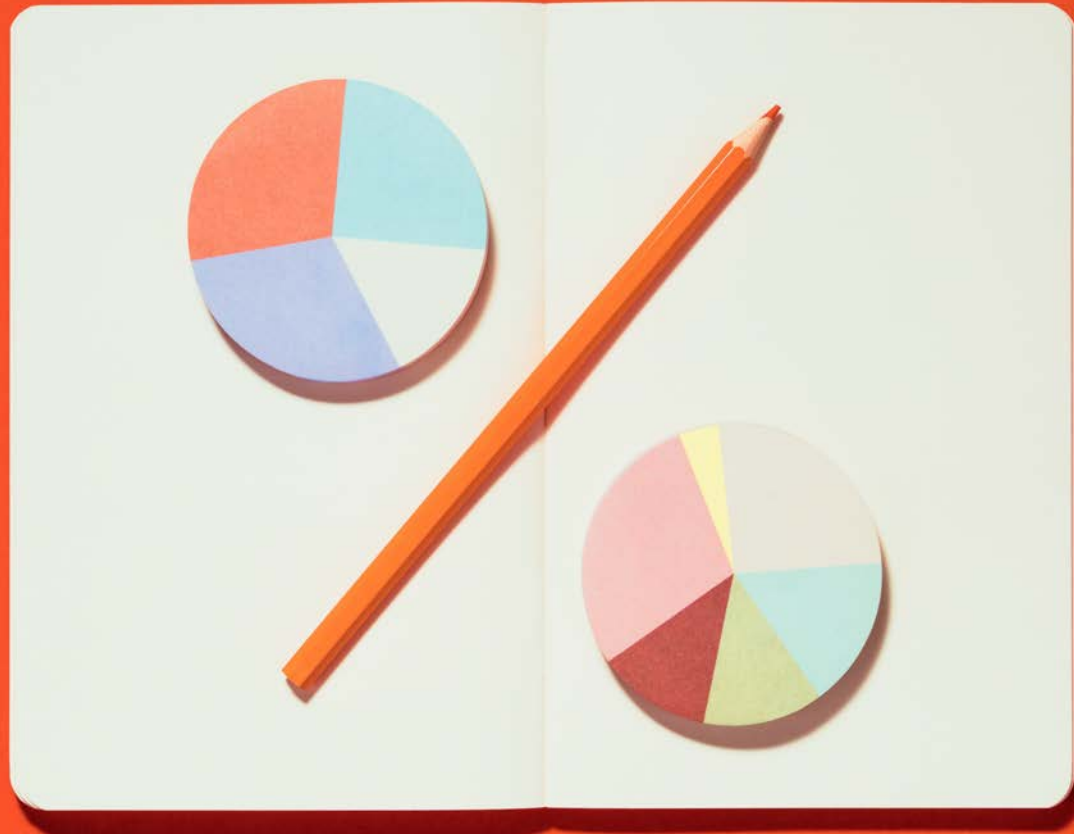# THE AUTISTIC BIRTH EXPERIENCE

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**\*An autistic mother researching the autistic birth experience**

# Contents

# Introduction



**Background:**
**Why is important to focus on the autistic birth experience?**

I. Most studies take a biomedical perspective or medical model of disability

II. There is a scarcity of studies looking taking a biopsychosocial approach

III. Autism is a complex condition with a heterogenous population- affecting medical, social, interpersonal interactions

IV. The birth experience has been particularly under-researched

V. We need to elevate autistic mothers/birthers' voices as well as their partners/significant others

# Research Aims

TO DEVELOP A BETTER UNDERSTANDING OF AUTISTIC MOTHERS' PERSPECTIVES OF ANTENATAL AND POSTNATAL CARE.

TO EXPLORE THE AUTISTIC PERSON'S BIRTH PARTNERS' EXPERIENCE OF THE TRANSITION TO FATHERHOOD.

OFFER RECOMMENDATIONS FOR BEST PRACTICE WITH REGARDS TO MIDWIFERY TRAINING AND MATERNAL SUPPORT.

