

RESEARCH SUMMARY:

The lived experiences of parent carers of children with learning disabilities attending mainstream education

What the research was about:

The study wanted to find out four things:

1. What life is like for parent carers of children with learning disabilities who go to mainstream school.
2. Whether their relationships with professionals affects their mental health and wellbeing.
3. Whether storytelling in research is helpful.
4. Whether parent carers trust researchers and would allow their children with learning disabilities involvement in future research.

What we already know from previous research studies:

A review of the research from the last three decades highlighted that parent carers often struggle to have their voices heard and have been found to be in continuous battles with education and health care professionals.

Life as a parent carer...

“I didn’t really know what I was doing ...nobody could tell me what to do”

[P002]

- After receiving their child’s learning disability diagnosis life for participants in this study suddenly changed and became full of uncertainty.

“Once you have a child with disability, I think it shows you the true, the true side of the world, ... I think the majority of people that have got nothing to do with disabilities live in that sort of perfect bubble ... they’re absolutely clueless on what’s really going on behind the scenes, and they cannot grasp or comprehend ...

He actually opened my eyes to so many things.” [P003]

“...unfortunately, there just isn’t support, you get these diagnosis and then you’re just left to get on with life [slight shrug of shoulders] there is NO [emphasised] support at all really.” [P002]

- There was a sense that nobody could fully understand the challenges of parenting a child with learning disabilities, trying to navigate different support and services.
- Difficulties around accessing and maintaining a good level of support and education for their children within mainstream schools was found to be particularly challenging.
- COVID-19 created setbacks to any progress already made.

“I had this speech and language assessment over the phone, it’s like, are you taking the micky! ...it [Covid] really created this opposite effect, and I think this is what has caused so much anger in me ... because it sets you back.” [P003]

Relationships with professionals...

“I am labelled ...the parent from hell.” [P001]

- Parent carers didn't feel listened to or understood when trying to communicate their child's needs to professionals which often left them feeling negatively judged.

It's the negativity, the constant negative comments that shouldn't even be a negative comment because he's got a disability.” [P001]

- Participants described a lack of support from professionals which led to feelings of loneliness and isolation but also a drive to learn as much as they could to support and advocate for their child.

[P003] ... how many children are failed because parents just take the answer from what they've been told from the authority? (p. 41)

- There was a sense that if professionals weren't listening or understanding it meant that they didn't have their child's best interest at heart and so the opposite must be true – they were fighting against them.

“It's always a fight, I've fought with so many different scenarios ... it's just constantly a battle. ... the way that everything runs is really, really, poor.

You do have to fight for a lot of things which is sad ... but yes, it's a constant fight for everything ... and it shouldn't be like that.” [P002]

Mental health and wellbeing...

“I just went home and thought and thought about it. A harmless comment but it will play on your mind as a parent”

[P002]

