*“We want to be parents like everybody else”: Stories of parents with learning disabilities*

Kate Theodore1, Daniel Foulds2, Paul Wilshaw2, Alison Colborne2, Joyce Nga Yu Lee2, Lisa Mallaghan2, Mary Cooper2, Julia Skelton2?

1Department of Clinical Psychology, Royal Holloway University of London

2Mind the Gap

Corresponding Author:

Kate Theodore, Doctorate in Clinical Psychology, Department of Psychology, Royal Holloway University of London, Egham, Surrey TW20 0EX. Telephone: 01784414303 Email: kate.theodore@rhul.ac.uk

*Brief biographies:*

Kate Theodore is a Clinical Psychologist and Lecturer at Royal Holloway University of London

Daniel Foulds, Paul Wilshaw and Alison Colborne are all learning disabled researchers and performers at Mind the Gap

Joyce Nga Yu Lee is Resident Director and Artistic Lead for the ‘Daughters of Fortune’ project at Mind the Gap

Lisa Mallaghan is a Senior Producer at Mind the Gap

Mary Cooper is a writer for Mind the Gap

Julia Skelton is Executive Director at Mind the Gap

Funding: With funding from the Wellcome Trust

Conflicts of Interest: None

**Acknowledgements:** Sincere thanks most significantly to the parents who shared their stories, and to the Elfrida Society Parenting Group for their support to the research.

**Abstract**

**Objectives:** This project represents a unique collaboration between creative and research processes using an inclusive qualitative methodology.

**Method**: Semi-structured interviews with five mothers and three fathers with learning disabilities were led by learning disabled researchers, and thematic analysis conducted with input from people with learning disabilities.

**Results**: Five main themes are presented; (1) subjective experiences of becoming parents, (2) perceptions that other people assume people with learning disabilities are incompetent parents, resulting in a need to prove worthiness, (3) experiences of services, (4) overcoming ‘knock-backs’ and (5) support for the rights of other parents. An additional subgroup analysis is presented: fathers feel ‘left out’.

**Conclusion**: Parents felt criticized by others, who they felt questioned their competence as parents unfairly by comparison to those without learning disabilities. The collaboration between academic research and an inclusive theater group allowed dissemination of parents’ stories to wider public, and professional, audiences through creative performances.

(overall word count: 8307 words)

# Introduction

There has been an increasing focus in research on the needs of families where one or more parents have learning disabilities[[1]](#footnote-1). Despite this, there have been a number of limitations to this literature, which leave the experiences of this group of parents still less well understood. These limitations include sampling issues, such as the almost exclusive focus to date on the needs of mothers with learning disabilities (Emerson *et al.* 2015). Estimates of numbers of parents with learning disabilities have varied widely from 23,000 to upwards of 250,000 (Department of Health and Department for Education and Skills 2007; McGaw 1998); accuracy of estimates have been limited by the reliance in the literature on identifying parents already known to services, poor records, and shifting and unclear definitions (Booth *et al.* 2005). It has been reported that most parents with learning disabilities are likely to have mild or even borderline intellectual disabilities, and as such are less likely to be known to services, or in some cases to meet eligibility criteria for adult social services (Emerson *et al.* 2015). Therefore, reliance in the research to date on samples already known to services is likely to have biased inclusion of parents with more significant disabilities, or additional challenges such as mental health difficulties or identified difficulties with parenting, bringing them into contact with services.

A unique population-based survey in the UK attempted to identify the health needs of parents thought to have learning disabilities, rather than relying on identification of parents already known to services, to compare their health needs with parents without learning disabilities (Emerson *et al.* 2015). This methodology had limitations in its accuracy of identifying people with learning disabilities, but it still represents a unique way to attempt to identify a group of individuals who may be regarded as the ‘hidden majority’ (Emerson 2011) of those with less severe learning disabilities, who may not otherwise be identified. As a group, it is known that people with learning disabilities face multiple disadvantages in their parenting role. Emerson *et al.* (2015) identified that parents with learning disabilities were significantly more socio-economically disadvantaged, experienced more neighbourhood adversities, and less intergenerational support than parents without learning disabilities.

It has been identified that such factors of multiple disadvantage, although not necessarily all attributable to an individual’s learning disabilities per se, may influence parenting ability, and parents with learning disabilities have been reported to be disproportionately likely to lose custody of their children (McGaw and Newman 2005). Many parents with learning disabilities will have their parenting ability formally assessed by social services (McGaw and Candy 2010). Whilst multiple factors still compromise the accuracy of current figures, estimated rates suggest that 40 – 60% of parents with learning disabilities have children removed from their care (Emerson *et al.* 2005). Families where one or more parent has learning disabilities or borderline learning disabilities were reported to make up to almost a quarter of cases following a review of court findings conducted in 2000 in the UK (Leeds and Sheffield areas), with just 10% of the children identified as having parents with learning disabilities returning to live at home (Booth *et al.* 2005). Recent studies outside the UK also report that parents with learning disabilities represent a similarly significant proportion of children removed from parental custody by welfare services (20-25% of cases in Norway; Tossebro *et al.* 2017).

Specific good practice guidance for services supporting families where one or more parent has a learning disability was developed a decade ago in the UK (Department of Health and Department for Education and Skills 2007), and recently updated (Working Together with Parents Network 2016) to reflect current policy and legislation. However, there are concerns about the application of these good practice principles to services provided to parents with learning disabilities and their families, and that services remain patchy across the UK.

