

**Developing Autism Care Pathways in Maternity Care is
fundamental to address health inequalities.**



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What is Neurodiversity?





Neurodiversity in Action

MYOTAS

'MY OWN TIME AND SPACE'



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Prevalence

1 in 44 people have autism.

Does this correlate to your current statistics?

Are you currently able to collect and collate this data?

Can their care trajectory and outcomes be mapped and interventions monitored and accounted for?



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Objective

Development of Autism Care Pathways in Midwifery and Obstetric care is fundamental to provide a multidisciplinary approach to support the complexity of autistic families needs.

Background

80% of autistic women are not diagnosed by the time they turn 18.

Therefore, many pregnant women may not have a diagnosis or support in place. Women may 'mask' or hide their needs in childhood and adulthood, leading to lifelong health inequalities impacting on psychological, physiological and sociological wellbeing of families.

In pregnancy, this may lead to crisis support and intervention from a wide multidisciplinary team. Midwives and Obstetricians need to develop care pathways to support this complex health presentation in partnership with autistic pregnant women.



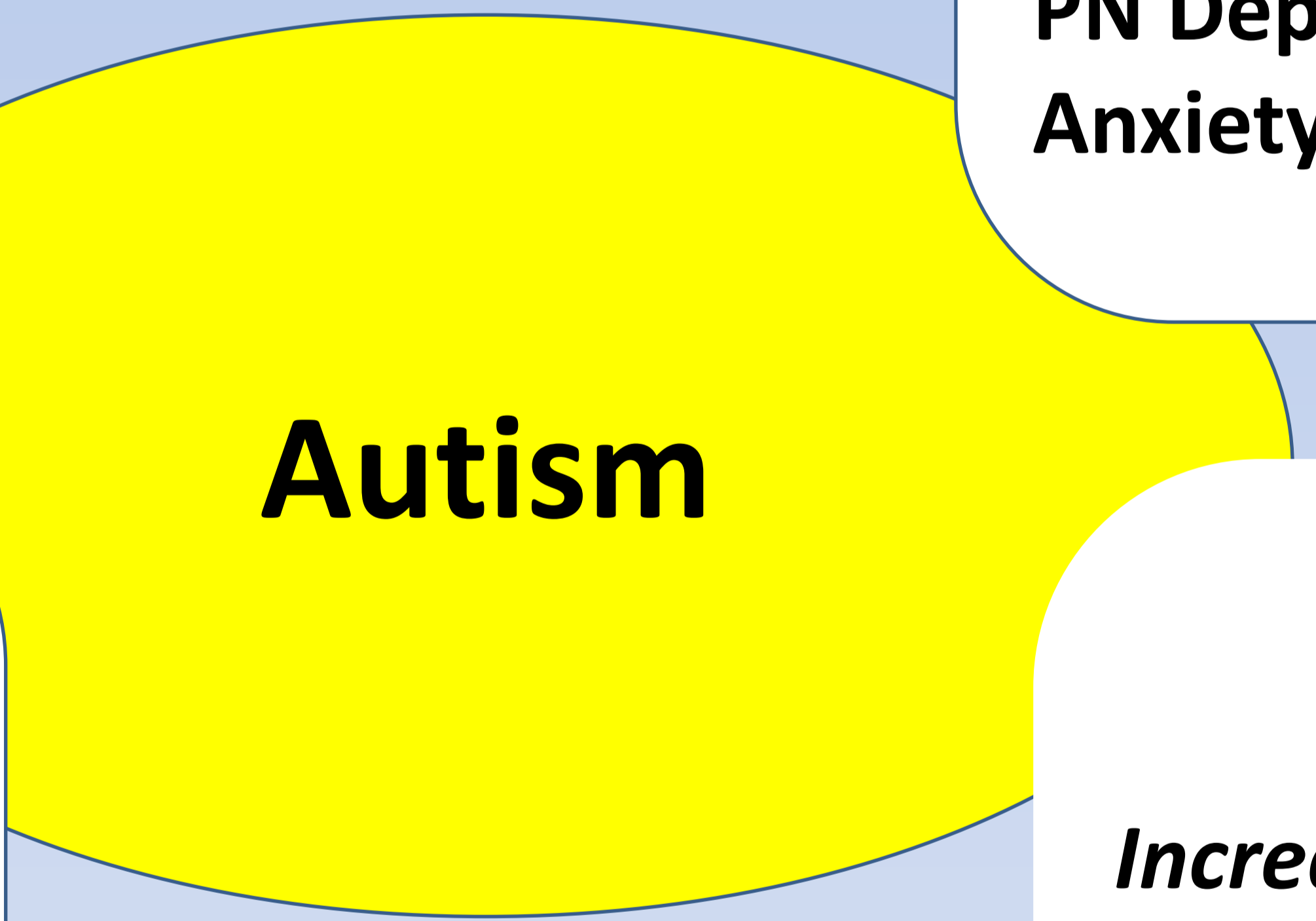
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Increased Prevalence:

