



# **Daughters of Fortune: Stories of Parents with Learning Disabilities**

## **Final Research Report**

**July 2020**

Dr Kate Theodore, Senior Lecturer & Laura Franklin, Trainee Clinical Psychologist  
Department of Clinical Psychology, Royal Holloway University of London

A joint research project with Mind the Gap, learning disability theatre company

Contact: [kate.theodore@rhul.ac.uk](mailto:kate.theodore@rhul.ac.uk)

**CONTENTS PAGE**

	<b>Page</b>
<b>Executive Summary</b>	<b>3</b>
<b>Acknowledgements</b>	<b>4</b>
<b>Easy Read Summary – Easy Words &amp; Pictures</b>	<b>5</b>
<b>Easy Read Summary – Easy Words</b>	<b>14</b>
<b>Full Research Report</b>	<b>21</b>
<b>Abstract</b>	<b>21</b>
<b>Background</b>	<b>22</b>
<b>Method</b>	<b>29</b>
<b>Results</b>	<b>36</b>
<b>Discussion</b>	<b>52</b>
<b>Conclusion</b>	<b>61</b>
<b>References</b>	<b>62</b>
<b>Appendices</b>	
<b>Appendix 1: Interview guidelines and prompts</b>	<b>72</b>
<b>Appendix 2: Additional illustrative quotes</b>	<b>77</b>
<b>List of Tables:</b>	
<b>Table 1: Participant Demographics</b>	<b>31</b>
<b>Table 2: Themes, Sub-themes and Contributing participants</b>	<b>37</b>
<b>List of Figures:</b>	
<b>Figure 1: Thematic Map</b>	<b>51</b>



## Daughters of Fortune: Stories of Parents with Learning Disabilities Research Executive Summary

Dr Kate Theodore, Senior Lecturer & Laura Franklin, Trainee Clinical Psychologist

Department of Clinical Psychology, Royal Holloway University of London

A joint research project with Mind the Gap, learning disability theatre company.

*"We want to be parents like everybody else,  
but we're not having opportunities because of their attitudes"*

**Background:** People with learning disabilities are increasingly becoming parents. Despite good practice guidance existing in the UK (Working Together with Parents Network, 2016), learning disabled parents still face multiple disadvantages in their role as parents, and are more likely to live apart from their children. An innovative project funded by the Wellcome Trust has allowed Mind the Gap, the largest UK learning disability theatre company, to collaborate with university researchers from Royal Holloway University of London, to collate and share stories about the experiences of parents with learning disabilities through qualitative research alongside a number of artistic outputs (film, forum theatre, national touring theatre production, giant outdoor theatre events, and book). Here we summarise the research element of this broader project.

**Method:** Twenty-two parents with learning disabilities (17 mothers and 5 fathers), from across the UK, were interviewed by a small research team from Mind the Gap, including a principle researcher with learning disabilities. This user-led research methodology collected detailed accounts of the parents' experiences. The interviews were analysed qualitatively using Thematic Analysis by academic researchers from Royal Holloway University, with continued involvement from researchers and participants with learning disabilities, to enhance research quality.

**Results:** Whilst there has been wealth of parents' experience shared, the research has generated four substantive themes: (1) parents often feel in '**positions of powerlessness**' in their relationships, many have experienced bullying or abuse in intimate relationships, and

have felt let down and lost trust in others, especially professionals; (2) they face **‘assumptions of incompetence’**, that professionals and others think they cannot be good enough parents; (3) parents fight to **‘challenge assumptions and prove competence’**; and (4) from these experiences of powerlessness and stigma, parents want to **‘claim power’** in their lives, speak up for their own and other parents’ rights, often through parent peer support and self-advocacy. An additional subgroup analysis of fathers interviewed revealed a fifth theme: (5) specific experiences of **‘fathers feeling excluded’**.

**Conclusions:** The themes generated from the qualitative research reflect parents’ experiences of feeling in powerless positions in various relationships, and facing assumptions of incompetence about their parenting ability. However, parents also talked about wanting to prove to others that they can be good parents, and about (re)claiming power in their lives through self-advocacy.

**Implications:** The broader project attempts to encapsulate ‘inclusive research’; working collaboratively with learning disabled researchers and parents, to make sure ‘academic’ research resonated with their lived experience. Working with an artist-led research team has demonstrated the importance of ‘research impact’; translating research into powerful stories, theatre and films, which aim to influence professionals, tackle stigmatised attitudes, and help parents themselves to *“take power back”*.

***“We go out... telling them our story... so they can get the right services.”***

**Contact:** If you want to find out more about the research, please contact: Kate Theodore on 01784414303 or email [kate.theodore@rhul.ac.uk](mailto:kate.theodore@rhul.ac.uk)

Or you can find out more at Mind the Gap website: <http://www.mind-the-gap.org.uk/projects/daughters-of-fortune>

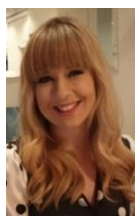
**Acknowledgements:** With sincere thanks to:

- All the parents who shared their stories
- The Elfrida Society Parents with Learning Disabilities peer support group for taking part and for their support to the research
- Other groups who took part in the research: CHANGE; Bradford People First; Cloverleaf Advocacy; Geordie Mums; The Lawnmowers; WomenCentre, Mothers Apart Project
- The Mind the Gap team:
  - Daniel Foulds, Paul Wilshaw, Alison Short (Artists & Learning Disabled Researchers)
  - Lisa Mallaghan (Senior Producer)
  - Joyce Nga Yu Lee (Resident Director)
  - Mary Cooper (Writer and Researcher)
  - Emilie Flower (Film maker)
- Funding from the Wellcome Trust.



**Daughters of Fortune:**  
**Stories of Parents with Learning Disabilities**  
**Research Easy Read Summary**  
*Easy Words and Pictures*

*“They don’t think I can cope, because I have got a learning disability...  
it always came back to that.”*

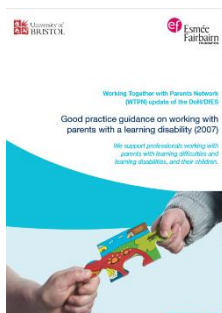


This report is written by:

Dr Kate Theodore and Laura Franklin

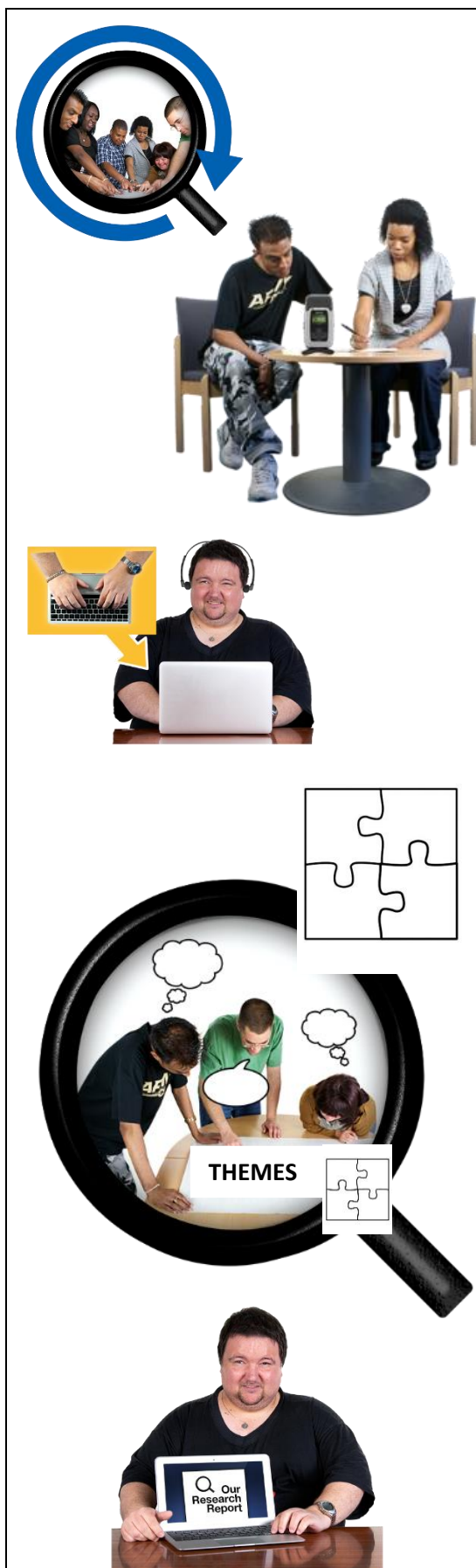
Researchers, Clinical Psychology,  
Royal Holloway University of London.

It is a joint research project with Mind the Gap, learning disability theatre company.



### Why did we do this research?


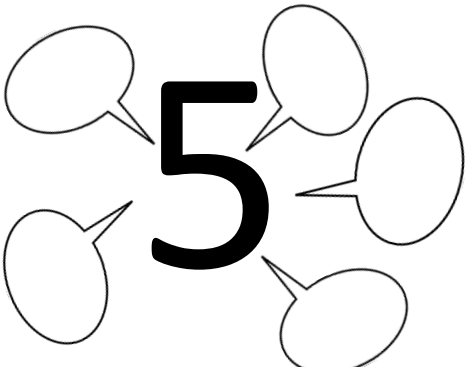
- More people with learning disabilities are becoming parents. We don’t know how many parents with learning disabilities live in the UK.
- There is [good practice guidance](#) to help professionals to support learning disabled parents.
- But people with learning disabilities still face lots of difficulties when they become parents. They are still more likely to live apart from their children.
- We wanted to share more real stories of parents with learning disabilities with professionals and the public.



### **Research Method: What did we do?**

- We wanted to involve people with learning disabilities in this research as much as possible. This is called 'inclusive research'.
- Parents with learning disabilities were interviewed by learning disabled artists and researchers from Mind the Gap, with a writer and a film-maker who did not have learning disabilities.
- The interviews were recorded and written up word for word.
- University researchers read the stories over and over.
- Each parent has a different story, but there are also some things that are the same about the different stories. These are called 'themes'. The researchers looked for these themes in the different stories – a bit like putting a jigsaw together.
- This type of research is called 'Thematic Analysis' – this means looking carefully for the 'themes' or the bits of the stories that are the same.
- The university researchers worked with a learning disabled researcher from Mind the Gap and with parents with learning disabilities to check that the themes from the stories made sense for people with learning disabilities.
- We have written this research report about the themes from all the stories.



 <p>22 parents</p>	<p><b><u>Results: What did we find out?</u></b></p> <p><b>Who took part in the research?</b></p> <ul style="list-style-type: none"> <li>• We interviewed 22 parents. There were 17 mums and 5 dads.</li> <li>• The parents came from Greater London, Yorkshire and Tyneside.</li> <li>• Parents were different ages. The youngest parents were in their 20s. The oldest parents were in their 60s.</li> <li>• The 22 parents had 48 children altogether. Some children were young and some had grown up and were adults.</li> <li>• 18 parents had some involvement from Children's Services.</li> <li>• Some parents lived with their children and some lived apart. Sometimes this was the parents' own choice and sometimes it was not. <ul style="list-style-type: none"> <li>○ 16 parents lived apart from their children for some time or forever. They lived apart from their children for lots of different reasons.</li> <li>○ 12 parents had been separated from some or all of their children through legal processes, for some time or forever.</li> </ul> </li> </ul>
	<p><b><u>Results: What did we find out?</u></b></p> <p><b>What were the research themes?</b></p> <p>There were <b>5 research themes</b>. These are some of the main things that we learnt from the parents' stories.</p> <p>Some of this is in the parents' own words.</p>

	<h2><u>Research Themes</u></h2> <h3>1) <u>Feeling Powerless</u></h3> <p>Parents talked a lot about feeling <b>powerless</b>. They felt like other people had <b>put them down, bullied them or abused them</b>.</p> <p><i>"Special needs was not a nice thing to have... you get bullied no matter what you do, no matter where you go."</i></p> <p><i>"It was good to start, but it did go downhill. He started beating us and stuff."</i></p> <p>Parents also felt like they had been <b>let down or tricked by professionals</b>. They <b>lost trust</b> in professionals.</p> <p><i>"I thought they were gonna help us, but I think they were just doing it to take the child off us..."</i></p> <p><i>"Snakey, too snakey. And then they want to know why people with learning difficulties don't trust them..."</i></p> <p>Sometimes parents felt like other people treated them <b>"like a child"</b>.</p> <p>These difficult experiences left parents feeling like <b>they could not speak up for themselves</b>.</p> <p><i>"People with learning disability, they're too frightened of speaking up. They daren't. They won't...or they can't do it on their own."</i></p>
--	--



## 2) People say we can't be good parents

Parents felt like professionals and others **assumed that people with learning disabilities can't be good parents.**

*"If you've got a learning disability you get judged you can't parent."*

Parents felt like they **had to prove they were good parents.** Parents felt like they had to be **even better than other parents** without learning disabilities. This felt **unfair.**

*"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."*

Parents felt like they **can't get it right**, however hard they tried to show they were good parents.

*"I couldn't do right for doing wrong."*

Sometimes parents **did not know** what they had to do to show they were good parents and to keep their children living with them. They felt confused and frustrated about this.



*"I did do what they told us to do and I still got wronged for it."*

Parents felt **"set up to fail"**.

Some parents **did not feel listened to** when they asked for help. Some did not feel they got the right support. Some only got support in a **"crisis"**.

*"They knew I was struggling, and I asked for their help and they wouldn't listen."*



	<p>Some parents felt like <b>prejudice or stigma towards people with learning disabilities</b> stopped parents getting more support.</p> <p><i>“We want to be parents like everybody else, but we’re not having opportunities because of their attitudes and that needs to stop.”</i></p>
	<p><b>3) <u>Dads feel especially “left out”</u></b></p> <p>Dads felt like professionals focused on mums, and did not give dads the support they needed.</p> <p><i>“If you’re a father the focus is on the mothers, not the fathers.”</i></p>



#### 4) We CAN be good parents!

Parents wanted to show that **people with learning disabilities can make good parents.**

*“Don’t let people tell you what you can’t do... just because you’ve got a learning disability, you can do lots of things.”*

Parents said it is important to know what help you need to be a good parent. They told other parents to **ask for help** if they needed.



*“If you need help, get help, because there’s help there. Don’t do it on your own. Go and see somebody, tell somebody.”*

But some parents did not have good support around them, even though they really needed it.

*“I begged everybody that I knew [to help]...and no one would, no one cared enough.”*



It was important to parents for professionals to **believe they could be good parents.**

*“[She] was the best social worker ever...she was the only ever children’s social worker that believed we could keep our children.”*

## 5) We WILL feel powerful!

After feeling let down or bullied by others, now **parents wanted to speak up for themselves and their rights as parents with learning disabilities.**

*"I speak up more for myself now than I used to...if you keep quiet that's when you get picked on."*

Parents felt like the difficulties they faced had made them **stronger.**

*"It's made us stronger. I can speak out more, and I encourage the other [parents] to do the same."*

Some parents started to **believe in themselves.**

*"I feel like I've took power back... I've got confidence now."*

**Parent peer support and self-advocacy groups** were important places where parents could share experiences, feel less lonely and to learn to trust people.

*"I didn't think there was no one else going through it...till I came to the group."*

*"Trust... I can tell them anything and they don't tell no one else, and that's how I like it."*

Parents wanted to **make things better** for other parents. They did this through speaking up, sharing their experiences with other parents and training professionals.

*"We go out...telling them our story...so they can get the right services."*







### How is the research being shared?

- Mind the Gap are sharing the amazing stories of parents with learning disabilities in lots of different ways through their theatre work.
- There is a book with more of the parents' stories in it.
- There are films of the interviews with parents that can be used to help train professionals.
- There is a longer research report available for researchers and professionals.

# Thank you!



Supported using public funding by  
**ARTS COUNCIL  
ENGLAND**

We want to say a **big thank you** to:

- All the parents who shared their stories
- The Elfrida Society Parents with Learning Disabilities peer support group for taking part and for their support to the research
- Other groups who took part in the research:
  - CHANGE
  - Bradford People First
  - Cloverleaf Advocacy
  - Geordie Mums
  - The Lawnmowers
  - WomenCentre, Mothers Apart Project
- The Mind the Gap team:
  - Daniel Foulds, Paul Wilshaw, Alison Short (Artists and Learning Disabled Researchers)
  - Lisa Mallaghan (Senior Producer)
  - Joyce Nga Yu Lee (Resident Director)
  - Mary Cooper (Writer and Researcher)
  - Emilie Flower (Film maker)
- Funding from the Wellcome Trust and Art Council England.

If you want to find out more about the research, please contact Kate Theodore on 01784 414303 or email [kate.theodore@rhul.ac.uk](mailto:kate.theodore@rhul.ac.uk) or you can find out more at Mind the Gap website [www.mind-the-gap.org.uk/daughters-of-fortune](http://www.mind-the-gap.org.uk/daughters-of-fortune)



**Daughters of Fortune:**  
**Stories of Parents with Learning Disabilities**  
**Research Easy Read Summary**  
*Easy Words*

Dr Kate Theodore & Laura Franklin

Researchers, Clinical Psychology, Royal Holloway University of London

A joint research project with Mind the Gap, learning disability theatre company.

*“They don’t think I can cope, because I have got a learning disability...  
it always came back to that.”*

**Background: Why did we do this research?**

- More people with learning disabilities are becoming parents. We don’t know how many parents with learning disabilities live in the UK.
- There is [good practice guidance](#) to help professionals to support learning disabled parents.
- But people with learning disabilities still face lots of difficulties when they become parents. They are still more likely to live apart from their children.
- We wanted to share more real stories of parents with learning disabilities with professionals and the public.



