The importance of Autistic-led research on Autistic maternity

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#ActuallyAutistic

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Overview

- Autistic health inequalities
- What we know about Autistic maternity experiences
- Illustrating the research gaps
- Priorities for research
- The need for MARG





Health inequalities

- Autistic people consistently report barriers to equitable healthcare
- This has massive impacts on our lives:
 - Worse physical and mental health
 - Die 16 -30 years early
 - 9 x the suicide rate of non-Autistic people
- But most Autism research is focused on:
 - Autistic children (98% of USA funding)
 - Genetics

Autistic maternity

- Increasing diagnosis of women and girls
- Just under 1% of births in Wales are to those recorded as Autistic (personal correspondence, SAIL databank)
- Many Autistic birthing people are diagnosed after the birth of their own children



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Autistic women's views and experiences of infant feeding: A systematic review of qualitative evidence



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Abstract

Low breastfeeding ratios are driven by multiple bit opportho-social factors. Superismon of breastfeeding is known to differ by material demographic factors (age, education and educative) but there is best resequition of factors can be an exemple-segmen. This review, prospectively registered with PROPERIO (registration smaller: CRD42021271465), systematically identified qualitative reasserth, convenerance and porsonal accusant related to Autotic mechans and infant feeding. Database searching intentified [225 recench, with themselic synthesis undervalem on 22 (sight pero enviewed stateders and 14 gays Brenstone) pieces. Our analysis identified that materially and infant feeding services were built on a lack of understanding of Austrain conduct, and were often maccostable at a time when Autotic monthers shough first a know of control and back of social support. Specifically relating to breastfeeding, leowhelps and determination were others high, and a misority of mothers reported by a lack of negaciny made breastfeeding inpossible for assess their formula seas viewed as according to be materially and estantistic of temporal made sincerial of the property made breastfeeding inpossible for assess. Bellet Specifically relating to breastfeeding inpossible for assess them formula position. There is an argent need for materially and infant feeding survices to accommodate the needs of Austractic mothers, including service deeps and staff testing.

Lay abstract

What is already known about the topic?

Mothers are encouraged to hexactified their balloss due to known health benefits for both balves and noothers. However, although breastleading is 'instead', that does not make it saay and many women experience challenges. Autistic women may foce additional barriers to breastleading when compared to near-copyinal women.

What this paper edits?

We reviewed all existing evidence on Autistic mothers' infant feeding experiences (22 pieces) and found that although many Autistic womes wanted to breastfeed, breastfeeding send effects for Autistic excellers for three key reasons. First, materiaty and infant feeding services were inaccessible and unapportive to Autistic mothers for excellenging they did not receive help when needed. Second, becoming a mother was challenging because of exhaustion, loss of control over routines and a lack of accid support. Third, when breastfeeding Autistic mothers experienced sensory dullingue, such as 'being stoched out,' and pan, which could feel unbearable. Despite these difficulties, many Autistic mothers had done a lot of reading about breastfeeding and were determined to breastfeed their habites; some mothers found breastfeeding positive. Infant formula was often viewed as second-best compared to breastfeed, but some mothers found the ritual of proporing booths of formula to be calving.

Implications for practice, research or policy

The findings of this work show that Autistic mothers urganish need better support from health professionals to help meet their breastleeding goals, including how to remove or reduce the extra barriers being Autistic brings to breastleeding.

Keyword

autism, breamfooding, infant feeding, maternity

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FindingsStrong d

Autistic experiences of infant feeding

- Existing literature
 - 8 papers
 - 14 pieces of grey literature
 - Strong desire to breastfeed
 - The same challenges as non-Autistic people
 - Additional challenges
 - Inadequate support

Inaccessible infant feeding support

- Lack of information/conflicting information (-)
- Grabbing breasts (-); giving verbal descriptions and watching feeds (+)
- Telephone calls (-)
- Group support (+/-)
- Online (+)
- Researching themselves (+), but hard to put it into practice (-)

I received a lot of conflicting information which I found incredibly stressful.

They kept grabbing my breasts and nipples without my permission and pushing it into my baby's mouth.

I was very lucky to have a great breastfeeding support group locally with an in person and online presence so there was always someone to contact day or night.

Lots of general support and positioning advice/nipple shield offered by special care staff. Was incredibly useful

Research gaps

- Limited research to date
 - Not all is in a neurodiversity affirming paradigm
 - Limited input of Autistic people in the development of the research
 - Limited data on the experiences of multiply-marginalised Autistic people
 - Limited data on the experiences of Autistic staff

Conclusion: the importance of MARG

Everybody is Autistic

