Cross Party
Autism Group

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Cross-Party Autism Group

Minutes

Thursday 2nd October 2025 ,15:00 - 16:30 pm Microsoft Teams

Present: Mark Isherwood MS (Chair), James Radcliffe (Secretary - NAS), D Jones, Nigel Morgan, H Wilson, K Jones, Mike Hedges, Kirsty Rees, Kerrie Hopwood, Alex Still, Ioan Bellin, Laura Fergusson, Eluned Evans, Alex Swift

Apologies: Llyr Gruffydd, Kara Monkiewicz, Lee Green

1. Welcome

Mark Isherwood (MI) welcomed everyone to this meeting of the Senedd's Cross-Party Autism Group.

2. Minutes of previous meeting

Nigel Morgan (NM) proposed and Kerrie Hopwood (KH) seconded the minutes from the previous meeting as fair and accurate.

3. Matters arising

James Radcliffe (JR) explained that the letter to the Cabinet Secretary had been sent, and a reply had been received and circulated to the group.

4. Tributes to Hefin David

Tributes were paid from the group to Hefin David MS following the recent tragic news of his death. MI stated he was a big supporter and ally of the group, in particular highlighting his work supporting the Stolen Lives Campaign. Alex Still thanked the group for the support and kind words.

5. Presentation – Laura Ferguson (Association of Directors of Adult Social Services)

Laura Ferguson (LF) from ADASS — the Association of Directors of Adult Social Services presented on her work blamed instead of helped, and the work the ADSS were doing on the issue

Laura explained that her team were approached by NHS England Midlands to carry out this work following concerns parents had raised about how they'd been treated by health services when seeking autism assessments for their children. Rather than dealing with it only through complaints processes, NHS England wanted to commission a piece of research to understand what was happening and why.

LF noted that the partnership between ADASS and NHS England was key. However, what was originally meant to be a six-month, part-time project has now grown far beyond that — the project started in 2022 and is still going strong.

LF and the team built a professional and parental advisory group, bringing in people from different networks and parents with experience. With their help, the team set out the research ambitions and ensured proper academic oversight for credibility.

They began with a systematic literature review to establish an evidence base. What they found was striking — there had been very little prior research in this area, particularly across health, social care and education combined. The studies that did exist showed blame towards parents occurred in multiple ways: from professionals, from communities, even as self-blame. Parents described being disbelieved, dismissed and not listened to. At its worst, this escalated into accusations — especially when parents pushed for support or made complaints. The impact on those parents was severe: symptoms of trauma, anxiety, and parents feeling they had to become experts just to advocate for their children.

There was also a notable lack of research into professional perspectives, and very limited exploration of fathers' experiences — the focus was mostly on mothers

The research team conducted a survey and focus groups, and several themse emerged from this research:

- Autism is widely misunderstood by professionals. Support offered is often unhelpful and can even cause harm.
- Accusations of blame can result in long-term trauma and even risk of suicide.
- Parents have high mistrust of services and professionals.
- Parents' knowledge of their child is often dismissed or viewed with suspicion.
- Parental blame is more likely before diagnosis.
- Autistic parents experience more blame than non-autistic parents.
- Parents of autistic children may face a higher risk of child protection proceedings.
- Accusations of Fabricated or Induced Illness (FII) are much higher than would be expected in the general population.

The survey specifically found that:

- Less than 2% of parents said they received the help they needed from services.
- One in four reported that their child was at *high risk of suicide* following parental blame.

- A third of parents feared their child might be removed from their care.
- 81% of parents who experienced blame said they weren’t believed about their child’s presentation.
- 86% said their parenting was criticised before diagnosis.

Education was the most common setting where parents experienced blame, followed by health and social care. The result of parental blame is widespread trauma, mistrust and disengagement from services — families often withdraw completely after these experiences.

LF then explained her team are now working on Phase 2 of the research, which focuses on professional perspectives. They have launched a short survey for practitioners in health, education and social care to understand their training, awareness and experiences related to safeguarding and FII.

The results will be published in a follow-up report early next year.

The group discussed the research, with a few participants sharing personal experiences. A specific question was asked about the next steps for the research. LF explained that they were working on the next phase to explore awareness and training amongst health, education and social care professions. MI explained that there is growing awareness of the problem, but it takes time for this to result in changed practices.