# My background

## Personal

I. Diagnosis of autism – 'autistic bubble'
II. Biopsychosocial model of disability- (h)EDS, ASC, ADHD, stigma
III. Two babies in 3 years, two different Welsh Health boards.
IV. Blog, social media
V. Community identity and awareness
VI. Member of LGTBQIA+ community (George and Stobbs, 2017)
VII. Autivist (autistic activist)
VIII. Feminist (Ehrenreich & Deirdre English, 1989; Oakley, 2016) using inclusive language i.e. 'The Power of And' Einion (2021)

## Academic

I. Undergrad: linguistics, MSc: Autism and Related Conditions
II. Two presentations at London Southbank University's Participatory Autism Research Collective conference
III. Final dissertation data: strong findings inc no statistically significant difference between formal and self-diagnosed responses
IV. PhD: self-funded. MSc lacked midwifery and birth partner input.

## Professional

I. Let's Talk Birth conferences
II. Birth Rights Org e.g. UN Joint Response
III. Book via Jessica Kingsley Publishers
IV. Consultation work for accessibility include Birth Rights and Let's Talk Birth

# The Autistic Birth Experience: the findings of a self-reporting survey. Morgan, unpublished (2019)

◦ "I was filmed giving birth and it was shown as a perfect example because I was so quiet. I just assumed I'd die.  It still makes me weep over 40 years later."

◦
**"I was seen as a difficult patient and admonished, scolded, patronised, dismissed, or threatened."**

◦
"I've been very well aware that one should not share your diagnosis with any medical staff if possible as it's more often not well received, or the response is way more harmful than helpful".

# Research questions

○ • What is the autistic birther's perspective of antenatal and postnatal care?

• What's the experience of birth partners and what role does it play?

• What is the midwifery perspective of autism awareness and related training competencies?

• What is best practice with regards to midwifery training and maternal support?

# Key themes in literature

I.  Autism awareness issues (Sundelin, 2018; Higgins, 2018; Morgan, 2019, Bargiela, 2016; Sandland, 2018; Yasuda, 2016)

II.  Double empathy challenges (Milton, 2018; Milton 2019, Suplee, Gardner, Bloch, & Lecks, 2014)

III.  Communication barriers (Sundelin et al., 2018, Hull et al (2017)

IV.  Access to healthcare (Little, 2017; Redshaw, Malouf, Gao, & Gray 2013),

V.  Conflicting models of disability

**Methodological limitations and recommendations for further research:**

VI.  Elevating the autistic voice: working in partnership with autistic people (Hersh, 2021; Dugdale, 2021)

VII.  Mono-method designs: including mothers, birth partners and midwives in the sample

VIII. Elevating the voice of diverse and marginalised communities (Hussein, 2021; Brede et al., 2022)

# Qualitative Methodology: Exploratory approach

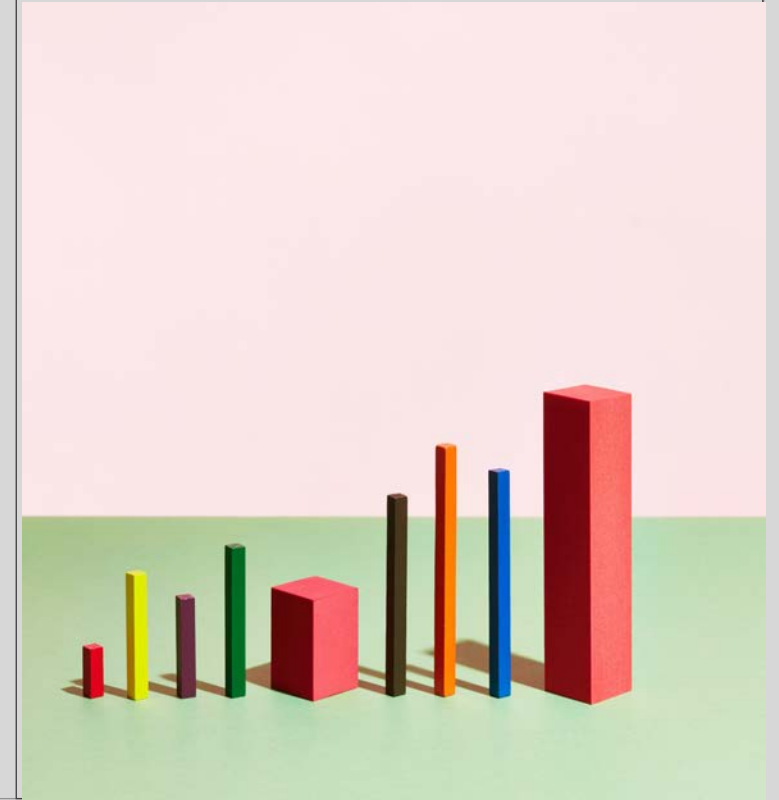**<u>Phase 1</u>**:
Data collection:

3-4 focus groups with 3-5 autistic mothers/birthers
3-4 focus groups with 3-5 fathers/birth partners

Sampling strategy/recruitment criteria:
Purposive and snowball sampling
via social media

For autistic parents, inclusion criteria were:

I.     participants 18 years and above,

II.    formal or self-diagnosis accepted (due to the under-diagnosed female autistic population), given birth (or have a partner who gave birth).

