Research Report

Daughters of Fortune: Stories of Parents with Learning Disabilities

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ABSTRACT

People with learning disabilities are increasingly becoming parents, however they face multiple disadvantages to their parenting. There is a small, but growing and important, largely qualitative academic literature which aims to explore the experiences of this group of parents. This study aimed to use an inclusive research methodology to add to this literature, exploring the stories of 8 parents with learning disabilities; 5 mothers and 3 fathers. This research formed part of a larger creative project 'Daughters of Fortune', led by Mind the Gap, the UK's largest inclusive theatre company for people with learning disabilities. This report presents the findings of the research, which represents a unique collaboration between the creative and academic research processes. An inclusive research methodology, with semi-structured interviews led by learning disabled researchers, and the analysis conducted with input from people with learning disabilities, allowed a number of themes (developed through Thematic Analysis) to be developed. One of the strongest of these was the idea that parents with learning disabilities believed that others (including professionals) assumed they would be incompetent in parenting, and from that stand-point parents felt compelled to prove their competence (and worthiness) as parents, often trying to meet targets that appeared much higher than those set for parents without disabilities. The report outlines this and other key themes from the research, in the light of background literature in this field. Strengths and limitations of the research are considered.

If a society values its children, it must cherish their parents. (John Bowlby)

BACKGROUND

Learning disabilities[1] are defined by an individual having a significantly impaired intellectual and social / adaptive functioning, which has been present since childhood and has a lasting impact on development (DSM-5; APA, 2013). For the past 70 years, there has been an increasing focus in research on the needs of families where one or more parents have learning disabilities. 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 have been recently outlined by Emerson et al. (2015), and include sampling issues, such as the almost exclusive focus to date on the needs of mothers with learning disabilities. Estimates of numbers of parents with learning disabilities have varied widely from 23,000 to upwards of 250,000 (McGaw, 1998; DoH & DfES, 2007), however this is likely to be influenced by a limitation in the literature to date of reliance of identifying parents already known to services. Other issues in estimating numbers of parents known to have learning disabilities in the UK, include poor records and shifting and unclear definitions (Booth, Booth & McConnell, 2005). In reality, it has been reported that most parents with learning disabilities are likely to have mild or even borderline intellectual abilities, and as such are less likely to be known to services, or in some cases to meet criteria for adult social services (Emerson et al., 2015). Therefore, reliance to date in the research 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.

Emerson et al. (2015) therefore attempted to identify the health needs of parents thought to have learning disabilities from a contemporary population-based survey in the UK, rather than relying on identification of parents already known to services, and to compare the health needs of this group with a group of parents without learning disabilities. This study used various means to identify which individuals from the over 50,000 randomly selected households were likely to have learning disabilities, including review of cognitive testing completed as part of the research, and comparing this with educational attainments reported. These procedures identified 1.2% of the sample to be likely to meet criteria for learning disabilities. This methodology does have 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 if not known to social care services. Of the people with learning disabilities identified in this study, 66% identified as parents; this is slightly higher than proportion of people without learning disabilities identifying as parents (57%), and is likely a higher estimate of proportion of people with learning disabilities identifying as parents in other studies.

This increased proportion of people with learning disabilities identifying as parents may reflect the unique methodology that aimed to identify parents with learning disabilities much more broadly, not only those already known to social care services. However, it may also reflect that the numbers of people with learning disabilities becoming parents in the UK are reported to be increasing (Booth,

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[1] Also known in the academic literature as intellectual disabilities, but the term 'learning disabilities' (or occasionally 'learning disabled') is used here and throughout as the term favoured by the self-advocacy groups and people with learning disabilities involved in this study.

Booth & McConnell, 2005). Yet, as a group, it is also known that people with learning disabilities face multiple disadvantages in their parenting role. Emerson et al.'s (2015) study went on to identify that parents with learning disabilities were significantly more socio-economically disadvantaged, experienced more neighbourhood adversities, and less intergenerational support than parents without learning disabilities. Parents with learning disabilities also reported significantly more health difficulties than those without; however on controlling for socio-economic disadvantage, statistically significant differences in health status were no longer present (with exception of obesity). This suggests that a significant proportion of the health difficulties of parents with learning disabilities may be attributable to their poorer living conditions rather than their learning disabilities as such (Emerson et al., 2015).

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 & Newman, 2005). As such, many parents with learning disabilities will have their parenting ability formally assessed by social services (McGaw & Candy, 2010). Whilst multiple factors make it difficult to know accurate current figures regarding how many parents with learning disabilities are actively parenting their children, 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 are reported to make up to almost a quarter of cases following a review of court findings conducted in 2000 in Leeds and Sheffield, with just 10% of the children identified as having parents with learning disabilities returning to live at home (Booth, Booth & McConnell, 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 over a decade ago in the UK (DoH & DfES, 2007), and updated by the 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 can 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 still a relatively small, but a growing and important literature base on the experiences of parents with learning disabilities. It is still the case that 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, as a most often qualitative evidence base, it still gives a rich and valuable insight into the experiences of parents with learning disabilities. Mayes, Llewellyn & McConnell (2011) provide a reflective account of how women with learning disabilities take on the mother identity; in a field with much discussion around how women assume the mother identity, this is the first study to look at this experience for women with learning disabilities. A key finding was how women with learning disabilities align themselves to a social 'ally' as a key person in their social network who can advocate for them as mothers and support both them and their children. These authors have also researched the lives of mothers with learning disabilities whose children have been compulsorily removed from their care, with the mothers interviewed often having multiple experiences of child removal (Mayes & Llewellyn, 2012). Gould & Dodd (2014) also looked specifically at 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. A study looking at the experiences of parenting from the perspectives of mothers, and their family and professional support networks highlighted the emotional context of decision making for mothers during pregnancy and parenting, and the importance of the quality of a women’s relationships in supporting her (Jamieson, Theodore & Raczka, 2016). 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 this is the focus of a current research project being led by the Norah Fry Centre for Disability Studies.

Across these, and other, qualitative investigations into the lives of parents with learning disabilities are 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 experiences 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 mothers (or parents) and those in their social or professional ‘support’ network.

This literature serves the academic background to the current initiative. The idea for the innovative project from Mind the Gap, the largest UK inclusive theatre company for people with learning disabilities, to develop ‘Daughters of Fortune’ however came from a more personal source; one of the actor’s sibling’s own experiences of becoming a parent (as a person who also has learning disabilities) and undergoing a parenting assessment. This inspiration led the group to initially research the topic, and to secure funding for a national touring theatre production ‘Daughters of Fortune’, to enable a number of different creative processes (including forum theatre and a national touring theatre production) to share the stories of the experiences of parents with learning disabilities. Parents with learning disabilities were interviewed by a small team from Mind the Gap including a learning-disabled principle researcher and a writing mentor, as part of the research and development for the project. These transcribed interviews and collected stories have contributed to the development of the theatre production. The current research project additionally aims to independently qualitatively analyse these stories to identify themes across the transcripts, to produce reports for academic and professional purposes, as well as to support sharing of these stories in an ‘accessible’ way for people with learning disabilities.