Understanding the experiences of parents with learning disabilities is therefore essential to continue to inform professionals within health and social care, and the wider community who will come into contact with parents. There is a growing and important literature base on the experiences of parents with learning disabilities. Largely this literature has focused on the experiences of mothers, and as above recruitment strategies may also often have focused on those who are already in contact with services, which can lead to skewed samples. However, it still gives a rich and valuable insight into the experiences of parents with learning disabilities, often using qualitative methodologies. Mayes *et al.* (2011) provided the first reflective account of how women with learning disabilities adopt, and how much they value, their mother identity when they become parents. Interestingly, Kaspar and Stenfert Kroese (2017) found in an interpretive phenomological analysis that women with learning disabilities, who were not mothers, had sometimes differing views about whether having a learning disability was compatible with being a mother. Perhaps reflecting this idea that others may not always be positive about the identity of a mother with learning disabilities, another key finding from Mayes *et al.* (2011) was how mothers with learning disabilities align themselves to a social ‘ally’ as a significant person in their social network who can advocate for them as mothers and support both them and their children. Another study looking at the experiences of parenting from the perspectives of mothers, and their family and multi-disciplinary professional support networks, again highlighted the importance of the quality of a woman’s relationships in supporting her through, often emotional, periods of decision making during pregnancy and parenting (Jamieson *et al.* 2016). Gould and Dodd (2014) explored experiences of mothers with learning disabilities who had had their children removed from care within the UK, and drew attention to the ‘presumed incompetence’ and high levels of scrutiny mothers reported experiencing. Mothers with learning disabilities whose children have been compulsorily removed from their care, often have multiple experiences of child removal (Mayes and Llewellyn 2012). It is notable that to date there has been much less emphasis in the research literature on the experiences of fathers with learning disabilities, however a recent research project in the UK found that fathers often experienced even greater exclusion from services (Dugdale and Symonds 2017).

These qualitative investigations into the lives of parents with learning disabilities highlight some common themes; the importance of a mother’s (or parent’s) social support and securing social allies in the support network, the experience of stigma and prejudice experienced by parents both in the social care system but also in their wider communities; and perhaps most significantly the experience of powerlessness (particularly around child removal and when questions are raised about parenting ability) and the power differentials identified between parents and those in their social or professional support network.

***Current project: rationale and design***

The idea for this innovative project came from Mind the Gap, the largest UK inclusive theatre company for people with learning disabilities, and specifically from a personal source; the experience of a parent-to-be known to the theatre company, who was undergoing a parenting assessment. This inspiration led the team of performers with learning disabilities to begin researching the subject matter, through immediate circles as well as reviewing what literature already existed regarding the lives of parents with learning disabilities, including on the internet and in the media. They quickly established that not only is the subject matter difficult to access for non-academics and non-professionals, as it exists mostly in the form of professional articles and advice for non-disabled people, but that there was an absence of the voices and perspectives of learning disabled parents in the information available and accessible to them. The company wanted to bring this hidden subject to a ‘mainstream’ audience using their creative means. They wanted to base their project on ‘real lives’, which led to their aim to interview parents about their experiences.  Mind the Gap secured funding to recruit an academic researcher to support the research element of the project. Qualitative interviews have been established as an effective way of giving a voice to people with learning disabilities (Booth and Booth, 1994) in research. It was agreed that the researcher would take the semi-structured interviews conducted by Mind the Gap, and qualitatively analyse the content, using Thematic Analysis. This led to the current collaboration and inclusive research design, which had the following aims:

* To collect stories of a group of parents with learning disabilities, to contribute directly to the creative outputs of ‘Daughters of Fortune’.
* To add to the body of qualitative literature regarding the experiences of parents with learning disabilities, using an inclusive user-led research methodology.

Furthermore, the original vision from Mind the Gap was that the voices of parents with learning disabilities be shared much more broadly with people with learning disabilities themselves, but also professionals and the wider community; with aims to help enhance the impact of research on policy, and to help support the wider goals of reducing stigma and (mis)perceptions of parents with learning disabilities in the wider public arena (e.g. Tarleton 2015). The research has directly fed into and impacted the public facing outputs of the overall project from Mind the Gap, ‘Daughters of Fortune’: ‘Anna’, a Forum Theatre interactive workshop, which is aimed at parents with learning disabilities, and supporting professionals; ‘Mia’, a touring theatre production, which is aimed at the general public across the UK; ‘Paige’, a planned book that will combine images of the parents, artistic responses such as extracts, poems and short stories, and the research findings; ‘Zara’, the ultimate vision for the overall project, a large-scale spectacle which will reach large audiences in London, Halifax and online (Mind the Gap 2017).

**Method**

***Ethical review***

The research was approved by Royal Holloway University of London College Ethics Committee. All participants had capacity to give informed consent to participate in the research. The information relating to the confidentiality and procedures of the interview were discussed with all participants at the start of the interview, and their understanding of this checked verbally, prior to individuals giving their informed consent. Additional written consent for interviews to be used for the purposes of research was sought. The nature of the interview topic (about experiences of parenting) was sensitive; support was available from participants’ self-advocacy groups, or from Mind the Gap for interviewers.

***Participants***

Participants were adults with learning disabilities living in the community, who were parents, and who had capacity to give consent to be interviewed and share their experiences verbally. Participants were identified by self-advocacy groups, in two areas of the UK. The eight participants represented a heterogeneous group with varied characteristics. Five participants were mothers, and three fathers. Five were from White British backgrounds, and three from minority ethnic backgrounds. Their ages ranged from 31 to 61 years at the time of the interview. The eight parents had 22 children between them; their children’s ages spanned widely from 2 years to 29 years, with seven of the parents having at least one child who was still under 18 years old. Two of the participants were also grandparents.

All but one of the parents had direct experience of children’s services involvement, for example through assessment of parenting abilities or undergoing child protection proceedings. Six parents had at some time experienced separation from their children, who had been adopted, placed in foster care, or in kinship care or special guardianship arrangements, or lived with their other parent. Three parents were currently living with at least some of their children at the time of the interview. Four parents were currently married or living with a partner. All except one parent interviewed lived independently; one currently lived semi-independently in sheltered housing, following separation from his family.

Table 1 presents a summary of participant characteristics including participants’ history of parenting, and current contact with children where known; for the purposes of preserving anonymity, limited personal characteristics have been ascribed to individuals.