6. Neuro-Divergent friendly Cardiff – Eluned Evans, Cardiff Council.

Eluned Evans (EE) introduced the Neuro-Divergent Friendly Cardiff initiative. This initiative involves all public services in Cardiff, and aims to make Cardiff a Neurodivergent Friendly City as a citywide partnership initiative.

In 2024 they consulted with public services and neuro-divergent people, and the results of this consultation led to the launch of the Neuro-divergent friendly Cardiff strategy in July 2025.

The consultation found that people wanted to see better training for professionals across all sectors (not just health), inclusive and accessible environments, more opportunities for social participation, increased public awareness and positive messaging around neurodiversity, and better access to clear, trusted information about available support.

The draft strategy, involving 46 partner organisations (including Cardiff Council, Cardiff & Vale Health Board, South Wales Police, the education sector and Transport for Wales,), contains a number of organisational commitments by the partners to become more neurodivergent-friendly within their services.

Their draft vision is *“to increase awareness and understanding of neurodivergence and make Cardiff a place where neurodivergent people are supported to live well.”*

The strategy is structured around six key aims. The aims are:

- Being included and part of your community – expanding inclusive social opportunities and peer support networks, ensuring local groups are truly welcoming to neurodivergent people.
- Reaching your goals in education and employment – improving understanding of neurodivergence in schools and workplaces, and supporting smooth transitions into employment.

- Accessing information you can trust.
- Supporting the health and wellbeing of neurodivergent people and families – addressing mental health and daily living needs through better partnership working.
- Being understood and celebrating difference – promoting awareness, challenging stigma and celebrating neurodiversity across the city.
- Improving environments for neurodivergent people – making public buildings and spaces more accessible, including for sensory and hidden disabilities

There then followed a discussion on the presentation. EE explained that they wanted to go above and beyond the legislative requirements on the local authority and would continue to consult with the community and address issues that were raised.

7. Re-defining Our Lives: Towards a Social Understanding of Neurodiversity – Alex Swift – Autism Activist

Alex Swift (AS) presented his own experience of having autism. As a 13-year old, he had an assessment from an occupational therapist. They described his “developmental trajectory” as being like that of a nine-year-old — measured against a so-called “normal” standard for neurotypical people, rather than recognising his individual development.

Alex explained that the assessment used what’s called the medical model of disability, which assumes disability is something “wrong” that needs to be fixed. In autism, that often means trying to suppress autistic behaviours rather than supporting people to live authentically.

By focusing on “fixing” individuals, the medical model ignores the **social barriers** that disable autistic people — such as unsupportive environments, misunderstanding and exclusion.

Alex then explained the Social Model of Disability, which sees disability as something society *does* to someone and something that happens when institutions fail to adapt to the needs of people.

He noted both his sisters are autistic. After a traumatic event, one of his sisters developed mental health difficulties and withdrew from school due to bullying. Even though it was clear autism was a factor, she wasn’t yet diagnosed — and the school blamed his father for her behaviour. When his father tried to discuss the bullying, they dismissed him and implied the problem was parenting.

AS noted that this example is exactly what the UN’s Human Rights Commission highlighted in reports from 2017 and 2024 — a culture that devalues disabled people and undermines their dignity, portraying them as a burden rather than citizens deserving support.

AS noted that an alternative is to build environments based on inclusion and well-being.

Public spaces like libraries, youth centres, parks and cafés are vital “third spaces” where people connect, access support and reduce isolation. When those disappear, people lose key lifelines. He noted that research shows:

- 77% of young disabled people in the UK feel lonely most days.

- Autistic people are four times more likely to experience chronic loneliness than non-autistic people.

- Communities with fewer meeting spaces suffer poorer social and economic outcomes.

AS noted that the social model of disability can be connected to the Well-being Economy model — an economy that prioritises health, happiness and community rather than GDP growth alone. That means supporting community wealth building (e.g. living wage, local procurement, community assets), designing inclusive public spaces with neurodivergent people co-producing decisions and Measuring progress by quality of life, not just financial indicators.

He noted that Autistic people don't want to be judged on whether they're "exceptional" — they want to live ordinary lives with dignity, without having to hide who they are. He noted that if we design our societies and economies around that principle, we'll create better outcomes for everyone.

MI thanked AS for his presentation, noting the clear links to much of the work this group, and the cross party group on disability, focuses on. A brief discussion followed on the presentation in which the presentation was appreciated.

8. AOB

It was agreed to follow up the letter from the minister noted earlier in the meeting with another letter that reflected the research highlighted in this meeting

The provisional date for the next meeting was agreed for 9th Jan at 11am.