A number of the elements of this research adds to the small but growing and important body of literature that already exists in relation to the lives of parents with learning disabilities. There is much written on the impact of power on research interviews, particularly relevant where interviewees have learning disabilities and interviewers usually do not, and in fact may often hold positions of power as professionals. 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 & 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 a learning disabled researcher, who was also a performer within ‘Daughters of Fortune’, would best support participants to talk openly about their experiences, and may lead to different or enhanced narratives to emerge from the interviews. Furthermore, often in previously reported research in this area there are stories shared by parents, and the need for these voices to be shared more broadly with professionals and the wider community, 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).

We believe that the use of creative processes underpinned by research can enhance the impact and distribution of these messages from parents with learning disabilities themselves.

Research Aims

In addition to the stories contributing directly to the creative outputs produced by Mind the Gap, the research specifically had the following aims:

- To qualitatively analyse the stories of a small group of parents with learning disabilities, to identify patterns and themes in their experiences.
- To add to the small body of literature regarding the experiences of parents with learning disabilities, using an inclusive user-led research methodology.

METHOD

Design

Semi structured interviews were analysed using Thematic Analysis.

Research Ethical Review

The research was reviewed by Royal Holloway University of London College Ethics Committee. Ethical issues requiring review were as follows. All participants were people with learning disabilities, and therefore by nature of having a learning disability potentially had cognitive impairments that can impact informed consent processes; however, all participants had ‘mild’ level of learning disabilities, and were deemed to have 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. As described further below, additional written consent for the interview to be used for the purposes of research was also sought. The nature of the interview topic (about experiences of parenting) is sensitive, however it was not anticipated that the interview would cause undue distress to participants. However, participants were recruited via self-advocacy groups, and should there have been any participants who became distressed during the interview, interviewers were aware how / where to signpost participants for further support if needed. Interviews took place in places where the participant felt comfortable (e.g. self-advocacy group or home), however no interviewers were lone-working, and therefore there were thought to be minimum risks of harm to interviewers. Should interviewers have become distressed by any topics discussed in the interviews, support was provided by 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 largely by self-advocacy groups, specifically in two areas of the UK, Leeds / Bradford and London. Four participants were living in the Leeds / Bradford area, and four from London. Although this was a convenience sample, recruiting from two different geographical areas allowed some broader experiences to be explored. Equally, the eight participants represented a heterogeneous group with varied characteristics. Five participants were mothers, and three fathers. Five were from White British backgrounds, one Black British / Caribbean, one British Asian, and one Mixed Caribbean / Asian. Their ages ranged from 31 to 61 years at the time of the interview. The eight parents had 22 children between them. Their children spanned wide age range 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 also spoke about being 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; with the one remaining parent having experience of child protection in relation to his grandchild. Six parents had at some time experienced separation from their children, who had been either adopted, placed in foster care, or in kinship care or special guardianship arrangements, or were living with the other parent. Three parents were currently living with at least some of their children at the time of the interview. All except one parent interviewed lived independently; four were currently married or living with a partner. One parent lived semi-independently, in sheltered accommodation.

Table 1 presents a summary of participant characteristics; for the purposes of preserving anonymity, limited personal characteristics have been ascribed to individuals.

Table 1. Participant characteristics

Pseudonym	**Gender**	**Age**	**Ethnicity**	**Children**	**Children's living arrangements**	**Parent's living arrangements**
Pippa	Female	31	White British	1 (aged 2 years)	Child lives with parents	Independent – with husband
Mary	Female	61	White British	1 (aged 23 years)	Child (now adult) lives with mother	Independent – with partner
Caroline	Female	43	White British	2 (aged 17 and 14 years)	One child adopted, one child fostered; limited contact	Independent
Steve	Male	44	White British	3 (aged 25, 23, and 14)	Children living with their mother (separated from father); has contact with adult children.	Independent
Naadir	Male	35	British Pakistani	3 (aged 15, 11, and 6 years)	Children living with mother and grandparents (separated from father); has supervised contact.	Semi-independent; sheltered accommodation
Andrew	Male	48	Black British / Caribbean	4 (ranging from 16 – 29 years old) (also 6 step-children)	Separated from children; living arrangements unclear.	Independent – with wife
Sandra	Female	36	White British	3 (aged 12, 10, and 8 years)	Living with children	Independent – with partner
Selina	Female	N/K	Mixed – Caribbean / Asian	5 (aged 14, 11, 9, 6, and 3)	One daughter living with mother; varied contact with two of the other children, no contact with two of the other children.	Independent – with daughter

Measures

The interview guide can be seen in Appendix 1; this was very much a guide to broad questions around experiences of parenting that may be asked in the interview, as the qualitative nature of the interview and research meant that interviews were guided by the individual participant's experiences.

Procedure

Eight parents with learning disabilities were identified largely by self-advocacy groups. They were each interviewed individually by a small team from Mind the Gap, consisting of a learning-disabled principle researcher, a writing mentor and a photographer and film-maker (where appropriate).

Parents with learning disabilities initially gave their consent to be interviewed, for the interview to be audio tape-recorded and transcribed, and for their story to be used to inform the production and research. They may have additionally given consent for photography and video / film recording. See Appendix 2 for the initial interview consent form. Therefore at the time of the interviews, participants gave informed consent to participate in the audio-recorded interview, and for the data from the interview to be used for the purposes of the research. A further research information sheet (see Appendix 3) and explicit consent form (see Appendix 4) was provided to the participants to seek their further explicit informed consent to participate in the research processes, including giving some brief demographic information alongside their interview (see Appendix 5), to use their interview data for research analysis and writing up the report for academic purposes, as well as developing a summary (which may include photos / film) of the research findings to be shared with a broader audience of people with learning disabilities and professionals as well as academics. All parents who were originally interviewed gave their written consent to also be involved in the research.

Researcher Reflection

As a qualitative researcher, it is essential to share my own background and perspective as the lead academic researcher, to allow readers to judge how my own position may also influence the research I have conducted. I am a white British woman, and clinical psychologist by professional background. Since qualifying as a clinical psychologist almost 10 years ago, I have specialised clinically in working with adults with learning disabilities in an integrated health and social care community team in London. For past 6 years I have combined my clinical work with an academic post at a university within the doctorate for clinical psychology department. This has enabled me to continue my own, and to supervise others', research focusing on the needs of people with learning disabilities. My particular interest in the needs and strengths of parents with learning disabilities began when I began my first qualified clinical psychologist post working with people with learning disabilities, when I was struck by the challenges faced by these individuals in their journey to become parents, and began to work with our local services to improve services and develop joint working pathways between children's and adults' services to better support the needs of families with parents with learning disabilities. I have continued this passion both in my clinical and research work. It has also taken a more personal outlook for me more recently as I became a mother myself a couple of years ago, bringing with it my own perspective on my experience of motherhood, with its similarities (and differences) to the experiences of those who I work with and for.

Data Analysis

A Thematic Analysis (Braun & Clarke, 2006) qualitative methodology was chosen. This 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. An inductive 'bottom up' approach was used.