[insert Table 1 about here]

***Semi-structured interviews***

There is much written on the impact of power on research interviews (Raheim *et al.* 2016). There has equally been much written about the powerlessness felt by parents with learning disabilities going through the ‘system’ of health and social care (e.g. Gould and Dodd 2014). This power differential may then be even more influential when parents with learning disabilities are being interviewed by researchers who are often also powerful professionals. Therefore, we felt that having learning disabled researchers, who were also performers within the overall project, would best support participants to talk openly about their experiences, and may lead to different or enhanced narratives to emerge from the interviews.

An interview guide was developed together with the learning disabled researchers and the writing mentor prior to interviews. This was very much a guide to broad questions around experiences of parenting that may be asked in the interview. The questions in the interview schedule covered broad areas related to parenting experiences, including the participants’ experiences of choosing to have children, and / or finding out they or their partner was pregnant, experiences of pregnancy, childbirth and early parenting experiences, as well later parenting experiences such as supporting child going to school (if parent had continued to actively parent their child), and / or experiences of separation from children (e.g. if child had been removed from parent’s care or there was parental separation), and experiences of help from others, including professionals. The interview schedule included a number of open questions (e.g. “How did you feel when you found out you were/your partner was pregnant?”) but also possible prompts to be used (e.g. “Who did you tell?”), but was deliberately flexible, so that interviews could be guided by individual participant’s varied experiences.

***Procedure***

All interviews were audio-recorded. Parents were each interviewed individually by a small team from Mind the Gap, consisting in each interview of a learning-disabled principal researcher, the ‘writing mentor’ and a photographer and film-maker (where appropriate). The term ‘writing mentor’ is used here to describe the relationship between the non-learning disabled writer from Mind the Gap (MC), and the team of learning disabled researchers. The writing mentor supported the learning disabled researchers to develop their writing practice and supported the interview process, through supporting the development of questions for interviews, training the writers on interview techniques, and providing pastoral support for the team during and after the interviews. The learning disabled researchers and writing mentor also make up the writing team which provide the artistic strand of the research, reviewing the same research interviews and creating short artistic responses in the forms of extracts, poems and short stories, which will eventually form part of another strand of the overall ‘Daughters of Fortune’ project: the planned book, ‘Paige’.

There was careful consideration with each participant to ensure they fully understood and consented to sharing their stories for the purposes of the different parts of the project, including both the research and the creative outputs. To support this informed consent process, once interviews had been conducted, a summary of the story as shared was written up by the writing mentor and learning disabled researchers, and a copy given and read back to the individual participant, to check again they were happy with the content of the information they had shared. Following this process, all of those interviewed confirmed they were happy to share their stories.

***Data Analysis***

Thematic Analysis was deemed an appropriate qualitative methodology for this project, as it is used as a method for under-researched topics or where participants’ views are less well known, has been used successfully with qualitative research with people with learning disabilities, and allows a theoretical flexibility.

Interviews were transcribed verbatim for the purposes of the research analysis. Braun and Clarke’s (2006) method of Thematic Analysis was followed. As the academic researcher (KT) conducting the initial analysis had not conducted the interviews, the initial phase of *‘familiarisation with the data’* was important to attend to; this was achieved through listening and re-listening to the audio files, reading the transcripts whilst listening to the audio, and reading and re-reading the transcripts, noting down initial thoughts. Initial codes were generated by line-by-line reviewing of the transcripts, highlighting data comprehensively and inclusively to comprise the initial codes. Initial codes were then reviewed across the interviews, and eventually combined into themes.

There were a number of recommendations followed to ensure quality in qualitative research (Elliot *et al.* 1999; Mays and Pope 2000; Yardley 2000). The researcher is experienced in working with people with learning disabilities and in conducting qualitative research. Following the development of the initial themes, these were presented, reviewed and discussed with one of the learning disabled researchers, to explore interpretation differences, and to check credibility of the interpretation. This led to some subtle adjustments to interpretation, including the language used to name the themes. A further process of triangulation occurred by presentation of some of the key themes from the analysis to a group of parents with learning disabilities at one of the self-advocacy organisations, who acted as a reference group to the research. The themes presented resonated strongly with the reference group, some of whom had been interviewed and others had not, but this process also led to some changes to the language presented in the final report. Following these processes, key themes from the final analysis are presented below.

Quotations from participants are provided to ground the analysis in examples. Direct quotes are presented below in *italics*, with the interviewee’s pseudonym. Square brackets indicate substituted or added words needed to maintain anonymity or to add clarification to the quotation. Where there is a break in the text presented from the direct quotation, this is denoted by ‘….’.

***Reflections of the research team***

Throughout this collaborative process of research, as is core to qualitative research, we have reflected together as a research team on our individual roles and perspectives. The lead author and academic researcher is a clinical psychologist, and a mother herself, with particular research and clinical interests in supporting the needs of families where a parent has learning disabilities. All of the learning disabled researchers had considered future parenthood, although none were parents at the time of the research. The research team throughout have reflected on the emotional impact of the stories shared by parents; there was potential for this to have a significant emotional impact for all the researchers, particularly those with learning disabilities, for whom the stories had potentially very personal resonance. All learning disabled researchers felt they were well supported by the writing mentor and by Mind the Gap in reflecting on the personal impact of hearing these powerful and emotive stories.

We have reflected on the benefits of having learning disabled researchers conducting interviews, to allow participants to share their stories honestly with peers rather than professionals. We were also keen to have no fixed agenda for the interviews, and the interview schedule was very flexible to allow participants to just ‘tell their stories’. The consent processes and transparency around how material shared by parents would be used by the team also supported parents to feel confident in divulging information.

We have also reflected on the position of being researchers who with varying degrees could be considered as ‘insiders’ or ‘outsiders’ (as people with or without learning disabilities, as parents or not), and we have reflected that there may be benefits and challenges of each position. Perhaps between our various membership roles we have occupied ‘the space between’ ‘insider-outsider’ (Corbin Dywer and Buckle 2009), and made attempts to balance these positions. We outline these positions here to help the reader also better understand how our different positions may have influenced the research conducted.