## **Research Method: What did we do?**

- We wanted to involve people with learning disabilities in this research as much as possible. This is called 'inclusive research'.
- Parents with learning disabilities were interviewed by learning disabled artists and researchers from Mind the Gap, with a writer and a film-maker who did not have learning disabilities.
- The interviews were recorded and written up word for word.
- University researchers read the stories over and over.
- Each parent has a different story, but there are also some things that are the same about the different stories. These are called 'themes'. The researchers looked for these themes in the different stories.
- This type of research is called 'Thematic Analysis' – this means looking carefully for the 'themes' or the bits of the stories that are the same.
- The university researchers worked with a learning disabled researcher from Mind the Gap and with parents with learning disabilities to check that the themes from the stories made sense for people with learning disabilities.
- We have written this research report about the themes from all the stories.

## **Results: What did we find out?**

### **Who took part in the research?**

- We interviewed 22 parents. There were 17 mums and 5 dads.
- The parents came from Greater London, Yorkshire and Tyneside.
- Parents were different ages. The youngest parents were in their 20s. The oldest parents were in their 60s.
- The 22 parents had 48 children altogether. Some children were young and some had grown up and were adults.
- 18 parents had some involvement from Children's Services.
- Some parents lived with their children and some lived apart. Sometimes this was the parents' own choice and sometimes it was not.
  - 16 parents lived apart from their children for some time or forever. They lived apart from their children for lots of different reasons.
  - 12 parents had been separated from some or all of their children through legal processes, for some time or forever.

## **Results: What did we find out?**

### **What were the research themes?**

There were **5 research themes**. These are some of the main things that we learnt from the parents' stories. Some of this is in the parents' own words

#### **1) Feeling Powerless**

Parents talked a lot about feeling **powerless**. They felt like other people had **put them down, bullied them or abused them**.

*"Special needs was not a nice thing to have... you get bullied no matter what you do, no matter where you go."*

*"It was good to start, but it did go downhill. He started beating us and stuff."*

Parents also felt like they had been **let down or tricked by professionals**. They **lost trust** in professionals.

*"I thought they were gonna help us, but I think they were just doing it to take the [child] off us..."*

*"Snakey, too snakey. And then they want to know why people with learning difficulties don't trust them... "*

Sometimes parents felt like other people treated them *"like a child"*.

These difficult experiences left parents feeling like **they could not speak up for themselves**.

*"People with learning disability, they're too frightened of speaking up. They daren't. They won't...or they can't do it on their own."*

## 2) People think we can't be good parents

Parents felt like professionals and others **assumed that people with learning disabilities can't be good parents.**

*"If you've got a learning disability you get judged you can't parent."*

Parents felt like they **had to prove they were good parents.** Parents felt like they had to be **even better than other parents** without learning disabilities. This felt **unfair.**

*"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."*

Parents felt like they **can't get it right**, however hard they tried to show they were good parents.

*"I couldn't do right for doing wrong."*

Sometimes parents **did not know** what they had to do to show they were good parents and to keep their children living with them. They felt confused and frustrated about this.

*"I did do what they told us to do and I still got wronged for it."*

Parents felt **"set up to fail"**.

Some parents **did not feel listened to** when they asked for help. Some did not feel they got the right support. Some only got support in a **"crisis"**.

*"They knew I was struggling, and I asked for their help and they wouldn't listen."*

Some parents felt like **prejudice or stigma towards people with learning disabilities** stopped parents getting more support.

*"We want to be parents like everybody else, but we're not having opportunities because of their attitudes and that needs to stop."*

### 3) **Dads feel especially “left out”.**

Dads felt like professionals focused on mums, and did not give dads the support they needed.

*“If you’re a father the focus is on the mothers, not the fathers.”*

### 4) **We CAN be good parents!**

Parents wanted to show that **people with learning disabilities can make good parents.**

*“Don’t let people tell you what you can’t do... just because you’ve got a learning disability, you can do lots of things.”*

Parents said it is important to know what help you need to be a good parent. They told other parents to **ask for help** if they needed.

*“If you need help, get help, because there’s help there. Don’t do it on your own. Go and see somebody, tell somebody”*

But some parents did not have good support around them, even though they really needed it.

*“I begged everybody that I knew [to help]...and no one would, no one cared enough.”*

It was important to parents for professionals to **believe they could be good parents.**

*“[She] was the best social worker ever...she was the only ever children’s social worker that believed we could keep our children.”*

## 5) **We WILL feel powerful!**

After feeling let down or bullied by others, now **parents wanted to speak up for themselves and their rights as parents with learning disabilities.**

*"I speak up more for myself now than I used to...if you keep quiet that's when you get picked on."*

Parents felt like the difficulties they faced had made them **stronger.**

*"It's made us stronger. I can speak out more, and I encourage the other mums to do the same."*

Some parents started to **believe in themselves.**

*"I feel like I've took power back...I've got confidence now."*

**Parent peer support and self-advocacy groups** were important places where parents could share experiences, feel less lonely and to learn to trust people.

*"I didn't think there was no one else going through it...till I came to the group."*

*"Trust... I can tell them anything and they don't tell no one else, and that's how I like it."*

Parents wanted to **make things better** for other parents. They did this through speaking up, sharing their experiences with other parents and training professionals.

*"We go out...telling them our story...so they can get the right services"*

**What will happen next with the research?**

- Mind the Gap have shared the stories of parents with learning disabilities in lots of their theatre work. This shares the amazing stories of parents with lots of people in different ways.
- There is a book with more of the parents' stories in it.
- We want to share some of the stories as films for training resources for professionals.
- A longer research report will be written for researchers and professionals.

We want to say a **big thank you** to:

- All the parents who shared their stories
- The Elfrida Society Parents with Learning Disabilities peer support group for taking part and for their support to the research
- Other groups who took part in the research:
  - CHANGE
  - Bradford People First
  - Cloverleaf Advocacy
  - Geordie Mums
  - The Lawnmowers
  - WomenCentre, Mothers Apart Project
- The Mind the Gap team:
  - Daniel Foulds, Paul Wilshaw, Alison Short (Artists and Learning Disabled Researchers)
  - Lisa Mallaghan (Senior Producer)
  - Joyce Nga Yu Lee (Resident Director)
  - Mary Cooper (Writer and Researcher)
  - Emilie Flower (Film maker)
- Funding from the Wellcome Trust.

**If you want to find out more about the research, please contact  
Kate Theodore on 01784 414303 or email [kate.theodore@rhul.ac.uk](mailto:kate.theodore@rhul.ac.uk)  
or you can find out more at Mind the Gap website  
<http://www.mind-the-gap.org.uk/projects/daughters-of-fortune/>**





# Daughters of Fortune:

## Stories of Parents with Learning Disabilities

### Research Report

Dr Kate Theodore, Senior Lecturer & Laura Franklin, Trainee Clinical Psychologist

Department of Clinical Psychology, Royal Holloway University of London

A joint research project with Mind the Gap, learning disability theatre company

Contact: [kate.theodore@rhul.ac.uk](mailto:kate.theodore@rhul.ac.uk)

*"If you've got a learning disability you get judged you can't parent"*

#### Abstract

The growing literature base exploring the experiences of parents with learning disabilities provides essential insight into the challenges they face, including a widely-held 'presumption of incompetence' within their network that places them under pressure to prove their parenting competence and worthiness. However, the conclusions that can be drawn from this research have been limited by a number of methodological issues; namely, a sampling bias toward parents with more severe disability or higher need, a general neglect of fathers' experiences, and inherent power disparities in the researcher-participant relationship. The current study therefore sought to address these limitations using an inclusive research methodology to explore the experiences of mothers and fathers who self-identify as having a learning disability, with a specific focus on what their experiences tell us about the operation of stigma in their lives. In a unique research collaboration with a learning disabled theatre company, semi-structured interviews with 17 mothers and 5 fathers with learning disabilities were led by learning disabled co-researchers and a writing mentor, and analysed inclusively using thematic analysis, with input from people with learning disabilities. Four main themes were generated in the analysis: (1) positions of powerlessness, (2) assumptions of incompetence, (3) challenging assumptions and proving competence, and (4) claiming power. An additional theme, relating to fathers' experiences of being excluded, emerged from the sub-group analysis of fathers. Parents reported experiencing stigma and disempowerment within their social and professional networks, yet despite this they continued to embrace their highly valued identity as a parent, and drew strength and belonging from their involvement with self-advocacy organisations. The study demonstrates the meaningful participation of learning disabled co-researchers in the research process, and the unique collaboration with the learning disabled theatre company enables dissemination of parents' experiences to a broader public and professional 'mainstream' audience with the aim of increasing awareness and reducing stigma.

**Key words:** parents, learning disabilities, intellectual disabilities, stigma, qualitative interviews, thematic analysis, self-advocacy.

## RESEARCH REPORT

### BACKGROUND

#### *Parents with learning disabilities*

With increasing recognition of the rights of people with learning disabilities<sup>1</sup> to live fulfilling and purposeful lives (McGaw, 1998), the number of those becoming parents has unsurprisingly grown (Emerson et al., 2005), and with it a small yet detailed literature on parents' experiences. Synthesis of research on individuals with learning disabilities is invariably hindered by the huge variation in how disability is defined (Schuengel et al., 2017). In parental literature this is further compounded by an almost exclusive focus on parents already known to disability or welfare services (Booth et al., 2005), which may bias the inclusion of parents with a higher level of disability and need (Emerson, 2011; Emerson et al., 2015). Recent studies employing secondary analyses of large population data-sets in an effort to identify the needs of the 'hidden majority' of parents with mild learning disability (Emerson, 2011), identify multiple disadvantages including significantly greater socioeconomic disadvantage, environmental adversity, poorer mental health, and less intergenerational support (Emerson et al., 2015; Llewellyn & Hindmarsh, 2015). Yet despite these challenges, research has suggested parents can and do offer 'good enough' parenting when appropriate support is in place (MacIntyre et al., 2019; Tarleton & Ward, 2007; Wade et al., 2008).

Although learning disabled parents may struggle with the demands of parenting without the provision of appropriate support, it has been suggested this is not causally related to cognitive ability per se (Llewellyn & Hindmarsh, 2015), but rather mediated by contextual factors including poor housing, social isolation and history of abuse (Schuengel et al., 2017). Nonetheless, parents with learning disabilities remain disproportionately likely to lose custody of their children (McGaw & Newman, 2005), with estimates suggesting that 40-60% of children born to parents with learning disabilities are removed from their care (Emerson et al., 2005). Described as an "almost systematic removal...for many years" (Sheerin, 1998, p.129), this appears to be the case not only in the UK, but internationally. The New York State Commission on Quality for the Mentally Disabled (1993, as cited in Booth, 2000) found that half of every family with a parent with learning disabilities had lost custody of a child at one time, whether temporarily or permanently, whilst a more recent study (McConnell et al., 2011) found that in Australia, the US, and England, parents with learning disabilities featured in 9%, 15% and 22% of child welfare court proceedings, respectively. Parents with learning disabilities are at higher risk than any other parents of losing custody of their children (Mayes & Llewellyn, 2009).

---

<sup>1</sup> People diagnosed with learning disabilities are described as having impairments in understanding new or complex information and learning new skills, which impacts on ability to cope independently; onset begins before adulthood and has a lasting effect on development (Department of Health, DoH, 2001). Also known as 'intellectual disabilities' in the wider literature, the terms 'learning disability' and 'learning disabled' have been used throughout this paper as the favoured terms of the co-researchers and reference groups involved with this study.

***Professional support for learning disabled parents***

Where specialist support services have been developed for parents, outcomes relating to parental custody have been particularly promising. For example, in an evaluation of the 'Valuing Parents Support Services' (VPSS), Tarleton and Porter (2012) found that the children of parents in receipt of specialist support were more likely to remain with their parents (78%), than a comparison group supported by mainstream children's services (24%). This suggests parents can adequately meet the needs of their children and maintain parental custody where adults' and children's services work together to provide appropriate, pro-active support based upon the principles of Good Practice Guidance (published by DoH & Department for Education and Skills, DfES, 2007; updated by the Working Together with Parents Network, WTPN, 2016). As the diagnosis of a learning disability is protected under the UK Equality Act (2010), services are required by law to make 'reasonable adjustments' to ensure equal opportunities for parents with learning disabilities; in line with this, guidance recommends programmes (whether offered by mainstream or specialist providers) should "be adapted to meet the particular learning needs of the parents concerned" (WTPN, 2016, p.16). The guidelines outline clear, accessible features of good practice, including the need for long-term support where necessary, to support professionals to provide an equitable service to learning disabled parents and their children.

Despite advances in policy, legal provisions and non-statutory guidelines, there remain concerns that these principles are not being consistently applied. As research interest moved away from parental adequacy and evaluation of training interventions toward more of a focus on the contextual factors that support or hinder parenting, attention turned to understanding parents' lived experiences (Llewellyn et al., 2008). Largely focussing on the experiences of mothers, this small yet growing literature base has provided a rich insight into the unique experiences of these parents, and has consistently highlighted parents' perceptions of negative attitudes, opposition and presumptions of incompetence within their social and professional networks (Booth & Booth, 2005; Gould & Dodd, 2014; Malouf et al., 2017). Further, studies of parents subject to child protection and care proceedings have repeatedly found that parents experience the process as confusing and unjust (Llewellyn et al., 2010), and are left feeling unclear as to the reasons for the removal of their child from their care (Baum & Burns, 2007; Gould & Dodd, 2014). Whilst some parents have reported a perception of being denied crucial support from services (Baum & Burns, 2007; Malouf et al., 2017), others have shared their reluctance to engage with services and professionals for fear of their children being removed (Ward & Tarleton, 2007). Where parents refuse to engage with children's services, it's been suggested that a vicious cycle may ensue whereby services become even more concerned about parenting competence and thus the risk of child removals heightens (Jamieson et al., 2016; Traustadottir & Sigurjonsdottir, 2010; Ward & Tarleton, 2007). Although parents' individual experiences vary, it is apparent in the literature that services are not routinely and consistently adapting their practice to meet the needs of these parents or the standards set by good practice guidelines (Theodore et al., 2018), which may go some way to explaining why parents remain at increased risk of losing custody of their children despite involvement with support services.

Parents with learning disabilities are frequently labelled as non-cooperative and difficult to engage (McConnell et al., 2011), yet in order for support to be effective, it must be offered in a way that is acceptable to the parent (James, 2004). Given the higher likelihood of a small or non-existent informal support network amongst parents with learning disabilities (Llewellyn & McConnell, 2002), it is especially important to understand how professionals may serve to promote or impede parents' acceptance of support. Tucker and Johnson's (1989) model of competence-promoting and

competence-inhibiting support for parents with learning disabilities proposes that the mere provision of support alone is not sufficient to promote parenting competence, but rather that the nature of the support provided is key. Specifically, they posit that where supporters assume the parent has the potential and capability to acquire the necessary skills to parent, support is offered in a 'competence-promoting' manner that encourages the parent to feel self-sufficient and competent. Competence-inhibiting support, conversely, assumes parental incompetence and is underlined by a belief that extensive intervention will be necessary for the sake of the child (Tucker & Johnson, 1989).

A study by Mayes et al. (2008) found that expectant mothers with learning disabilities actively negotiated social networks to include those who recognised their central importance in their child's life, and would distance themselves from those who they felt would try to usurp their central role. However, many parents with learning disabilities remain socially isolated and dependent on professionals as their sole source of support (Llewellyn & McConnell, 2002); in these instances parents have little power to choose or negotiate the support offered, and attempts to distance themselves from disempowering support can be seen by services as an indication that parenting will not improve (Booth & Booth, 2004; Willems et al., 2007).

### ***Learning disability and stigma***

Despite global and national policies aimed at increasing social inclusion, independence, and empowerment in recent years, people with learning disabilities remain a highly stigmatised group (Scior, 2011). Stigma is defined as the "process by which certain groups...are marginalised and devalued by society because their values, characteristics or practices differ from the dominant cultural group" (Ali et al., 2012, p.212), and typically involves the co-occurrence of labelling, stereotyping and prejudice, leading to a loss of status and discrimination (Link & Phelan, 2001). Importantly, Scior (2016) points out that "for stigmatisation to occur, power must be exercised" (p.5); that is, the subjugation of people with learning disabilities as a social group is maintained by the disempowerment felt by having one's access to rights, resources and opportunities determined by 'powerful others' in the social hierarchy. Scior (2016) identified three components of stigma: (a) cognitive (what 'powerful others' think about people with learning disabilities); (b) emotional (what they feel toward them); and (c) behavioural (how they act toward them). The degree to which individuals with learning disabilities recognise and identify with the label of being 'learning disabled' remains contested in the research literature (Ali et al., 2012). However, there is a general consensus that the majority demonstrate some awareness of their stigmatised status (Logeswaran et al., 2019), expressing feelings of difference and rejection (Monteleone & Forrester-Jones, 2017) that can impact negatively on self-esteem and sense of belonging (Forrester-Jones et al., 2006).

### ***Parenting, learning disability, and stigma***

Although it appears that no studies have specifically focussed on experiences of stigma in parents with learning disabilities, the growing literature base exploring the qualitative experiences of these parents consistently highlights the scrutiny and opposition they routinely face from those in their social and professional network, representing a widely-held 'presumption of incompetence' that places undue pressure on parents to prove their parenting abilities and 'worthiness' above that expected within the non-learning disabled population (Booth, 2000; Gould & Dodd, 2014; Murphy &

Feldman, 2002). In a review of child custody removal cases in Iceland between 2002 and 2014, Sigurjonsdottir and Rice (2016) detected discriminatory practices throughout the process, and highlighted two key assumptions on the part of professionals that they felt resonated with the wider international literature: (a) interpreting a diagnosis of a learning disability as evidence of incompetent parenting in and of itself; and, (b) assuming parents with learning disabilities could not benefit from support, education and training. They suggested that despite progression in policies, anxieties may nonetheless be rooted in older eugenic concerns that continue to (possibly unconsciously) shape the prism through which the reproductive rights of people with learning disabilities are viewed. Indeed, although the governance of sexuality and reproductive rights using sterilisation has notably declined in recent decades (Hamilton, 2015), parents with learning disabilities still continue to face strong opposition and disapproval from family and professional networks when disclosing pregnancies (Aunos & Feldman, 2002; McConnell & Strike, 2002).