Following receipt of consent from participants to be included in the research, audio interviews were transcribed verbatim. Braun and Clarke's (2006) method of Thematic Analysis was followed. As the researcher conducting the 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 the process of combining these into themes was completed by moving and moving again codes and data, until an initial pattern of themes was developed.

There are a number of recommendations that have been made to ensure quality in qualitative research (Yardley, 2000; Mays & Pope, 2000; Elliot, Fischer & Rennie, 1999). 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 principle 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 in this way 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, the final analysis is presented in the report 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 / added words which were 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 '….'.

RESULTS

Setting the Context for Becoming a Parent

Desire for Becoming a Parent

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

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

> *I've always known I wanted children. (Selina)*

> *I would have children, yeah. (Naadir)*

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. We reflected with the research team whether this was something that may be different for people with learning disabilities than those without, and whether expectations of others about whether these are aspirations of people with learning disabilities may reflect people's abilities to voice these as hopes for their future. Some parents expressed themselves that they were concerned that they may not be *'good enough'* to be parents themselves, 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 wasn't sure about it myself, I thought it might be a bad idea, I don't know. I didn't believe in myself. (Steve)*

> *I always wanted children but I didn't think I would find anyone who would accept me for me and be able to have children with. (Pippa)*

We also wondered as a research team whether this may also be related to wider societal expectations of whether people with learning disabilities can be parents. 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, which has led to a lack of focus on sex education for people with learning disabilities, perpetuating the lack of access to this aspect of 'ordinary lives' for any adults. 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. Some of the parents interviewed (such as Steve) were older and may be more likely to have had a limited access to sex education), however others (such as Pippa) should have been educated under more progressive policy, and yet still faced challenges of the attitudes of others in developing their intimate relationships:

> *Society has all these rules about where and when you can show each other you love each other, and then the one place we thought we could be ourselves we're having to fit into an even tighter space of rules. Where it used to be we didn't have to fit into that box, the box was made big enough for us. (Pippa)*

Developing Intimate Relationships

Despite the challenges faced, including these mixed reactions from others, Pippa in particular spoke about the narrative of the **development of an intimate relationship** with the father of her child as a love story:

> *I fell in love with him at first sight. Which I know sounds very cheesy but is very true. And I'm still in love with him now even if he struggles to see it. But I am. So yes, I fell in love with him at first sight. (Pippa)*

She also reflected on this as a relationship that remained strong, and even strengthened, through challenges faced in their shared journey through parenthood:

> *It was, we were very good, we were very strong as a couple. Yes we were both struggling but we were communicating. We were communicating very well. Yeah it did make us stronger as a couple. (Pippa)*

However, in many ways Pippa's story was unusual in this regard, as other parents tended to talk about **challenges in their relationships** with the fathers or mothers of their children:

> *When we were together it was just hard work; I just feel that I was undermined. I did feel that I were being pushed out by her mum and dad and her family. Her mum and dad really didn't like me at all. I don't know why, I didn't do nothing wrong. I just felt pushed out, but I were determined to be there; nobody pushes me out from my child. (Steve)*

For some these challenges became serious concerns about abuse within the relationship:

> *I had fun bringing up Michael but then it affected my husband because he thought he didn't have a role to play. So then he started going out drinking and he would come back drunk and if something wasn't done the way he wanted it to be done I would get a slap. (Caroline)*

These and other parents talked about traumatic experiences of financial, emotional, physical, and sexual abuse in the relationships, largely as victims of such abuse, but occasionally also as people who engaged in abusive behaviour with their partners. When abuse occurred, it was usually cited as part of the influence of later separation of parents from their children. Parents who spoke about such experiences however were indisputably reflective about the impact of this on others' beliefs about the person's ability to provide 'good enough' parenting experience, and a sense of learning and reflection on the experience:

> *Things got messy because of… With the first one, yeah, things got messy with his mum because you see she…she's a little…so the family involvement. The second one there was… I was on medicine and I lost my temper and lashed out to which…. That's why I didn't get to live with my other three cause she didn't want me back. I'd done with her then and I told myself at the end and the police and she said, Right and that was it. It made me, it got me depressed and all of that to the point I wanted to end it all. This is what I'm saying… there are points of my life that I'm not proud of but I think at the end of the day I've got to put it as a learning curve… (Andrew)*

Own experiences being parented

Some parents also spontaneously reflected on their own **experiences of being parented**, including challenges with this and influence this had had on making them want to be a **different kind of parent**:

> *Well when I had children of my own I learnt from seeing my family grow up how it was, I thought I'm not gonna be like my dad, I'm not gonna be like my mum…. So I did get a clip round the ear once by my father, but I… but I've never hit my children, you know…. I didn't have any favourites between my two sons because I didn't… I learnt that growing up how it was like to be favourite; so I treated them equally. (Caroline)*

Selina in particular reflects on her history of abuse in her childhood and early adulthood, and also reflects thoughtfully on how one of her daughter's experiences of separation is similar to her own:

> *So now I've got, she's three today, I've got [daughter] who's in [country], a third world undeveloped country who's pretty much going to have quite a similar life to what I had, but without the loving grandparents. A child in the Caribbean without a mother and father is classed as an orphan, whether the parents are alive or dead that's just the stigma that goes with it, and then being from that country she's even going to speak [different language] so I can't even communicate with her. (Selina)*

Planning for Parenthood

Contrary to some of the literature that suggests that people with learning disabilities most often present with 'unplanned' pregnancies, several parents spoke about **planning their family**.

> *Planned it, to have family… (Naadir)*

Whilst a number of parents talked about families and pregnancies being planned in some way, Pippa's story in particular is one of great **preparedness** for her journey to becoming a mother, which is somewhat singular as a story in the depth of the preparation undertaken. Interestingly, Pippa reflects on the paradox between expectations of people with learning disabilities deciding they may be 'ready' to become parents in comparison with people with such disabilities:

> *I think it was just, well, no one's ever ready, or no one realises if they're ready until they have one. But no one ever is ready. (Pippa)*

This seems to highlight that even at this early stage, there may be a greater expectation placed on people with learning disabilities than there is on those without; that we may 'expect' people with learning disabilities to ensure they are 'ready' for parenthood, despite the far more common narrative in the wider population that *'no one is ever ready'*. Pippa's narrative however reflects how she took on this 'challenge' of preparation:

> *Cos we were trying to wait until we were ready because we knew we'd have to face social services and everything with being on the spectrum….. Yes we had been told that we would probably have to get social services involved… I think they said something like 80% or something of Asperger's don't get to keep it. I can't remember the exact ones. My mum might be able to. So… that's it something like 1 in 10 were allowed to keep their baby… So I was determined we'd be the 1 in 10! But no, it doesn't exactly encourage you to start a family even if it's something you've always wanted. (Pippa)*

Prior to conceiving their baby, this led Pippa, and her partner, to complete an NVQ in childcare, and to endeavour from the start of the pregnancy that they were doing everything 'right':

> *We did the childcare course. We both passed. We got the NVQ Level 1 in Childcare. And I went to all the midwife appointments, all the scan appointments that I got through from when I was pregnant. (Pippa)*

This also included telling people early about the pregnancy, something which commonly pregnant women may not do until later in the pregnancy.