**Results**

The following includes the most prominent themes developed from the Thematic Analysis. A number of the themes also comprised of sub-themes; Table 2 presents the themes and sub-themes where relevant, and the participants who contributed to each of the themes.

[insert Table 2 about here]

***Becoming a Parent***

*Desire for Parenthood*

Many parents (both mothers and fathers) talked about their own desire for becoming a parent being a long-held aspiration:

*And I told him I always wanted kids, I always you know, felt I was meant to be a mum. (Georgina)*

However, at least some parents explicitly said they had not expressed these ideas with people other than their partners, before becoming parents or trying to conceive. Some parents expressed that they were concerned that they may not be *‘good enough’* to be parents, or that this may not be a realistic life aspiration for a person with learning disabilities:

*Being honest, I didn’t really think about kids at the time because I’d feel like I wasn’t good enough… I didn’t believe in myself. (Ian)*

*Planning for and being ‘ready’ for parenthood*

Several parents described that they had *“planned it, to have family…” (Tariq)*. However, Georgina reflects on the paradox between expectations of people with learning disabilities deciding when they are ready to be parents in comparison with people without such disabilities:

*You never know how ready you are to be a parent until you’ve got kids. So to say to people with special needs, you need to make sure you’re ready before you try, that’s already setting you up to fail. (Georgina)*

Preparation for parenthood for a number of parents also followed the ‘typical’ experiences, common for all parents, such as preparing equipment needed, and considering names:

*We went through some names while I was pregnant. If it’s a boy this, if it’s a girl this. So we chose her first name and middle name while I was still carrying her…. (Georgina)*

However for a number of parents this was also tinged with an uncertainty, based in reality, about whether the preparation would be in vain, and whether after the pregnancy and birth of the child, their child may not return home with them:

*We wanted to decorate her room, but given there was no guarantee we would be able to keep her, we felt we couldn’t. (Georgina)*

*No the cot was… the cot was in the next room but [son] wasn’t in the cot, he was living with [paternal grandmother]… (Lisa)*

***Assumption of incompetence and proving worthiness as parents***

A strong theme that emerged was parents’ experiences of others (often professionals) making assumptions of incompetence towards parents with learning disabilities, that they would not be able to be good enough parents:

*They say learning disability can’t look after a child and they just assume straight away that you can’t look after your child. (Lisa)*

There was a sense of needing to ‘prove’ competence as parents:

*I’d changed everything they wanted around….. And I proved I could do it. (Eliza)*

This presumed inability to be good enough parents was experienced as unfair by parents. It was also felt that in fact more was being expected of parents with learning disabilities than those without:

*I think you can’t say that just because these people have learning disabilities they have to go through all the social services and all the hoops. Because there are a lot of people that don’t have a learning disability that are really naff parents and they don’t have to go through all the social services. (Georgina)*

Parents talked about feeling like they needed to demonstrate being not only ‘good enough’, but in fact ‘better’ than other parents without learning disabilities in order to stop their abilities being questioned. Georgina spoke of this in a number of contexts, including that prior to conceiving, she and her partner chose to complete a course in childcare in order to prove competence:

*“At least if we do this, it shows we’ve got a qualification, it will give us a tick, it will be a tick for us rather than tick against us, because it shows we’re taking it seriously.” (Georgina).*

Parents felt that expectations on them were unfairly high, so that they would actually never be able to meet them, and that others, even professionals, if in their position, would not be able to do better than them:

*All the assessments I passed, both independent social worker and the guardian’s, I passed all the assessments. So I don’t know what they needed more from me. (Maria)*

*I said [to the social worker], you have [daughter] for a fortnight, and see how you cope with her. Oh, [social worker said] I don’t…. I couldn’t cope with her. I said no, but then you’re telling me I’m not doing my job… (Eliza)*

*I said, who do you expect me to be, Mother Theresa? (Lisa)*

Parents interviewed also talked about something that felt more ominous and threatening about this. Ian talked about frustrations about others “*always look[ing] at us like we’re different”* possibly ‘lesser’, than others without learning disabilities, and that professionals were *‘just too eager to take the child away’ (Ian)* from parents with learning disabilities:

*They prey on our disability and our vulnerability… it’s just unfair, ‘cause we’ve got learning disabilities… but we want to be parents like everybody else. We want to have the opportunity; we want support from the beginning like everybody else. Parents without learning disabilities can be bad parents too, but they get support… if you’ve got a learning disability you get judged you can’t parent.” (Ian)*

***Experiences of Services***

Parents’ talk about their experiences of services often resonated with the ideas already presented within good practice guidance, such as appreciating support that was long-term, and the benefits of advocacy. As this is well-documented elsewhere (Working Together with Parents Network 2016), repeating this here is not the focus of this article. However a couple of sub-themes within this are reported below.

*Feeling criticised and let down by services*

Parents often did recognise their own support needs:

*If you need help, get help… don’t do it on your own, it’s hard. (Eliza)*

However, they often spoke about feeling criticised by professionals:

*It’s just them dictating and I don’t like that… “You’re not a good mother. You’re not this. You’re not that...” (Patricia)*

Furthermore, some described they had not received services that had been agreed:

*They said they would do a pre-birth assessment… I was okay with that agreement… but it didn’t happen. I didn’t get the pre-birth assessment…. (Lisa)*

For Lisa this resulted in negative consequences after the birth of her son:

*Now, the doctor had discharged me and said I could go home with my son, so but the social worker wasn’t having it. He said no, he said we haven’t done the assessment on you… He said, oh we’ll have to put [son] into foster care… (Lisa)*

Lisa also spoke about being offered support that did not meet her needs, but being criticised for not engaging with it:

*They were teaching me stuff I could already do like how to feed my son… and they made a report to the social worker to say [I’m] not fully taking part in these courses… I told her… they’re telling me stuff I already know, I don’t need those courses, they’re not right for me. (Lisa)*

