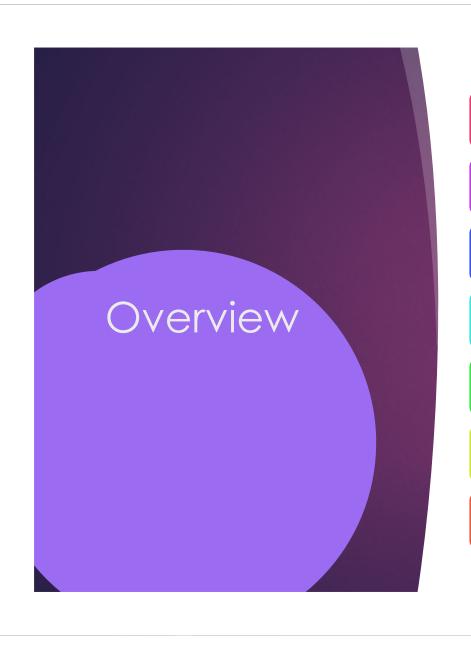


Supporting Autistic parents with infant feeding

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Autism and terminology

Bodily & sensory differences

Research methods

Communication with maternity staff

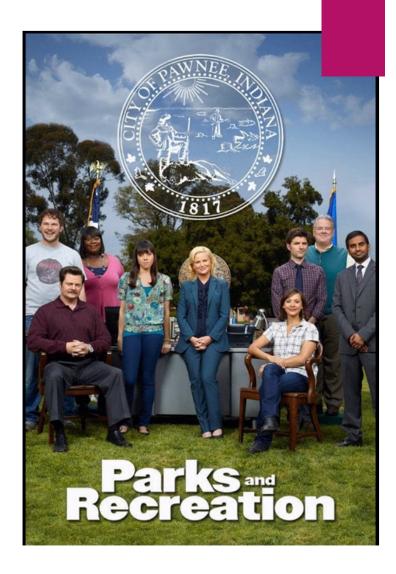
Maternity experiences

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	 Autistic Spectrum Disorder/Condition (ASD/ASC) Asperger's Syndrome (unless the patient uses it first)
✓ Autistic person/people	 "suffers from Autism" Person with Autism "On the spectrum" "severely Autistic" /"high functioning Autistic" / Autism Level 1-3
✓ Allistic or non-Autistic person/people (everyone not Autistic)	 "we're all a little bit Autistic" "normal people"
✓ Neurotypical person/people (everyone not neurodivergent)	

More info:

How To Talk About Autism:

https://coda.io /@mykola-

bilokonsky/publ

neurodiversitysupport-

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
- ► Hypermobile, dysautonomia & pain -
- EDS Allergies (Mast Cell Activation Syndrome) - Long COVID –
- Pain processing

How they could impact BF

- Hypermobile, 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

autism Autistic women's views and experiences of infant feeding: A systematic review of qualitative evidence Aimee Grant 10, Sara Jones 10, Kathryn Williams 10, Jennifer Leigh³ and Amy Brown¹ Abstract
Low breasfeeding rates are driven by multiple his peptho-social factors. Experience of breasfeeding is known to differ by natural denographic factors (sp., education and elevinity) but there is been recognition of factors and sensor of the senso

Lay abstract.

What is already issues about the tape?

Mother as similar losses about the tape?

Mother as encouraged to breamfeed their babies due to known health benefits for both babies and mothers. However, should be a supported to the second of the

Implications for practice, research or policy.

The findings of this work show that Austric mothers urgently need better support from health professionals to help mee their brastfeeding goals, including how to remove or reduce the entre lawriers being Austric brings to breamfeeding.

Swarses University, UK Pauline UK CK, UK University of Kars, UK

Cyngor Cyllido Addysg Uwch Cymru Higher Education Funding Council for Wales

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



- ► 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/

It's not rocket science:

https://www.ndti.org.uk/assets/files/lts-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 do 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"
- ▶ Challenging to prepare
- Felt judged
- Easier than BF

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

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

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

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

BIRTH BEYOND BEYOND PUESTIONS ANSWERED

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

Pregnancy	Birth	Postnatal
 Autistic experiences General information Antenatal appointments Complications Pregnancy loss 	 Autistic experiences Hospital survival guides Different places to give birth What to expect Types of pain relief 	 Autistic experiences Shortly after birth Feeding your baby I think something might be wrong Rights over your child

RESEARCH WALES INNOVATION FUND (RWIF)











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
- Contact me
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