

How autistic parents feel about breastfeeding and the support they receive

November 10 2023, by Aimee Grant, Catrin Griffiths and Kathryn Williams



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Surprisingly little is still known about autism and breastfeeding. A few years ago, [we reviewed](#) all of the research evidence and found limited

information about the experiences of autistic parents—beyond highlighting that the sensory differences when breastfeeding could be very challenging for them. We also found that communication by health professionals didn't always meet the [needs](#) of autistic parents.

So, for our newly released [study](#), we asked 152 autistic parents from across the UK about their breast- and formula-feeding experiences. Some 87% of those who breastfed were strongly motivated to keep [breastfeeding](#) even if they ran into difficulties, while only 54% of all the parents we interviewed used any [infant formula](#). This is a substantially lower rate of formula use than we'd typically see in the UK, where [88% of babies](#) receive some infant formula during their first six months.

Almost half of our respondents found breastfeeding to be a positive or enjoyable experience most or all of the time. This included the experience of feeling bonded with their baby and enjoying learning about breastfeeding.

That said, many of these autistic parents described experiencing sensory difficulties, with touch-related issues being their most frequently reported challenge. These issues ranged from discomfort caused by "little hands" touching their skin, to pain from infants suckling, biting and "latching on" to the breast.

Some 10% of our participants expressed breastmilk all of the time. This is higher than we would expect in an average group of parents, as expressing milk for every feed is [usually only done](#) when babies are premature or parents have returned to work. On the other hand, the feeling and sound of breast pumps could be unbearable for some of the parents we interviewed.

Interoception

Most people know about the five basic human senses: touch, sight, sound, smell and taste. But we also have three other senses that are just as important. The [vestibular system](#) helps us keep our balance and move around safely; [proprioception](#) lets us know how our muscles and joints are moving; and [interoception](#) tells us about what is happening inside our bodies, such as our heart rate, breathing and digestion.

Autistic people often have [different interoceptive experiences](#) to non-[autistic people](#)—such as either not knowing or being acutely aware that they are hungry, thirsty or need the toilet.

With regard to breastfeeding, 41% of our participants who breastfed told us that their interoceptive experiences relating to the [milk let-down reflex](#) (the response from your body that causes breastmilk to flow) was uncomfortable or painful always or most of the time. This included having "a feeling of dread" or the let-down reflex feeling odd in some way. One of our parents noted that "it felt like I had an old-fashioned telephone ringing in my breasts."

Adaptation strategies

Whether our parents breast- or formula-fed, the intensity of babies' frequent feeding could be overwhelming—a [well-known issue](#) among the general population of parents too. However, for autistic parents, carefully developed strategies to stay regulated and de-stress, such as going for a walk or watching an episode of a favorite TV show, could be disrupted by the busy routine of new parenthood.

The parents in our study had done a lot of problem-solving to reduce the sensory challenges of feeding their babies. This included adapting their clothing and distracting themselves during feeding by looking at a mobile phone, for example.

There is evidence that bonding is [not negatively impacted](#) by the use of smartphones when breastfeeding in a general population. So, these types of distraction should be encouraged for all parents who are finding breastfeeding hard but want to continue doing so.

While 76% of our parents had received some form of breastfeeding support, nearly three-quarters of these parents (71%) still reported feeling unsupported. Issues included there not being enough breastfeeding support available, and [health professionals](#) providing conflicting information—concerns that also found in the accounts of [non-autistic parents](#).

It also appears that those supporting infant feeding, such as midwives and health visitors, did not have a good understanding of autistic communication. For example, some parents felt they were not listened to or that their concerns were dismissed.

Furthermore, some parents felt that staff did not appear to understand the specific sensory and interoceptive differences that could affect autistic people while breastfeeding.

Room for improvement

Overall, our study suggests there is a need for better understanding of autism among those providing infant feeding support. The national autism training [program](#), which is developed and delivered by autistic adults, aims to improve this situation across England. Ideally, similar programs should be implemented in the other UK nations.

A second area for improvement is for autistic parents, their partners and other people supporting them to be aware of potential feeding issues in advance, so they can be better prepared. Our project provides a [suite of videos](#), designed and created by autistic health professionals and parents,

to help provide this information in an autism-friendly way.

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Provided by The Conversation

Citation: How autistic parents feel about breastfeeding and the support they receive (2023, November 10) retrieved 12 May 2024 from <https://medicalxpress.com/news/2023-11-autistic-parents-breastfeeding.html>

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