

Response to the Inquiry into Attention Deficit and Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) Pathways and Support.

1. Introduction

This report provides a response to the Health, Social Care and Sport Committee's inquiry into neurodevelopmental pathways and support for Attention Deficit and Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD). It draws on the extensive experience and expertise of SWAN Autism (Scotland), the only autistic-led Scottish charity focused on the intersection of gender and autism since 2012.

This submission is informed by the collective experience of SWAN's network of over 1,500 autistic women and non-binary people of all ages across Scotland. It highlights critical issues driving the current crisis, including historically flawed diagnostic criteria, significant barriers to diagnosis, and systemic failures in providing appropriate, preventative, and timely support.

The report outlines the views and experiences of neurodivergent people, particularly focusing on the disproportionate impact on autistic women, girls, and minority genders. It aligns with the Committee's ongoing inquiry into ADHD and Autism Spectrum Disorder (ASD) pathways and support, and concerns regarding long waiting times and unmet support needs for neurodivergent people.

2. Reasons for increasing demand for diagnosis

The current unprecedented demand for neurodevelopmental diagnosis is driven by a number of compounding factors:

- **Gender-biased historical understanding:** Until recently, autism was primarily understood as a condition affecting boys and men. This resulted in low awareness and understanding of how autism presents in women, girls, and other minority genders among practitioners, educators, and families.
- **Late and missed identification:** Due to this historical bias, many autistic women and girls were not identified until much later in life, if at all. This means that successive generations are only now realising they may be autistic and are seeking diagnosis concurrently, rather than being diagnosed across their lifespan.
- **Prevalence of masking:** Autistic women and girls are more likely to "mask" or camouflage their traits to fit in, making their autism hidden from others. This internal masking is a significant contributor to the deterioration of mental health.
- **Misdiagnosis and medical misogyny:** Autistic women and girls are frequently misdiagnosed with other conditions, such as anxiety, general mental health conditions, or hormonal issues. This often

involves being prescribed inappropriate and expensive medications, with the underlying autism or autism-related mental health impacts left unaddressed due to medical and societal misogyny.

- Deficit-based and outdated diagnostic tools: Standard diagnostic criteria were originally designed to identify traits prevalent in males and are therefore not fit for purpose for assessing women and other genders. The process itself is deficit-based and can be disempowering and humiliating for individuals.
- Inaccessible diagnostic process: The frequent requirement for an account from childhood excludes many individuals from accessing assessment. This disproportionately affects those with strained family relationships or those from marginalised backgrounds (LGBTQ+, minority ethnic, refugees) whose families may not be willing or able to participate.
- Increased awareness: The growth of understanding and visibility of neurodivergence, particularly through platforms such as social media, has enabled people across all ages to recognise their own traits and seek assessment.

3. Impact of a lack of diagnosis

The consequences of long waiting times and a lack of timely diagnosis for autistic individuals are profound, severe, and have serious human rights implications.

3.1 Human rights violations

Autistic women and girls experience significant difficulty accessing their human rights, including in employment, housing, and education. A "double discrimination"—being female and autistic—exacerbates these systemic failures.

3.2 Mental health crisis

A lack of understanding of one's identity, coupled with constant masking, microaggressions, and bullying, significantly impacts mental health. The risks are disproportionately high for autistic women:

- Autistic women are 13 times more likely to die by suicide than non-autistic women.
- More than 75% of autistic adults have associated mental health conditions, compared to 25% of the general population.
- 40–50% of autistic people are estimated to meet the criteria for an anxiety disorder.
- Autistic individuals are at a higher risk of developing Complex Post-Traumatic Stress Disorder (cPTSD) and eating disorders, with up to 30% of autistic adults having an eating disorder and up to 50% of adults with anorexia nervosa being autistic.
- Studies indicate that 79% of autistic people report feeling socially isolated.

3.3 Victimization and violence

Autistic individuals, particularly women, face increased risks of violence and abuse:

- 9/10 autistic women have experienced sexual violence.
- 75% of autistic people experience bullying at school, continuing into adulthood, where 50% of autistic employees report harassment or discrimination at work.