Vicious cycle

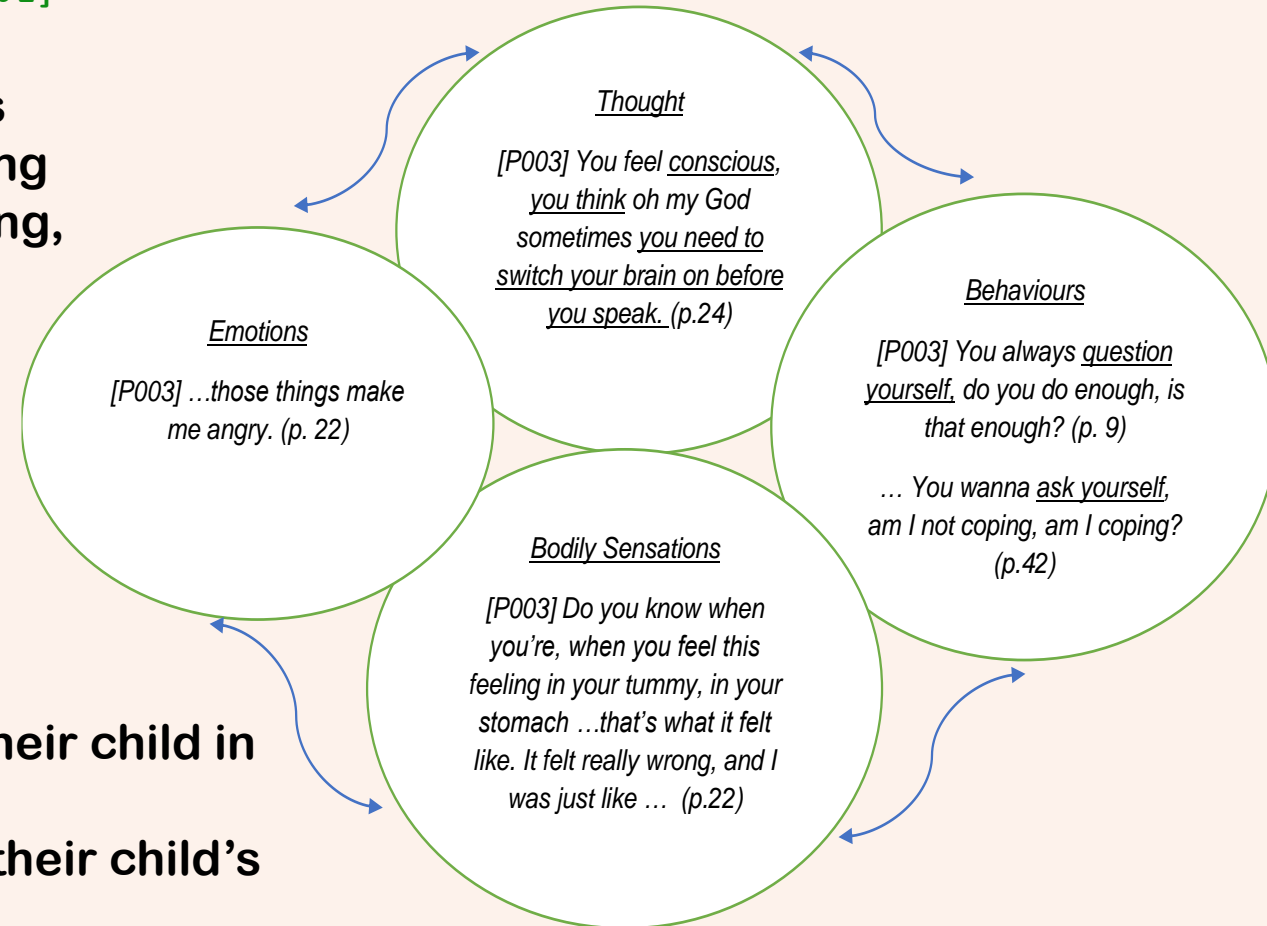
- The mental health and wellbeing of parent carers was found to be affected by negative relationships with professionals in mainstream education causing psychological distress including anger, overthinking, questioning, and a mistrust of professionals:

“They say one thing but do another.” [P001]

“They’re never completely honest.” [P002]

“I’ve actually lost faith in schooling full stop.” [P003]

- This mistrust was found to lead to fear:
- Fear of failing - to be heard when advocating for their child in mainstream education.
- Fear of being failed - by professionals involved in their child’s care.



Storytelling in research...

“...trying to pick and put together pieces of a puzzle to be able to move forward ” [P002]

- Storytelling was found to be a helpful way to gain understanding and promote mutual respect between participants and researcher.
- Co-production of stories painted a picture of parent carers lives.
- The birth of the story was at the point of their child's learning disability diagnosis.
- Metaphors were used as safe way to communicate difficult emotions and experiences that were hard to describe.
- Metaphors were symbolic of the meaning of participants experiences travelling on a bumpy, bumpy, road, experiencing a whirlwind of emotions, losing the plot, and trying to pick up and put together pieces of a puzzle, thinking outside the box, and moving forward.