> *I told my mum, my support worker, well support workers…. And we had, we had advocates before that when we were starting to talk about starting a family, so I rang them up. Well I didn't tell them*

straight away, I told them a few weeks in when we found out. Because I found out when I thought I was 7 weeks but I was probably more like 6 weeks. But they never got back to us. (Pippa)

As a research team we reflected on what may be driving this desire to 'prove' selves as good candidates for parenthood; seemingly this was related to awareness of others' negative expectations of parenting abilities of people with learning disabilities, but whether this may also reflect some internalised self-stigma, and a need to seek approval and validation from others about impending parenthood.

Preparation for parenthood for a number of parents also followed the 'typical' experiences, common for all parents, such as preparing cots and 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…. (Pippa)

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, whether people would experience actively parenting their child, or whether their child may not return home with them:

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

Emotions of self and others about the pregnancy

All mothers and fathers talked about the **joy** in finding out they, or their partner, were pregnant. Commonly people talked about feeling '*over the moon', 'ecstatic',* and '*proud'*, or '*scared but happy at the same time'*. These emotional experiences seem universal for parents who have planned or aspired to starting a family, whether they have learning disabilities or not.

Some also spoke of **others' reactions** (particularly their own mothers') to hearing the news being positive:

My mum helped us out a lot. Well she came the first time, well when she found out she got up off our couch and gave us a massive hug. (Pippa)

Mum already knew. Yeah well, see mothers know when their daughters are pregnant. Even before they tell them… Her face lit up. She gave me such a great big hug. Everyone congratulated me then. (Caroline)

Mayes, Llewellyn & McConnell (2011) also talked about the importance of mothers with learning disabilities being able to recruit a 'social ally' in their journey to motherhood, and this seemed reflected in the value that some parents in our study placed on this initial support from a valued other in their social support network, and ultimately the support that this provided in their later parenthood.

However, others' reactions (such as wider family members' reactions) to the news of their loved one becoming pregnant were often more mixed. Some spoke of more negative reactions from others, sometimes as initially negative reactions that warmed to positive over time, or sometimes reactions that remained negative:

She didn’t accept it at the beginning, my mum…. But then, when it came further on and further on, she accepted it. And then when I had her, she were over the moon. (Mary)

My mum was angry at me, because she was worried, not to be nasty. I told my dad about it, he didn’t care, he just didn’t care. ‘Another failure’ he said... (Steve)

Discussing this experience with the research team and through credibility checks with the reference group, led to some further interpretations and ideas around this. This experience of a negative initial reaction from others resonated with experiences of the parents in the reference group. Some of these experiences seemed more aligned with what we may have come to expect as reactions to young people’s or ‘teenage’ pregnancies; however often our participants were not particularly ‘young people’ but adults of sometimes quite mature age, choosing to start a family. It is interesting to reflect whether this may reflect the persistence of the ideas of people with learning disabilities as ‘eternal children’. Again, given that a number of parents interviewed in our studies had become parents over 15 years ago, we may optimistically consider whether such societal expectations have changed even since the experiences of these parents. However, for the parents interviewed in this study, there sometimes remained this conflict regarding their own (joyful) emotional reaction to impending parenthood, and a wider perceived societal reaction to their pregnancy:

I loved being pregnant. I had no…you know when someone is not worried about anything, it’s like you’ve pushed your worries away and they focus on the one thing that is there, that is growing inside them every minute of every day… But it is hurtful when other people don’t know where disabled people are coming from. (Sandra)

Experience of labour and childbirth

Most parents referred to childbirth occurring in hospital, although Sandra spoke of her second child being born at home with her mother and teenage sister in attendance. People had mixed experiences of labour and birth of their children. Some of these differences may be explained by the time passed since the experience. Pippa was able to provide a detailed explanation for her complex caesarean section, for her daughter born prematurely; this may reflect the level of her understanding, but also that this was a much more recent experience for her less than 2 years previously:

I remember them saying that yes I was ok to have the epidural, I was going to be awake, because my platelets were that low they were saying they weren’t sure they were going to be an acceptable level for the epidural, spinal sorry. But they just climbed high enough in time. So I was conscious thankfully. (Pippa)

By contrast, other parents tended to give accounts of childbirth that were unclear or lacking in at least some detail. For example, Mary (whose daughter is now over 20 yeas old) gave minimal details and described a seemingly very straightforward childbirth:

The birth? It were easy. Never had any pain or nowt. I went in on the Monday, and I had her on the Tuesday, without any pain. (Mary)

Although there seemed to be some complications after her daughter was born, minimal details are given:

She were… Well, I had her in the hospital. She had to go down… She had to go down to another room because she had something wrong with her, her, her breathing. But then I… Then they brought her back, and she were fine. (Mary)

So her minimal details may reflect both the time passed, but perhaps also do also reflect her understanding of the health complications at the time, given her learning disability.

One father, Steve, also spoke about his experiences of his children being born, including feeling *'proud and honoured'* to be there for the birth of his first child. He also describes warmth and support from the professionals in the delivery room:

The people in the room were being quite kind with me. I kind of felt the first kindness I really feel for a long time with professionals. (Steve)

However, he also spoke of the frustration of missing his daughter being born, and how this made him feel left out as a father; feeling side-lined being a common theme in other ways for the parents we interviewed:

I felt happy but I missed her being born. I were looking after my son, I just missed out by 20 minutes, I were gutted. What got me annoyed, her friends got to see her being born, I felt last to know. I was really not happy about that. (Steve)

Breastfeeding

It has been reported that mothers with learning disabilities are less likely that those without to breastfeed (Guay, Aunos & Collin-Vezina, 2017). Three of the five mothers in this study spoke spontaneously about their attempts to breastfeed, but each of these spoke about challenges:

…the other thing I didn't like was breastfeeding [laughs]… (Sandra, who did breastfeed her children)

I felt so guilty because I didn't breastfeed her the way I did with my others…. (Selina, who was unable to breastfeed her youngest daughter due to early separation from her)

And then of course I had to wake myself up every few hours to express breast milk… (Pippa, whose daughter was in neonatal unit)

It was not evident from the interviews how much support parents received or sought out in relation to breastfeeding or other infant feeding decisions.