3.4 Employment barriers

Without a diagnosis, individuals face immense challenges accessing and maintaining employment. While legal protections exist, a lack of awareness and willingness from employers means that reasonable adjustments are often not provided, leading to autistic burnout and discrimination.

4. Systemic issues impacting pathways and support

Beyond diagnostic delays, several systemic issues exacerbate the crisis:

- **Regional disparity:** Inconsistent provision across Scotland means some areas have no adult diagnostic pathway, while others restrict access to those already in significant mental health crisis. This is a reactive, rather than preventative, approach.
- **Inaccessible support:** Many services, particularly in mental health, are not equipped to support neurodivergent individuals effectively. The Scottish Human Rights Commission has found human rights breaches related to the institutionalisation of autistic people, highlighting a lack of community-based alternatives.
- **Economic privilege influencing access:** Those with financial means can access private diagnoses but may face additional barriers, such as GPs refusing to recognise the diagnosis or provide shared care for medication.
- **Discouraging assessment:** Some Health Boards send letters to individuals on waiting lists, seemingly to discourage them from continuing their pursuit of diagnosis. This can induce feelings of hopelessness and cause significant distress.
- **Internalised guilt:** Some individuals, especially those with less visible support needs, report feeling they are not "badly enough" affected to warrant a spot on a waiting list, further hindering access to care.
- **Increased stigma and backlash:** Growing public visibility of neurodivergence, particularly online, has led to a backlash, with individuals being accused of "making it up." This can discourage people from seeking help and perpetuate poor outcomes.

5. Recommendations for action

To address these critical issues, the Committee should consider the following recommendations, focused on improving neurodevelopmental pathways and support in Scotland:

5.1 Diagnostic process reforms

- **Mandate neurodiversity-affirming training:** Implement mandatory, comprehensive training for all healthcare professionals, educators, and social care staff, focusing on neurodiversity-affirming practice and addressing the specific presentations of autism and ADHD in women and marginalised groups.
- **Review and update diagnostic tools:** Move away from outdated, deficit-based diagnostic tools and criteria that rely on historical knowledge derived from male presentations.
- **Reform the assessment process:** Remove the dependency on childhood accounts for adult assessments, ensuring the process is accessible and person-centred.

5.2 Improve pathways and access to support

- **Standardise and expand pathways:** Establish accessible, comprehensive adult neurodevelopmental pathways across all 14 Health Boards, ensuring equitable access regardless of region or financial status.
- **Adopt a stepped-care model:** Implement a tiered, "stepped-care" model, involving third-sector organisations and multi-disciplinary teams. This model should offer neurodiversity-affirming support before, during, and after diagnosis, focusing on prevention rather than only addressing acute mental health crises.
- **Invest in "waiting well" support:** Provide immediate, pre-diagnostic support for individuals on waiting lists, including peer support, psychoeducation, and access to neurodivergent-informed resources.
- **Ensure inclusive support:** Address inconsistencies in how private diagnoses are handled by GPs to ensure access to appropriate medical support, including shared care for medication.

5.3 Address systemic inequalities and workforce issues

- **Strengthen accountability for human rights:** Hold services accountable for upholding the human rights of autistic people, including the right to live independently and access appropriate community-based care, as highlighted by the Scottish Human Rights Commission.
- **Invest in neurodiversity-affirming workforce development:** Build workforce capacity and expertise across all sectors—health, social care, education, and employment—to ensure services are equipped to meet the needs of a neurodiverse population.

- **Combat stigma and discrimination:** The Scottish Government must take a strong, clear public stance against misinformation and discriminatory attitudes towards neurodivergent people.

5.4 Focus on prevention and intersectionality

- **Take a proactive, preventative approach:** Prioritise early identification and support to prevent the onset of severe mental health conditions, autistic burnout, and social isolation.
- **Examine intersectional discrimination:** Fund research and policy initiatives to better understand and address the compounded discrimination faced by autistic women and those with intersecting marginalised identities.

By implementing these recommendations, the Health, Social Care and Sport Committee can drive necessary systemic change, ensuring autistic people in Scotland receive timely, appropriate, and affirming support, thereby improving health outcomes and upholding their human rights.