“...they're trying to push my buttons.”
“...I'll fight my corner,” “...I won't take it lying down.” “I will nit-pick at everything.” [P001]
“So yeah, bumpy, a bumpy road, not ideal.”
“...knock backs and setbacks like that ALL the time.”
“...it's just [shakes head, small shrug of shoulders, slight pause, small smile] ...mind blowing.”
“It's definitely been a, a whirlwind.” [P002]
“...losing the plot on occasions,” “...that's the bottom line,” “...moments I think, my God everything is going to pot.” “You just have to make do with what you can do basically. Or think outside the box.”
“... it all sounds very doom and gloom [soft laugh] which it isn't [laughs].” [P003]

Parent carers attitudes to research...

“Awareness for me is absolutely THE important bit ... that is something I feel so very strong about.” [P003]

- **Parent carers appear open to their and their children’s involvement in research.**

“... it’s useful isn’t it, anything you can do to be helpful. ...plus, I found it important for myself because I learnt something else as well.” [P003]

- **Having a voice in research was understood to be important but there was a fear that data collected would not directly impact services and provision or the day to day lives of parent carers.**

“...you do all the hard work and that’s for you know multiply people but its whether you then get listened to because you’re trying to make a difference and trying to make a change, so I’ve always been open to it, [research] I think it’s a really good thing, um it’s just you know, that part of ...I hope that people listen you know?”

- **Participation in the research promoted understanding and mutual respect, offering an opportunity for the sharing of knowledge and experience.**
- **Being involved in research was identified as an opportunity to share a view of the world which can’t always be seen or understood.**

*“...to me Down Syndrome isn’t a disability, he’s just a different type of human.”
“He’s just deals with things differently you just have to teach him differently but that doesn’t make him disabled.”
“It’s just a different point of view.” [P003]*

Surviving and thriving - evidence of post traumatic growth...

“This is just a temporary downer and I know it will improve ... I’m trying, trying, trying” [P003]

- Advocating for inclusion and equity for their children was found to **counteract psychological distress**.
- Fear of failing to be heard and fear of being failed was found to drive their resolve and offer **purpose and meaning** leading to post traumatic growth.
- **Post traumatic growth** was evidenced to lead to **surviving and thriving**:
- Development of a growth mindset – being open to different perspectives and the sharing of knowledge and experiences.
- Supportive relationships with professionals – genuine, open, honest conversations.
- Respite – mindfulness, yoga, friends, hobbies.
- **Accessing specialist counselling/psychotherapy services.**

“I do know I need a break sometimes, so we have things planned.” [P002].

“I know when I have to take time out for myself.”

“... appreciate the little things.”

“... if you’re flexible and able to adapt that’s more beneficial.”

“Avoid all the outside stress.” [P003]

“I really don’t have time for negativity in my life” [P002]

“Practice mindfulness.” “Go to yoga.”

“See friends.” “Photography ... that keeps me sane.”

“... it’s just a different point of view.” [P003]

“... he’s had really good teachers. [P001]

“There should be counselling there for parents.” [P002]. “...a neutral person ...just listens, then the perspective sometimes is more helpful.” [P003]

Conclusion

- Although only a small study involving three participants it provides evidence that parent carers lives can often be adversely affected by their relationships with professionals in mainstream education settings, adding to existing research where for over thirty years parent carers have been found struggling to have a voice and facing battles when advocating for their children with learning disabilities.
- Involvement in research using storytelling offers a safe and effective way to facilitate a change of experience and knowledge for both researcher and participants, supporting mutual respect. Giving parent carers a voices offers purpose and meaning to support post traumatic growth with the potential to impact services and provision to improve their lives.
- Future research involving children with learning disabilities can be facilitated by building trusting relationships with parent carers.

“I feel as if like I’ve got all these balloons in my hand and I’m floating above everybody else because somebodies actually LISTENED to what I’ve got to say and, I feel as if, ACTUALLY. I’m not wrong.” [P001].