Children's additional needs

Six of the eight parents interviewed talked about at least some of their children having some sort of additional needs; these included premature birth resulting in neonatal care, learning needs, behavioural needs, genetic conditions, and physical disability. These needs varied in their impact, and for some with younger children it was not clear whether these needs would have a lasting effect. However, the parents who faced these additional challenges may have also experienced additional questions raised about their parenting ability. Mary talks about how she felt her ability to engage with her child's social worker was questioned, when she was just trying to respond to her daughter's additional needs related to ADHD and behavioural problems:

> *She never liked any, anybody coming to the house. No. I had to… It were her all the time, which I says to her, I can't do that [daughter]. I says, I've got to talk to people as well as you. But she never understood….. What she [children's social worker] saw, and that. Of her behaviour. And I just… I said I can't talk to you [children's social worker], and talk to her [daughter], and see to her at… I said, what do you want me to do? I said, do you want me to talk to you and not talk to her? Not get her attention as… I couldn't do both. I couldn't do both, get her att… Look after her, and talk to her at the same time. I couldn't do that…. Her social worker wanted her to be taken off me, because I couldn't… They were saying I wasn't doing my job right. I weren't looking after her right, and I couldn't cope with her. (Mary)*

I wondered how services (and wider society) perceived the additional needs of the children of parents with learning disabilities, whether this increased questions about the parents being 'good enough', or even raised (often unspoken) queries that are aligned with historical eugenic concerns; where there were steps taken to actively prevent people with learning disabilities, or others deemed as 'feeble minded' from having children due to perceptions of the continuation of such 'deficits'. Although policy has moved far from these ideas in current thinking, and these ideas were not explicitly spoken about by parents in the study, however I was curious whether this may still (unconsciously) influence society's stigma towards parents with learning disabilities, and how this is experienced by parents themselves.

Experiences of Services

Once people had become parents, many spoke about the importance of being proactive with seeking support from services. For example, Mary, whose example above outlines the additional needs of her daughter, advised:

> *If you need help, get help, because there's help there. Go and ask, like, an advocate, for an advocate. Don't do it on your own. It's hard. Go and see somebody. Tell somebody… Don't struggle. It's very hard struggling on your own. (Mary)*

Others also spoke not only of being proactive in asking for help from others, but also advised other parents to demonstrate an active engagement with social services, rather than trying to 'fight' against involvement from services:

> *Which is very unfair as [partner] has said but I know that if we go through it and not fighting them it's going to be over and done with quicker than if we fight them. So if we need to go through social services involved, do not fight against them 'cos it works better for you, and be completely honest with them about everything. (Pippa)*

However, parents may not always get the support they are asking for, even when being proactive. Caroline spoke about her and her partner's attempt to ask for help:

> *and so was my partner, but my partner wanted to make sure we got the right help because I also have epileptic fits. So he rang Social Services up, adult… children's social services, to make sure we got some help. So a meeting was arranged with a social worker, the midwife… the local community midwife, the health visitor, I remember it was a room somewhere in the hospital and I hated that social worker at the time. They were going on what… what they could do to support me, they said they would do a pre-birth assessment and the community midwife would give me parenting lessons after the child was born, and the health visitor would come in and all that lot…. Yeah, I was okay with that agreement, yes, but it didn't happen. I didn't get the pre-birth assessment. I didn't get*

> *it……..No, no they didn’t give an assessment. They did it after the child was born… there’s one called the pre-birth assessment and one where they can do an assessment after your child’s born. So this one was going to be one before my son was born, but they didn’t give me an assessment before [son] was born, they didn’t do it. (Caroline)*

This ultimately had very negative impact for Caroline, and her family:

> *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 you need to stay in…. I turned round and said, well that’s your fault that you haven’t done the assessment, I’m not staying in. He then said to me, well you can’t take [son] home, and I said, well I’m taking [son] home. He said, no ‘cause you haven’t done… we haven’t done an assessment on you… you can’t take your son home. He said, oh we’ll have to put [son] into foster care, and he said… and I said, well [son] ain’t going into foster care….So we then came to an agreement where [son] would go home with my husband’s mother and so [son] stayed with Nana for two months while they did some… while the midwives worked with us and did some tests on us and… But at that time I went into depression because I… I couldn’t see my son, they barred me from going to see him while he was at Nana’s bungalow and so… (Caroline)*

Negative experiences of (children’s) (social) services

Seven of the eight parents described experiences of some sort of parenting assessment; the one parent who did not, had however experienced children’s services involvement with his grandchildren. Parents spoke often negatively about their experiences of children’s social services, at times contrasting these experiences with experiences of other services:

> *My social worker, my… I didn’t like my social worker, because she’d take me like, as though I were a child. But the midwife, she was really good. She understood. She, she… She went on and found out about ADHD, and we sat down and we, and we… She explained it to me more than what… (Mary)*

> *I don’t, I don’t trust social services. You know, I don’t hate them I just… I just don’t feel nothing towards them and with people, because everybody that has been in my life since I’ve been into this country it’s always been untrustworthy people. (Selina)*

The context to the involvement of children’s social services is important. Children’s social services will be in a different role to many other support agencies in the parents’ lives, and their emphasis on the needs of the children seems at times to preclude the consideration of the wider needs of the parents or indeed the family as a whole. Most significantly, parents noted that involvement of children’s services came with the threat of child removal:

> *Social put us on child protection. Every day was hard. It was so hard. Yes you are right I did feel like I was losing them but [sigh] I didn’t want to lose them so I did everything in my power to try and keep the kids. (Sandra)*

Six of the eight parents had experienced some sort of separation from at least some of their children at some point. A number of parents experienced multiple threats of child removal related to each of their children. Mary described how for her only daughter there had been three attempts to decide whether she should continue to live with her:

> *They couldn't make a decision up, because some of them were saying yes, and some of them were saying no, so it were just… And then the third time, it were just relief when I finally got, I got, I got [daughter]. (Mary)*

Mary's experience also encapsulates the relief experienced by parents if decision was made for the children to remain with their parents:

> *And I came off…when we came off child protection I was so over the moon. (Sandra)*

It is understandable how stressful parents found the additional pressure of involvement in parenting assessments. Often parents described coping with additional assessments or meetings at a time of new parenthood which is a challenging life change for anyone, with or without learning disabilities. For some parents, this was occurring alongside other challenges. For example, for Pippa, managing additional healthcare needs of a premature baby, or Mary, managing her daughter's behavioural and learning needs:

> *During everything even while we were at [hospital] we were doing things like the PLO, the public law outline. We had child protection meetings we still had to go to. So on top of our baby girl's poorly, we still had all the social services meetings we still turned up to, regardless, with all professionals involved that needed to be there, there. So that was very stressful, as you can imagine. (Pippa)*

> *Oh, they were all about not coping with [daughter], and we're supposed to get [daughter] to go into foster care. It were awful. In fact, I just had to up and go out the room. I couldn't listen to any more. (Mary)*

Parents talked about a large number of people involved both in the assessments and in the meetings to discuss these:

> *There were loads of people involved, the school and all. Linden Brook, everybody. Everybody were involved, and they, they all wanted [daughter] to go into care because I couldn't cope with her. They were saying I couldn't cope with her. And that's the same time I went down to see a solicitor, and that's when I got a solicitor's advice to see what I could do to stop them from taking her. That's when I got the advocacy involved, and they told them. (Mary)*

A number of parents did not feel appropriately included or involved in the meetings themselves:

> *I had to sit and listen. But they weren't talking to me… My advocacy said, there's a person in the room who should… You talk to, instead of going all the way round it. She's in the room. They weren't speaking to me, at all. They spoke to me like a child. (Mary)*