Emerging research exploring how mothers and fathers with learning disabilities adopt and value their parental role suggests becoming a parent represents a highly desirable identity (Shewan et al., 2014; Mayes et al., 2011), offering a much-valued 'adult' status (Booth & Booth, 1994) that acts as a rebuttal against the "enforced primary identity" of being learning disabled (Edmonds, 2000, p.21). It has been suggested, however, that where this comes under threat, such as when children are removed from a parent's care (Edgerton, 1967), or where the parent identity is 'attacked' through opposition, scrutiny and presumptions of incompetence (Edmonds, 2000; McConnell & Strike, 2002), this may act to negate the positive self-evaluation associated with the parental role, and further emphasise the stigmatised status of being 'learning disabled'. Crucially, this can lead to an increased vulnerability to psychological distress and a rejection of the perceived 'attacker' (Edmonds, 2000), which has important implications where the individuals and systems being rejected are the very services designed to provide parents with support.

### ***Support network of learning disabled parents***

Although the literature base has largely focussed on the experiences of learning disabled mothers, thus limiting understanding of parents' experiences more generally, these studies nonetheless offer valuable insight. Research examining the role of social networks in supporting learning disabled mothers found that where mothers received practical support from formal services, they remained dependent on non-learning disabled family members to negotiate with the service providers, advocate for them, and protect them from professionals' negative attitudes and power to remove their children (Traustadottir & Sigurjonsdottir, 2008). Similarly, in a study exploring how women with learning disabilities assume the 'mother identity', Mayes et al. (2011) found that mothers often align themselves with a key 'ally' in their social network who they can trust to advocate for them without usurping their position as the central figure in their baby's life. Taken together, these findings suggest that in order to be appropriately supported and accepted in their parental role, learning disabled mothers remain reliant upon the support of non-learning disabled allies who hold stronger positions of power relative to themselves, highlighting the inherent power imbalance between mothers and those in their network.

Research indicates, however, that the degree of support provided by families varies; the mere presence of a social network does not guarantee support received will be helpful (Stenfert-Kroese et al., 2002), and can even inhibit parenting when offered in a manner that assumes parental incompetence (Tucker & Johnson, 1989). Indeed, in a recent exploration of the involvement of

grandparents where a parent has a learning disability, it was found that attitudes ranged widely from “strong resistance to vigorous encouragement” (Gur & Stein, 2019, p.7), and in some cases involvement was described as excessive and overbearing, thereby undermining the parent’s role. Further, parents with learning disabilities are often socially isolated (Schuengel et al., 2017) and excluded within their communities (Llewellyn & McConnell, 2002), and thus may be entirely reliant on the professional network for support. Given perceptions of parental incompetence may directly affect the nature of the support provided to the parent and child (Tucker & Johnson, 1989), it will therefore be essential to understand how stigma and prejudice operate within parents’ social, professional and societal networks, and specifically exploration of whether this prevents parents from accessing appropriate support to enable them to develop the competence to fulfil their valued parental role.

### ***Limitations of existing research literature***

Although the growing literature base exploring the experiences of parents with learning disabilities has helped to provide essential insight into the challenges these parents face, the conclusions that can be drawn from these studies have been severely limited by a number of methodological issues (Emerson et al., 2015).

Firstly, the majority of studies have relied on samples already known to services (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008), raising concerns of bias toward inclusion of parents with a higher degree of disability and/or need, and thus neglecting the ‘hidden majority’ of parents who are likely to have mild or borderline learning disabilities (Emerson, 2011). This makes it especially difficult to synthesise the research evidence to date, given the varied and often unclear definitions of learning disability applied, and limits the generalisability of the findings, possibly leading to an overestimation of the impact that having a learning disability has upon parental competence and child outcomes (Emerson et al., 2015).

Secondly, the almost exclusive focus on mothers neglects the experiences of learning disabled fathers. Their absence in the literature, with the exception of a few notable studies in recent years (Dugdale & Symonds, 2017; Shewan et al., 2014), reflects an ‘invisibility’ that is simultaneously mirrored in the caseloads of social care services, highlighting gaps in service provision (Dugdale & Symonds, 2017).

Thirdly, despite purporting to redistribute power through the co-construction of knowledge (Ebbs, 1996), power imbalances between the researcher and ‘researched’ remain inherent in qualitative research (Raheim et al., 2016). Given the multiple disadvantages faced by parents with learning disabilities (Emerson et al., 2015), and the sense of powerlessness felt by those who have undergone formal involvement of social care services (Gould & Dodd, 2014; Llewellyn et al., 2010), there is a risk power differentials may have been amplified when interviews have been conducted by ‘powerful’ professionals associated with health and social care services, possibly limiting parents’ ability or willingness to speak openly and honestly. There have been calls for increased research participation of people with learning disabilities (Beail & Williams, 2014; Ditchman et al., 2016), involving “people who may otherwise be seen as subjects for the research as instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users” (Walmsley & Johnson, 2003, p.10); however, inclusive methodologies have not yet been extensively employed in research with learning disabled parents.



## Current study

The idea for this innovative collaboration between arts and academic research, 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 learning disabled parent-to-be known to the theatre company, who was undergoing a parenting assessment, and facing some of the challenges outlined as above in the literature. 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.

Initially, Mind the Gap secured preliminary funding to recruit an academic researcher to support the research element of the project. This resulted initially in eight learning disabled parents being interviewed and their data included in a qualitative thematic analysis, which was the subject of the first research phase (Theodore et al., 2018). Following this, funding was secured to extend the research. The current report outlines this next phase of the extended research project.

The present study therefore aimed to address gaps in the literature by extending the data collection and analysis of Theodore et al.'s (2018) preliminary research on the experiences of parents with learning disabilities, with a specific focus on what their experiences tell us about the operation of stigma in their lives. In addition to this novel research question, the study aimed to enhance understanding of the needs and experiences of this vulnerable population more generally by addressing aforementioned methodological limitations in the existing literature. Specifically, in line with recent calls from the WTPN (2016) for more research concerning the needs and experiences of learning disabled parents who are not in contact with social care services, the study recruited on the basis of participants self-identifying as having a learning disability through connection with non-statutory organisations (such as self-advocacy groups for parents with learning disabilities), in an effort to represent the 'hidden majority' (Emerson, 2011) of parents who may otherwise be neglected in the research literature. Secondly, the study sought to share the perspectives of both mothers and fathers, representing a large, heterogeneous sample of parents that represent a broader range of experiences than those in the existing literature. Finally, in line with recent calls for more inclusive participation (Beail & Williams, 2014), the study involved learning disabled co-researchers in the design, data collection, analysis and dissemination of the research (Walmsley & Johnson, 2003), in an effort to partly redress the traditional power hierarchies inherent in qualitative research with parents with learning disabilities, and benefit from the knowledge and expertise of those with lived experience (Nind, 2017).

By exploring what parents' experiences tell us about the operation of stigma in their lives, the study aimed to inform advances in clinical practice, staff training and service provision. The research therefore formed part of a broader creative project which employed inclusive methodology to collate and share parents' stories, with broader aims to reduce societal stigma and increase progressive attitudes towards the parenting rights of those with learning disabilities through improved awareness of their experiences. The research has therefore 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', including a photo book combining images of the parents with artistic responses such as extracts, poems and short stories, and a series of training films; and 'Zara', a large-scale outdoor theatre which reached large audiences in London, Halifax and online (Mind the Gap, 2020).

## **METHOD**

### **Design**

The study used a cross-sectional qualitative design, employing an inclusive research methodology involving the participation of learning disabled co-researchers. Qualitative interviews have been established as an effective means of exploring learning disabled parents' experiences and perspectives of parenthood, offering a crucial 'counterweight' (p. 169) to earlier literature that drew exclusively on professionals' interpretations (Booth & Booth, 1994). The study was conducted within a critical-realist framework, acknowledging the way individuals make sense of their experiences within the context of broader socio-cultural factors (Clarke, Braun & Hayfield, 2015).

### **Ethical Approval**

Ethical approval was obtained from Royal Holloway University of London College Ethics Committee, including an amendment to extend the original study of eight participants, using the same materials and procedures. 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, who were parents, and living in the community. All 22 participants were deemed to demonstrate mental capacity to give informed consent to participate. Participants were identified through seven different self-advocacy groups for parents with learning disabilities across the UK (namely Yorkshire, Tyneside and Greater London), and were recruited through opportunistic sampling.

Unlike many previous studies of parents with learning disabilities (Gould & Dodd, 2014; Shewan et al., 2014), inclusion criteria did not stipulate a need for participants to be in receipt of, or eligible for, specialist adult social care services. Given most parents with learning disabilities are likely to have mild or borderline learning disabilities, and thus are less likely to be known to adult services unless they present with complex needs (Emerson et al., 2015), participants were recruited on the basis of self-identifying as having a learning disability and being connected with non-statutory learning disability organisations (such as self-advocacy groups for parents with learning disabilities). In line with recent calls for more research concerning the needs and experiences of learning disabled parents who are not in contact with social care (WTPN, 2016), it was hoped the sample would more likely represent the 'hidden majority' (Emerson, 2011) of parents with less severe learning disabilities who may otherwise be neglected in the research literature; this seemed borne out in the participants ultimately recruited, the vast majority of whom lived independently.

The sample represents a relatively 'large' sample size comparative to other studies in the research literature on parents with learning disabilities, in an attempt to capture a heterogeneous sample of parents with a broad range of experiences. Notably, the sample included a variation in gender (17 mothers and 5 fathers), age (ranging from 26 to 61 at the time of interview) and child arrangements. The 22 parents shared 48 children in total, with children's ages spanning from 1 to 33 years old. In total, 18 parents reported some involvement from children's services, often in relation to Child Protection proceedings or formal parenting assessments, and 12 parents reported temporary or permanent enforced separation from one or more child at some time. The research team collectively agreed following the 22<sup>nd</sup> participant that data saturation had been reached, and recruitment was ended.

Table 1 summarises demographic and parenting details, where known. Pseudonyms have been assigned and limited personal characteristics detailed for the purpose of maintaining anonymity.

<b>Pseudonym</b>	<b>Gender</b>	<b>Age</b>	<b>Ethnicity</b>	<b>Children (ages)</b>	<b>Parents' living arrangements</b>	<b>Children's' contact arrangements</b>	<b>Children's Services Involvement</b>
Megan	Female	26	White British	1 (aged 1)	Independent	Living together	N
Kimberly	Female	31	White British	1 (aged 2)	Independent	Living together	Y
Helen	Female	36	White British	3 (aged 8-12)	Independent	Living together	Y
Kelly	Female	40	White British	1 (aged 18)	Independent	Living together	Y
Carol	Female	55	White British	2 (aged 22 & 33)	Independent	Living together	Y
Jill	Female	61	White British	1 (aged 23)	Independent	Living together	Y
Marie	Female	53	Black British	6 (ages unknown, 2 under 18)	Independent	Under 18s living together (previously fostered)	Y
Fatima	Female	51	Indian	4 (aged 13-31)	Independent	Under 18 living together (previously fostered)	Y
Jenny	Female	43	White British	2 (aged 17 & 20)	Independent	One living together, one living in specialist housing; regular contact	N
Denise	Female	60	White British	1 (aged 23)	Independent	Living apart; regular contact (previously fostered)	Y
Khalil	Male	35	British Pakistani	3 (aged 6-15)	Semi-independent	Living separately from father; supervised contact	Y

Rick	Male	43	White British	1 (aged 1)	Independent	Living separately from father; regular contact	N
Neil	Male	44	White British	3 (aged 14-25)	Independent	Living separately from father; contact with adult children	N
Mike	Male	48	Black British/ Caribbean	4 (aged 16-29)	Independent	Living separately from father; contact unclear	Y
Amy	Female	43	White British	2 (14 & 17)	Independent	One child adopted, one child fostered; limited contact	Y
Linda	Female	-	White British	3 (ages unknown, youngest 24)	Independent	One adopted, two fostered; no contact	Y
Dawn	Female	42	White British	3 (aged 10-20)	Independent	Two fostered, one adopted; contact with eldest two, postal contact with youngest	Y
Rachel	Female	26	White British	2 (3 & 9 months)	Independent	Both adopted; postal contact with adoptive parents	Y
Alison	Female	-	White British	1 (aged 3)	Independent	Adopted; postal contact with adoptive parents	Y
Patrick	Male	-	White British	2 (aged 3 & 19)	Independent	Adopted; postal contact with adoptive parents	Y
Jessica	Female	29	Mixed White and Black Caribbean	1 (aged 7)	Independent	Adopted; no contact	Y
Julie	Female	-	White British	1 (unknown, under 18)	Independent	Adopted; no contact	Y



## Interviews

It was planned that participants would be interviewed by a learning disabled researcher with the support of a 'writing mentor' (a non-learning disabled writer working with Mind the Gap), in the hope of redressing potential power differentials and thus supporting parents to speak honestly and openly about their experiences. This was also in line with the inclusive 'participatory methodology' (Bergold & Thomas, 2012) of the research project as a whole.

An interview guide (see Appendix 1) 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 guide 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 participants' varied experiences.

Parents were interviewed individually by a small research team from Mind the Gap, consisting of a learning disabled researcher (hitherto referred to as 'co-researcher'), the writing mentor (MC), and where appropriate, a film-maker (EF) (for the artistic outputs). Participants were interviewed individually due to the sensitive nature of the topic and the heterogeneity of the sample. In total, three learning disabled co-researchers were involved in the interviews, although one co-researcher (DF) was most prominently involved in the recruitment, interviews, analysis and dissemination, in his role as a research intern on the project. All but 3 of the interviews were co-facilitated by a co-researcher; these 3 interviews took place in a women's centre and thus it was felt inappropriate to have a male co-researcher physically present.

## Procedure

Mind the Gap actively approached self-advocacy groups for parents with learning disabilities, and attended group sessions to introduce the organisation and outline the aims of the project. If a parent expressed an interest in participating, the co-researcher and writing mentor then met with the parent for an initial introduction, to talk through the information sheet outlining the project and consent form in greater detail. Interviews typically took place at a later date, involving reiteration of the consent and confidentiality procedures. After the initial interview, a narrative account was written up by the writing mentor and co-researcher and shared with the participant at a later meeting, to reaffirm their informed consent and ensure they were happy with the information they had shared in the interview. Participants also completed a brief demographics questionnaire including questions related to gender, age, ethnicity, number of children and their ages, and their own and their children's living arrangements. It was emphasised that participants were free to withdraw from any element of the project at any time. Participants met with the research team for

at least three meetings (some more), supporting the development of a strong working relationship between the interviewer and interviewees and affirmation of informed consent to participate. All participants consented to audio recording and transcription of the interviews for the purpose of this research.

As there were usually at least three meetings with each participant, there was potential for information to be included in the research data from more than one recording for each participant. In practice however, there was usually one substantive interview for each participant (average length of this was 51 minutes, ranging from 16–97 minutes). At additional meetings between the research team and participants, where additional interviews were recorded with the participants' consent, these were reviewed by the academic researchers and where appropriate transcribed for inclusion in the analysis.

As aforementioned, a narrative account of the interview content, using participants' own words, was written up by the writing mentor and co-researcher following each interview, for the purposes of sharing this with the participant at a later date to ensure they were fully aware of information they had shared, and to affirm their consent to be included in both the creative and research processes; elements of these narrative accounts were also used in creative outputs. Once participants had affirmed their consent to be included in the research, interview audio recordings were transcribed verbatim for the purposes of the research analysis.

## **Analysis**

Thematic analysis (TA) was chosen as it seeks to describe patterns across the data (Braun & Clarke, 2006), allows for analysis of larger, heterogeneous samples, and has been successfully employed in previous studies involving the participation of learning disabled co-researchers (Stevenson, 2014; O'Brien, McConkey & Garcia-Iriarte, 2014; Beail & Williams, 2014). Thematic analysis' theoretical flexibility was also compatible with the critical-realist and inductive frameworks of the study (Clarke & Braun, 2013).

An inductive, bottom-up analysis was conducted to ensure generated themes were driven by the data (Braun & Clarke, 2006). Braun and Clarke's (2006) six-phase method of thematic analysis was followed to ensure analytic rigour: (a) familiarisation with the data was facilitated through repeatedly listening to the audio files, listening whilst reading the verbatim transcripts, and then noting initial thoughts whilst re-reading the transcripts (particular emphasis was placed on this stage given the academic researchers had not conducted the interviews); (b) each transcript was then inductively coded line-by-line using NVivo computer software; (c) codes were collated across the transcripts and clustered to generate preliminary 'themes'; (d) candidate themes and sub-themes (including the candidate thematic map) were reviewed and refined at the level of coded data excerpts and the full transcripts to ensure they accurately reflected the data-set; (e) themes and subthemes were defined; and (f) themes and extracts were written up in an analytic narrative.

## **Methodological integrity**

Quality of analysis was maintained through adherence to published guidelines for qualitative research (Elliot, Fischer, & Rennie, 1999): (a) owning one's perspective through disclosure of the

author's position and assumptions, use of reflective journal, and reflective discussions with the research team; (b) situating the sample using anonymised participant demographic information (see table 1); (c) use of quotations to illustrate how themes are grounded in the data (see Results section); and (d) use of multiple credibility checks at various points in the analytic process to ensure credibility of the interpretation. Further detail regarding (a) and (d) specifically is provided in the sections below.