- Pre diabetes
- Diabetes Type 1 and 2
- PCOS
- Hypertension
- Thyroid Disorders
- Autoimmune Disorders
- Obesity
- Cardiac Arrhythmia

Outcomes- Increased Prevalence:

- LSCS
- Pre-eclampsia
- Preterm labour and birth
- PTSD
- Suicide
- PN Depression
- Anxiety



Autism

Co-occurring Conditions/Considerations:

- Connective Tissue Disorders
- Ehlers Danlos Syndrome
- Fragile X
- Fibromyalgia
- Sensory Processing Issues
- Learning Difficulties
- Dyslexia, Dysgraphia, Dyspraxia, Dyscalculia
- ADHD
- Eating Disorders
- Non-Binary/ Gender Fluid

Increased Prevalence:

- Non compliance with care and treatment
- Exploitation
- Physical/Sexual/Domestic Abuse
- Social Services Intervention





Psychological Health for Autistic Women

MBRRACE-UK (2018-2020)

- Leading cause of death mental ill health (suicide/substance misuse)
- Black women **3.7x** more likely to die
- Asian women **1.8x** more likely to die

Autism Research

- Autistic people are **6x** more likely to attempt suicide
- Autistic people are **7x** more likely to die by suicide
- Young autistic women are **13x** more likely to attempt suicide than non-autistic women
- More vulnerable groups are those who experience discrimination based on race and sexuality
- Black and Asian communities less likely to get diagnosis and support



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Discussion

Raising autism awareness, understanding and acceptance in maternity and obstetric care and pre-registration training is key.

Linking care outcomes and implementing targeted care provision is crucial to improve inequalities by exploring the medical and care needs of these women with empathy and compassion.



Developing Autism Care Pathways in Obstetric Care is fundamental to address health inequalities.

Dr Luke Beardon



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Challenges Autistic People might experience

Sensory Issues

- May have hyper or hypo sensitivity to sounds, light, tastes, touch, speech, personal space, eye contact, pain and bodily functions. Therefore, it is important to discuss in detail what their sensory needs are and adjust the environment to accommodate these needs.

Communication

- May have difficulty understanding small talk, jokes, social norms, social cues, double meanings, facial expressions and taking turns to talk.

Extreme Anxiety

- Autistic people may be very anxious in new places and meeting new people, anxious about changes in routine and unexpected events and transitions.
- If things become overwhelming this may result in a 'shutdown' or a 'meltdown'. This can be very exhausting, lots of time and space will be needed to recover.
- Some people may cope by non attendance and non compliance with medical care. Others may be highly anxious throughout pregnancy and motherhood.



SPELL Framework (National Autistic Society)

STRUCTURE

- Continuity of Carer/ Personal Care Plan
- Predictable routine and environment can help an autistic person feel calm, safe and in control.

POSITIVE

- Be positive, kind and understanding without bias- especially in new situations and challenges.
- Support the decisions and explain procedures, take their lead

EMPATHY

- Use empathy to communicate to reduce anxiety and distress
- 'Tell me what you need to make it ok'
- Be accepting of behaviour that may be needed