*Being believed in as a parent*

Having someone who believed in and positively encouraged parents’ capabilities, seemed to be one of the most valued qualities of professionals, and often occurred where parents reported positive experiences of services:

*In all those eight social workers that my children have had there’s been one nice one… she was the one believed in me and got me to keep my children. All the rest didn’t, you know, didn’t believe in me. So they… they all labelled me and think I couldn’t parent. (Lisa)*

*Throughout all of this I’ve learned how good it is to have positive encouragement and positive support. (Maria)*

***Overcoming ‘knock-backs’***

*I’ve had my knock backs in life… and I know that the knock-backs they could, if I let it, get to me (Gary)*

All the parents talked about the *‘knock-backs’* they had experienced in their lives. But these were also stories of strength and resilience against adversity, and of hope for the future. Some parents spoke about personal strength achieved through supportive relationships or support from others, which helped them to cope:

*You just have to do it. You try to do it. You’ve got to cope. If you need help, get help, because there’s help there. (Eliza)*

Parents also talked of their own internal coping resources and personal strength:

*Hope. Strength. Love for my kids. The fact that I’m a strong person but at the same time emotional. (Patricia)*

Furthermore, parents spoke about taking the challenges they had experienced as *‘a learning curve’ (Gary)* and a way to become stronger for the future:

*In life you go through things and they either break you or make you stronger. I’ve gone through too much; I didn’t lose my family to gain nothing. (Maria)*

***Support for rights of parents with learning disabilities***

Parents were supportive of the rights of other parents with learning disabilities. Georgina also reflected on the need to move towards seeing disability as ‘difference’ that is not necessarily ‘lesser’, in a way that was reflective and eloquent:

*Well I don’t think that just because you’re a learning disabled parent, that you’re going to be less able to parent, I think, if anything it gives you a different perspective on parenting and helps you… So I think that as long you understand how your disability affects you, you can stop that from impacting your child in a negative way. (Georgina)*

***Fathers feel ‘left out’***

Much of the parenting literature to date has focused on the experience of women with learning disabilities becoming mothers, and the experiences of fathers has been largely neglected. Our study interviewed both mothers and fathers, which allowed some analysis of the subgroup of fathers. Whilst many experiences as described above were shared by mothers and fathers, it was of note that two of the three fathers that we interviewed also talked specifically and significantly of feeling *‘pushed out’ (Ian)* or even *‘cheated’ (Gary)* in their role as father, both by professionals and others in their social network.

*Being a father is a very, very good thing. I’m proud to be a father, but…. fathers need to be included…. if you’re a father the focus is on the mothers, not on the fathers and we feel left out. I felt really left out before my son being born. I hated it. (Ian)*

Both of these fathers had experienced some separation with their children, although still had some contact currently with their (now adult) children. Interestingly, the one father (Tariq) who did not specifically talk about feeling his subjective experience was one of being ‘left out’, objectively had still been excluded to some extent from his (still younger) children’s lives, and was no longer living with his children, although he did have some supervised contact.

**Discussion**

This collaborative project has used an inclusive qualitative research methodology to gather and analyse the stories of a diverse group of eight mothers and fathers with learning disabilities. Some previous literature (McGaw, 1996) has suggested that people with learning disabilities most often present with ‘unplanned’ pregnancies. In our study, at least a couple of parents spoke of actively planning their families, and more still spoke about a strong desire to be a parent, which resonates with literature that has emphasised the value attached to the ‘parent identity’, which can provide a positive and distinct identity from that of learning disability (Baum and Burns 2007; Shewan *et al.* 2014). However, some participants also spoke of not having talked to others about their desire to be a parent. As a research team we reflected whether this was related to an internalised self-stigma about not being ‘good enough’ to be parents, as voiced by some parents in our study, which also reflects the perspectives of some women with learning disabilities about the capabilities of women with learning disabilities to be good mothers in other literature (Kaspar and Stenfert Kroese 2017). We also wondered, however, how much wider societal expectations and perceived stigma from others about the parenting rights of people with learning disabilities impacts on people’s decisions to voice such aspirations. Historically it has been the case that people with learning disabilities have been viewed as ‘asexual’ or ‘eternal children’ with society not placing expectations around sexuality and parenthood as synonymous with having learning disabilities. Current policy indicates that adults with learning disabilities should be supported to have access to the rights and responsibilities of ‘ordinary lives’ including sexual lives and parenthood. However research has suggested that although public attitudes towards sexuality of people with learning disabilities are increasingly positive, this often still does not extend to progressive attitudes towards parenting rights (Cuskelly and Gilmore 2007; Scior 2011).

One of the key themes to come from the research data was the parents’ experiences of others (including professionals) assuming that they, as people with learning disabilities, would not make competent parents. This mirrors other qualitative research (Gould and Dodd 2014). In our study, this left parents struggling to prove their abilities (and worthiness) as parents, but further left them feeling that in order to do this, they may need to be even ‘better’ than parents without learning disabilities. The research team and reference group were again curious where these expectations were coming from, and whether this also resulted from internalised self-stigma. Recent literature has also explored how middle-class UK mothers without learning disabilities consider, and largely resist, pressure to live up to the ‘ideal’ mother (Pedersen 2016). Although this parenting pressure is not unusual for all parents, it contributed to an powerful emotional experience for our parents with learning disabilities, when coupled with the intense scrutiny and criticism they experienced from others, and the often very real threat of child removal each time they may get it ‘wrong’. These ideas of assumed incompetence and the need to prove oneself as a worthy parent is something that resonated strongly with the research team and reference group. We also wondered whether this reflects broader (historical) narratives around who is deemed ‘worthy’ of bringing children into the world, and that although policy has progressed far from it, the shadow of these ideas from the eugenics movement (Kempton and Kahn 1991), still has some (unconscious) influence on society, as reflected perhaps in some of the wider stigmatised beliefs still held about parents with learning disabilities (Scior 2011).