### **Inclusive Participatory Research Processes and Credibility Checks**

Throughout the entire process, from initial immersion through to final write-up of themes, the analysis was discussed and continuously reviewed within the 'academic' research team. The analysis was also discussed and reviewed with the wider research team, including the co-researcher and writing mentor, at multiple time-points throughout the analysis (including immersion, initial stages of coding, generation of 'preliminary themes' and defining themes). This allowed for the review and refinement of codes and emerging themes, and ongoing reflections relating to the positions, assumptions and perspectives of those within the research team.

The inclusive participatory research methodology (Walmsely et al., 2017) ensured that multiple credibility checks occurred throughout the research process, as outlined here. Prior to conducting an initial credibility check, the academic researchers introduced the co-researcher and writing mentor to the method of thematic analysis and supported them to code a short portion of a transcript. A transcript was then selected, and the wider research team (i.e. academic researchers, co-researcher, and writing mentor) each independently coded this transcript, before meeting together to compare and discuss codes and interpretations. Interpretational similarities and discrepancies were explored, and ideas and learning points were taken forward to inform the academic researchers' coding of further transcripts. As the analysis progressed, codes and preliminary themes were reviewed within the academic research team.

A second formal credibility check then took place during the fourth phase of the analysis (Braun & Clarke, 2003), whereby the preliminary themes (as generated by the academic researchers) were presented, reviewed and discussed with the academic researchers, co-researcher and writing mentor. Some subtle adjustments to the language and interpretation of the themes were made (including greater emphasis on the social-cultural context of the parents' lives), and ideas from the meeting were used to support the ongoing refinement of the themes.

A further credibility check then took place with a learning disabled parents peer support group, who were presented with an easy-read summary of the main emerging themes and subthemes from the analysis. The reference group, which consisted of some parents who had been interviewed for the research and some who had not, all fed back a strong resonance with each of the themes presented. Considerations and feedback from the group were incorporated into the final analysis, write-up and discussion of the results.

Following completion of the study, an easy-read summary was developed in consultation with a self-advocacy organisation to ensure it would be largely accessible and acceptable to a learning disabled audience. To try to meet communication needs and preferences of a broad range of people with learning disabilities, two versions of this easy-read summary were ultimately developed; both used the same words, but one included PhotoSymbols pictures and one did not (see pages 5 - 21 of this report for easy read summaries).

## 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. Of the academic researchers, one (KT) 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, and currently, alongside her academic role, working clinically in a community team supporting people with learning disabilities. The other academic researcher (LF), not a parent herself, is a trainee clinical psychologist with a long-standing interest in parenting and attachment professionally, who during the research was working clinically in a community perinatal mental health team, and who had previous experience of working in a community team for people with 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 Thematic Analysis generated four substantive themes. There was also an additional theme generated from a subgroup analysis of the fathers within the sample. These five themes (comprising of 15 subthemes) are outlined below, followed by the thematic map which represents an interpretation of how these themes may relate to each other in this dataset.

Table 2 shows how the 22 participants contributed to the themes and subthemes. Additional illustrative quotes are presented in Appendix 2.

Theme	Subtheme	Contributing participants																						
		Kelly	Rachel	Marie	Helen	Mike	Khalil	Jenny	Rick	Kimberly	Amy	Neil	Denise	Linda	Julie	Dawn	Alison	Patrick	Carol	Jill	Fatima	Jessica	Megan	
Positions of powerlessness	Early experiences of powerlessness		✓	✓	✓						✓	✓		✓	✓	✓	✓	✓	✓		✓	✓	✓	
	Feeling betrayed by powerful others		✓	✓	✓	✓					✓	✓		✓	✓	✓	✓	✓	✓			✓		
	Abuse of trust in intimate relationships	✓	✓	✓	✓			✓	✓		✓	✓	✓	✓	✓	✓	✓				✓	✓		
	Denied a voice		✓	✓	✓	✓					✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Assumptions of incompetence	Presumed parental inadequacy		✓	✓	✓	✓		✓		✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓		
	Onus on parents to prove competence	✓	✓	✓	✓	✓				✓	✓	✓	✓	✓		✓	✓	✓	✓	✓		✓		
	Unreachable and elusive standards and expectations		✓	✓	✓	✓				✓	✓			✓		✓	✓	✓		✓		✓		
	Set up to fail: denied opportunities and support				✓	✓	✓				✓	✓	✓	✓	✓	✓	✓	✓				✓		
Challenging assumptions and proving competence	Rejecting stigma and beating the system	✓			✓	✓	✓	✓		✓	✓	✓				✓			✓	✓	✓			
	Getting ready to be a parent							✓	✓	✓	✓	✓							✓	✓	✓			
	Acknowledging support needs	✓	✓	✓	✓			✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	
	Qualities of the support network	✓	✓	✓				✓			✓	✓				✓			✓	✓	✓		✓	
Claiming power	Finding a voice	✓	✓	✓	✓	✓		✓		✓	✓	✓		✓	✓			✓	✓	✓	✓			
	Empowerment	✓	✓	✓	✓	✓	✓			✓	✓	✓		✓	✓	✓	✓		✓	✓	✓	✓		
	Mobilising change		✓			✓	✓	✓			✓	✓			✓	✓			✓			✓		
Sub-group analysis: Fathers' experiences of being excluded		-	-	-	-	✓		-	✓	-	-	✓	-	-	-	-	-	✓	-	-	-	-	-	

Table 2: Themes, Sub-themes and Contributing participants

**Theme 1: Positions of powerlessness**

Parents shared their experiences of being in persistent, and often inescapable, positions of powerlessness throughout various points in their lives. This imbalance of power existed relationally, with parents often being involuntarily placed in a 'lesser' position by a range of individuals, including partners, families and professionals.

For many parents, this appeared to extend beyond a layer of powerlessness associated purely with their learning disability, touching upon a more pervasive sense of vulnerability associated with the intersectionality of social class, poverty, gender, ethnicity, and physical disability.

***Subtheme 1: Early experiences of powerlessness***

Parents consistently shared examples of operations of power during their earlier years that placed them in a 'powerless' position. Although the exact nature and severity of these experiences varied between individuals, a consequent sense of disempowerment was shared by all. Some spoke about the lack of prospects that powerful others (e.g. teachers) had held for them, leaving them with the sense they weren't expected to 'achieve' in life.

"She [teacher] kept putting me down all the time, you know, you're not going to do too well and that" (Megan)

Others spoke of family over-protecting them, and how this severely restricted their sense of independence and self-efficacy as they approached adulthood, despite positive intentions.

"I didn't know how to do it because my brother did everything for me" (Neil)

Parents spoke of the bullying they'd endured throughout their early life, often directly attributing this to their learning disability. For many, this represented the beginning of a repeating pattern of stigmatisation and victimisation on the basis of perceived difference and vulnerability.

"Special needs was not a nice thing to have. I mean, you get bullied no matter what you do, no matter where you go" (Dawn)

Early traumas were prominent in many of the parents' lives. Whilst seven parents explicitly shared their experiences of physical, emotional and sexual abuse growing up, others shared more implicit suggestions of trauma through their description of growing up in potentially toxic and neglectful environments, often featuring domestic abuse, parental mental ill-health and substance misuse. Some shared how despite their experiences of abuse being known within the immediate or wider system, they were not afforded safety or protection.

" She [mum] tried her hardest to protect me from my dad...but at that time, erm, people didn't leave their husbands like that" (Carol)

### ***Subtheme 2: Abuse of trust in intimate relationships***

Many parents shared how their trust had been abused within intimate relationships, most notably through being subjected to emotional and/or physical abuse by current or past partners. This was often a gradual process, with partners initially appearing supportive, before shifting toward abusive behaviours once the relationship was more established.

"It was good to start, but it did go downhill. He started beating us and stuff" (Linda)

Whilst specific experiences of abuse varied, underlying their partners' behaviours often appeared to be an intention to isolate or undermine them. For some, this took the form of coercive and controlling behaviours, whilst others shared their experiences of being consistently put-down. A number of parents also shared experiences of their children being used against them.

"I wasn't allowed to go out with my friends...I wasn't allowed to wear dresses nowhere" (Dawn)

"She always used the kids like a weapon against me to get her own way" (Neil)

Parents also spoke of feeling victimised by their children, where they presented with additional needs or challenging behaviours, having imitated behaviours they had observed from the abusive parent.

"She does copy...She says a lot of things what he says to me " (Kelly)

In all instances of abuse, there was a clear sense of powerlessness associated with the subjugation and victimisation they faced from their partners, which for many served as a continuation of earlier experiences of relationships. Some women described repeated experiences of abuse or exploitation in relationships, suggesting heightened and pervasive vulnerability.

"Back then I didn't know anything about getting into a relationship, how dangerous it is" (Rachel)

### ***Subtheme 3: Feeling 'betrayed' by powerful others***

Parents spoke of feeling betrayed and deceived by professionals, particularly where children had been removed from their care following parenting assessments. Parents expressed feeling 'tricked' by the system and surprised by the outcomes, highlighting possible issues with the way in which the

process and expectations of the assessment, including potential results and consequences, had been communicated to and understood by the parents (see also theme 2, subtheme 3).

"I still believed what the social worker said, once I'd done all the assessments I can have my son home. But she lied to get what she wanted" (Jessica)

"I thought they were gonna help us, but I think they were just doing it to take the bairn off us to tell you the truth" (Alison)

Parents spoke of how their trust in professionals had been broken after outcomes did not match expectations. This not only led to a breakdown in their relationships with professionals, but more enduring difficulties with developing trust, with a number of parents disclosing difficulties with letting people 'in' and feeling emotionally guarded and suspicious of professionals' intentions.

"Snakey, too snakey. And then they want to know why people with learning difficulties don't trust them..." (Mike)

"She just sat there befriending, betraying. But I was stupid to think that I could trust her" (Jessica)

Despite some parents sharing their negative perceptions of social care professionals as "child snatchers" (Neil), others spoke of how they'd initially trusted professionals, and in doing so had been open about their own adverse early experiences. However, some parents spoke of how they perceived professionals as using this information 'against' them in parenting assessments.

"I was honest with them...It was like it was used against us. Just because [relative]'s done that me doesn't mean I'm going to do it to me little boy" (Alison)

#### ***Subtheme 4: Denied a voice***

Some parents shared their difficulties finding a voice, often relying on other, non-learning disabled people to speak up for them. Whilst it was difficult to elicit quite why this was so difficult for parents, there was a sense that historically they had not been given a platform or opportunity to do so. Some parents shared their sense of feeling victimised and identified as an "easy target" (Marie) as a consequence of feeling unable to assert themselves.

"People with learning disability, they're too frightened of speaking up. They daren't. They won't...or they can't do it on their own" (Jill)



Many parents shared perceptions of being spoken down to and treated “like a child” (Jill). This was particularly prominent where professionals from multiple services were involved, with parents sharing their experiences of feeling largely ignored and then patronised when spoken to, indicating a sense that the significance and centrality of the parents’ role was often lost in the child protection/safeguarding process.

"Social Services talked to them [other professionals] more than they talked to me...when they did talk, they treat us like a two-year-old, talking down to us..." (Dawn)

One parent shared the difficulties those with learning disabilities face when they attempt to stand up for their rights, suggesting they are perceived and responded to differently to those without disabilities.

"[If] you're able-bodied, you'll be standing up making up a lot of noise...but for somebody who has a learning disability... guess what they would be classed as? A trouble-maker" (Mike)

## **Theme 2: Assumptions of incompetence**

"They don't think I can cope, because I have got a learning disability...it always came back to that" (Marie)

Parents described their experiences of those without learning disabilities (predominantly professionals) presuming they would not be competent parents. Parents felt they were regarded differently to those without learning disabilities, resulting in learning disabled parents facing unique pressures to prove competence in the face of what they felt were unreasonable expectations.

Whilst the root of professionals’ assumptions and anxieties must also be contextualised within the complexity of many of the parents’ broader social contexts and vulnerabilities, it was apparent that the parents themselves interpreted others’ assumptions and judgements as directly attributable to prejudices associated with their learning disability.

### ***Subtheme 1: Presumed parental inadequacy***

Parents shared the messages they’d received that parenthood was an unattainable prospect for them as a result of their learning disability. Despite many parents sharing long-held desires for parenthood, some were actively discouraged from seeing through their pregnancy.

"The doctors didn't really want me to have the baby, with me having a learning disability"  
(Carol)

Understandably, some parents appeared to internalise these stigmatising messages, expressing concerns prior to becoming a parent that they wouldn't be "good enough" (Neil) and expressing surprise when they found they were able to cope.

"I was surprised at myself when I did it...all through me childhood I got told I couldn't cope with a child" (Dawn)

Parents felt that professionals struggled to see beyond their learning disability, making assumptions and judgements based upon their disability rather than their capabilities and skills as a parent. Parents felt they were evaluated through a lens of incompetence and described their perception that professionals were "just looking out for faults" (Alison).

"If you've got a learning disability you get judged you can't parent" (Neil)

Amongst those co-parenting with a non-learning disabled individual, there were often suggestions of the wider system minimising the learning disabled parent's role by automatically assuming greater competence from the non-learning disabled parent/carer, even in cases of domestic abuse. This appeared to reinforce disempowerment and feelings of being dismissed and silenced (see theme 1, subtheme 4).

"My relationship with their dad got bad...the social workers said if I left him, they will put all the three kids in care. I wouldn't have got no support. He used to hit me" (Marie)

### ***Subtheme 2: Onus on parents to prove competence***

Parents described feeling pressure from the outset to actively demonstrate their parenting skills and commitment to professionals. This stands in comparison to those without learning disabilities, who are generally presumed to possess the baseline knowledge and skills to be adequate parents. One mother even described taking steps to complete a childcare course with her partner prior to conceiving.

"At least if we do this, it shows we've got a qualification...it will be a tick for us rather than against us, because it shows we're taking it seriously" (Kimberly)

Once pregnant, a number of couples proactively self-referred to social care as a means of pre-emptively acknowledging their support needs and demonstrating their commitment to working with services to develop their abilities.

“My partner wanted to make sure we got the right help...so he rang social services up” (Amy)

“I referred us rather than anyone else...which again is a tick in the box, they’re serious”  
(Kimberly)

However, for some parents there was a sense this backfired when they experienced professionals as prioritising assessment of current parenting capabilities over the identification and implementation of support.

“She [midwife] even got social services involved to see if they’ll help me...she assessed me and they decided that he couldn’t come home with me” (Jessica)

Parents felt they had to demonstrate a higher level of competence and commitment than might be expected from non-learning disabled parents, with one professional even reportedly acknowledging that she’d be unable to parent the child in question herself.

“I said [to professional]...you take her for a fortnight...and see how you cope with her. ‘Oh...I couldn’t cope with her’. I said no, but then you’re telling me I’m not doing my job right” (Jill)

Comparisons to the perceived experiences of non-learning disabled parents left some parents frustrated with having to endure increased scrutiny and heightened expectations as a consequence of their learning disability.

“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” (Kimberly)

### ***Subtheme 3: Unreachable and elusive standards and expectations***

Many parents expressed the apparent impossibility of the standards they were being held to, describing that they “couldn’t do right for doing wrong” (Linda) and were unable to win the approval of professionals no matter how hard they tried. Parents shared their experiences of feeling criticised by professionals, and like they were actively trying to “bring me down” (Helen).

“I did do what they telt us to do and I still got wronged for it” (Linda)

“Every opportunity he put me down” (Amy)

From parents’ perspectives, the standards they felt they were being held to were unreachable, or were perhaps elusive; that is, parents were perhaps unaware of what was expected of them and the processes by which they’d be assessed, thus leaving them feeling bereft, confused and frustrated when told their efforts weren’t enough.

“She [social worker] said ‘you can’t keep your son...because you didn’t pass the assessment’. I didn’t know an assessment had been done” (Amy)

Amongst those who had undergone parenting assessments and child protection proceedings, many parents felt they’d done everything asked of them and yet still faced the prospect of their children being removed from their care.

“I thought I was going to get my children back ‘cause I was doing all the right things” (Rachel)

Some parents expressed difficulties comprehending the complexity of the factors that ultimately led to the decision to remove children from their care. They felt professionals had failed to do their jobs properly after outcomes were experienced as unexpected and disappointing, shifting the ‘blame’ and responsibility onto others when reasons for the judgement remained unclear to them.

“I paid my solicitor to help me get my children back, but she didn’t...[she should] do her job better” (Rachel)

#### ***Subtheme 4: Set up to fail: denied opportunities and support***

Parents shared experiences of being denied services or not receiving the support that had been agreed, despite having proactively sought this based upon recognition of their needs (see theme 3, subtheme 3). This left parents feeling their voice and parental role had been dismissed.

“They knew I was struggling, and I asked for their help and they wouldn’t listen” (Dawn)

Where support was offered, some parents spoke of it not appropriately meeting their needs, yet being penalised for not engaging with it. Others spoke of feeling “dictated to” (Helen), possibly reinforcing the message that others are more competent and powerful and thus feeling their parental identity had been attacked.

Parents reflected on how support was often too slow to arrive; for some, it was only after children had been removed, and the impact of this on their mental health became severely apparent, that professionals moved to put support in place. There was a sense that support is only offered in a “crisis” (Neil), with authorities missing crucial opportunities to implement support at an earlier stage.

“For months there was no support there. Then I got ill and like the support came, but it were too late for me and my son” (Jessica)

Exploring why, some parents felt this was rooted in prejudice and stigma towards those with learning disabilities.

