ACCOUNTABILITY IMPACT IN MATERNAL EQUITY

BRIDGING THE GAP:

Advancing Equity in Neurodivergent Maternal Care through the IMPACT Framework

THE WHITE RIBBON ALLIANCE UK

ND Birth

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WHY NEURODIVERGENCE MATTERS IN MATERNITY CARE

An estimated 15% of the UK population, over 10 million people, are neurodivergent*, with increasing numbers of women being diagnosed.

Yet in the UK, where access to safe, high-quality maternity care is a fundamental right, neurodivergent women and pregnant people continue to face significant structural disadvantages that compromise safety, legal rights, and health outcomes.

"The language they used - 'you can't', 'you're not allowed' - was very triggering... it took control and choice away from me."

15%

OF THE UK IS NEURODIVERGENT

THE LIVED EXPERIENCES OF NEURODIVERGENT SERVICE USERS

Sensory Distress and Unsafe Environments

Many neurodivergent people are highly sensitive to bright lighting, noise, and physical contact. In hospital maternity settings, where these stressors are routine, the risk of sensory overload and psychological distress is significantly increased. Some report these conditions as more traumatic than labour itself *(1)*.

Despite a statutory legal duty under the Equality Act 2010 to make reasonable adjustments, these are frequently unmet in practice *(2)*. Pressured midwifery staff, working in unsafe conditions, are not given necessary tools and training to meet the needs of neurodivergent people. As a result, maternity services cannot provide equitable care, with many reporting feeling dismissed, misunderstood, or unfairly labelled as "difficult" by staff *(3)*.

> ***"Being able to understand my sensory profile, how much noise I did or didn't want, and being able to have a plan that was based around sensory needs was a game changer."***

Barriers to Communication and Consent

Communication failures are a recognised risk factor in maternity care, contributing to harm and poor outcomes. Where neurodivergence is undiagnosed or undisclosed due to stigma, and with inadequate time for appointments, communication needs are overlooked, further compromising care *(3)*.

This is further compounded by evidence that neurodivergent women and pregnant people are less likely to voice concerns or seek clarification from their care providers *(4)*, with the risk of harm increased when informed consent is inconsistently sought, particularly for physical contact. Pain is also frequently misinterpreted, leading to inadequate pain management and, in some cases, neglect during labour *(5)*.

Perinatal Risk and Inequity

Research regarding the health outcomes of neurodivergent women and pregnant people is limited but shows they are disproportionately affected by perinatal mental health challenges, including elevated stress, anxiety and depression *(6)*.

They are also less likely to access the appropriate support, especially in the postnatal period *(4)*. With suicide the leading cause of maternal death between six week and one year after birth *(7)*, failure to address these inequities represents a significant and preventable risk.

*This policy brief refers to a range of neurodivergent groups including ADHD, dyslexia, dyspraxia, Complex PTSD, OCD, and Tourette's syndrome, yet due to a lack of research into other groups, the main evidence provided here is from those with autism and to a lesser extent ADHD. If we utilise a wide definition of neurodivergence, including learning difficulties, then as an estimated 15-20% of the population are dyslexic, the figures provided for total number of neurodivergent people within the UK are vastly underestimated.

IMPACT: A FRAMEWORK FOR ACCOUNTABILITY AND PROGRESS

A structured framework to assess equity in maternity services for neurodivergent women and pregnant people is needed to ensure accountability and progress. The Inequities in Maternity Policy and Care Tracking (IMPACT) framework provides a robust, consistent approach to identifying barriers, implementing improvements, and measuring outcomes in practice.

The framework is organised around four domains: Understanding Inequities, Addressing Inequities, Evaluating Inequities, and Community Participation. Each domain includes specific criteria to assess whether policies recognise disparities, propose interventions, track outcomes, and involve marginalised communities in decision-making *(see Figure 1).*

Fig1. Evaluating Equity in Maternal Health

Focus Area	Evaluation Criteria
Understanding Inequities	• Does the policy recognise or acknowledge in access or outcomes for marginalised groups? • Does the policy recognise underlying health system or structural factors that underpin inequities in maternal healthcare (e.g. institutional racism)? • Is language inclusive and appropriate?
Addressing Inequities	• Does the policy allow for marginalised groups to access the service (e.g. undocumented migrant women)? • Do policies specifically address issues to improve access to, or quality of care for marginalised groups using evidence-based interventions? • Do policies suggest changes to underlying health systems and structures that contribute to inequities? • Is money ringfenced for paying for specific interventions to reduce inequities?
Evaluating Inequities	• Are targets included for reducing inequities in utilization or outcomes? • Are there measures in place to ensure there is adequate routine data to monitor access or outcomes for marginalised groups? • Are measures in place to evaluate the success of the policy with an equity focus?
Community Participation	• Is the policy based on meaningful consultation with stakeholders from marginalised groups? • Does the policy recommend processes for ensuring the ongoing engagement and feedback of service users from marginalised groups?

