

# Equalities, Human Rights and Civil Justice Committee

## Inquiry into Neurodivergence in Scotland

Notes from online engagement session, 9 February 2026

### Breakout group 1

#### 1. Challenges in Diagnosis Pathways

- A number of participants shared painful experiences about the long waiting times they'd experienced in seeking a diagnosis both for themselves and their children.
- Participants stressed that the fight to get a diagnosis and support thereafter is exhausting and seemingly never ending. They talked about being constantly doubted, questioned and challenged.
- Others highlighted experiences of being unable to get onto a waiting list at all with some Health Boards simply closing waiting lists in response to increasing demand.
- Frustrations were expressed about the lack of a holistic approach to diagnosis with people experiencing multiple diagnoses for different conditions rather than going through one process for diagnosis.
- All participants highlighted concerns about the extent to which people are having to seek a private diagnosis and the unwillingness on the part of the NHS to then rely on a private diagnosis and instead put people through an NHS diagnosis too.
- Participants also highlighted that the NHS is unwilling to enter into shared care agreements on medication, forcing people to have to pay for medication as well as a diagnosis.
- Participants stressed just how severe the implications are of not getting that diagnosis or of having significant waits for a diagnosis. Delays or failure in diagnosis can sometimes result in people finding themselves in the criminal justice system. Even more starkly, participants highlighted just how many people they had lost as a result of suicide while they waited for a diagnosis.
- It was also stressed that a late diagnosis or the absence of a diagnosis entirely significantly impacts on someone's ability to succeed in education and in turn the workplace.

- There was a strong view amongst participants that the process of getting a diagnosis was only expedited when something extreme happened to the person seeking a diagnosis.

## **2. Inequity and Inconsistency of support**

- Participants were able to share different experiences of diagnosis and post diagnostic support from across Scotland. What members heard pointed to a postcode lottery of diagnosis and post-diagnosis support.
- More specifically, the Committee heard about discrepancies in support for children as they transition from one stage to another. It was noted that support is not sustained. Support might be strong at primary school, but that is not sustained into High School and is diluted still further as people transition out of education and into the workplace.
- Participants also stressed the inequity of the current benefits system, with some people having to obtain a diagnosis to obtain benefits and others accessing them without such a diagnosis.

## **3. Financial Pressures and Inequality**

- As noted earlier, participants highlighted the extent to which people are having to obtain a private diagnosis. Participants stressed that people are getting into poverty in order to fund a diagnosis, subsequent medication and follow-up appointments. In circumstances where people were having to pay for both their own diagnosis and medication and their children's diagnosis and medication, participants spoke of having to forsake their own medication to ensure their children could have medication due to the costs of doing so. They also spoke of the significant impacts this has on them.
- Participants stressed the significant economic and societal benefits of early diagnosis. They argued that investing early in diagnosis will significantly reduce long-term costs.
- They also pointed to the savings that could be made by the public sector partnering with third sector organisations on the delivery of services rather than duplicating their work.

## **4. Lived Experience**

- All participants stressed that we don't live in a world that supports autistic people and allows them to thrive.
- Participants pointed to basic adjustments that could be made by schools and workplaces that would make their lives much simpler. For example, in a school setting when thinking about testing of presentation skills, recognising that requiring a child to maintain eye contact is not reasonable. Or in a work

setting, not placing someone in a office at a desk that is close to strong lighting or smells.

- Participants shared personal stories that amplified the constant struggles they have faced in their lives.
- They pointed to the exhausting efforts they mask to hide their struggles and how this has also contributed to misunderstandings.
- Some participants did, however, highlight the life changing impact of medication, which has allowed them to live their lives.

#### **5. Importance of Understanding and Identity**

- All participants stressed the importance of early diagnosis in helping understand themselves, but they also stressed that this must be paired with meaningful support.
- Participants also stressed that it is essential that there is a wider societal understanding of autism and ADHD. It was stressed that we must begin by educating children on neurodivergence to effect that wider societal change.
- Participants also pointed to the increasing diagnosis of Fetal Alcohol Spectrum Disorder and the need for significant improvements in societal understanding of it.
- Participants also advocated for better data to understand whether progress is being made in the diagnosis and subsequent experience of people with autism and ADHD.