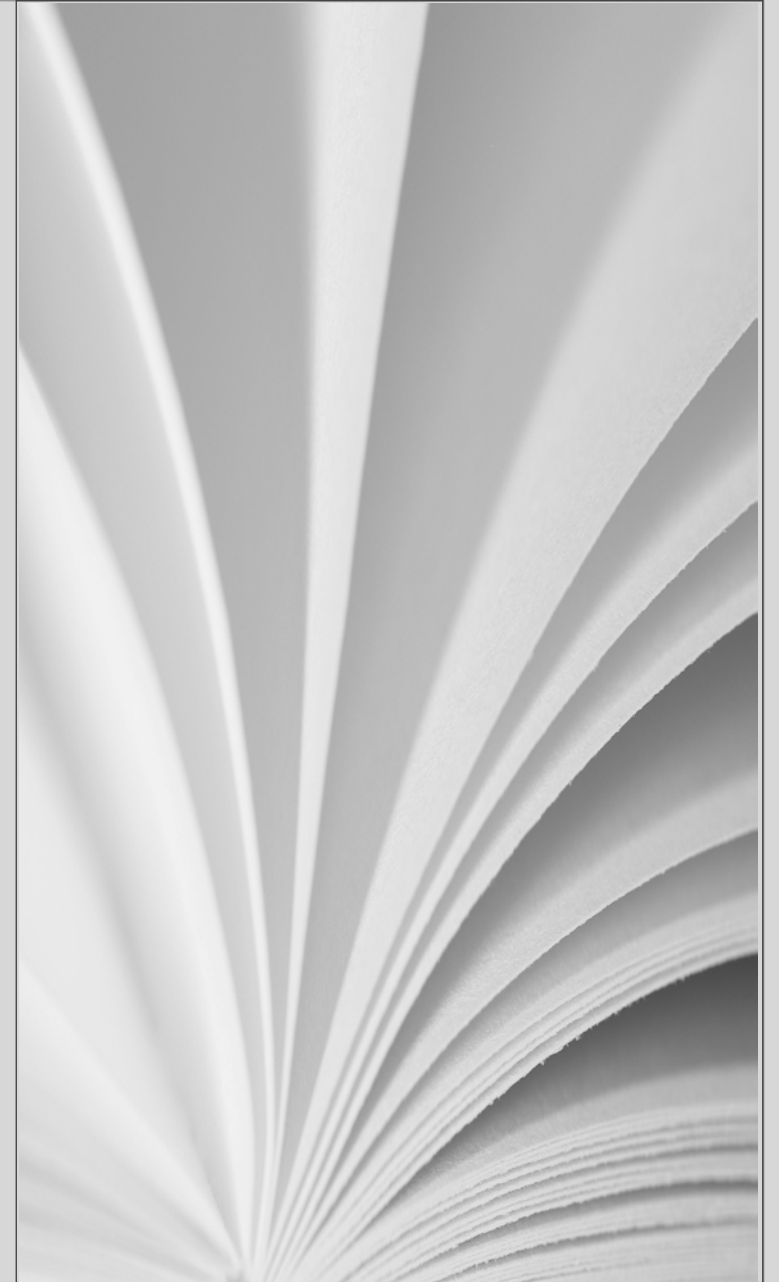III.   Given birth in the last 12 years, data needs to be relevant

## Phase 2:

Midwives at different career points to help cohesively contextualise both data sets

Interviews with midwives (10-15 until data saturation)

Interview schedule developed from Phase 1 data analysis

Sampling strategy/recruitment criteria: institutions, existing networks/gatekeepers within midwifery.

## Ontological and epistemological underpinnings

I. Critical realism *"illuminates the complexity of healthcare, through recognising that knowledge of this complexity is filtered through an interpretative lens* (Bhaskar in Walsh and Evans, 2013).

