

Research summary:

The lived experiences of new mothers accessing feeding support for infants with Down syndrome during the COVID-19 pandemic.

1 What was the research about?

Parents of infants with Down syndrome may require more support with feeding than parents of typically developing infants and high quality feeding support is important for maternal wellbeing. Throughout the pandemic, many feeding support services were offered virtually rather than face to face. Recent research suggests that virtual feeding support offered during the pandemic has impacted mothers' feeding experiences negatively. Studies conducted before the pandemic suggested that feeding support for mothers of infants with Down syndrome was already insufficient. As such, we were interested in finding out how changes to feeding support services as a result of COVID-19 have affected mothers of infants with Down syndrome and wanted to explore their personal feeding experiences in rich detail. Thirteen mothers of infants with Down syndrome who gave birth shortly before or during the pandemic took part in semi-structured interviews.

2 Results



Every baby with Down syndrome has a unique journey

This theme deals with the assumptions and expectations that can come with a diagnosis of Down syndrome and their conflict with the reality that every baby with Down syndrome has unique needs, strengths and a unique experience.

Taking the scenic route

- Negative expectations automatically placed on baby's feeding due to diagnosis.
- Babies able to reach developmental milestones but may need different levels of support and time.

Down syndrome is just one aspect of a whole person

- Don't want health professionals to make assumptions about feeding due to Down syndrome.
- Babies with Down syndrome have differing strengths and challenges.
- Babies should be treated as individuals and personal strengths and needs explored.
- Health professionals focussed on Down syndrome diagnosis but it is just one part of a person.

Positive expectations

- Important to be given positive expectations of baby- improved coping and perseverance during feeding difficulties.
- Positive information about lives of people with Down syndrome aids acceptance of diagnosis.
- Wanted more positive information before leaving hospital instead of searching for it afterwards.

"Just because she has Down syndrome, it shouldn't mean that she's held back from doing things. It might take her a little longer...they started describing things as taking the scenic route, which I think is quite a nice way of looking at it, really... It just means that yes, you might not necessarily meet all these milestones that nuns feel pressured to have the baby doing by set points, but she will get there eventually."

There's no point asking, they won't know

This theme addresses the relationship breakdown between mothers and health professionals. Eight mothers felt disappointed and lost faith in health professionals working with them and became reluctant to seek their support.

Communication breakdown

- Lack of faith/trust in health professionals
- Online resources/charities e.g. Positive About Down Syndrome (PADS) and the Down Syndrome Association (DSA) were a safety net- turned to the internet instead of asking health professionals.
- Had to make extra effort to access support as they couldn't get this from health professionals around them.

Can't understand the lack of effort

- Health professionals lacked knowledge of feeding infants with Down syndrome
- Unable to signpost mothers to other services when they didn't have answers.
- Mothers questioned why health professionals wouldn't take the time to learn more about Down syndrome.
- Felt like health professionals didn't care about supporting them.

Postcode Lottery

- Shouldn't be down to luck as to whether they can access the appropriate level of care.
- All babies with the same diagnosis should have access to the same services.
- However, one mother felt it should not be automatically assumed that infants with Down syndrome will struggle with feeding- preferred idea of waiting for a specific reason for concern.
- Service adaptation varied by area
- Feeding support services adapted in different and inconsistent ways during lockdown. Adaptations differed within services, trusts and across geographical locations.

"There were a couple of general midwives on the normal ward who actually said, I wouldn't even attempt to try and combi feed because it can be confusing for normal babies at the best of times. So which I thought OK. Normal babies, mine must be some kind of alien."

Lack of in-person support

This theme explores the unmet needs of the mothers which resulted from reduced in-person contact due to social distancing measures.

I need to be physically shown

- Virtual feeding support not effective.
- Mothers wanted to be shown what to do in-person.
- Mothers not confident that professionals could see what they were doing properly over video call.
- Difficult to describe some feeding issues.

"I'm not very good at following instructions on the screen or from a piece of paper or something, I'm much better if somebody sits down with me and goes this is how you do it."

Lonely journeys

- Reduced peer support due to social distancing measures.
- No one to turn to for emotional support when things were difficult.

3 Conclusions

- Vast inequality and inconsistency in service access.
- Feeding support available throughout the pandemic was insufficient for some, virtual support could not completely replace the need for face to face support.
- Room for better education of health professionals regarding feeding infants with Down syndrome.
- Emotional support and encouragement are very important when encountering feeding problems.
- Health professionals should be more aware of support services they can signpost parents to.
- Recognition of individuality is important.
- Online resources are a safety net when parents are unable to access support via traditional routes.

Thank you to everyone who took part in this study! If you would like more information, please contact Laura Hielscher at l.hielscher@herts.ac.uk

With special thanks to: Positive About Down Syndrome (PADS), Down Syndrome Association (DSA), Sandra Redman and Barnet Integrated Group for Down Syndrome, Karen Afford and Hertfordshire Community NHS Trust, Johanna King and 'We Can Too' for photo reuse.