“We want to be parents like everybody else, but we’re not having opportunities because of their attitudes” (Amy)

“They prey on our disability and vulnerability” (Neil)

### **Theme 3: Challenging assumptions and proving competence**

In light of the perceived prejudice experienced, parents sought to challenge the stigma associated with parenting with a learning disability by rejecting labels and presumptions and demonstrating their capability to parent with the right support in place.

#### ***Subtheme 1: Rejecting stigma and ‘beating the system’***

Parents shared defiant rejections of the stigmatising messages that their learning disability had rendered them incapable of parenting. Central to all assertions was the idea that a learning disability does not define or limit a parent, despite societal attitudes.

“You don’t have to listen to the negative stuff...you’re just as good as anybody else” (Carol)

“Don’t let people tell you what you can’t do and stuff just because you’ve got a learning disability, you can do lots of things” (Jenny)

Parents spoke of their pride where they’d maintained care of their children in the face of adversities and social care involvement. Underlying this, however, appeared to be an assumption that their experience of the professional system accepting that they, as an individual with a learning disability, could make a good parent, represented the exception and not the rule.

“Being a mum with a learning disability I just, I beat the system” (Carol)

“I’d changed everything what they wanted around...and proved I could do it” (Jill)

### ***Subtheme 2: Getting ready to be a parent***

In contrast to earlier literature suggesting pregnancies for people with learning disabilities are most often unplanned (McGaw, 1996), many of the parents expressed a longstanding desire to become a parent, often exploring their aspirations and readiness for parenthood through internal reflection or in conversation with partners prior to conception.

“We sat down and we talked about it” (Rick)

“We planned it, to have [a] family” (Khalil)

Some parents shared insightful reflections on their own experiences of being parented, and how this had shaped their beliefs and approaches to parenting. Others spoke of experiences looking after younger siblings and how this had developed their confidence and ‘readiness’ to parent.

“I learnt from seeing my family grow up...I thought, I’m not gonna be like my dad, I’m not gonna be like my mum” (Amy)

“I take my role model from my mother with my kids” (Neil)

Parents advised others to “think about it first before you rush into anything” (Jenny), sharing how those with learning disabilities face additional pressure to appear ‘ready’ for parenthood prior to conceiving, given the heightened scrutiny and barriers they would likely face on their parenting journey. One parent reflected on the bind this places parents with learning disabilities in, given the impossibility of truly knowing, and demonstrating, you’re ‘ready’ prior to having a baby.

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

### ***Subtheme 3: Acknowledging support needs***

Parents often recognised their support needs, and spoke of the importance of proactively seeking support. Parents felt strongly that one should not try to go through their parenting journey alone, and encouraged others to ask for support when needed.

“If you need help, get help, because there’s help there. Don’t do it on your own. Go and see somebody, tell somebody” (Jill)

Parents were open about the challenges they faced and sought to lessen the shame of acknowledging difficulties and accepting help, conceptualising this as a sign of strength.

“Go to a social worker and say that you need help with learning difficulties...there’s nothing wrong with that, just be a good parent” (Kelly)

Many parents specifically spoke of how crucial the support of their family and friends had been, encouraging others to reach out to those around them.

“Don’t be scared to ask your family and friends to help out, they will be there with you to guide you” (Rick)

However, it should be noted that not all of the parents in the sample had a readily available support network. A number of parents shared their experiences of social isolation, whilst others described remaining within previously neglectful or abusive family systems. It was noticeable that the only four parents within the sample who reported no assessment of parenting competence through involvement with children’s services had all benefitted from the involvement of a secure and supportive family network. Arguably, those most in need of support (those with the highest vulnerability associated with chronic and persistent experiences of powerlessness) were the same parents who had no ready support network or advocacy involvement available to them in times of need.

“I begged everybody that I knew [to help]...and no one would, no one cared enough” (Jessica)

#### ***Subtheme 4: Qualities of the support network***

Some parents spoke of the qualities of the support network that enabled them to engage with, and make good use of, the help offered. Feeling believed in by professionals was crucial; parents felt validated when professionals expressed recognition of their efforts, capabilities and strengths as a parent.

“[She] was the best social worker ever...she was the only ever children’s social worker that believed we could keep our children” (Amy)

Given perceptions that professionals struggled to see beyond their learning disability (see theme 2, subtheme 1), it was especially important for parents to feel they’d been clearly seen and

understood. Those with experiences of being assessed in mother and baby units, for example, spoke positively of the opportunity this offered for a more comprehensive observation of their parenting skills.

“When I went into the assessment place, they gave me a chance to see what I was like”  
(Marie)

Where parents reported positive relationships with professionals, this not only related to the interpersonal aspects of the relationship (e.g. encouragement and validation), but the way professionals had tailored the support based upon their own and their child’s individual needs. Parents appreciated opportunities to ‘opt in’ when support was needed, enabling them to develop self-efficacy whilst feeling reassured that support remained available if required.

“We still have social services involved even now, but that’s not necessarily because they’ve got any worries about us...[she] doesn’t want to close the case and us not know how to access the support” (Kimberly)

Some parents also acknowledged their own responsibility for maintaining positive relationships with professionals, emphasising the benefits of working alongside professionals and complying with social care requests in an effort to demonstrate commitment.

“She came over to see me and said ‘well done’...I got points for all these things I went to [courses, groups, therapy]...I went out of my way to get help” (Kelly)

#### **Theme 4: Claiming power**

A distinct theme was generated around parents’ efforts to redress the imbalance of power in their lives. Parents shared their experiences of feeling empowered, both as a parent and an individual with a learning disability, despite, and even because of, stigma, adversities, and losses faced.

##### ***Subtheme 1: Finding a voice***

Parents spoke of their experiences of making themselves heard, standing up for themselves and asserting their rights as a parent and as a person with a disability. Previous experiences of feeling victimised or ignored when unable to speak up (see theme 1, subtheme 4) appeared to provoke a desire to defend and advocate for one’s own and others’ rights.

“I speak up more for myself now than I used to...if you keep quiet that’s when you get picked on” (Marie)



Some parents used their voice to call out professionals for what they believed to be unrealistic expectations or dispute claims they regarded as untrue. Others spoke of asserting themselves with family by affirming their independence and right to make their own decisions.

“I said who do you expect me to be, Mother Theresa?” (Amy)

When rendered powerless to the actions (or inactions) of powerful others, some parents spoke of their attempts to garner media coverage in an effort to make themselves heard.

“I didn’t have nowhere to live. The council were looking for somewhere but couldn’t find it, so you know what I did? I went to a news reporter. I got put in a newspaper which I felt very happy with” (Helen)

A number of parents were driven to assert themselves by the prospect of their children’s needs being dismissed. Their parental identity appeared to help them develop a newfound confidence to advocate for their children, ensuring their child would encounter a different experience of growing up to their own.

“We had to keep going into school to try to get support for [son] to get him a support assistant...then he started to get the help he needed” (Jenny)

### ***Subtheme 2: Empowerment***

Parents spoke of self-empowerment and shared their experiences of developing confidence and self-belief. They encouraged others not to underestimate the potential of people with learning disabilities, and reflected on how their approaches to parenting had been enhanced by qualities and internal resources they ascribed to their learning disability. This reflected a clear shift away from the dominant narrative of ‘presumed incompetence’ shared within the wider system.

“No one knows what it’s like to have learning disabilities until they’ve got them...try not to put yourself down, don’t let other people put you down either. If you want to do something, you do it” (Helen)

“I feel like I’ve took the power back...I’ve got confidence now” (Neil)

Some parents spoke of the inner strength they’d developed as a consequence of the adversities, challenges and losses they’d faced on their parenting journey. In instances where the valued role of being a parent had been negated by children being removed from their care, parents appeared to strongly align with and value their identity as a ‘strong person’.

“It’s made us stronger. I can speak out more, and I encourage the other mums to do the same” (Dawn)

Parents also spoke of feeling empowered by being with others with similar experiences, emphasising the benefits of self-advocacy and peer support. Sharing experiences appeared to help parents to feel less isolated, enabling them to develop trust in a safe space, which for many represented an initial step towards personal recovery. For those with complex histories of abuse, this often represented their first experiences of feeling cared for and held in mind by people they trust.

“I didn’t think there was no one else going through it...till I came to the group” (Jessica)

“Trust, [I can] talk to the other mams...I can tell them anything and they don’t tell no one else, and that’s how I like it” (Julie)

### ***Subtheme 3: Mobilising change***

Parents spoke of their involvement with self-advocacy groups, parenting projects and peer mentoring. There was a strong sense of parents wanting to make a difference and improve the experiences of other learning disabled parents. Parents spoke of sharing their own experiences with professionals as a way of influencing change and fostering understanding towards learning disabled parents.

“I deliver [training]...because I want people to have a better life than I had” (Carol)

“We go out...telling them our story...so they can get the right services” (Dawn)

Other parents spoke of their efforts to advocate for the rights of people with learning disabilities more broadly, and attempts to mobilise changes in societal attitudes and policies.

“We speak up for learning disability people...we speak about hate crime, housing, health things” (Khalil)

Although for many of the parents involved the outcomes for themselves and their children had already been determined, their efforts demonstrated a commitment to addressing wider systemic issues associated with the imbalance of power between parents with learning disabilities and non-learning disabled others.

## **Theme 5: Fathers’ experiences of being excluded**

Although the aforementioned themes encapsulated both mothers’ and fathers’ experiences of parenting with a learning disability, a sub-group analysis of the five fathers within the sample

highlighted a specific theme around fathers feeling excluded and minimised within their parenting role, either by professionals or partners and their extended network.

Three fathers specifically spoke of their subjective experiences of feeling excluded, sharing how professionals' primary focus on the mother of their child/children left them feeling "left out" (Neil) and "cheated" (Mike). The fathers reported feeling deprived of support for their parenting and opportunities to demonstrate their competence, and expressed confusion as to why they should be treated any differently to mothers.

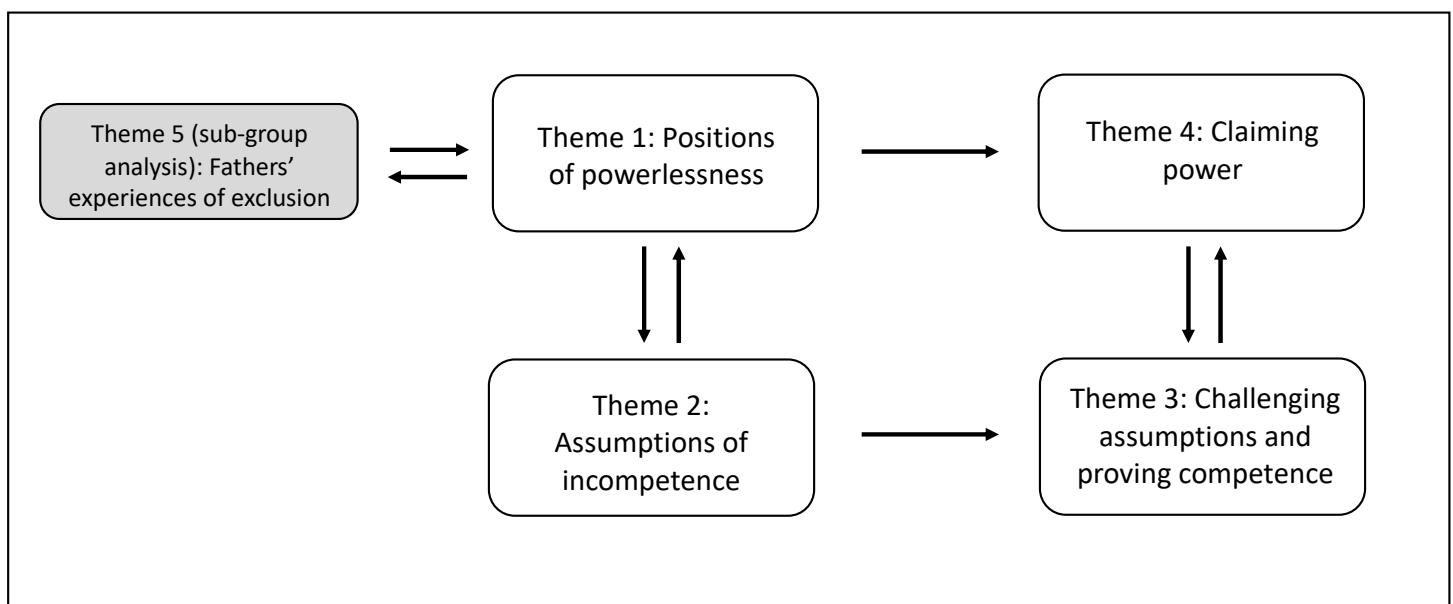
"If you're a father the focus is on the mothers, not on the fathers" (Neil)

"I'm a parent as well...we've all got the same hands, we've got the same brain" (Patrick)

Although the other two fathers (Rick and Khalil) did not express subjective perceptions of being excluded, they shared experiences that could be objectively considered so. Rick shared his experience of only learning he was a father second-hand after his child had been born, whilst Khalil spoke of being separated from his children by a care order and limited to supervised contact.

### Thematic Map

The imbalance of power between the learning disabled parents and non-learning disabled powerful others presented as a clear overarching theme across the data-set and underpinned the five themes yielded from the Thematic Analysis. The thematic map (figure 1) presents an illustration of how these themes appear to relate to one another in the dataset.



**Figure 1: Thematic Map**

The themes broadly mapped on to parents' experiences of 'powerlessness' (Themes 1, 2 and 5) and 'asserting power' (Themes 3 and 4) in the context of the power differentials at play. Arrows indicate the proposed direction of influence, but do not seek to imply causality.

The bidirectional relationship between 'positions of powerlessness' and 'assumptions of incompetence' reflected the way in which parents' experiences of chronic powerlessness appeared to not only influence, but were also reinforced by, the presumptions they felt professionals made about their parenting competency and the pressure they felt to prove themselves to powerful others. Similarly, the bidirectional relationship between 'challenging assumptions and proving competence' and 'claiming power' reflected the reciprocal influences between parents' determination to demonstrate capability as a parent in the face of stigma and prejudice, and efforts to redress the imbalance of power.

A unidirectional relationship was indicated between 'positions of powerlessness' and 'claiming power'; parents' efforts to claim power were born out of their subjugation into powerless positions. This was also the case for 'assumptions of incompetence' and 'challenging assumptions and proving competence'; parents sought to reject labels and demonstrate their competence as a function of the presumptions and prejudice they'd faced.

'Fathers' experiences of being excluded' was presented as related to, yet distinct from, 'positions of powerlessness'. Bidirectional arrows reflected how fathers' perceptions of being excluded may have been influenced and shaped by their broader experiences of powerlessness, whilst simultaneously reinforcing these feelings of powerlessness by subjectively representing yet another experience of feeling disempowered by non-learning disabled powerful others.

## DISCUSSION

The study sought to extend previous preliminary research (Theodore et al., 2018), and specifically to explore what the experiences of parents with learning disabilities tell us about the operation of stigma in their lives. In line with previous findings, parents' accounts depicted substantial power differentials between themselves and non-learning disabled 'powerful others' in their social and professional networks (Gould & Dodd, 2014).

Parents' perceptions of others (predominantly professionals) presuming they lacked the competence to be adequate parents mirrored much of the existing qualitative literature (Gould & Dodd, 2014; Malouf et al., 2017; Booth, 2000). Parents described receiving stigmatic messages both prior to and during parenthood that they would not be able to cope with the demands of parenting, and were left feeling pressure to prove a level of competence exceeding that expected from non-learning disabled parents (Gould & Dodd, 2014). Despite intense scrutiny, parents felt professionals struggled to see beyond their learning disability and evaluated their parenting through a lens of incompetence, echoing earlier assertions that professionals frequently undermine parents in their parenting through "the belief that parents' innate limitations make them unfit for parenthood...only seeing the evidence that supports this preconception" (Booth, 2000, p.3). These assumptions and evaluations frequently served as a continuation of earlier experiences of stigma for parents, having been exposed to narratives defined by their limitations throughout their lives (Scior & Lynggaard, 2006).

Despite best efforts, parents were often left feeling they could never do enough to prove themselves and felt they were being held to impossible standards, leading to expressions of confusion and

frustration. It seemed parents faced 'elusive expectations'; they were aware of the costs of getting it wrong yet were not aware of what was expected of them or the processes by which they were being assessed. This is consistent with many other studies of learning disabled parents (Baum & Burns, 2007; Gould & Dodd, 2014; Malouf et al., 2017) and is perhaps best described by Booth and Booth (2005) as "like playing a game without being told of the rules" (p.113). Notwithstanding both the good practice guidance (WTPN, 2016) and researchers' repeated calls for professionals to clearly outline to parents why assessments/proceedings are being carried out, what they will involve, the level of skill they must demonstrate, and the possible outcomes (for example, Gould & Dodd, 2014; Malouf et al., 2017), it seemed parents were still being disadvantaged by a clear lack of understanding, thus rendering them vulnerable to child removal and powerless to take control.

Research into professionals' attitudes and approaches to supporting learning disabled parents may offer some insight into why parents appeared to remain vulnerable to elusive standards despite guidelines emphasising the need for clear communication. Sigurjonsdottir and Rice (2016) highlight discriminatory practices throughout the process of child custody removal cases, whereby both implementation and outcomes of child protection work proceeded from an assumption of incompetence and a belief that support measures would not work. Indeed, research suggests many professionals responsible for supporting learning disabled parents remain doubtful of their capacity to benefit from training and support measures (Starke, 2011; Meppelder et al., 2014; McConnell et al., 2006), despite evidence to the contrary (e.g. Tarleton et al., 2006), possibly reflecting the limited awareness about individuals with learning disabilities shared in wider society (Scior, 2011). Where assessments are undertaken by social care professionals lacking knowledge, awareness and resources to support learning disabled parents, approaches have been found to narrowly focus upon the perspective of child protection (Mansell & West, 2000) to the detriment of identifying the broader needs arising from the parent's disability (Goodinge, 2000). Whilst professionals' subjective beliefs remain beyond the scope of this study, it remains possible that limited knowledge and presumptions of incompetence may have impacted upon the degree of clarity and transparency reflected in professionals' communication with parents.

