

# The importance of Autistic-led research on Autistic maternity

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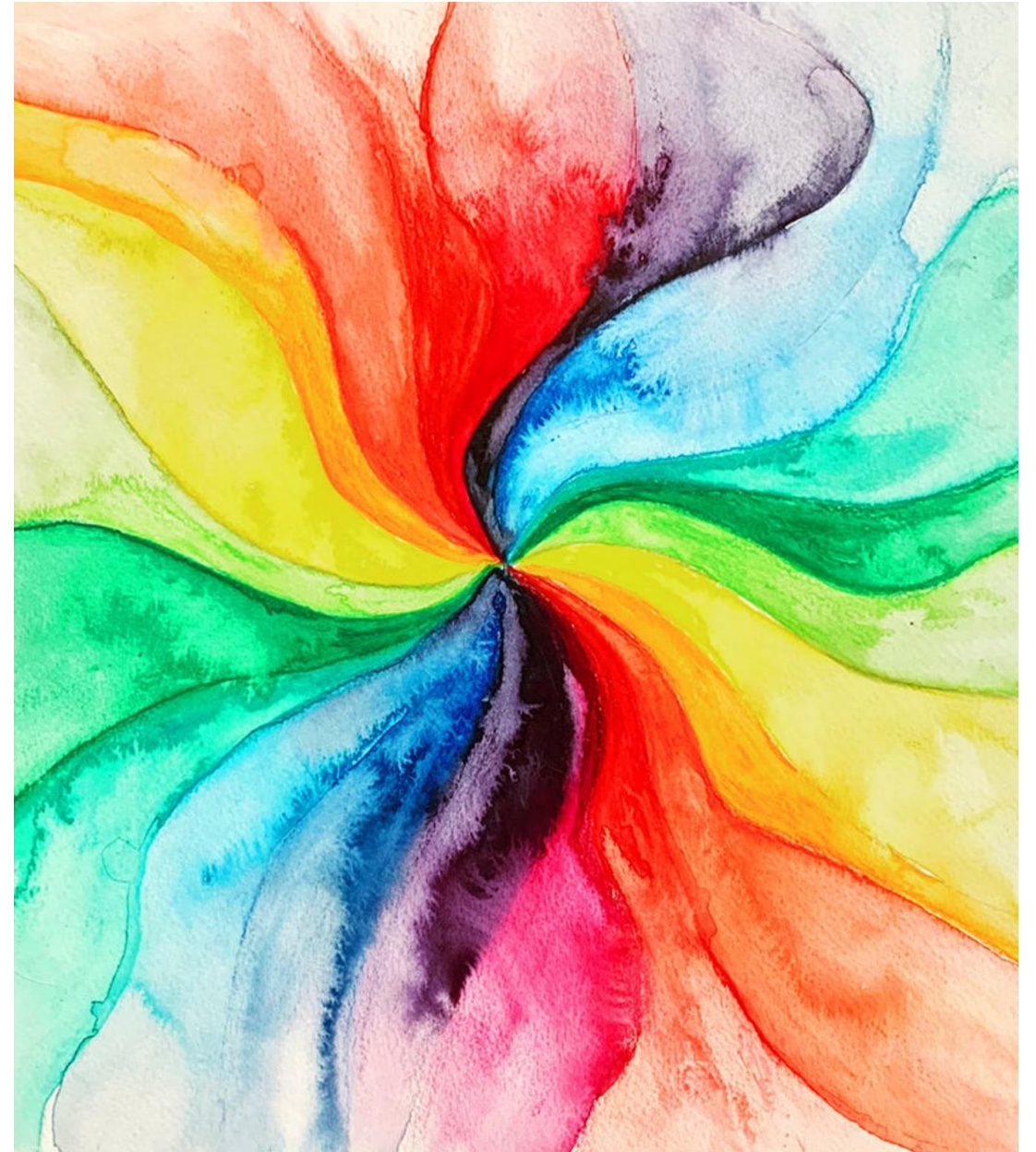
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#ActuallyAutistic

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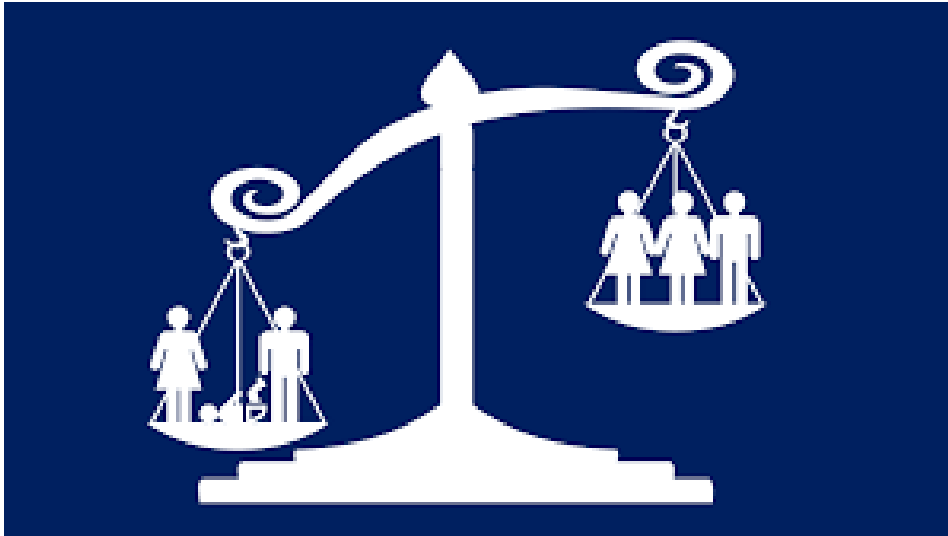


# Overview

- 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





# Autistic experiences of infant feeding

- Existing literature
  - 8 papers
  - 14 pieces of grey literature
- Findings
  - 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

