



# THE AUTISTIC BIRTH EXPERIENCE

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

# 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





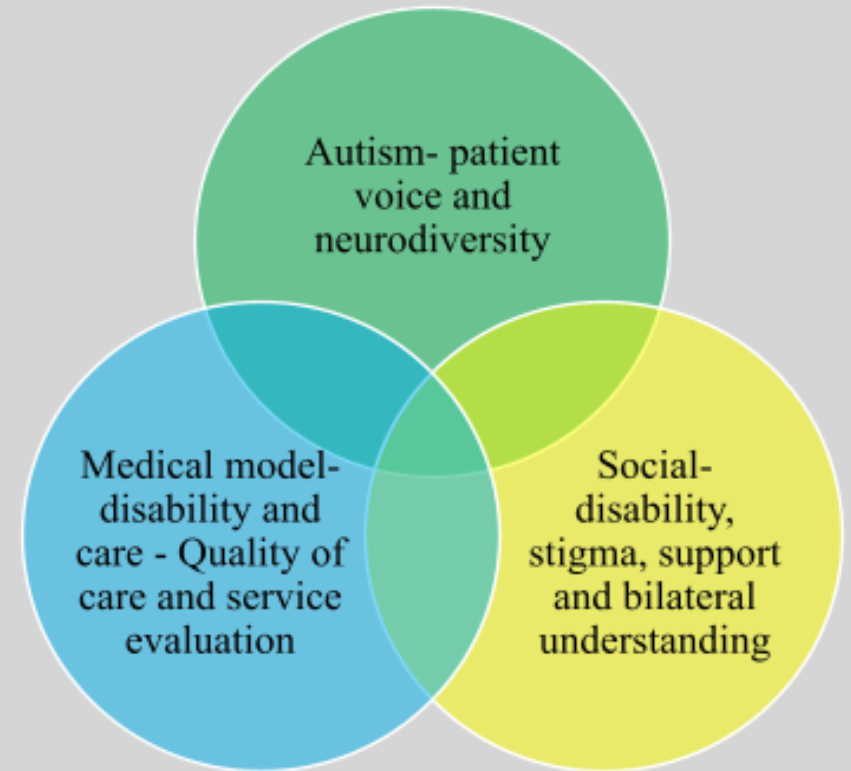
# My autistic birth experience



# Background(s)

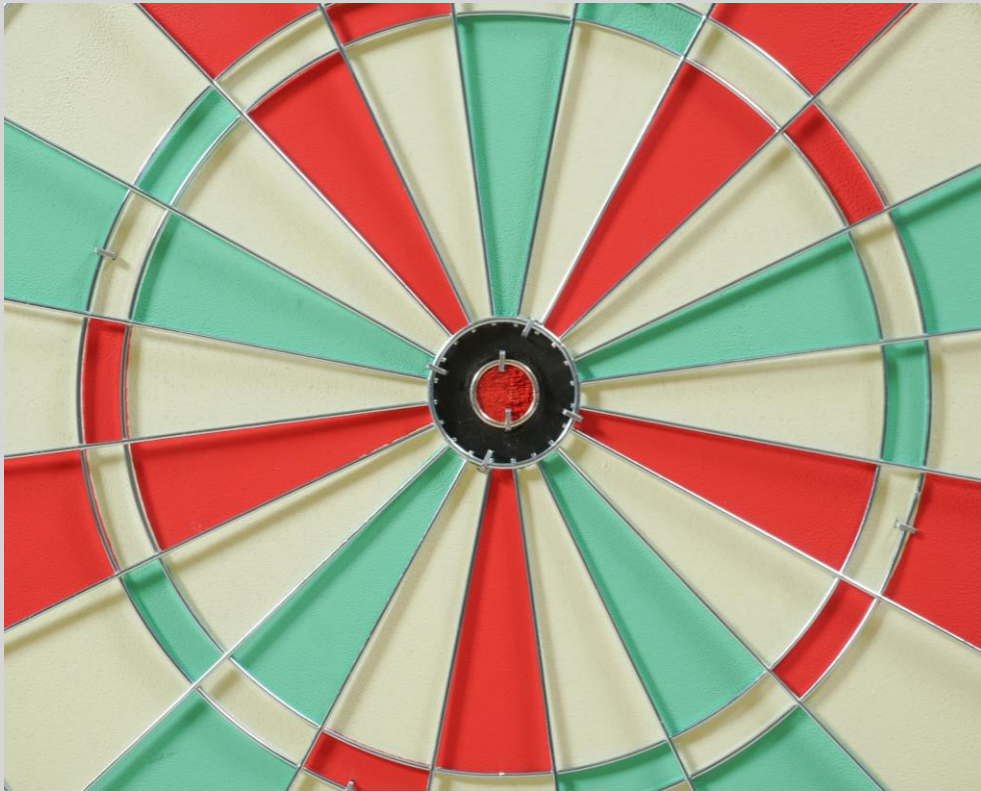
1. Diagnosis of autism – motherhood
  - Biopsychosocial model of disability- (h)EDS, ASC, ADHD, stigma
  - Birth experiences- two babies in 8 years, two different Welsh Health boards.
  - Community identity and awareness
  - Member of LGTBQIA+ community (George and Stobbs, 2017)