Parents shared experiences of feeling betrayed and deceived by professionals, particularly in instances where children had been removed from their care, and struggled to comprehend the complexity of factors that led to this decision. Parents' sense of surprise and bewilderment at the outcomes, and subsequent feeling of victimisation, mirrored experiences reported in other literature (e.g. Baum & Burns, 2007; Llewellyn et al., 2010), possibly reflecting a failure of services to clearly address potential outcomes with parents. Where outcomes were experienced as surprising and disappointing, the parents were quick to lose trust in services and professionals more broadly. Given disengagement and non-compliance with support is commonly regarded by professionals as an indication parenting will not improve (Booth & Booth, 2004), this suggests the implications of losing trust have the potential to perpetuate parents' likelihood of child removals by further feeding into professionals' concerns about their parenting ability (Traustadottir & Sigurjonsdottir, 2010).

Interestingly, one pertinent form of support that seems noticeably absent from both the experiences of parents and the broader literature, was the provision of interventions with an attachment or relational focus (for example, attachment-informed parenting programmes or video interaction guidance, VIG), despite the benefits of these interventions being increasingly recognised for vulnerable parent-child dyads (Wright & Edginton, 2016). Whilst a focus on attachment and parent-infant psychotherapy has arguably increased in mainstream services (e.g. parent-infant psychology services and perinatal mental health services), it seems the application of these interventions to

families with parental learning disability has been largely neglected, despite high rates of attachment trauma in the learning disabled population (Vervoot-Schel et al., 2018) which, alongside other social adversities, may impact upon parent-child relationships (Llewellyn & Hindmarsh, 2015). It is possible this may reflect a broader, historical neglect of the emotional lives of those with learning disabilities (Arthur, 2003), and may also go some way to explain the 'elusive expectations' findings in the research, whereby concerns about attachment and emotional attunement may be at the core of professionals' concerns about parents with learning disabilities, but are neglected at the expense of focussing upon more practical considerations and 'observable' skills deficits. Emerging research into the application of VIG with parents with learning disabilities has demonstrated promising findings and offers a helpful framework for adapting the intervention for this client group (Hodes et al., 2018).

Taken together, these findings emphasise the need for clear and transparent information about the processes parents are subject to, level of competence they must demonstrate, and outcomes they may face as a consequence of service involvement (Malouf et al., 2017). Given professionals cannot assume that parents possess a shared understanding of what it means to have a learning disability and the possible impact of this on their parenting (Shewan et al., 2014), it is especially important that the reasoning for any assessments and/or interventions are made clear. However, this clarity is not only crucial for parents, but professionals too; given the high prevalence of stigmatic and prejudiced beliefs parents encountered from professionals, reflexivity will be essential in order for professionals to notice and query how their assumptions and interpretations may guide the support and communication they provide.

Another key theme to emerge from the data was parents' attempts to challenge the stigma and prejudice faced by demonstrating their capability to parent with support. Interestingly, although parents were quick to dismiss professionals' assumptions of incompetence, they nonetheless acknowledged the need for support and often reflected on the challenges they faced as parents in the context of their learning disability. This contrasted with previous research suggesting learning disabled parents may lack the ability to make realistic judgements about their parenting skills, and feel ambivalent about accepting support as a consequence of it reinforcing the negative social identity associated with their learning disability (Aunos & Feldman, 2002; Baum & Burns, 2007). This finding must be considered, however, in the context of the stage of participants' parenting journeys; many of the parents interviewed were reflecting back on earlier experiences of parenting, and thus it is possible their positive perceptions of the need for support may have been shaped by their own (often painful) experiences and outcomes of assessments and proceedings, rather than necessarily reflective of how accepting they had been of support at the time when their parenting was under assessment and scrutiny, particularly if discrepancies existed between professional and parental perceptions of the type of help needed (Llewellyn et al., 1998).

Parents particularly emphasised the importance of securing support from families, mirroring much of the existing literature around the typical composition of learning disabled parents' support networks (Llewellyn & McConnell, 2002; Traustadottir & Sigurjonsdottir, 2008). It was notable, however, that not all of the parents interviewed had a readily available support network (MacIntyre & Stewart, 2012); many were socially isolated and/or remained within previously neglectful and abusive family systems and relationships. The absence of support, often intersecting with a multiplicity of other adversities including poverty, lack of positive parenting role models, and poor mental health, arguably rendered these parents especially vulnerable and powerless. Consistent with the findings of Llewellyn & McConnell (2002), it seemed those who were most socially isolated

were most heavily reliant on professionals as their sole source of support, yet these were the very same parents who simultaneously appeared to generate the most concern and anxiety within the professional systems, most likely in response to their degree of vulnerability. Without the support of non-disabled 'allies' in the form of family, friends or advocates, who could use their more 'powerful' position in the system (relative to the learning disabled parent) to liaise with professionals and advocate for them (Traustadottir & Sigurjonsdottir, 2008; Mayes et al., 2011), it appeared these vulnerable parents were left exposed to assumptions of inadequacy and the threat of their children being removed by the very systems they looked to as their only source of support. This resonates with a recent study of practitioners, which found constructions of learning disabled parents as 'vulnerable' were inaccurately equated with a perceived lack of capacity to parent, thereby creating further barriers to offering appropriate support (MacIntyre et al., 2019).

Where parents spoke of the qualities of the support network that enabled them to accept and engage with the support offered, parents emphasised the importance of others believing in their capabilities and recognising their efforts and strengths. This stood in stark contrast to other experiences of assumed incompetence. Conversely, whilst many parents felt they were denied support (in line with Baum & Burns, 2007; Malouf et al., 2017) or had support withheld from them until the point of crisis, others spoke of being offered support that didn't appropriately meet their needs, and a perception of being 'dictated to' and undermined in their parenting role. These findings may be helpfully understood in line with Tucker and Johnson's (1989) model of competence-promoting and competence-inhibiting support for parents with learning disabilities, which proposes that it is not the provision of support alone, but the quality of the support, which promotes parenting competence. They assert that even well-intentioned support may have negative consequences if "offered in a context that assumes incompetence or helplessness" (Tucker & Johnson, 1989, p.96). Given the stigma and prejudice parents within the sample perceived from those within their professional network, professionals must remain mindful that support will only be experienced as competence-promoting if they can communicate with it their belief that parents are capable of becoming self-sufficient and competent. Taken together, the findings suggest parents' continued experiences of feeling denied support, encountering unnecessary delays, and being offered support that did not appropriately meet their needs, served to reinforce their sense of powerlessness and despondency with services, and thereby limited their prospects of being deemed as 'competent' enough to retain care of their children. It is essential therefore, that professionals not only clearly communicate to parents the standards and criteria by which they'll be assessed, and subsequently, the areas in which they may present with skills deficits, but also provide parents with sufficient opportunity to develop these skill and knowledge gaps with the appropriate support. For this to be effective, however, it will need to be offered in a sensitive and empowering way, ultimately motivated by an underlying belief that the parent *does* possess the potential to change.

In the face of the stigma and prejudice participants perceived in their lives, they appeared to highly value and embrace their identity as a parent. This resonated strongly with other literature that has highlighted the value attached to the 'parenting identity', simultaneously confirming 'adult' status and refuting the dominant label of 'learning disability' (Edmonds, 2000; Mayes et al., 2011; Shewan et al., 2014). Where parents face threats to this identity through scrutiny of parenting competence or possible separation from their child(ren), it has been suggested this may negate the valued 'parent' status and reinforce the stigmatised identity of being 'learning disabled' (Baum & Burns, 2007; Gould & Dodd, 2014); this may go some way to explaining why parents in this study were so motivated to challenge the stigma levelled against them as parents and to redress the imbalances of

power at a more systemic level. Broader literature on the exploration of identity in people with learning disabilities contests the degree to which they show awareness of their stigmatised status; whilst some authors have suggested they show little awareness (Beart et al., 2005), others have suggested they seek to reject their stigmatised status by distancing themselves from the 'learning disabled' identity (Jahoda & Markova, 2004). Whilst it's arguable that the value attached to their parental status facilitated a degree of shift in their social identity, the parents in this study remained very much aware of the stigma attached to being 'a parent with a learning disability'. Yet, although some of the parents spoke of apprehensions around being 'good enough' to be a parent, indicative of some possible internalised stigma (Kaspar & Stenfort-Kroese, 2017), the majority of parents perceived the stigma as unjust and expressly rejected the stigmatic messages they had received, without seeking to distance themselves from the stigmatised 'in-group' (Tajfel et al., 1979). Similar to Roth et al.'s (2016) study of self-advocates' experiences of stigma in the wider learning disabled population, it appears the parents "swallowed the insult, but did not accept it" (p.53).

However, drawing parallels with Roth et al.'s (2016) study necessarily highlights a common factor between both studies; this is, findings were drawn from samples of self-advocates. It is possible, therefore, that involvement with self-advocacy organisations, and the sense of social belonging and social affirmation this offered, afforded parents the opportunity to challenge the stigmatised notions of incompetence, incapacity and dependency previously attached to their social identity as a learning disabled parent (Anderson & Bigby, 2017). In line with Branscombe et al.'s (1999) Rejection-Identification Model of Group Identification and Self-Evaluation, it appears that identifying as a member of the stigmatised group of 'learning disabled parents' (or even, 'learning disabled parents who have had a child removed from their care') provided the parents with the social support and resources to reject the prejudice and discrimination experienced by the group. The finding that parents not only rejected stigmatising messages, but described feeling empowered to support others and mobilise wider societal change, represented a two-fold redressal to the power imbalances parents had experienced; both externally, through explicit attempts to influence service/policy change, and internally, through the shift away from a stigmatised self-identity to that of an 'expert' position.

The reference group were clear to emphasise, however, that the journey towards becoming more powerful is typically fraught with pain and struggle; indeed, many of the parents in this study only came into contact with self-advocacy organisations after they encountered a significant challenge to their parenting (e.g. separation from a child), and not all parents in similar positions have access to such organisations. This is especially pertinent to consider given the dearth of self-advocacy organisations in many countries, and the continued cuts to funding in the UK threatening the sustainability of this much-valued resource (Anderson & Bigby, 2017). The current findings highlight the crucial role self-advocacy organisations play in protecting and maintaining parents' positive self-evaluations and offering an opportunity to redress the power imbalances in their lives. This emphasises the need to not only protect such organisations from further funding cuts and closures, but to invest in and expand the availability of this support to help reach out to parents at an earlier stage of their parenting journey.

The sub-analysis of fathers' experiences generated a specific theme around fathers feeling excluded and minimised in their parenting role, mirroring the limited existing literature (Dugdale & Symonds, 2017; Sigurjonsdottir, 2004; Mayes & Sigurjonsdottir, 2010). Fathers felt ignored and deprived of support by professionals and services, and shared frustration at their perception of support having been primarily directed towards the mothers. This resonated closely with previous reports which



found support services disempower fathers by focussing resources principally on mothers, on the assumption that the mother will be the 'primary carer' (Sigurjonsdottir, 2004; Dugdale & Symonds, 2017). Interestingly, studies of fathers without learning disabilities (for example, Fenwick et al., 2012) have found they too share the experience of feeling excluded by health professionals, yet the learning disabled fathers in this study appeared to interpret their experiences as driven by stigma. In a study of learning disabled mothers, Malouf et al. (2017) found women's sense of themselves outside of 'normal' (as a consequence of their learning disability) led them to interpret ordinary aspects of care as abnormal and discriminatory. It is possible, therefore, that learning disabled fathers' experiences of feeling left out may have been exacerbated by the sense of powerlessness associated with the intersection of being a father *and* a man with a learning disability.

### **Strengths and limitations of the research**

To the best of our knowledge, this is the first project to employ an inclusive approach to explore the experiences of parents with learning disabilities. In line with recent calls for more inclusive participation (Beail & Williams, 2014), the involvement of co-researchers at multiple stages of the research process (including development, data collection and analysis), in addition to the involvement of the reference group with credibility checks and write-up, represented a clear strength of the study. In an overview of the existing literature on the impact of stigma on the lives of people with learning disabilities, Ditchman et al. (2016) concluded that "the research world itself may be the last frontier of unrecognised stigma as it plays out in the often-implicit assumption that those with intellectual disabilities cannot meaningfully participate" (p.42). The meaningful participation of multiple researchers and self-advocates in this study therefore provides evidence refuting this assumption. Given the nature of the research question, and the subsequent findings around the chronic stigma and power imbalances reported by those who participated, the involvement of learning disabled researchers in the research interviews was especially important to help reduce the power disparities inherent in the researcher-participant dynamic, enabling parents to speak more openly about their experiences, and thus offering an enhanced narrative that resonates with, and arguably builds upon, the themes identified in other (non-inclusive) literature (e.g. Gould & Dodd, 2014; Dugdale & Symonds, 2017; Malouf et al., 2017). Further, it can be argued that the broader aims of the 'Daughters of Fortune' project, to disseminate stories of learning disabled parents to a wide public and professional audience in an effort to increase awareness and reduce societal stigma, closely aligns with Walmsley et al.'s (2017) definition of inclusive research as research that specifically aims to "contribute to social change, help to create a society in which excluded groups belong, and...improve the quality of their lives" (p.758).

Nonetheless, the inclusive approach is not without its limitations. Firstly, the study may have benefited further from opportunities for greater involvement of learning disabled co-researchers, and parents specifically, for example through enhanced involvement in the data analysis and final write-up. Without a strong evidence-base, however, developments in inclusive research methodologies have typically been left to individual researchers to pioneer new ways of working and attempt to "kick start change" (Walmsley, 2004, p.69), and it is arguable this study represents a step in the right direction, in the hope of influencing other researchers in the field by showing such approaches can be meaningfully employed. To support this, this paper has sought to clearly specify who has been involved in the inclusive methodology, what they have done, and how they have been supported to do it, in attempt to 'de-mystify' the inclusive process (Walmsley, 2004).

Secondly, whilst on balance it was felt that the benefits of having learning disabled co-researchers and a non-learning disabled writing mentor conduct the interviews out-weighed the costs associated with less involvement from the academic researchers in the data collection, this nevertheless meant that the academic researchers had less control over the questions asked and degree of fidelity to the interview schedule. Interviews were often led by the participant's own narrative, and thus touched upon broad-ranging topics; the findings presented in this paper represent the themes that appeared important across all the interviews in relation to the research question posed, but there were many other initial codes that could have been used to develop additional themes in the inductive thematic analysis that could have similarly formed the focus of another paper.

A further limitation is the limited representativeness of the sample, given parents were recruited through their involvement in self-advocacy groups and relied upon them self-identifying as learning disabled. Whilst this arguably supported the researchers to capture a broader range of individuals who may present with mild or borderline difficulties – thus representing the 'hidden majority' of learning disabled parents who may not typically have contact with disability and welfare services (Emerson, 2011) – this does, nonetheless, limit the degree to which findings can be generalised. It is possible, for example, that the group includes parents with a relatively higher level of functioning than if recruited through formal services. Furthermore, in their journey toward contact with self-advocacy groups, it is possible that these parents had encountered a higher degree of adversity and challenges, both in their parenting role and in other aspects of their lives (for example, the high prevalence of childhood abuse within the sample). This increased degree of marginalisation arguably enhances the need for these parents' experiences to be heard and understood, but it must nevertheless be acknowledged that as self-advocates these parents may be more experienced in talking about painful issues (Roth et al., 2016), and thus there may still exist other parents who have gone through similar adversities whose voices remain unheard. As highlighted by the reference group, this also raises the point that other parents not involved with self-advocacy may not share the same opportunities and support to reject stigma and redress power imbalances as shared by this sample of parents.

Finally, the parents interviewed represented a heterogeneous sample given the range of gender, ages of participants, ages of children, living arrangements of children, and geographical areas in which they live and access services. Whilst this is arguably a strength of the study, it also functions as a limitation insofar as analysing these diverse parents in one sample limits the degree to which individual experiences could be understood in the context of changing attitudes and beliefs held by professionals and wider society, and how this relates to policy developments over more recent times (e.g. DoH/DfES, 2007).

### **Future research**

Future research could explore the impact of sharing parents' experiences on reducing stigma and prejudice both within wider society and within specific groups of professionals that work with learning disabled parents. This could seek to incorporate co-production and co-facilitation with learning disabled parents, given existing findings that interventions involving interpersonal contact with members of the stigmatised group appear have a greater and long-lasting impact than education interventions (Werner & Scior, 2016). It also remains to be evaluated what impact the creative outputs (e.g. theatre, workshops, training films etc.) of Mind the Gap's broader 'Daughters of Fortune' project, of which this research project represents just one stream, may have on reducing

stigmatic attitudes and beliefs related to parents with learning disabilities amongst both professionals and wider society.

Whilst research in the field of mental health has developed an understanding of the specific processes involved in the formation of stigma and discrimination, to date the mechanisms involved in learning disability stigma, such as the role of causal attributions or emotional responses, remain largely unknown (Scior, 2011). Furthermore, researchers have tested few theories of the functions of disability stigma in relation to learning disability (Scior, 2016). Although calls have been made to better understand the different variables implicated in learning disability stigma, it will also be important to research this specifically in relation to stigma associated with parenting, given the current findings that suggest parents with learning disabilities may face specific and unique forms of stigma, prejudice, and operations of power.