> *But they weren't sending me the reviews through and I had to put a complaint in recently saying I've not received any copies of any reviews since [son] was 11 years old. So I finally got them all and I read them. Now [son]'s old enough now to be asked if he wants me there and he has been asked if he wants me there, he just says he's not bothered if I'm there or not….. Yeah. So… so because he can't make that decision the social worker's manager will make that decision. So it'd be took out of [son]'s hand and they decided no I shouldn't be there. So the social worker's supposed to ring me up and ask what would I like to say in the meeting, but she never does. She never includes me. So, but I know now what went on in the meetings so, because I've… I've read them all. (Caroline)*

This appeared to leave parents feeling dissatisfied and disheartened by their experiences of services. For the one individual who had not had formal involvement from children's social services, it was hypothesised that this was because the mother of his children was not identified as having learning disabilities; this was seen as a successful outcome:

> *I'm being honest, lucky for us they weren't involved. That was good! ……. Yes; I think, from what I understand, I think she did pass, my partner with learning disabilities but she went to the same special school as me. The only thing that I can think is she had behavioural issues, it's the only thing I can think of. That's what me and my mum think. That's why we got away with it. I was happy about that. That's the only thing I can put my finger on. (Steve)*

This makes me wonder whether it is thought to be just the label of learning disabilities itself that raises questions about parenting ability; those who present as more able or who do not identify themselves to services as having learning disabilities may 'get away' with it as Steve describes above. But where does this leave individuals who do want (or need) to access some additional support, but in doing so risk social services learning about their learning disabilities? This may contribute to the 'vicious cycle' often described (Jamieson, Theodore & Raczka, 2016), whereby parents may minimise their support needs to reduce likelihood of additional scrutiny, but this leads to concerns from services about parents' understanding of what support they need, and consequently also concerns about their parenting ability.

A strong theme emerged of parents feeling criticised by children's social services:

> *He was really critical, the social worker. He went, did you know, he said, you had a fit holding you son. I said, well I can't help that, and I said… he was… every opportunity he put me down and I hadn't even had a test to see if I could be a mother to my son. He hadn't even tested me out by then and he was like, well not slagging me off but putting me down. (Caroline)*

> *It's just them dictating and I don't like that. Or "You're not a good mother. You're not this. You're not that. You should go here. You should take them to the park." And I'm saying, "It's my child not yours." (Sandra)*

Parents sometimes felt that the needs they had were not being met by the support they were offered:

> *But I didn't like the way Barnardo's were working with us because they were teaching us parenting skills, but I didn't like the way they were teaching me. They were teaching me stuff I could already do like how to feed my son, and I thought I already know how to do this, and they made a report to the social worker to say [I'm] not fully taking part in these courses. I thought well, and I told her, I said they're telling me stuff I already know, I don't need those courses, they're not right for me. (Caroline)*

Furthermore, short-term input and frequent changes to social workers were experienced as disruptive and difficult:

Then that social worker left and then we got another one, and then she left, she disappeared; they don't stay around for long!....... Now the social worker that was working with us at the time wanted to keep the case because she worked so hard to get it… everything in place, but because she was on the crisis team she couldn't keep the case, she had to pass it to the full-time team in [city]. So when we went to full-time team we got a different social worker again…. my children have had eight social workers all together during their lifetime. So they don't stay with you for long… (Caroline)

Similarly, some parents also talked about lack of consistent support from adults' social services for the parents themselves:

> *The children's social worker had to help me. It was supposed to be adult social team, but adult team weren't helping me. It was the children's social worker. That's not her job, her job is for [sons], not to help me…. (Caroline)*

There was also a reduction in support for parents if children were removed from care, arguably a time when the parent needs support for themselves even more, given the emotional impact of the separation:

> *Yes, yeah 'cause once the children were removed, boom, I saw both children's teams go and the adult team disappeared because they couldn't support me anymore. (Caroline)*

What worked well when services were working well?

Some parents also talked about positive experiences of services. A number of parents commented on the importance of support that is long term, in line with good practice guidance (e.g. Working Together with Parents Network, 2016).

> *Because we still have social services involved even now. But that's not necessarily because they've got any worries about us as parents. It's more because her social worker doesn't want to close the case and us not know how to access the support if we need it. She'd rather close it down once and for all, rather than she closes it down and then we have to go through it all again. (Pippa)*

There were also some positive experiences of (children's) (social) services:

> *Some people with social workers did have good services, I had two social workers, and I had good relationship with them, good support with them, yeah, good relationship, yeah. (Naadir)*

One quality that was mentioned as positive was professionals having a belief in the parent's abilities:

> *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. (Caroline)*

> *Throughout all of this I've learned how good it is to have positive encouragement and positive support. So I know what I've been missing and I know what I've been getting a lot of so I'm just going ignore all those bits and just stick with the positive. (Selina)*

People also talked positively specifically about legal services and advocacy support:

> *In the end I went to see a solicitor and she told me that that social worker had no right to do that without going to court, and he broke the… like some law or something and she managed to get [son] back living with us…. Oh she was very good, she said that that social worker had no right to do that without going to court and getting a court order, and she managed to get [son] with us. (Caroline)*

> *Well, [advocate] goes, she goes to court with you, if you've got to go to court. She went to court. She spoke… if I… I wouldn't speak to anybody. She spoke to them for me. She spoke up and told them.… I thought it were a good experience, because… People with learning disability, they're too frightened of speaking up. They daren't. They won't. They won't, they can't do it, or they can't do it on their own. (Mary)*

There were also positive experiences of self-advocacy and parents peer support groups, from four of the parents who were already connected with these groups:

> *Because I feel it includes other parents with learning disabilities who got to keep their kids to do peer to peer support. (Steve)*

> *Oh, it gave us support to come to Parents Group, and to support babies, kids, yeah. (Naadir)*

These positive qualities of services when they were working well, as shared by parents, very much reflect current good practice guidance (e.g. Working Together with Parents Network, 2016).

Experiences of Loss and Separation from Children

Six of the eight parents interviewed had experienced some form of separation from at least some of their children at some point, be it permanent or temporary. Some parents had since been reunited with their children, and some continued to have some contact despite the children not being able to continue living with them. These were certainly difficult decisions often made by children's services with the thought of the best interests of the child; but understandably for parents these were stories of often multiple losses and traumas, with significant negative impacts for the parents. For example for Caroline, she experienced an initial loss related to her first son when he was temporarily looked after by his paternal grandmother while Caroline underwent a parenting assessment; but this initial separation resulted in depression:

> *and I couldn't cope with this depression because I… the cot was in the next room to where I was. It was really sad and I didn't know what depression was and what I was going through. (Caroline)*

Subsequently, her first son was returned to her care and she went on to have a second son. However, following her own admissions of abuse she received in her relationship and further serious concerns raised, her parenting came under scrutiny again, and ultimately her older son was again removed from her care. However, the experience of this was sudden and traumatic for Caroline:

> *So [son] was took straight from the school, I never got to say goodbye to [son] because he was took straight from the school. That was… that was so hurtful because I dropped him off but I couldn't go and pick him up. (Caroline)*

Selina also talks about not being able to say goodbye to her youngest daughter, and the difficult decisions that she had to make around this time, when battling multiple family court cases:

> *What happened with [daughter], my youngest, she was taken away at birth because obviously the social services went to court to say that my four children were taken away…. So I didn't say goodbye to her, she left April this year, before that she was with her aunts. I didn't say goodbye to her because how do you say goodbye to your daughter and at the same time I was in the middle of a court case with [older daughter] and I could only function… I've given [youngest daughter] everything and they still took her. So my thing was I've given it my best shot, she can see all the court papers towards the end, Mummy didn't abandon her, I fought, the judge just said no but I still have a chance with [older daughter] so I just put everything into that and gave it my all. (Selina)*

Assumption of incompetence

A strong theme that emerged was one of 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. This is something that is mirrored in other qualitative research (Gould & Dodd, 2014).