LOW AROUSAL

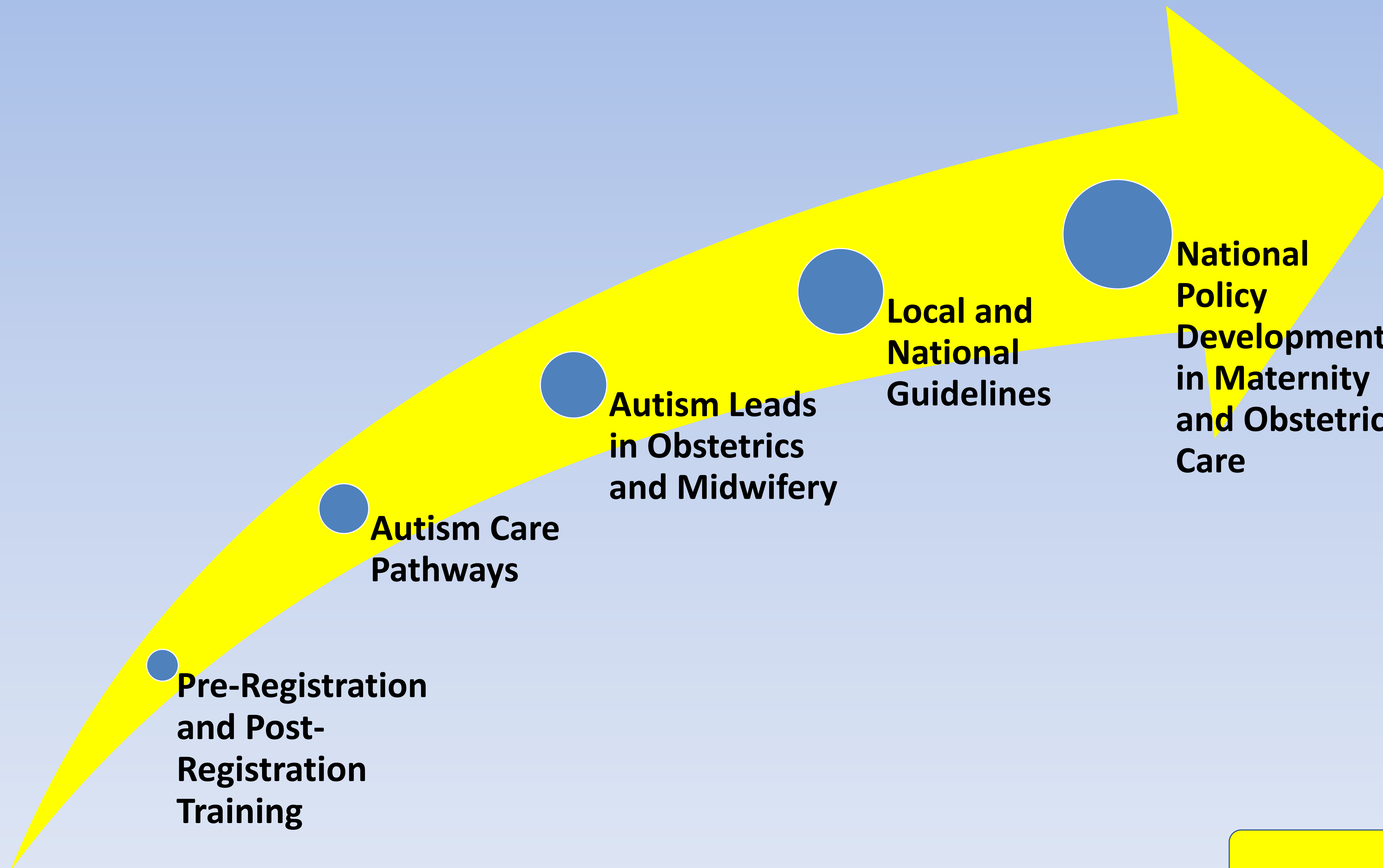
- Low sensory environment may help reduce anxiety
- Low lights, sounds, no small talk, minimal interruptions

LINKS

- Help create and maintain links to a support network – family, friends and professionals.
- Ensure clear links and updates are in place with GP's and Health Visitors prior to discharge



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Best Practice Guidance

- **Personalised Care Plan**
- **Continuity of Carer**
- **Maternity Autism Passport**
- **Screening Tools at booking (NICE recommends AQ10/AQ50 questionnaires)**
- **Multidisciplinary Teams**
- **Alerts on hospital notes, computer records, wristbands**
- **Maternity Voice Partnerships – work in partnership/co-production**
- **Perinatal Mental Health Teams**
- **Learning Disability Leads**
- **Leaflets for service users**
- **Mandatory Training on Neurodiversity**
- **Accessibility for patients- consider posting videos and ward layouts**
- **Long term Care Planning with Health Visitors and GP's for autistic families**



Developing Autism Care Pathways in Obstetric Care is fundamental to address health inequalities.

East and North Hertfordshire
NHS Trust

- Pilot Autism Midwifery Led Clinic.

Cornwall NHS Trust

- Designing a clinical change project around caring for families who experience Neurodiversity in Maternity Care.

Royal Free London NHS
Foundation Trust

- Developing an Autism Care Pathway for Maternity

Dartford and Gravesham NHS
Trust

- Developing a Neurodiversity Pathway in Maternity



Think Neurodiversity in
complex care planning and
decision making.

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MARG www.maternityautismresearchgroup.co.uk

The Neurodivergent Birth Podcast

<https://theneurodivergentbirthpodcast.buzzsprout.com/>

A podcast exploring neurodivergent experiences of pregnancy, birth and the postnatal period

@AutismMenstruationToMenopause

(YouTube Videos by autistic health professionals for autistic people)

