

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

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