> *The social workers need more training, they need to understand and not stick labels on us. They… they say learning disability can't look after a child and they just assume straight away that you can't look after your child. They…. They need to… they need to get to know you. (Caroline)*

Parents also gave their sense of needing to ‘prove’ their competence, and themselves, as parents to professionals who took an initial stance that they would not be ‘good enough’.

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

Because I’d changed it all around. I’d changed everything they wanted around….. And I proved I could do it. (Mary)

As an example, Pippa talked about her experiences of her and her partner choosing to do an NVQ in childcare even before trying to become pregnant, which whilst she says wasn’t exclusively to ‘prove’ to anyone, did also serve this purpose:

Well childcare is something, I’ve always been interested in kids anyway, for me it wasn’t so much of a we’ll do this to prove to anyone, it was something I was interesting in anyway. But like I was saying to [partner], at least if we do this, it shows we’ve got a qualification, it will give us a tick, it will be a tick… (Pippa)

These ideas of assumed incompetence and the need to prove selves as worthy parents is something that resonated strongly with the research team and reference group, who also acknowledged that it is harder to get support when you have disabilities, despite this being a time that people most need support.

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. (Pippa)

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:

And especially with all those feeding tubes, we were doing all that as well. It kind of stopped them from questioning our parenting skills and capabilities, because we were doing so much much more. (Pippa)

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

And I asked them. I said well, I tell you what. Why don’t you take her for a fortnight? You have her for a fortnight. The social worker, I said, you have her for a fortnight, and see how you cope with her. Oh, I don’t…. I couldn’t cope with her. I said no, but then you’re telling me I’m not doing my job… (Mary)

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

When they did their assessment, 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. (Selina)

With the research team and reference group we were curious where these expectations were coming from. Some wondered whether this also resulted from ‘self-stigma’ people held about themselves not being ‘good enough’ as people with learning disabilities. We also discussed how judgement from others about their parenting style or ability is something that most if not all parents feel they experience at some point. My own experience as a relatively new mother (but not one with learning disabilities) is one of feeling inadequate and judged on my parenting much of the time, even though my parenting is not formally under the spotlight, being assessed. But this, coupled with the intense scrutiny and criticism that parents with learning disabilities describe being under, and the often very real threat of child removal each time you do get it 'wrong', seems to contribute to intense experience of parents with learning disabilities.

However, parents interviewed also seemed to talk about something that feels even more ominous and threatening about this. They talked about their frustrations about others (often professionals) treating them as 'different', and possibly 'lesser', than others without learning disabilities. There seemed to be an idea that professionals were *'too keen'* to take away children from parents with learning disabilities:

> *It's so frustrating when they look at us, it's just like, you know, they always look at us we're like different. We are just people like them, why… why have they… labels to us every time? We're just human beings like them, we can't be treated no different. How does a learning disability stop us being good parents? So we are good parents but we're not having opportunities to be good parents because the attitudes are putting us in boxes… We are sick and tired of it. That… social workers before they come to us need training by parents with learning disabilities and people with learning disabilities about how they can work with us with the attitude, how to talk to us, how to report us. They need to treat us the same, not like second class citizens because we want to be parents like everybody else, but we're not having opportunities because of their attitudes and that needs to stop..… they're just too eager to take the child away. You've failed, in their eyes you're always a failure and that is wrong. (Steve)*

> *They play on our disabilities, they prey on our disability and our vulnerability. It's just like… it's just unfair, 'cause we've got learning disabilities but we want to have… 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 but you get learning… if you've got a learning disability you get judged you can't parent. That needs to stop because we want to be good parents and we want support from the beginning, we demand it... (Steve)*

> *The social worker was really rude to this mum with the learning disability. She actually said to her in one of the meetings, she said you know, she said, I haven't [not] won a case… I've won every case when I take them to court, she said. She said, even the ones with the learning disabilities. She said that to her. Then she said, I ain't gonna lose this case either. (Caroline)*

> *What happened with [daughter], my youngest, she was taken away at birth because obviously the social services went to court to say that my four children were taken away. They made it seem like I'm Jack the Ripper, which that wasn't the case. (Selina)*

Parents made comparisons to high profile cases in the media, such as that of Madelaine McCain, and suggest that if a parent with learning disabilities made the same 'mistake' made by those parents, their other children would also have been removed:

> *they haven't got a learning disability, they left her in the apartment with the other two siblings, they were checking on her but unfortunately Maddie McCain went missing. Now they can't find her, but they kept her siblings, the other two children…. Yeah, if that was and we did that, well the other two siblings would be put into care and put up for adoption because they said you weren't looking after them; but now because they're doctors, no. (Caroline)*

I wonder 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, still has some (perhaps unconscious) influence on society.

Related to this, other parents expressed concerns about the people that their children, when removed from their parents' care, were placed with. It seemed from parents' perspectives at times that professionals made decisions to place children in the care of others (without learning disabilities), despite there being concerns about those individuals, but that these seemed preferable to keeping children in the care of their parents with learning disabilities. Selina talked about this in relation to one of her sons:

> *The dad had the residential order but he also has seizures and he smokes cannabis which is known to social services, and he drinks, and they still gave him the residential order. (Selina)*

And also for her youngest daughter:

> *So they took her from birth, I had to give her to the dad's side of the family whilst they do their investigation on the dad to see if the dad could have her. Eventually the judge said that the aunt who's now got her, the same judge, had identified that the aunt was using the child for financial gain. (Selina)*

Other parents spoke about being advised to stay with partners who were known to be abusive, to be able to maintain care of their children. Again, this seemed to raise questions how the rights of people with learning disabilities to a family life, are prioritised.