CREATING A TOOL FOR EVALUATING POLICY AND PRACTICE

Co-created with service users and based on the IMPACT framework, White Ribbon Alliance UK, Neurodivergent Birth CIC, and the University of Southampton have developed a policy analysis tool and scorecard to evaluate neurodivergent equity in maternal healthcare. Embedding this tool into the design and delivery of maternal health policy transforms equity from a stated ambition into a practical reality. It equips policymakers with a structured, evidence-based approach to identify disparities, implement targeted interventions, and monitor progress. It also supports advocacy groups to coordinate more effectively and pursue unified strategies to advance equity in maternal care.

HOW THE SCORECARD WORKS

The Neurodivergent Equity Scorecard adapts the IMPACT Framework to assess how current maternity policies and services address equity for neurodivergent service users.

Each focus area identifies where policy or practice can improve, and how progress can be measured. From this, more specific tools can be developed to reflect equity needs at policy and service delivery level.

Fig 2. The IMPACT Neurodivergent Maternal Equity Scorecard

IMPACT Dimension	Criterion	Score	Evidence/Reasoning	Further Comments
Understanding Inequities	Clear definition and scope of neurodivergence across conditions and sensory profiles in relevant policies	2	Policy refers to "serious mental health concerns" or "learning disabilities" on page 1-2. Page 8 policy refers only to ADHD/autism and possible adjustments.	Lack of clarity and consistency in scope and naming of Neurodivergence.
Addressing Inequities	Neurodivergent awareness and legal equality rights included within staff training and professional education	4	Trust provides twice yearly, mandatory, CPD accredited training to MDTs online/in person on Neurodivergent Equity and reasonable adjustments. Staff time is protected for the training. Training impact is externally evaluated.	
Evaluating Inequities	Systematic learning from feedback, complaints, and lived experiences from neurodivergent service users, their birth partners, families, and staff	2	Postnatal Service user feedback survey is the primary collection point. Complaint information not disaggregated for Neurodivergence/disability. MNVP meetings not accessible online.	
Community Participation	Co-production of maternity policy and services with ND organisations and communities	3	Policy reviewed with panel of lived experience experts inclusive of three local Neurodivergent parents. Draft update policy will be sent to representatives from 2 disability and neurodivergence orgs to review and comment.	Trust is at the early stages of a full policy review. Some steps towards co-production but not yet widespread and embedded for this policy.

Scoring guide

0 - Harmful/exclusionary: Policy risks active harm to neurodivergent people or staff; reinforces misunderstanding, penalisation, or barriers.

1 - Absent/not considered: No indication that neurodivergence or sensory/communication needs were considered despite clear relevance.

2 - Acknowledged but undeveloped: Neurodivergence is mentioned, but the policy offers little practical value; commitments are rhetorical, vague, or optional.

3 - Partial/inconsistent action: Some meaningful ND-relevant actions or adjustments appear, but coverage is inconsistent, incomplete, or dependent on individuals.

4 - Strong, Embedded and actionable: Neurodivergence is explicitly integrated throughout the policy with clear standards, mechanisms, accountability, and lived-experience involvement.

THE NHS 10-YEAR PLAN: GAPS AND OPPORTUNITIES

Despite growing awareness of the service gaps neurodivergent people face when accessing maternal healthcare, policy and practice responses remain inadequate.

The University of Southampton conducted a rapid review of ten national maternity policy documents from 2016 to 2022, and found that, while inequities were acknowledged, few policies included targeted, costed, or measurable actions to improve them. Equity efforts largely focused on ethnicity and economic deprivation, while neurodiversity and disability were routinely overlooked.

The NHS's 10-Year Plan, *Fit for the Future*, outlines a progressive vision for maternal health, emphasising faster access, technology use, and prevention. It also commits to individualised care plans and reducing inequalities.

However, it lacks specific, actionable commitments and does not recognise neurodivergence as a category of inequity. The plan's ambitions will only deliver improved outcomes if the needs of neurodivergent people and other marginalised groups are explicitly addressed in implementation.

10-YEAR PLAN

RECOMMENDATIONS FOR ACTION

1. EMBED THE IMPACT SCORECARD

Use the Scorecard as a standard tool to assess how maternity policies and services identify and address inequity for neurodivergent women and pregnant people. Apply it consistently to guide design, evaluation, and continuous improvement.

2. MAKE NEURODIVERGENCE VISIBLE IN DATA

Record neurodivergence as a distinct category in routine maternity data, separate from intellectual disability. This will enable monitoring of access, experience, and outcomes, support inclusive service design, and improve targeted support across the maternity pathway.

3. CO-DESIGN WITH NEURODIVERGENT SERVICE USERS

Co-design maternity services, Health Hubs, and digital innovations with neurodivergent service users. Ensure patient-reported experience measures (PREMs) include neurodivergent voices and use accessible formats that reflect diverse cognitive needs.

4. BUILD AN INCLUSIVE WORKFORCE

Strengthen staff understanding through neurodiversity-specific training, accessible workplaces, and inclusion in professional education. Support neurodivergent maternity staff through reasonable adjustments, inclusive cultures, and partnerships with specialist organisations.

5.BROADEN THE EVIDENCE BASE

Expand research beyond autism to include the experiences of those with ADHD, dyslexia, dyspraxia, Complex PTSD, OCD, and Tourette's syndrome. A broader evidence base is essential to design maternity services that reflect the full spectrum of neurodivergence.

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Date of Production: January 2026