This continued questioning whether parents with learning disabilities can be ‘good enough’ parents, from the starting point that it is unlikely they will be, left parents feeling heavily scrutinised and criticised by services. All but one of the parents within our study had experience of statutory services’ involvement in supporting their parenting; all but two had experienced some form of separation from at least some of their children, be it temporary or permanent. It therefore seems pertinent to note that it is the *quality* of the involvement from services that is important, not just that services are involved; with highly critical support likely to inhibit rather than promote parenting competence (Tucker and Johnson 1989). Good practice guidance in place (Working Together with Parents Network 2016) emphasises the need for service providers to make ‘reasonable adjustments’ to ensure appropriate services and fair processes are provided to disabled parents, in line with the Equality Act (2010) and the Human Rights Act (1998). However, the experiences of our parents suggests services are not always adjusted to meet individuals’ needs or the standards set by good practice, such as ensuring support is centred around parents’ strengths, not only their deficits.

Fathers interviewed also reported an additional feeling of being alienated from processes and aspects of parenting that they felt their partners, the mothers of their children, had been included in. Although fathers with learning disabilities have been largely neglected in the literature, our small subgroup analysis also supports the recent larger qualitative study that investigated experiences of eight fathers with learning disabilities, which similarly found that fathers often felt excluded and received little statutory support in their parenting role (Dugdale and Symonds 2017).

 One of the key elements of professional and peer support that parents found important was having someone who believed in parents’ capabilities, and who therefore did not assume incompetence as was so often parents’ experiences. This is resonant with other research highlighting the importance for mothers in recruiting a ‘social ally’ (Mayes *et al.* 2012). Parents also demonstrated great resilience and strength in the face of adversity and challenges to their parent identities, and identified the need for professionals and the wider community to reduce stigmatised ideas and to instead demonstrate a belief that, with support, parents with learning disabilities can be ‘good enough’ parents.

We hope that writing up our experiences of the process of this inclusive qualitative research methodology will also encourage others to consider similar inclusive research designs, in line with recent calls for further articles attending to the voices of co-researchers with learning disabilities in academic research (Strnadova and Walmsley 2018). Although a number of recent research studies have ensured significant involvement from people with learning disabilities in their research processes (e.g. Dugdale and Symonds 2017), to the authors’ knowledge this is the first paper that has used such an inclusive design to further explore the experiences of parents with learning disabilities, including people with learning disabilities conducting interviews and contributing the analysis and dissemination. We believe that the inclusive research methodology is a strength of the research. Many of the themes developed from this study still resonate with other qualitative literature in this area, which has not been conducted with such an inclusive methodology (e.g. Dugdale and Symonds 2017; Gould and Dodd 2014; Kaspar and Stenfert Kroese 2017, Mayes *et al.* 2012). However, people with learning disabilities, within the research team and reference group, have appreciated the opportunity to be involved throughout, and we feel that the study has demonstrated that such involvement can enhance, rather than compromise, the quality of the research. Having people with learning disabilities conduct the research interviews, jointly with others without learning disabilities, reduced the usual power dynamics that can inhibit interviewees with learning disabilities from sharing their experiences openly, particularly groups such as parents whom we know have already experienced significant power disparities with professionals. This enabled parents to talk openly about difficult experiences, and extended themes, such as the ‘assumption of incompetence’ initially explored in previous research (Gould and Dodd 2014). Furthermore, including the processes of credibility checks with individuals with learning disabilities meant that the ultimate themes were shaped further by, and resonated with, the experiences of people with learning disabilities. Learning disabled researchers, as any novice researchers, will understandably require support both to develop skills in interviewing and analysing data, and also support to manage any emotional impact of hearing the sensitive stories of participants, which may have personal relevance. This support requires some additional resource than if research is conducted by experienced academic researchers alone. However we feel this resource is justified for both its impact on research results, and also the skills development it brings for learning disabled researchers.

The research is a small-scale qualitative project, and has a number of limitations that should be noted. Given the small number of parents interviewed, they represented a broad range of mothers and fathers, for example with a wide range of ages of their children, from two to 29 years old, and living in two geographical areas of the UK. Whilst in some respects this means a broad range of experiences have been represented, as a small scale thematic analysis project, the heterogeneity of the sample may have made it challenging to differentiate how the experiences of parents with learning disabilities may change over time or place. For example, we may hope that the experiences of those who have more recently become parents for the first time, and after a number of policy developments over the past decade (e.g. Department of Health and Department for Education and Skills 2007) may be very different from parents with now much older children. However in this study experiences of these individuals have been considered together. It is of note that it was more challenging to recruit parents with younger children, including those going through current parenting assessments or other involvement with children’s services, with some such parents approached but ultimately deciding not to participate in the interviews. This may have been both due to the nature of being a parent with young children, but also likely reflects the increased pressures on these parents’ time due to additional appointments with social or legal services, as well as being an indication of parents’ ‘readiness’ to talk at such a difficult time in their lives. It would however be invaluable to hear the experiences of more parents going through child protection proceedings currently or recently.

As with other research in this area (e.g. Mayes *et al* 2011), individuals in this study self-identified as having a learning disability. This therefore may include those who would be recognised by services as meeting diagnostic criteria for learning disability (American Psychiatric Association 2013), but may also include others who do not meet the eligibility criteria for services, who are functioning at borderline range of intellectual functioning, but who may present with significant learning difficulties, difficulty with literacy, and / or other needs such as being on the autistic spectrum, and also other complex needs related to living in socio-economic disadvantage (Emerson *et al.* 2015). This does therefore reflect a heterogeneous group, but likely a group with a high level of functioning (as indicated by the majority living independently) by comparison to the full range of individuals with global learning disabilities. This does however make it likely to capture the wide range of individuals who often present to services with some difficulties; in fact those who do not formally meet the eligibility criteria for learning disabilities services may face increased difficulties as the ‘hidden majority’ (Emerson 2011), due to lack of support services available to them. The majority of parents in this study were identified through self-advocacy or parent support groups, and a number of parents interviewed had a role as self-advocates or supporters of others. Therefore this is probably a group who are particularly informed and versed in talking about their own and others’ experiences of being parents with learning disabilities. Whilst it has been important to understand their stories, there may be a wider group of individuals who are less used to talking about their experiences, or who are not identified as, or who even self-identify as having learning disabilities, whose experiences may be different (or similar), but whose voices are even less heard.