II. Biopsychosocial model of disability

III. Milton's double empathy problem

IV. Feminist ideology

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Participants will be entered into a prize draw with 5 x £20 Amazon vouchers to be won

Your voice is important to us

## The Autistic Birth Experience: Partners

Swansea University
Prifysgol Abertawe

Are you aged 18+ and an autistic parent? ( self or formal diagnosis welcome)?
Have you supported a partner in birth in the last 8 years?
Can you spare 45-60 mins of your time to help us better understand the autistic birth experience?
Zoom focus groups will be held online (communication adjustments available)

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ENTER ETHICS APPROVAL #

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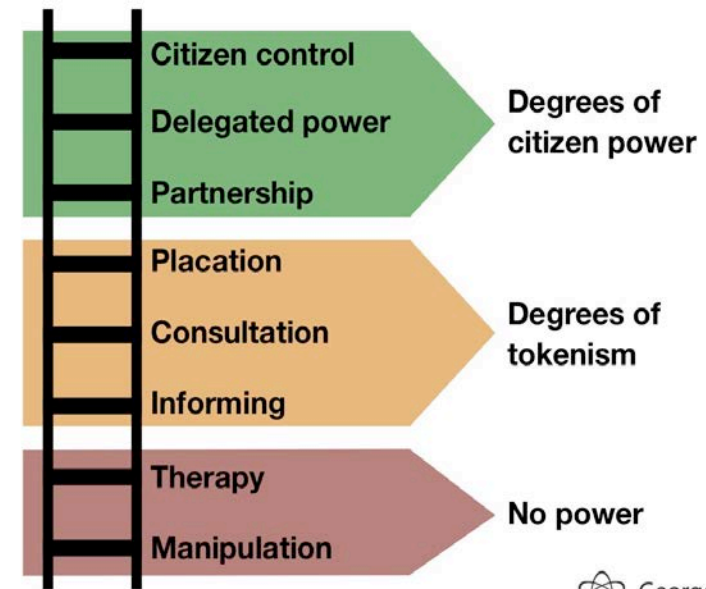
# Data analysis



- Braun and Clarke (2006) Thematic Analysis- to better serve the wider health, societal and personal contexts of responses. Power of voice.
- The Listening Guide (Woodcock, 2016). Self-reflection, mindful of own perspective.

- 'I Poems' 4 listens, transcription, 'I poems', themes generated.

- McCormack's Lens approach(2000) "identifying a multi-faceted 'natural' story that the participant is telling". An example of this is Dibley (2009)'s work where the researcher separates their identities as a nurse, a parent and a lesbian. Element of reflexivity for researcher too.

# Ethical considerations of working with the autistic population

◦ Inclusion and diversity: sampling considerations in relation to gender, sexuality, BAME representation
- Respect for Autonomy: Informed Consent (plain language etc.)
- Anonymity and confidentiality issues: when conducting focus groups
- Non-maleficence: What if participants get distressed?



Arnstein (1969) Ladder of citizen participation

Citizen control
Delegated power      Degrees of citizen power
Partnership

Placation
Consultation         Degrees of tokenism
Informing

Therapy              No power
Manipulation

George Julian
Knowledge Transfer Consultancy

# Who will be interested in the findings?

Autistic parents, relatives, friends and other members of support networks.

Midwives, Health Visitors, OBGYN consultants, GPs, obstetric registrars, certified midwife nurses, healthcare assistants on midwifery wards and other auxiliary staff.

Social workers, case workers, prenatal counsellors and advocates.

Academia: medicine, health and life sciences, nursing, health psychology, critical autism studies, campus autism specialist and other transition/disability professionals. Postdoc and policy.

# Conclusion- key issues

## Strengths

- Related topic evidence base comparatively strong: e.g., sensory considerations, co-occurring, transition planning.

- Increase in neurodiversity/autism awareness in previously under-diagnosed populations

- Medical, social and biopsychosocial model approaches aren't exclusive

- Rigor and reflexivity

## Challenges

- Few resources centre autistic voice without othering or pathologisation.

- Medical model, genetic investigation still dominant

- RCOG, NMC, NICE guidelines still aren't condition-specific for autism or other neurodivergent presentations except for MH

- Transparency over training

# Thanks for your time…

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