



# Supporting Autistic parents with infant feeding

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# Overview



Autism and terminology

Bodily & sensory differences

Research methods

Communication with maternity staff

Maternity experiences

Infant feeding experiences

Resources and contact details

# Autism: a brief description

- ▶ *Autism* from the Greek *autos* (self) – 1908
- ▶ Asperger – *little professors* V *autistic psychopaths*
- ▶ 1 in 36 people (CDC, 2023)
- ▶ Autism + Environment = Outcome (Beardon, 2021)
- ▶ **Differences** in communication style and sensory processing
- ▶ 1/3 learning disability (but 2/3 don't!)
- ▶ Many Autistic people flourish and experience significant joy
- ▶ Can be intensely Disabling without accommodations
- ▶ Equality Act 2010 – reasonable accommodations



# Terminology

Preferred	Offensive
✓ Autism	<ul style="list-style-type: none"><li>• Autistic Spectrum Disorder/Condition (ASD/ASC)</li><li>• <i>Asperger's Syndrome</i> (unless the patient uses it first)</li></ul>
✓ Autistic person/people	<ul style="list-style-type: none"><li>• "suffers from Autism"</li><li>• Person with Autism</li><li>• "On the spectrum"</li><li>• "severely Autistic" / "high functioning Autistic" / Autism Level 1-3</li></ul>
✓ Allistic or non-Autistic person/people (everyone <b>not</b> Autistic)	<ul style="list-style-type: none"><li>• "we're all a little bit Autistic"</li><li>• "normal people"</li></ul>
✓ Neurotypical person/people (everyone not neurodivergent)	

**More info:**  
How To  
Talk  
About  
Autism:  
<https://coda.io/@mykola-bilokonsky/public-neurodiversity-support-center/how-to-talk-about-autism-respectfully-84>

# Some key words

- ▶ Masking
- ▶ Regulation | re-regulation
- ▶ Stimming | self stimulatory behaviour
- ▶ Overwhelm | Dysregulated
  
- ▶ Meltdown
- ▶ Shutdown
  
- ▶ Burnout
  - ▶ (Suicide rate 9 x neurotypical people)

## **Stimming:**

- Toe/finger tapping
  - Touching hair
    - Biting nails
- Moving body from side to side
  - Pacing
  - Hand flapping
  - Chewing
  - Drinking
  - Eating



# Everyday sensory differences

- ▶ Sensory challenges
  - ▶ Sight
    - ▶ Light
    - ▶ movement
  - ▶ Sound
  - ▶ Touch
    - ▶ Clothing
    - ▶ Touch by people
  - ▶ Smell
  - ▶ Temperature
- ▶ Challenges reduce processing speed
- ▶ Sensory joy!
- ▶ Interoception



# Bodily differences and maternity

## Differences

- ▶ Mental health – depression/anxiety – but a likely response to trauma
- ▶ Hypermobility, dysautonomia & pain -
- ▶ EDS - Allergies (Mast Cell Activation Syndrome) - Long COVID –
- ▶ Pain processing

## How they could impact BF

- ▶ Hypermobility, EDS and/or dyspraxic – harder to hold baby
  - ▶ Pain
  - ▶ Subluxation of joints
- ▶ Fatigue – stamina
- ▶ Anxiety – are they getting enough milk?

# Systematic review

## 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



Cyngor Cyliddo Addysg  
Uwch Cymru  
Higher Education Funding  
Council for Wales

hefcw

Funded by RWIF



# Our study

## Online survey

- UK based
- Autistic adults
- Had been pregnant

## Participants

- 165 participants had given birth
- Privileged sample



Funded by  
Accelerate  
Healthcare  
Technology  
Centre

# Sensory experiences during pregnancy

- ▶ Increased sensitivity to sensory environment

- ▶ Light – 34%\*
- ▶ Sound – 48%
- ▶ Touch – 62%
- ▶ Smell – 79%

- ▶ Increased sensory sensitivity led to

- ▶ Anxiety – 70%
- ▶ Discomfort – 62%
- ▶ Distress – 43%
- ▶ Shutdowns – 30%
- ▶ Meltdowns – 22%

Medical settings  
are **very bright**

The doppler can  
be **overwhelming**  
to sensitive ears.

Gel for  
ultrasound was  
**horrible.**

I **shut down** and  
**couldn't talk** to  
anyone

\* Percentages are for “always” or “most of the time”

# Hospitals as “sensory hell”

- ▶ Need to consider multiple areas
  - ▶ Waiting rooms
    - ▶ Space causes anxiety; loud, visual clutter
    - ▶ Other patients cause anxiety
  - ▶ Antenatal clinic
    - ▶ Space: visual and audio clutter; hard to process
    - ▶ Touching: need plenty of warning
  - ▶ Delivery suite
  - ▶ Postnatal ward

Staying in hospital can only be described as **sensory hell**, being **out of control** of the situation, out of **routine**, unable to sleep, **inevitable meltdowns**.