- I. Undergrad: linguistics, MSc Autism and Related Conditions
- II. Initial essays at MSc level: critical reflection, policy and practice
- III. Presentations at London Southbank University's Participatory Autism Research Collective conferences
- IV. MSc data: strong findings inc no statistically significant difference between formal and self-diagnosed responses
- V. PhD: self-funded due to importance of topic and data from MSc. MSc lacked midwifery input.



- 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 Wales Autism Research Centre, Cardiff University.

# Research Aims



- TO DEVELOP A BETTER UNDERSTANDING OF AUTISTIC MOTHERS' PERSPECTIVES OF ANTENATAL AND POSTNATAL CARE.
- TO EXPLORE THE AUTISTIC FATHERS' EXPERIENCE OF THE TRANSITION TO FATHERHOOD.
- OFFER RECOMMENDATIONS FOR BEST PRACTICE WITH REGARDS TO MIDWIFERY TRAINING AND MATERNAL SUPPORT.





## Research questions

- To develop a better **understanding** of autistic **mothers'** perspectives of antenatal and postnatal care.
- To explore the autistic **father's** experience of the transition to fatherhood.
- To investigate the **midwife perspective** of autism awareness and related training competencies.
- Offer **recommendations** for best practice with regards to midwifery training and maternal support.

# PhD recruitment flyers

- 1) Biopsychosocial model of **disability**
- 2) Milton's double **empathy** problem
- 3) Feminist ideology- **intersectionality**



  
Swansea University  
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Your voice is important to us

## The Autistic Birth Experience

Are you aged 18+ and an autistic parent? ( self or formal diagnosis welcome)

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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ENTERETHICS APPROVAL #



5 x £20 Amazon vouchers to be won



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## The Autistic Birth Experience: Partners

Are you aged 18+ and an autistic parent? ( self or formal diagnosis welcome)?

Have you supported a partner in birth in the last 12 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)

Scan the QR code for participant information

NB: Participant selection will aim for 30% BAME representation.

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This study has been approved by the Research Ethics Committee, School of Health and Social Care, Swansea University

School of Medicine, Life and Health Science, Swansea University,  
Singleton Park  
Swansea  
SA2 8PP

Ethics ref  
171121



# Who will be interested in 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.





## Early Findings

Preliminary themes from birthers and birth partners include concerns over informed choice, misread and mismanaged pain communication, and 'luck'.

'Luck' often refers to whether the person is lucky enough to chance upon a midwife on shift with autistic awareness, the luck of whether their autistic coping methods are interpreted well enough to get their basic needs met.

# Strengths and limitations

## Strengths

- Related topic evidence base comparatively strong: e.g. sensory considerations, co-morbidities, transition planning.
- Increase in neurodiversity/autism awareness in previously under-diagnosed populations
- Medical, social and biopsychosocial model approaches aren't exclusive
- Rigor and reflexivity

## Limitations

- Few resources centre autistic voice without othering or pathologisation.
- Medical model, genetic investigation still dominant
- Many guidelines still aren't condition-specific for autism or other neurodivergent presentations except for MH
- Transparency over training (timing, frequency, patient voice)





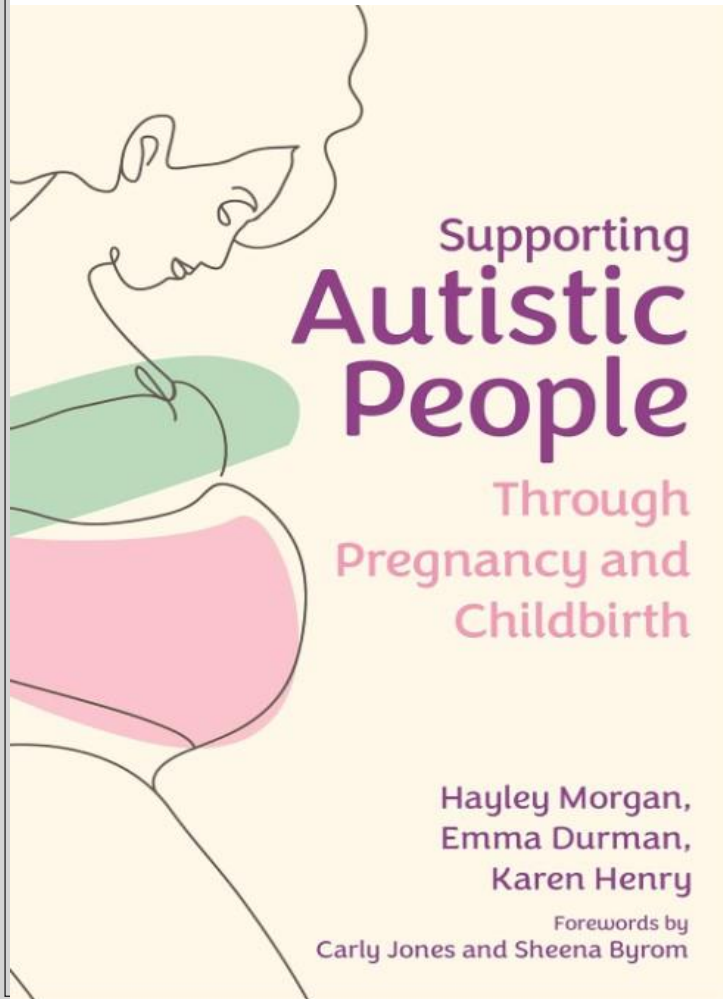
# Supporting Autistic People through Pregnancy and Childbirth

