.

Lavender, T., & Chapple, J., 2004. An exploration of midwives' views of the current system of maternity care in England. *Midwifery*, 20 (4), 324-334.

Leaviss, J., Ewins, W., Kitson, D. & Watling, E., 2011. *Inclusive support for parents with a learning disability*. MENCAP.

Lewis, S., & Stenfert Kroese, B., 2010. An investigation of nursing staff attitudes and emotional reactions towards patients with intellectual disability in a general hospital setting. *Journal of Applied Research in Intellectual Disabilities*, 23(4), 355-365.

MacIntyre, G., & Stewart, A., 2012. For the record: the lived experience of parents with a learning disability—a pilot study examining the Scottish perspective. *British Journal of Learning Disabilities*, 40 (1), 5-14.

Mayes, R., 2005. *Becoming a Mother: The Experiences of Women with Intellectual Disabilities*. Unpublished Doctoral Dissertation, University of Sydney, Sydney.

Mayes, R., Llewellyn, G., McConnell, D., 2006. Misconception: the experience of pregnancy for women with intellectual disabilities. *Scandinavian Journal of Disability Research* 8, 120–131.

McConkey R. & Truesdale M., 2000. Reactions of nurses and therapists in mainstream health services to contact with people who have learning disabilities. *Journal of advanced nursing*. 32 (1), 158-163.

McGarry, A., Stenfert Kroese, B., & Cox, R. 2015. How Do Women with an Intellectual Disability Experience the Support of a Doula During Their Pregnancy, Childbirth and After the Birth of Their Child?. *Journal of Applied Research in Intellectual Disabilities*.

Melville, C.A., Cooper, S.A., Morrison, J., et al., 2006. The outcomes of an intervention study to reduce the barriers experienced by people with intellectual disabilities accessing primary health care services. *Journal of Intellectual Disability Research*, 50, 11–17.

MENCAP., 2011. Holding the baby – supporting parents with a learning

disability. *Viewpoint*, 120.

Michael, J., 2008. *Healthcare for all. Report of an Independent Inquiry Report into Access to Healthcare for People with Learning Disabilities*.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255.

NHS Executive., 1998. *Signposts for success in commissioning and providing health services for people with learning disabilities*. London, Department of Health.

NHS Greater Glasgow and Clyde., 2006. *Inequalities sensitive practice initiative maternity pathways, Women with Learning Disabilities*. Retrieved from <http://www.ldhealthnetwork.org.uk/docs/women.pdf>.

NHS Highland., 2011. *Guidelines – working with pregnant women and new mothers with learning disabilities*. Retrieved from http://www.forhighlandchildren.org/4-icspublication/index_39_2880078746.pdf.

Ouellette-Kuntz, H., Burge, P., Cleaver, S., Isaacs, B., Lunskey, Y., Jones, J., & Hastie, R., 2012. Attitudes of medical clerks toward persons with intellectual disabilities. *Canadian Family Physician*, 58 (5), 282-288.

Parish, S. & Huh, J., 2006. Health care for woman with disabilities: population-based evidence of disparity. *Health and Social Work* 31, 7–15.

Porter, E., Kidd, G., Murray, N., Uytman, C., Spink, A., & Anderson, B., 2012. Developing the pregnancy support pack for people who have a learning disability. *British Journal of Learning Disabilities*, 40 (4), 310-317.

Royal College of Midwives., 2008. *Maternity Care for Disabled Women – Guidance Paper*. London.

Royal College of Nursing., 2007. *Pregnancy and disability – RCN guidance for midwives and nurses*. London.

Scottish Consortium for Learning Disabilities (SCLD)., 2009. *Scottish good practice guidelines for supporting parents with learning disabilities*. Glasgow, SCLD.

Smith, J., Flowers, P., & Larkin, M., 2009. *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage.

Sowney, M., Barr, O., 2006. Caring for adults with intellectual disabilities: perceived challenges for nurses in accident and emergency units. *Journal of Advanced Nursing*, 55, 36–45.

Stanley, R., 1998. Primary health care provision for people with learning disabilities: a survey of general practitioners. *Journal of Intellectual Disabilities*, 2(1), 23-30.

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

Ward, L. & Tarleton, B., 2007. *Sinking or swimming? Supporting Parents with learning disabilities and their children*. Tizard Learning Disability Review 12(2).

Working Together with Parents Network., 2008. Facts and figures about parents with learning disabilities in England. Retrieved from <http://www.bristol.ac.uk/wtwpn/resources/facts-pwld.pdf>.

Highlights

- Midwives face a number of significant barriers in providing care for women with LD.
- Midwives reported a lack of LD training for both qualified and student midwives.
- Barriers to accessing support for women with LD impacted upon midwifery care.
- Support for women with LD can make a difference to their parenting skills.
- Midwives were dedicated in delivering adequate midwifery care to women with LD.

Key words: Parenting, Learning Disabilities, midwives, Interpretative Phenomenological Analysis.

Acknowledgements

Firstly, I would like to express my gratitude to the midwives who participated in this study. Without their honesty and willingness to share their experiences, this research would not have been possible. I would like to thank my family, friends and supervisor, Dr Biza Stenfert Kroese. Without their continued support and encouragement, this study would not have gotten past the design stage!