Fathers' experiences

Much of the parenting literature to date has focused on the experience of women with learning disabilities becoming mothers, including how mothers with learning disabilities develop their 'mothering' identity (Mayes, Llewellyn & McConnell, 2011), and the experiences of fathers has been largely neglected until recently (e.g. current research study exploring experiences of fathers with learning disabilities underway by the Norah Fry Centre for Disability Studies). Our study attempted to interview both mothers and fathers, and whilst many experiences were shared, both challenges and joys in parenting, it was of note that two of the three fathers that we interviewed also talked specifically and significantly of feeling 'pushed aside' at times, 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 in your play, father's 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. (Steve)*

For one of the fathers it felt like the mother's parenting rights would be prioritised over the father's (although this also reflected a situation where there had been domestic violence from the father):

> *In fact there's people with learning difficulties, there's fathers with medical conditions, father's with disabilities up and down the country that would tell you that they've, that they have had, that they've, they've been cheated to the curb by this institution by them, by, by, by the government, by the, by the local and central government. Okay. Even by society itself. They have their, they have their mental health institutions which means they had their mental health issues which means that they probably lost their home because they were a little bit…with their…they were with their baby mother. They had the social worker stand up and threaten them and say, do you know what, oh, to*

the baby mother, oh, well I'll help you, I'll help you but you've got to get rid of him….. The minute that you've got a learning difficulty or you've got a disability or you've got a medical condition, and you're with a woman, the likely chances of you been able to be with your baby mother, if at all… the chances… the chances of a hundred are probably what? I'm being nasty and cruel because the world nasty and cruel. Ten percent. (Andrew)

Parenting Milestones

As outlined above, much of what parents talked about in these interviews were challenges they had faced in their journeys through parenthood. However, each parent also spoke of tender, loving and joyful moments of parenting milestones, as experienced by all parents, with or without learning disabilities, and whether they were currently living with their children or not:

When I saw his head coming out I felt really emotional. I felt really happy and proud; I were crying a bit. (Steve – during the birth of his son)

But I remember looking at her tiny little face, and saying hello [daughter]. (Pippa – after the birth of her daughter)

Yeah [sigh] I felt so happy, so calm. I didn't feel upset. I didn't feel stressed out. I felt "Wow I'm a mum." And every day since the day I have loved them and now I watch 'em all, so I've got three kids. (Sandra)

Like, going to help with them, to read them books, playing with them, yeah. (Naadir)

Watching her grow up. Watching her grow up and… Watching her grow up, and the changes. (Mary)

These were warm reminders of the common experiences of (all) parents, with or without disabilities, in fulfilling often a long-held dream to become a mum or dad, learning parenting skills, and the joy in developing relationships with their children, despite challenges also confronted.

Stories of strength, resilience, hope and coping with adversity

I've had my knock backs in life, and I…and…and…and I know that the knock-backs they could if I let it get to me [sniff]…yes. The knock-backs could if I kept on…if I thought about it and I make it to be it would make me walk out of the room and make me lose… (Andrew)

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 and faith for the future. Some parents spoke about personal strength supported by external means, which included faith in their beliefs, supportive relationships or support from others, which helped them to cope:

Faith. Yeah, my faith in god kept me strong. (Pippa)

It was, we were very good, we were very strong as a couple. (Pippa)

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. Go and ask, like, an advocate, for an advocate. Don't do it on your own. It's hard. Go and see somebody. Tell somebody. (Mary)

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. (Sandra)

Parents also spoke about taking the challenges they had experienced as *'a learning curve' (Andrew)* and a way to become stronger for the future:

Do you know what I'm not going to… 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. (Selina)

Support for rights of parents with learning disabilities

Parents were all supportive of the rights of other parents with learning disabilities. Pippa summed this up, also reflecting on the need to move towards seeing disability as ability:

Well I don't think that just because you're a learning disabled parent, that your going to be less able to parent, I think, if anything it gives you a different perspective on parenting and helps you, I mean with my Asperger's I've got heightened senses. So I've actually got a better idea of her what her senses are going to be like than the average parents. 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. It can actually help make you a better parent. I don't think it should be something that should hold you back. Given the right support I think anyone can, I think everyone should have a chance to raise their own baby. (Pippa)

RESEARCH STRENGTHS & LIMITATIONS

Academic research processes have aimed to bring a rigour to the data collection and analysis of these stories from parents with learning disabilities. The collaboration of this with the creative processes has enabled an inclusive research methodology, and for further dissemination of the stories to occur. Dissemination of the parents' messages has already begun, and will continue, through the creative means and theatre production touring. In terms of academic dissemination, the research has already been presented at UK intellectual disabilities research conferences as poster (16th 'Seattle Club' Conference on Research in Intellectual Disabilities at Glasgow Caledonian University; 12th – 13th December 2016) and oral (British Psychological Society Division of Clinical Psychology Faculty for People with Intellectual Disabilities Advancing Practice Conference; 30th March 2017) presentations, with a further presentation planned at a European conference (11th European Congress Mental Health in Intellectual Disability; September 2017). These presentations have been co-constructed and delivered jointly by the academic researcher and one of the learning disabled researchers. In addition to a paper outlining the research results, we also plan to write a peer reviewed journal article reflecting on the process of this inclusive research, in line with recent calls for further articles attending to the voices of co-researchers with learning disabilities in academic research (Stnadova & Walmsley, 2017). A 'plain english' or 'easy read' summary of the research processes and results will, most importantly, be developed and shared with people with learning disabilities. There are plans to enhance accessibility and dissemination of the messages through development of further film / photograph resources to support this, and plans for larger-scale sharing of these messages with health and social care professionals but also the wider community, in line with the parents' aspirations to share their experiences and educate others about the strengths and needs of parents with learning disabilities.

We believe that the inclusive research methodology is a strength of the research. Having people with learning disabilities conduct the research interviews, jointly with others who don't have 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 being at the mercy of power differentials from professionals. Furthermore, having a learning disabled researcher, and a further reference group of parents with learning disabilities, review and reflect on the themes that were initially produced by the academic researcher, ensuring a credibility check with individuals with learning disabilities meant that the ultimate themes were shaped further by, and resonated with, the experiences of people with learning disabilities.

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 years old to mid-30's. 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 have changed over time. 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. DoH and DfES, 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 represents a broad group, which may include those who would be recognised by services as meeting criteria for learning disability (APA, 2013), but may also include others who do not meet 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 Autism spectrum, but also other complex needs related to living in socio-economic disadvantage (Emerson et al., 2015). This makes this is again a broad 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 we find are often presenting to services with some difficulties, and in fact those who do not formally meet 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. It is also the case that the majority of parents in this study were identified through self-advocacy or support groups, and a number of parents interviewed had a role as self-advocates or supporters of others. They are likely then 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.

RESEARCH CONCLUSIONS

This collaborative project between creative and academic research processes 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. This small research project is part of a much larger creative project led by Mind the Gap inclusive theatre company, which has also used these parents' stories to inform its creative outputs, and enabling a much broader dissemination of the stories and messages of parents with learning disabilities to wider public, and professional, audiences. 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 left the 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. 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. It is disheartening, but perhaps not surprising that all but one had undergone a formal parenting assessment, and all but two had experienced some form of separation from at least some of their children, be it temporary or permanent. The 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. All the parents also however shared stories of their joy in becoming and being parents, that this was often a long held aspiration, even if it had not been shared with others previously. They also demonstrated great resilience and strength in the face of adversity and challenges to their parent identities, and identified the importance of peer support, but also 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.

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