Morgan, Durman & Henry

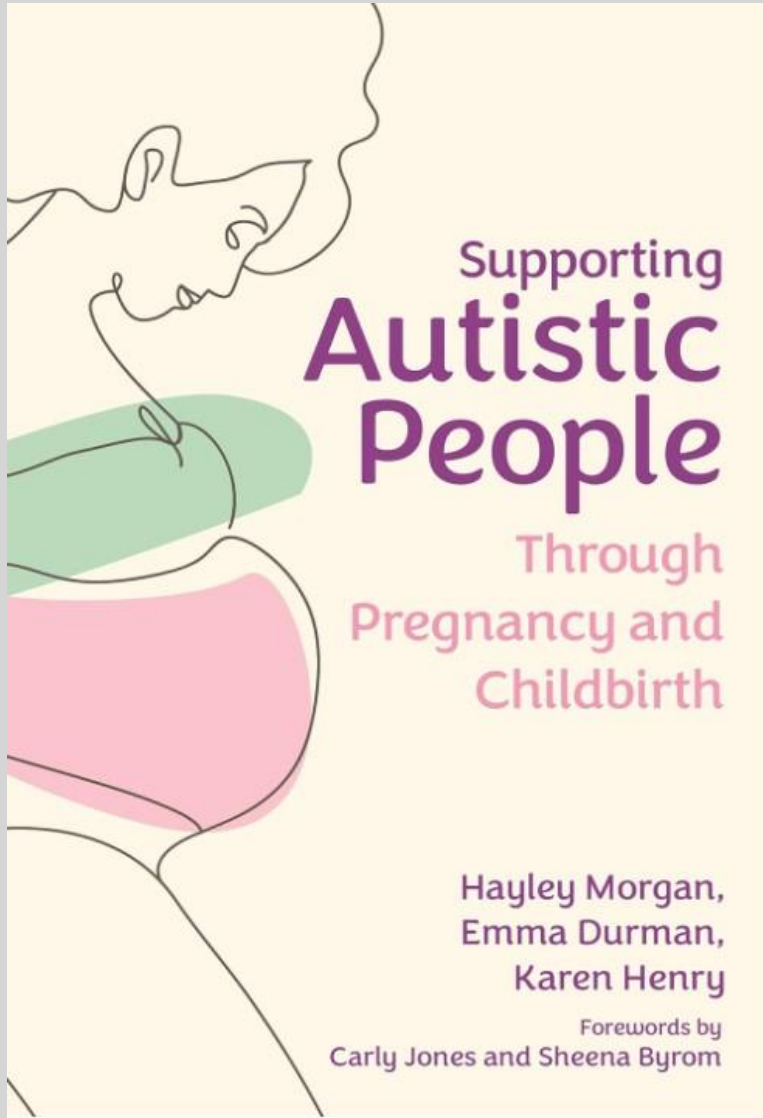
*Improving experiences of pregnancy, birth and parenthood through informed, evidence-based practice.*



Jessica Kingsley  
Publishers



*"As a result of the identified needs, this resource includes a toolkit of strategies for midwives, maternity and wider healthcare professionals, with an aim to increase understanding of the specific needs of autistic mothers and child bearers during pregnancy, childbirth and new motherhood. The ultimate aim here is to improve experiences through the provision of tailored, empathetic, insightful care.*



# Overview

Chapters include:

1. Background and History.
2. Intersectionality and Feminism.
3. Coexisting Conditions.
4. Pain and Sensory Differences.
5. Autistic Communication.
6. Advice for Professionals.
7. Practical Strategies and Information.

# Thanks for your time!



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