This small research project is part of a much larger creative project, ‘Daughters of Fortune’, led by Mind the Gap inclusive theatre company. As such, the research has informed Mind the Gap’s public-facing outputs, which has enabled a broad dissemination of the stories and messages of parents to wider public and professional audiences, allowing greater impact than is often the case for academic research. This has included the forum theatre workshop ‘Anna’ and national touring of theatre production ‘Mia’, in which performers with learning disabilities, some of whom were also researchers, tell the stories of the parents included in this research project. A ‘plain english’ summary of the research processes and results has been developed and shared with people with learning disabilities. Where the research has been presented at academic conferences, presentations have been co-constructed and delivered jointly by the academic researcher and one of the learning disabled researchers. There are plans to enhance accessibility and wider dissemination of the messages through further incorporation of research with photograph and film resources, through the planned book ‘Paige’ and plans for large-scale creative spectacle ‘Zara’. All of this is in line with the parents’ aspirations to share their experiences and educate others, including health and social care professionals but also mainstream public, about the needs but also the strengths of parents with learning disabilities.

**References**

American Psychiatric Association. 2013. *Diagnostic and statistical manual of mental disorders*. 5th ed. Washington, DC: American Psychiatric Association.

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

Booth, T, Booth, W. and McConnell, D. 2005, The prevalence and outcomes of care proceedings involving parents with learning difficulties in the family courts. *Journal of Applied Research in Intellectual Disabilities,* 18, 7–17.

Braun, V. and Clarke, V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3. 77-101.

Corbin Dwyer, S. and Buckle, J. L. 2009. The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods,* 8, 54-63.

Cuskelly, M. and Gilmore, L. 2007. Attitudes to sexuality questionnaire (individuals with an intellectual disability): Scale development and community norms. *Journal of Intellectual & Developmental Disability*, 32, 214–221.

Department of Health and Department for Education and Skills, 2007. *Good practice guidance on working with parents with a learning disability.* [pdf]London: HMSO. Available at: <[http://webarchive.nationalarchives.gov.uk/20080817163624/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\_075119](http://webarchive.nationalarchives.gov.uk/20080817163624/http%3A//www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_075119)> [Accessed 1 March 2018].

Dugdale, D. and Symonds, J. 2017. *Fathers with learning disabilities and their experiences of adult social care services.* Bristol: School for Policy Studies, University of Bristol.

Elliot, R., Rischer, C. T. and Rennie, D. L. 1999. Evolving Guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.

Emerson E. 2011. Health status and health risks of the ‘hidden majority’ of adults with intellectual disability. *Intellectual and Developmental Disabilities* 49, 155–165.

Emerson, E, Llewellyn, G, Hatton, C, Hindmarsh, G, Robertson, J, Man, W. Y. N. and Baines, S. 2015. The health of parents with and without intellectual impairment in the UK. *Journal of Intellectual Disability Research*, 59, 1142-1154.

Emerson, E, Malam, S, Davies, I. and Spencer, K. 2005. *Adults with learning disabilities in England 2003/4.* [pdf]Available at: <[http://webarchive.nationalarchives.gov.uk/20110504140405/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH\_4120033](http://webarchive.nationalarchives.gov.uk/20110504140405/http%3A//www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_4120033)> [Accessed 1 March 2018].

Equality Act. 2010. London: HMSO.

Guay, A, Aunos, M. and Collin-Vézina, D. 2017. Mothering with an Intellectual Disability: A Phenomenological Exploration of Making Infant-Feeding Decisions. *Journal of Applied Research in Intellectual Disabilities,* 30, 511–520.

Gould, S. and Dodd, K. 2014. ‘Normal people can have a child but disability can’t’: The experiences of mothers with mild learning disabilities who have their children removed. *British Journal of Learning Disabilities*, 42, 27-37.

Humans Rights Act. 1998. London: HMSO.

Jamieson, R, Theodore, K. and Raczka, R. 2016. Becoming a mother: Supported decision-making in context. *Journal of Intellectual Disabilities*, 20, 313-328.

Kaspar, P. and Stenfert Kroese, B. 2017. What makes a good mother? An interpretive phenomological analysis of the views of women with learning disabilities. *Women’s Studies International Forum,* 62, 107-115.

Kempton, W. and Kahn, E. 1991. Sexuality and people with intellectual disabilities: A historical perspective. *Sexuality and Disability,* 9, 93-111.

Mayes, R. and Lewellyn, G. 2012. Mothering differently: Narratives of mothers with intellectual disabilities whose children have been compulsorily removed. *Journal of Intellectual and Developmental Disability*, 37, 121-130.

Mayes, R, Llewellyn, G. and McConnell, D. 2011. ‘That’s who I choose to be’: The mother identity for women with intellectual disabilities. *Women’s Studies International Forum*, 34, 112-120.

Mays, N. and Pope, C. 2000. Qualitative research in health care: assessing quality in qualitative research. *British Medical Journal,* 320, 50–52.

McGaw, S. 1998. Practical support for parents with learning disabilities. In J. O’Hara and A. Sperlinger, eds. *Adults with learning disabilities.* New York: Wiley, pp.123–128.

McGaw, S. and Candy, S. 2010. Supported Decision Making for Women with Intellectual Disabilities. In G. Llewellyn, R. Traustadóttir, D. McConnell and H. Björg Sigurjónsdóttir, eds. *Parents with Intellectual Disabilities: Past, Present and Futures.* Chichester, UK: John Wiley and Sons, Ltd, pp. 137-154.