Another avenue for research will be to expand upon the limited understanding of gendered experiences of parenting with a learning disability; with a focus not only on ensuring fathers' voices are heard and understood, but also exploration of how health and social care services can work to better identify and attend to learning disabled fathers' needs, to ensure they do not continue to feel excluded and side-lined in their parenting role.

### **Impact & Dissemination**

There are a number of potential beneficiaries and benefits of this research at multiple levels of the system, in relation to both the academic impact and 'real-world' implications. The research offers an additional, unique academic contribution insofar as demonstrating the 'added value' of investing additional time and resources into inclusive research methods (Walmsley et al., 2017) and demonstrating how learning disabled co-researchers can participate meaningfully at multiple stages of the academic research process (Ditchman et al., 2016). The academic impact of both papers may be maximised by not only seeking publication in high-impact journals, but aiming to disseminate to a broader, multi-disciplinary audience of professionals outside of clinical psychology, by presenting at conferences aimed at the wider array of professionals involved with supporting parents with learning disabilities, such as nurses, midwives, social workers, child protection officers, and family law professionals. Additionally, the benefits of inclusive research methodologies may be further evidenced and maximised by co-presenting the empirical findings with co-researchers at academic conferences, and supporting co-researchers to write-up their experience of research participation for publication, with a view to influencing researchers to employ greater use of these methodologies.

Further to co-presentations of the preliminary research (Theodore et al., 2018) at UK and international conferences, the inclusive research process and emerging themes of this extended research were also presented by Kate Theodore and Daniel Foulds, a learning disabled artist and co-researcher, at the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) World Congress in Glasgow in August 2019, and again (updated to include the generated themes) at the "Seattle Club" Intellectual Disability Research UK Conference in London in December 2019. Further planned conference presentations to practitioners (including social workers, psychologists, midwives) were delayed in Spring / Summer 2020 due to the Covid-19 pandemic impacting events being held. However, there are plans to present the research further to practitioners in the field over the coming months.

As the research 'stream' within the larger project, 'Daughters of Fortune', the findings of this research will have also helped inform Mind the Gap's broader creative outputs, which include forum theatre, touring productions, outdoor theatre events and a series of training films for practitioners. Mind the Gap's website offers an overview of the outputs to date (<http://www.mind-the-gap.org.uk/projects/daughters-of-fortune/>). The themes from the research have been incorporated into a photo book developed by Mind the Gap, 'Paige', sharing the stories and images of some of the learning disabled parents, with the aim of raising the visibility and understanding of these experiences. Easy read research summaries have been made available, to be shared with the advocacy groups involved in the research, as well as more widely. The research findings and easy read summaries will also be shared with the Working Together with Parents Network; a UK-wide network based within the University of Bristol's School for Policy Studies, which seeks to engage with key stakeholders in social care, healthcare and children's sectors to promote policy development and encourage joint ways of working.

To disseminate the empirical findings to an academic audience, the paper will be prepared for publication and submitted to an academic journal, selected on the basis of impact ratings (Scimago, 2020), subject-matter scope and receptiveness to qualitative research. Given the breadth of services that come into contact with learning disabled parents, it will also be important to seek to disseminate the findings to a broader array of professionals. With this in mind, a second paper will be prepared detailing the collaborative empirical project as a whole, including the process of collaborating with Mind the Gap and the participation of co-researchers with learning disabilities in the research process, whilst also incorporating some of the key messages and implications from the research. This second paper can be submitted to relevant journals in social work, midwifery and nursing professions, such as the British Journal of Social Work, Midwifery, and Nursing Times, as well as submissions to present at conferences for these professions. Finally, given so many of these parents may not be known by specialist learning disability services (Emerson, 2011), yet may benefit from psychological input around the parent-child relationship, it is also important that the clinical implications of these findings extend beyond the immediate learning disability field, to include psychological services working more broadly with parents, mothers, children and infants, such as child and adolescent mental health services, perinatal mental health services, and parent-infant psychology services. Research findings will be presented to such relevant teams and professionals, and we will look to submit an article that targets the broader clinical psychology profession such as the British Psychological Society's 'The Psychologist'.

## CONCLUSION

Throughout their lives, parents reported experiencing stigmatisation in the form of feeling disempowered by non-learning disabled others within their social and professional networks. In particular, parents commonly faced assumptions of parenting incompetence, threatening their parental identity and placing them under pressure to demonstrate a level of competence they felt exceeded that expected of their non-learning disabled peers. Parents demonstrated a strong determination to reject their stigmatised status and prove themselves as parents, but were often left confused and frustrated by the elusiveness of the standards and expectations they were being held to. Where support was perceived to be withheld, or offered in a competence-inhibiting manner, parents often expressed a sense of disillusionment with services, and spoke of a breakdown in trust where outcomes of assessments and proceedings did not match expectations. However, despite the stigma, adversities and losses faced by parents in the sample, they continued to embrace their highly valued identity as a parent, and appeared to draw strength, belonging and social affirmation from their involvement with self-advocacy services. Self-advocacy appeared to provide a platform to redress the imbalance of power in their lives through the unique opportunities involvement afforded parents to collectively reject stigma, empower oneself and others, fight injustice, and mobilise wider societal change.

## REFERENCES

- Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities, 33*, 2122-2140.
- Anderson, S., & Bigby, C. (2017). Self-Advocacy as a Means to Positive Identities for People with Intellectual Disability: 'We Just Help Them, Be Them Really'. *Journal of Applied Research in Intellectual Disabilities, 30*(1), 109-120.
- Arthur, A. (2003). The emotional lives of people with learning disability. *British Journal of Learning Disabilities, 31*, 25-30.
- Aunos, M., & Feldman, M. A. (2002). Attitudes towards sexuality, sterilization and parenting rights of persons with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*(4), 285-296.
- 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.
- Beail, N., & Williams, K. (2014). Using qualitative methods in research with people who have intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 27*, 85–96.
- Beart, S., Hardy, G., & Buchan, L. (2005). How people with intellectual disabilities view their social identity: A review of the literature. *Journal of Applied Research in Intellectual Disabilities, 18*, 47-56.
- Booth T. (2000). Parents with learning difficulties, child protection and the courts. *Representing Children, 13*(3), 175–88.
- Booth, T. & Booth, W. (1994). Parental adequacy, parenting failure and parents with learning difficulties. *Health and Social Care, 2*, 161-172.
- Booth, W., & Booth, T. (2004). A family at risk: multiple perspectives on parenting and child

- protection. *British Journal of Learning Disabilities*, 32, 9-15.
- Booth, T., & Booth, W. (2005). Parents with learning difficulties in the child protection system. *Journal of Intellectual Disabilities*, 9(1), 109-129.
- Branscombe, N. R., Schmitt, M. T., & Harvey, R. D. (1999). Perceiving pervasive discrimination among African Americans: Implications for group identification and well-being. *Journal of Personality and Social Psychology*, 77, 135-149.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Clarke, V., & Braun, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage.
- Clarke, V., Braun, V., & Hayfield, N. (2015). Thematic analysis. In J.A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp.222-248). Sage.
- 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.
- Department of Health and Department for Education and Skills. (2007). *Good practice guidance on working with parents with a learning disability*. HMSO.
- [http://webarchive.nationalarchives.gov.uk/20080817163624/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_075119](http://webarchive.nationalarchives.gov.uk/20080817163624/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_075119)
- Department of Health. (2001). *Valuing people: A new strategy for learning disability for the 21st century*. London: The Stationery Office.
- Ditchman, N., Kosyluk, K., Lee, E.J., & Jones, N. (2016). How stigma affects the lives of people with intellectual disabilities: An overview. In K. Scior & S. Werner (Eds.), *Intellectual Disability and Stigma: Stepping out from the margins* (pp. 31-48). Palgrave Macmillan.
- Dugdale, D., & Symonds, J. (2017). *Fathers with learning disabilities and their experiences of adult social care services*. School for Policy Studies, University of Bristol.
- Ebbs, C. A. (1996). Qualitative research inquiry: Issues of power and ethics. *Education*, 117(2), 217-222.

Edgerton, R. B. (1967). *The clock of competence: Stigma in the lives of the mentally retarded*.

University of California Press.

Edmonds J. (2000) On being a mother: a positive identity in the face of adversity. *Clin Psychol Forum*, 137, 21–25.

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British journal of clinical psychology*, 38(3), 215–229.

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

Emerson, E., Llewellyn, G., Hatton, C., Hindmarsh, G., Robertson, J., Man, W. Y. N. & Baines, S. (2015). The health of parents with and without intellectual impairment in the UK. *Journal of Intellectual Disability Research*, 59(12), 1142–1154.

Emerson E., Malam S., Davies I. & Spencer E. (2005). *Adults with learning difficulties in England 2003/4*. <https://digital.nhs.uk/data-and-information/publications/statistical/adults-with-learning-difficulties-in-england/adults-with-learning-difficulties-in-england-2003-2004>

Fenwick, J., Bayes, S., & Johansson, M. (2012). A qualitative investigation into the pregnancy experiences and childbirth expectations of Australian fathers-to-be. *Sexual and Reproductive Healthcare*, 3(1), 3–9.

Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A., Beecham, J. & Wooff, D. (2006). The social networks of people with intellectual disability living in the community 12 years after resettlement from long-stay hospitals. *Journal of Applied Research in Intellectual Disabilities*, 19, 285–295.

Goodinge, S. (2000). *A jigsaw of services: Inspection of services to support disabled adults in their parenting role*. Social Services Inspectorate, Department of Health.

Gould, S. & 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(1), 27-37.

Gur, A., & Stein, M. (2019a). Social worker perception of grandparent involvement where a parent has an intellectual disability. *Research in Developmental Disabilities*, 92, 103427.

Hamilton, C. (2015). Sterilization and intellectually disabled people in New Zealand: rights, responsibility and wise counsel needed. *Kotuitui: New Zealand Journal of Social Sciences Online*, 10(1), 36-45.

Hodes, M. W., Meppelder, M., de Moor, M., Kef, S., & Schuengel, C. (2018). Effects of video-feedback intervention on harmonious parent–child interaction and sensitive discipline of parents with intellectual disabilities: A randomized controlled trial. *Child: care, health and development*, 44(2), 304-311.

IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities. (2008). Parents labelled with intellectual disability: Position of the IASSID SIRG on parents and parenting with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21(4), 296-307.

Jahoda, A., & Markova, I. (2004). Coping with social stigma: People with intellectual disabilities moving from institutions and family home. *Journal of Intellectual Disability Research*, 48(8), 719-729.

James, H. (2004). Promoting effective working with parents with learning disabilities. *Child Abuse Review: Journal of the British Association for the Study and Prevention of Child Abuse and Neglect*, 13(1), 31-41.

Jamieson, R., Theodore, K., & Raczka, R. (2016). Becoming a mother: Supported decision-making in context. *Journal of Intellectual Disabilities*, 20(4), 313-328.

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

Link, B. G., & Phelan, J. C. (2001). Conceptualising stigma. *Annual Review of Sociology*, 27, 363-385.

Llewellyn, G., & Hindmarsh, G. (2015). Parents with intellectual disability in a population context.

*Current developmental disorders reports, 2*(2), 119-126.

Llewellyn, G., Mayes, R., & McConnell, D. (2008). Towards acceptance and inclusion of people with intellectual disability as parents. *Journal of Applied Research in Intellectual Disabilities, 21*, 293-295.

Llewellyn, G., & McConnell, D. (2002). Mothers with learning difficulties and their support networks. *Journal of Intellectual Disability Research, 46*, 17–34.

Llewellyn, G., & McConnell, D. (2010). You have to prove yourself all the time: people with learning disabilities as parents. In G. Grant, R. Ramcharan, M. Flynn, & M. Richardson (Eds.), *Learning Disability: A life cycle approach* (2<sup>nd</sup> ed., pp.311-328). Open University Press.

Llewellyn, G., McConnell, D., & Bye, R. (1998). Perception of service needs by parents with intellectual disability, their significant others, and their service workers. *Research in Developmental Disabilities, 19*(3), 245-260.

Llewellyn, G., Traustadottir, R., McConnell, D., & Sigurjonsdottir, H. (2010). *Parents with Intellectual Disabilities: Past, Present and Futures*. Wiley-Blackwell.

Logeswaran, S., Hollett, M., Zala, S., Richardson, L., & Scior, K. (2019). How do people with intellectual disabilities construct their social identity? A review. *Journal of Applied Research in Intellectual Disabilities, 32*(3), 533-542.

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

MacIntyre, G., Stewart, A., & McGregor, S. (2019). The double-edged sword of vulnerability: Explaining the persistent challenges for practitioners in supporting parents with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 32*, 1523-1534.

- Malouf, R., McLeish, J., Ryan, S., Gray, R., & Redshaw, M. (2017). 'We both just wanted to be normal parents': a qualitative study of the experience of maternity care for women with learning disability. *BMJ Open*, 7(3), e015526.
- Mansell, J., & West, M. (2000). *Supporting parents with learning disabilities in Rotherham*. Rotherham Advocacy Partnerships supported by The South Yorkshire Coalfields Health Action Zone.
- Mayes, R., & Llewellyn, G. (2009). What happens to parents with intellectual disability following removal of their child in child protection proceedings? *Journal of Intellectual and Developmental Disability*, 34(1), 92-95.
- Mayes, R., Llewellyn, G., & McConnell, D. (2008). Active negotiation: Mothers with intellectual disabilities creating their social support networks. *Journal of Applied Research in Intellectual Disabilities*, 21(4), 341-350.
- Mayes, R., Llewellyn, G. & McConnell, D. (2011). 'That's who I choose to be': The mother identity for women with intellectual disabilities. *Women's Studies International Forum*, 34(2), 112-120.
- Mayes, R., & Sigurjónsdóttir, H. B. (2010). Becoming a mother - Becoming a father. In G. Llewellyn, R. Traustadóttir, D. McConnell & H. B. Sigurjónsdóttir (Eds.), *Parents with intellectual disabilities: Past, present and futures* (pp.17-31). Wiley-Blackwell.
- McConnell, D., Feldman, M., Aunos, M., & Prasad, N. (2011). Child Maltreatment Investigations Involving Parents with Cognitive Impairments in Canada. *Child Maltreatment*, 16, 21-32.
- McConnell, D., Llewellyn, G., & Ferronato, L. (2002). Disability and decision-making in Australian care proceedings. *International Journal of Law Policy and the Family*, 16(2), 270-299.
- McConnell, D., Llewellyn, G., & Ferronato, L. (2006). Context-contingent decision-making in child protection practice. *International Journal of Social Welfare*, 15, 230-239.
- McConnell, D., & Strike, J. (2002). Parents with intellectual disability: Just the same, only different. *Interaction*, 15(4), 11-15.

- McGaw, S. (1996). Services for parents with learning disabilities. *Tizzard Learning Disability Review, 1*, 21-32.
- McGaw, S. (1998). Working with parents who happen to have intellectual disabilities. In E. Emerson, C. Hatton, J. Bromley, & A. Caine (Eds.), *Clinical Psychology and People with Learning Disabilities* (pp. 193 – 209). Wiley.
- McGaw, S. & Newman, T. (2005). *What works for parents with learning disabilities?* Barnardo's.
- Meppelder, M., Hodes, M. W., Kef, S., & Schuengel, C. (2014). Expecting change: Mindset of staff supporting parents with mild intellectual disabilities. *Research in Developmental Disabilities, 35*, 3260-3268.
- Monteleone, R., & Forrester-Jones, R. (2017). 'Disability means, um, dysfunctioning people': A qualitative analysis of the meaning and experience of disability among adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 30*, 301-315.
- Murphy, G., & Feldman, M. (2002). Parents with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*(4), 281-284.
- Nind, M. (2017). The practical wisdom of inclusive research. *Qualitative Research, 17*(3), 278-288.
- O'Brien, P., McConkey, R., & Garcia-Iriarte, E. (2014). Co-researching with people who have intellectual disabilities: Insights from a national survey. *Journal of Applied Research in Intellectual Disabilities, 27*, 65-75.
- Petticrew, M., Egan, M., Thomson, H., Hamilton, V., Kunkler, R., & Roberts, H. (2008). Publication bias in qualitative research: what becomes of qualitative research presented at conferences? *Journal of Epidemiology & Community Health, 62*(6), 552-554.
- Råheim, M., Magnussen, L. H., Sekse, R. J., Lunde, Å., Jacobsen, T., & 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, 11*, 30996.

- Roth, D., Barak, D., & Peretz, H. (2016). How stigma affects us: The voice of self-advocates. In K. Scior & S. Werner (Eds.), *Intellectual Disability and Stigma: Stepping out from the margins* (pp. 49-60). Palgrave Macmillan.
- Schuengel, C., Kef, S., Hodes, M. W., & Meppelder, M. (2017). Parents with intellectual disability. *Current opinion in psychology*, 15, 50-54.
- Scimago. (2020). *SJR Scimago Journal and Country Rank*. <https://www.scimagojr.com>
- Scior, K. (2011). Public awareness, attitudes and beliefs regarding intellectual disability: A systematic review. *Research in Developmental Disabilities*, 32, 2164-2182.
- Scior, K. (2016). Toward understanding intellectual disability stigma. In K. Scior & S. Werner (Eds.), *Intellectual Disability and Stigma: Stepping out from the margins* (pp. 3-13). Palgrave Macmillan.
- Scior, K., and Lynggaard, H. (2006) New stories of intellectual disabilities. In S. Baum, and H. Lynggaard (Eds.), *Intellectual Disabilities: A Systemic Approach* (pp.100-120). Karnac Books.
- Sheerin, F. (1998). Parents with learning disabilities: A review of the literature. *Journal of Advanced Nursing*, 28, 126–133.
- Shewan, L., Crawley, R., McKenzie, K., & Quayle, E. (2014). A qualitative exploration of the identities of parents with a learning disability. *British Journal of Learning Disabilities*, 42, 19-26.
- Sigurjonsdottir, H. (2004). Intellectually limited fathers, their families and formal support services. In K. Kristiansen, & R. Traustadottir (Eds.), *Gender and Disability Research in the Nordic Countries*, (pp.239-254). Studentlitteratur.
- Sigurjonsdottir, H. B., & Rice, J. G. (2016). Stigmatic representation of intellectual disability and termination of parental custody rights. In K. Scior & S. Werner (Eds.), *Intellectual Disability and Stigma: Stepping out from the margins* (pp. 77-90). Palgrave Macmillan.
- Starke, M. (2011). Supporting families with parents with intellectual disability: Views and experiences of professionals in the field. *Journal of Policy and Practice in Intellectual Disabilities*, 8(3), 163-171.