## Improve your hospital environment:

More than

Words: [https://www.boingboing.org.uk/more\\_than\\_words/](https://www.boingboing.org.uk/more_than_words/)

It's not rocket science:

<https://www.ndti.org.uk/assets/files/Its-not-rocket-science-V6.pdf>



# Communication during maternity appointments and birth

- ▶ Half of participants had someone attend appointments most of the time
- ▶ 31%\* felt understood
- ▶ 26% felt listened to
- ▶ 49% felt things were explained in a way they understood
- ▶ 40% were asked to consent prior to examinations
- ▶ 29% felt that, overall, they were supported
  
- ▶ Staff weren't always told that the person was Autistic:
  - ▶ Some didn't know they were Autistic at the time OR
  - ▶ Knew but there were barriers to sharing

\*Percentages are for always or most of the time



# Birth experiences

- ▶ Very few positive comments about treatment/staff
- ▶ Examinations undertaken without consent (n=13)
- ▶ Pain expressions not understood, so under-treated (n=9)

Given injection for placenta **against my consent**, VE's **without consent**, told to remain on my back, shouty midwife, cervix checked for damage **without information and consent, pain relief taken away when needed**, no trust in my intuition.

I planned an epidural with first to avoid extreme pain. I ended up having a natural back to back delivery which was **extremely painful**. The **midwife didn't believe I was in much pain** or in advanced labour, presumably as I masked my discomfort.

# Breastfeeding: positive experiences

- ▶ Strong desire to breastfeed

- ▶ Sensory joy

The **sensation of baby's body** against mine is **wonderful** and **very calming** but I struggle with little hands touching my skin so I wear nursing tops that cover most of my skin now.

- ▶ A self-regulation tool

I found breastfeeding **comforting** as I could be in my own little bubble without worrying about anything but my son, and **I felt the oxytocin** from it.

- ▶ Accomplishment

I believe that breastfeeding helped me **overcome the feelings of being overwhelmed** it stopped me from completely shutting down as I had a purpose and a reason that required me to function at some level.

- ▶ Easier than formula

I would have found the **nightmare of bottle prep** much harder

# Breastfeeding challenges

- ▶ Sensory
  - ▶ Touch: “touched out”; aversion; milk let down; wet skin from leaking; suck feeling
  - ▶ Noise: crying; breast pumps; suckling
  - ▶ Distraction helped
- ▶ Interoception
  - ▶ Feels odd
- ▶ Disrupts existing routine
  - ▶ Intensity

I have **extreme aversion** and **my skin crawls** sometimes. I have to put her down sometimes as her touching me whilst feeding is too much

I **really struggled** with **feeling wet** from leaked milk and getting wet clothes.

It felt like I had an **old fashioned telephone ringing in my breasts** (don't know how else to describe it). Thinking about it now, I can feel it again and I haven't breastfed in over 9 years.

The intensity **was overwhelming at times** and the **need to be physically present prevented using usual coping strategies** of time alone to de-stress.

# Experiences of breastfeeding 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



# Formula feeding experiences

► Formula feeding reported by 84 participants

► HP recommended “top ups”

It was **forced on me** by the hospital in order to discharge. I found it **very distressing** because I wanted to breastfeed

► Challenging to prepare

I just found it **overwhelming** to keep track of making the bottles and keeping everything sterilised and ready.

► Felt judged

I felt **guilty**. I felt like I couldn't prepare it quickly enough. I felt **judged**.

► Easier than BF

I found formula feeding **easier than breastfeeding** but I got **very confused** with the changing rules with each baby

# The Autistic, pregnancy, birth and beyond: your questions answered project



- An entirely Autistic project
- Over 100 videos, divided into playlists:

Pregnancy	Birth	Postnatal
<ul style="list-style-type: none"> <li>• Autistic experiences</li> <li>• General information</li> <li>• Antenatal appointments</li> <li>• Complications</li> <li>• Pregnancy loss</li> </ul>	<ul style="list-style-type: none"> <li>• Autistic experiences</li> <li>• Hospital survival guides</li> <li>• Different places to give birth</li> <li>• What to expect</li> <li>• Types of pain relief</li> </ul>	<ul style="list-style-type: none"> <li>• Autistic experiences</li> <li>• Shortly after birth</li> <li>• Feeding your baby</li> <li>• I think something might be wrong</li> <li>• Rights over your child</li> </ul>

RESEARCH  
WALES  
INNOVATION  
FUND (RWIF)



Autistic Parents UK



Swansea University  
Prifysgol Abertawe

# Next steps & follow my work

- ▶ Building on the findings
  - ▶ [Maternity and Autism Research Group \(MARG\)](#)
  - ▶ Writing the Autism Friendly Guide to Pregnancy (Jessica Kingsley Publishers, 2025)
- ▶ Autism from menstruation to menopause
  - ▶ £2.4M Wellcome Trust Career Development Fellowship (2022-2030)
  - ▶ First 3 papers in press
  - ▶ Web: <https://www.autismmenstruationtomenopause.com>
  - ▶ Facebook: [Dr Aimee Grant: Autism from menstruation to menopause](#)
  - ▶ YouTube: [@https://www.youtube.com/@AutismMenstruationToMenopause](https://www.youtube.com/@AutismMenstruationToMenopause)
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