McGaw, S. 1996. Services for parents with learning disabilities. *Tizzard Learning Disability Review,*1,21-32.

McGaw, S. and Newman, T. 2005. *What works for parents with learning disabilities?* Essex: Barnardo’s.

Mind the Gap, 2017. *Daughters of Fortune*. [online] (updated January 2018). Available at: <<http://www.mind-the-gap.org.uk/projects/daughters-of-fortune/>> [Accessed 16 January 2018].

Pederson, S. 2016. The good, the bad and the ‘good enough’ mother on the UK parenting forum Mumsnet. *Women's Studies International Forum*, 59, 32–38.

Råheim, M, Magnussen, L. H, Sekse, R. J. T. Lunde, Å, Jacobsen, T. and Blystad, A. 2016. Researcher–researched relationship in qualitative research: Shifts in positions and researcher vulnerability. *International Journal of Qualitative Studies on Health and Well-Being* [e-journal] 11, Available through Taylor and Francis group [Accessed 16 January 2018].

Scior, K. 2011. Public awareness, attitudes and beliefs regarding intellectual disability: A systematic review. *Research in Developmental Disabilities*, 32, 2164–2182.

Shewan, L, McKenzie, K, Quayle, E. and Crawely, R. 2014. A qualitative exploration of the identities of parents with a learning disability. *British Journal of Learning Disabilities,* 42, 17-24.

Strnadova, I. and Walmsley, J. 2018. Peer reviewed articles on inclusive research: Do co-researchers with intellectual disabilities have a voice? *Journal of Applied Research in Intellectual Disabilities,* 31, 132-141.

Tarleton, B. 2015. A few steps along the road? Promoting support for parents with learning difficulties. *British Journal of Learning Disabilities*, 43, 114-120.

Tøssebro, J, Midjo, T, Paulsen, V. and Berg, B. 2017. Prevalence, trends and custody among children of parents with intellectual disabilities in Norway. *Journal of Applied Research in Intellectual Disabilities*. 30, 533-542.

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

Working Together with Parents Network, 2016. *Update of the Department of Health and Department for Education and Skills Good practice guidance on working with parents with a learning disability (2007).* [pdf]Bristol: Working Together with Parents Network, Norah Fry Centre for Disability Studies, School for Policy Studies, University of Bristol. Available at: <<https://www.bristol.ac.uk/media-library/sites/sps/documents/wtpn/2016%20WTPN%20UPDATE%20OF%20THE%20GPG%20-%20finalised%20with%20cover.pdf>> [Accessed 1 March 2018].

Yardley, L. 2000. Dilemmas in qualitative health research. *Psychology and Health,* 15, 215–228.

Table 1. Participant characteristics

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Pseudonym** | **Gender** | **Age** | **Ethnicity**  | **Children (ages)** | **Parent’s living arrangements** | **Parenting history & current contact with children** |
| Georgina | Female | 31 | White British | 1 (2 years)  | Independent – with husband | Child living with parents, following children’s services involvement and formal parenting assessment conducted. |
| Eliza | Female | 61 | White British | 1 (23 years) | Independent – with partner | Child (now adult) living with mother and mother’s partner, following children’s services involvement and formal parenting assessment previously. |
| Lisa | Female | 43 | White British | 2 (17 and 14 years) | Independent | One child adopted, one child fostered following children’s services involvement and formal parenting assessments conducted; limited contact currently with children. |
| Ian  | Male | 44 | White British | 3 (25, 23, and 14) | Independent | Children living with their mother following parent separation, no formal parenting assessment or input from children’s services reported; has contact with adult children. |
| Tariq | Male | 35 | British Pakistani | 3 (15, 11, and 6 years) | Semi-independent; sheltered accommodation | Children living separately from father and living with mother and grandparents following children’s services involvement; has supervised contact with children.  |
| Gary | Male | 48 | Black British / Caribbean | 4 (from 16 – 29 years old) (also 6 step-children) | Independent – with wife | Children separated from father, children’s services involvement reported previously; children current living arrangements unclear. |
| Patricia | Female | 36 | White British | 3 (12, 10, and 8 years) | Independent – with partner | Children living with parents, following children’s services involvement and formal parenting assessment conducted. |
| Maria | Female | N/K | Mixed – Caribbean / Asian | 5 (14, 11, 9, 6, and 3) | Independent – with daughter | One daughter living with mother; following children’s services involvement and formal parenting assessments conducted, varied contact with two children, no contact with two children.  |

Table 2. Themes, subthemes and contributing participants.

|  |  |  |
| --- | --- | --- |
| **Theme** | **Subtheme** | **Contributing participants** |
| **Georgina** | **Eliza** | **Lisa** | **Ian** | **Tariq** | **Gary** | **Patricia** | **Maria** |
| Becoming a parent | Desire for parenthood | ✓ | ✓ | ✓ | ✓ | ✓ |  |  | ✓ |
| Planning for and being ‘ready’ for parenthood | ✓ |  | ✓ |  | ✓ |  |  |  |
| Assumption of incompetence and proving worthiness as parents |  | ✓ | ✓ | ✓ | ✓ |  | ✓ | ✓ | ✓ |
| Experiences of services | Feeling criticised and let down by services |  |  | ✓ | ✓ |  |  | ✓ | ✓ |
| Being believed in as a parent |  |  | ✓ |  | ✓ |  |  | ✓ |
| Overcoming ‘knock-backs’ |  | ✓ | ✓ |  |  |  | ✓ | ✓ | ✓ |
| Support for rights of parents with learning disabilities |  | ✓ | ✓ |  |  | ✓ | ✓ |  | ✓ |
| *Subgroup analysis:*Fathers feel ‘left out’ |  | - | - | - | ✓ |  | ✓ | - | - |

1. Also known as intellectual disabilities, but the term ‘learning disabilities’ (or occasionally ‘learning disabled’) is used here and throughout as the term favoured by the people with learning disabilities involved in this study. [↑](#footnote-ref-1)