- Stenfert-Kroese, B., Hussein, H., Clifford, C., & Ahmed, N. (2002). Social support networks and psychology wellbeing of mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15(4), 324-340.
- Tajfel, H., Turner, J. C., Austin, W. G., & Worchel, S. (1979). An integrative theory of intergroup conflict. *Organizational identity: A reader*, 56-65.
- Tarleton, B., & Porter, S. (2012). Crossing no man's land: A specialist support service for parents with learning disabilities. *Child and Family Social Work*, 17(2), 233-243.
- Tarleton, B., & Ward, L. (2007). "Parenting with support": The views and experiences of parents with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 4(3), 194-202.
- Tarleton, B., Ward, L., & Howarth, J. (2006). *Finding the right support: A review of issues and positive practice in supporting parents with learning difficulties and their children*. The Baring Foundation.
- The Equality Act 2010, c.15. <http://www.legislation.gov.uk/ukpga/2010/15/contents>
- Theodore, K., Foulds, D., Wilshaw, P., Colborne, A., Lee, J. N. Y., Mallaghan, L., Cooper, M., & Skelton, J. (2018). 'We want to be parents like everybody else': stories of parents with learning disabilities. *International Journal of Developmental Disabilities*, 64(3), 184-194.
- Tracy, J., & Iacono, T. (2008). People with developmental disabilities teaching medical students: Does it make a difference? *Journal of Intellectual and Developmental Disabilities*, 33, 345-348.
- Traustadottir, R. & Sigurjonsdottir, B. H. (2008). The 'mother' behind the mother: Three generations of mothers with intellectual disabilities and their family support networks. *Journal of Applied Research in Intellectual Disabilities*, 21(4), 331-340.
- Traustadottir, R. & Sigurjonsdottir, B. H. (2010). Parenting and resistance: strategies. In G. Llewellyn, R. Traustadottir, D. McConnell & H.B. Sigurjonsdottir (Eds.), *Parents with Intellectual Disabilities: Past, Present and Futures* (pp.107-118). Wiley-Blackwell.

- Tucker, M. B., & Johnson, O. (1989). Competence promoting vs. competence inhibiting social support for mentally retarded mothers. *Human Organization*, 95-107.
- Wade, C., Llewellyn, G., & Matthews, J. (2008). Review of parent training interventions for parents with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 21(4), 351–366.
- Walmsley, J. (2004). Inclusive learning disability research: the (nondisabled) researcher's role. *British Journal of Learning Disabilities*, 32, 65-71.
- Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present and futures*. Jessica Kingsley Publishers.
- Walmsley, J, Strnadova, I & Johnson, K. (2017) The added value of inclusive research. *Journal of Applied Research in Intellectual Disabilities*, 31, 751–759.
- Ward, L., & Tarleton, B. (2007). Sinking or swimming? Supporting parents with learning disabilities and their children. *Learning Disability Review*, 12(2), 22-32.
- Werner, S., & Scior, K. (2016). Interventions aimed at tackling intellectual disability stigma. In K. Scior & S. Werner (Eds.), *Intellectual Disability and Stigma: Stepping out from the margins* (pp. 129-148). Palgrave Macmillan.
- 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)*. Working Together with Parents Network, Norah Fry Centre for Disability Studies, School for Policy Studies, University of Bristol.
- <https://www.bristol.ac.uk/media-library/sites/sps/documents/wtpn/2016%20WTPN%20UPDATE%20OF%20THE%20GPG%20-%20finalised%20with%20cover.pdf>
- Wright, B., & Edginton, E. (2016). Evidence-based parenting interventions to promote secure attachment: Findings from a systematic review and meta-analysis. *Global Pediatric Health*, 3(0), 2333794X16661888.

## Appendix 1

### Interview guidelines and prompts

#### **Interview Guidelines**

##### **Preparing for the interview**

Think about what you know about the person you're meeting.

For example, how old are they? If someone is 50, this means they have grown up in the 1960s and 70s and they are likely to have a different experiences from someone aged 25 who grew up in the 1990s and 2000s. This might influence the direction of your questions.

Ask yourself if you need to know more about the person you're interviewing.

If the answer is yes, do some research online.

Then *prepare your questions* bearing in mind what you know about your interviewee and in the light of your research.

##### **When you arrive at the interview**

Arrive on time.

Look tidy.

Make eye contact and look pleased to see your interviewee!

##### **Introductions**

Introduce yourself. Give your name and say you are part of the Daughters of Fortune team from Mind The Gap Theatre Company.

Explain the project – Daughters of Fortune is a theatre project aimed at raising awareness of the experiences of learning disabled parents and the difficulties they may face.

Explain why we want to talk to them. We want to hear their experiences so that we can ensure that the project is as accurate as possible about learning disabled parents.



**Explain what will definitely happen.**

We will ask them questions and record the conversation. We'll also take notes on the conversation and take some photos.

We'll write up the conversation and return it to them for their approval in written or audio-recorded form. If they're not happy with it, we'll do our best to change it and make it as accurate as possible.

The agreed complete version of the interview will only be shared within the Daughters of Fortune team to help make the Daughters of Fortune play, Mia.

From the long version of their story we will make a shortened version – around 250 words – which will be put on the Mind The Gap website alongside a photo. This shortened version and the photo will be checked out with them before it appears in public.

**Explain what may happen.**

These images and shortened personal stories may become part of a Daughters of Fortune book.

We may want to film them at a later date. This film may be used in the daughters of Fortune production: Mia. We will talk to them about this before going ahead.

Reassure them that, at all times, we will consult them before we make further use of the material.

Check that they understand this. (We'll ask them to sign the consent form at the end of the interview.)

Test the levels of the audio recorder and have it ready - but don't turn it on till you feel it's appropriate.

**Starting the interview**

This can be the trickiest part of the process. Try to set the interviewee at ease by asking them something about where they are now, their territory and role, and establish what's happening to them on this particular day, what's on their mind now. For example...asking [parent] about...the organisation he works for. However, don't allow this to hijack the interview.

I would try to give the interviewee the opportunity to find their own starting point for their story by asking something like, 'Are you from Leeds?' 'Were you born in Leeds?' And then asking them about their own experience of family life which will lead naturally into talking about relationships and family.

From this starting point, think about moving forward in time – but sticking to the subject of children and parenting.

### **Possible questions – Not all will be relevant or necessary**

Did you want to have children when you were growing up? (Develop)

How did you meet the mother/father of your child?

How did the relationship develop?

Did you discuss the possibility of having children with your partner?

Did you discuss contraception?

How did you discover you were pregnant? How did you feel about it? OR -  
When did you hear your partner was pregnant? How did you feel about it?

Who did you tell? (parents, friends, professionals)

What was their reaction?

How did the pregnancy progress?

What did you enjoy about the pregnancy/this time?

What were your fears?

Were you assessed by social workers for 'parental capacity'? What was that like for you?

What were the first signs you were going into labour? OR How did you hear your partner had gone into labour? Were you present at the birth?

Where did you give birth? Who was with you? How did it go for you?

OR - What was it like for you, watching your partner giving birth to your child?

OR - How did you hear your child had been born?

How did you feel when you first saw your child?

What happened then?

When were you first alone with your baby? How did you feel about this?

How was it when you first came out of hospital/took the baby home?

What were the best/worst things about this time?

.....

**If the parent has not been allowed to keep the child, think about asking...**

When was the child removed?

What were you told were the reasons?

How did you feel when you heard the decision?

Did you try to fight against it? What did you do?

What did you find most difficult?

Who helped you through this time?

Were there times when you felt you couldn't cope? (What happened?)

Looking back now, what could have been done differently which would have made this easier for you?

**If the parent has kept the child ...**

Think about asking about the following areas if relevant – and if they don't arise naturally.

Feeding the baby – breast/bottle/solids

Nappy changing/ general care for the baby/ when the baby is ill.

Sleep – the parent's and the baby's.

Who helped - or hindered? Childcare and professional support/ scrutiny?

Getting around with the baby. Playgroups etc

Other parents?

Asking for help from professionals/refusing help from professionals

Taking the child to school.

Dealing with schools.

Most difficult things?

Best things?

How is their relationship with their child now?

Looking back now, what would they change?

.....

**Whether they have kept the child or had the child removed...**

Anything else they want to add?

What's the most important thing for a play about learning disabled parents to get across to an audience?

.....

When the interview is drawing to a close – ask them to sign the Consent Form. Talk them through it. Make sure you have correct contact details and tell them when you'll get back to them with the written story.

*Writing Mentor, April 2016.*

## Appendix 2

### Additional illustrative quotes

#### Theme 1: Positions of powerlessness

##### *Subtheme 1: Early experiences of powerlessness*

"I hated school really. People just um, I used to get angry a lot, you know when I used to get bullied and stuff. And they used to....when I get angry I talk funny, I have a speech problem and people can tell and they'll laugh at me" (Louise)

"I think he (dad) was very over-protective of....of us and, which...which...I...I can understand why he...why he did it now, but back then I didn't understand"(Amy; referring to herself and her younger sister, who also has a learning disability)

"I was abused when I was the age of 8 [by father]...and then I was abused by my adoptive mam. But that was abuse of like hitting us with plates and like violent abuse" (Julie)

"When I was abused? I didn't tell anybody about it. I should of but I didn't. I kept it all in" (Alison)

"All through me childhood, I got told I couldn't cope with a child, but I proved them wrong...and they said I wouldn't have a job which I do" (Dawn)

##### *Subtheme 2: Abuse of trust in intimate relationships*

"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" (Amy)

"He was hitting us, and saying I was a rubbish mum which I wasn't, and he wouldn't have nothing to do with his son" (Dawn)

"My ex-husband treated me like...dirt, dirty because he wouldn't pay for buying clothes, I had to sell clothes for my daughter. And he wouldn't give me, you know, bus fare or anything, make me go walk...If I go out with him it's so hard, because he won't let me a drink or anything like that" (Fatima)

"I get up every morning try to help the kids get washed, get breakfast, get dressed and still he finds something to have a go at me about. He says I don't go enough" (Helen)

"I didn't trust anybody before then, because of what [partner] did. When he said things about us. I was watching a documentary and this documentary says, "The abuser normally comes from an abused..."...And I was worried in case I did with [child]...So every time we had an argument, or whatever, he told the social workers that I was actually doing things"  
(Linda)

### ***Subtheme 3: Feeling 'betrayed' by powerful others***

"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...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" (Amy)

"...the bad experience, when they took...my kids in care, the three last boys. The man said that oh, they are only going into care for a little while, I will get them back and that wasn't the case...We went to court, tried to fight custody to get them back, I couldn't get them back" (Marie)

"I think she um, she took advantage. And from me not understanding things and I think she [pause] she got what she wanted from the start" (Jessica)

### ***Subtheme 4: Denied a voice***

"My solicitor says if I don't agree to everything they say, they'll get adopted and I'll never see them again....I: They were telling you not to fight it? And what did you do? G: Nowt..I couldn't do nothing. Because nobody was no one to tell us otherwise" (Linda)

"My advocacy said, there's a person in the room who should...you should 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" (Jill)

- "It was hubby who was the problem because he hadn't...he's an alcoholic. He started causing problems again. Now I did inform the social worker but she didn't listen to me, she was all for hubby. So everything I had to say she didn't listen to me" (Amy)

## **Theme 2: Assumptions of incompetence**

### ***Subtheme 1: Presumed parental inadequacy***

"Just because with me having a mild disability because I've got dyslexia, and they thought I couldn't have children which I have got three" (Dawn)

"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" (Amy)

"They always had something to say...I remember them coming when she was a baby, and they says, Carol, why have you got teddy bears in her cot...what if that teddy falls on her face? I says, there's no way that teddy will fall on her face...I had ribbon and elastic bands so that the teddy's neck was stuck on the thing and couldn't fall on me baby....Everything she thought looked wrong was actually great" (Carol)

### ***Subtheme 2: Onus on parents to prove competence***

"It made (husband) very very frustrated at the fact that just because we're Asperger's we had to go through all this, it still does" (Kimberly)

"I felt a bit stressed with us being pregnant and all like ...do I need the social services to help us or not? But you got them involved, didn't you? (to Patrick) ...I thought they were gonna help us" (Alison)

"I don't have anyone watching over my backs now and we can just we relax as well, cause it's, it's not nice knowing that people wanna keep an eye on you to see if you're a good mam"

### ***Subtheme 3: Unreachable and elusive standards and expectations***

"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" (Amy)

"When we're at court, these bloody contact people, says "Patrick is too far forward" and "you're too far back". So, where do you put yourself? You do everything right and you're too far forward. And Alison's too far back" (Patrick)

"Even though I tried to keep it altogether they would always try to bring...bring the person down. Bring me down" (Helen)

"Parents with learning difficulties...they're always forever getting crucified" (Mike)

### ***Subtheme 4: Set up to fail: denied opportunities and support***

"[With] some support, maybe I would have, maybe um a chance to be a mother... There was a lack of help when I was pregnant and after I had him...I was on my own" (Jessica)

"It would have been nice if I'd had more help instead of them just taking the boy off us"  
(Alison)

"I think they're missing out not putting the support in at the beginning...the support is in a crisis. That's what's making it difficult for parents with learning disabilities to keep their kids. They're coming in too late. They should be there at the beginning step by step" (Neil)

### **Theme 3: Challenging assumptions and proving competence**

#### ***Subtheme 1: Rejecting stigma and 'beating the system'***

"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 (got to put) labels to us every time? We're just human like them, we can't be treated no different." (Amy)

"It were difficult but I did it. It took longer for me, but I got there and it got faster over time when I got more confident" (Neil)

"It was a lot of hard work but I did it" (Helen)

#### ***Subtheme 2: Getting ready to be a parent***

"My mam had so many children and I helped to bring my brothers and sisters up. So I knew all the ropes....babysitting and taking kids in and that. And that's how I learnt how to look after my siblings. And I wanted to do it for myself" (Carol)

"First conversation I had with him was like, it was more like, are you nuts? We're not ready to have kids and...not necessarily those words but that sort of message. But no he was just learning how to handle living with me" (Kimberly)

#### ***Subtheme 3: Acknowledging support needs***

"Go and get help because....don't struggle. It's very hard struggling on your own" (Jill)

"Just be strong and ask for help if you need it" (Dawn)

"There should be people there that can help and make a difference for them and help, you know, help them and guide them... there's always something, or someone out there that can help you" (Carol)

"It is difficult but there is support out there for you, to help you. Even if it isn't like professional help you've still got your family" (Megan)

#### ***Subtheme 4: Qualities of the support network***



"The midwife, she was really good. She understood. She went on and found out about ADHD and we sat down and...She explained it to me more than what..." (Jill)

"I had two social workers, and I had good relationship with them, good support with them, yeah, good relationship...they found some funding for three months for me to get support from Parents Group, to take one child out one week" (Khalil)

#### **Theme 4: Claiming power**

##### ***Subtheme 1: Finding a voice***

"I told social services if I didn't have food in my cupboard, why did they us shopping to get my shopping" (Dawn)

"There's so many people they say 'oh get married, get married'. I say, 'no I don't need, I don't need to get married, you know'. I don't have to marry just people they're telling me to marry. I don't want to, I just want to be on my own now" (Fatima)

"I said, you must be joking. I said, what if she falls all the way down the stairs, or has an accident? Then it will be me who's to blame. I said, I'm not doing that" (Jill)

##### ***Subtheme 2: Empowerment***

"I'm a lot stronger than I used to be" (Julie)

"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" (Kimberly)

"I think (I'm) more accepting of what's happened. I can't change what's happened but I've got more involved in teaching and I think I've come a long way since I've been there. I'm more confident" (Jessica)

"[I] came to mothers group...so many things going around here since 13 years, I have felt like was my second house, home, you know, coming here and meeting some other friends who the same problem" (Fatima)

##### ***Subtheme 3: Mobilising change***

"Last week I was up and down the country on behalf of parents with learning difficulties" (Mike)

"I also do peer to peer 'cause... 'cause I understand 'cause I've been through it. I know what these mums have gone through. So I can relate to their feelings." (Amy)

"I: You've been able to tell your story to midwives? Adopters? L: People who want to adopt children...Social workers and students that are training to be social workers" (Jessica)

### **Theme 5: Fathers' experiences of being excluded**

"There was a Christmas party in 2016 in December, was my boss told me that I had a child. I was in shock; I went 'No!' I thought he was kidding me, pulling my leg, I went 'No! I don't believe you'" (Rick)

"All the professionals always think it's okay to kick fathers to the kerb" (Mike)

"I wanted to know, but they were more focusing on the mother. Also they didn't really clue me in; I felt really quite left out" (Neil)