



## **Cross-Party Autism Group**

Minutes

Monday 22 January 2024, 10:00-11:30am

Microsoft Teams

**Present:** Mark Isherwood MS (Chair), Tim Nicholls (Secretary), Julie Morgan MS, Sian Lewis, Julie Annetts, Aoife Pryor, Hefin David MS, Samantha Lambert-Worgan, Jeffrey Morris, John Price, Kae Fairhill, Bill Fawcett, Chad Rickard, Jillian Purvis, Amy Gray, Alexander Still, Nigel Morgan, Ruth Parness, Julie Meese, Kerrie Hopwood, Kate Thomas, Sian Owen, Miriam Wood, Samantha Williams, Rob Kirby, Kyle Eldridge, Kara Monkiewicz, Nick Davies, Victoria Morgan-Beattie, Parent A, Sion Edwards, Joanne Crawford, Jessica Webb, Catherine Dyer, Denise McKernan

**Apologies:** Janet Finch-Saunders MS

### **1. Welcome**

Mark Isherwood MS welcomed everyone to the meeting of the Senedd's Cross-Party Autism Group.

### **2. Minutes of previous meeting**

A decision to agree the [minutes](#) of the Cross-Party Autism Group meeting held on 28 September as a true and accurate reflection was deferred until the next meeting.

### **3. Introduction to the Minister**

MI gave an overview of the themes of the meeting before introducing Deputy Minister for Health and Social Services, Julie Morgan.

JM stated the debate led by MI in the Senedd on parental blame and the pathological demand avoidance profile of autism (4 October 2023) raised issues she wanted to hear about directly. JM also introduced three officials who were also in attendance: Sian Lewis, Julie Annetts, and Aoife Pryor.

JM notified attendees that she would have to leave the meeting early but the three officials would remain on her behalf to listen to the issues raised.

#### **4. Q&A with the Deputy Minister**

JM heard from several attendees of the meeting who shared their experiences of the health and social care system. There were several key themes and issues raised by participants.

Participants shared feelings of being targeted by staff in services, with one participant stating this has affected their ability to feel safe in Wales. Some attendees felt that they had been intentionally parent blamed and noted this seemed to be aimed at mothers in particular. Some participants also described how damaging this has been, and how it has put the custody of their children at risk. One attendee described their experience with services as one of hostility and prejudice.

Participants raised a lack of training and awareness from staff in autism services and resistance to accepting an autism diagnosis. In one case, an attendee stated the local Health Board had not accepted a diagnosis, which meant they were unable to access the correct support and felt isolated. Another attendee stated that services had continuously disregarded their child's communication issues, despite a diagnosis of autism.

Record keeping was mentioned by several attendees, who stated there are issues and inconsistencies with administration and how information is recorded. They described feeling ignored or threatened when asking for information to be corrected. In one case, a participant noted there had been issues with how their diagnosis was recorded, meaning it had gone unrecognised. One attendee stated that administrative errors seem to have worsened since the pandemic and now had difficulty accessing information about their child despite having power of attorney for health and welfare.

A lack of adequate advocacy and access to it, as well as barriers to accessing other kinds of support, were raised by several members of the meeting. This included inadequate access to legal support and to disability social workers. One attendee noted they were unable to get a disability social worker because their local authority has stated a child must have a profound learning disability to be eligible.

#### **5. Response from the Deputy Minister**

JM thanked all attendees and highlighted the importance of sharing their experiences. JM stated that, whilst the Government could not intervene in individual cases, the general points raised can be looked at and taken forward. She said she will follow up with attendees on this.

JM also noted the Government has been putting money into developing neurodevelopmental services informed by experience and will also be undertaking consultation on a new neurodivergence code of practice.

JM left the meeting after her response.

## **6. Discussion Continues**

Hefin David, Member of the Senedd for Caerphilly, told attendees he has built links with his local authority and has regular meetings with them. He said this has led to improvements, including support for autistic children in mainstream schools. HD stated that MI and himself could work to raise awareness amongst Senedd members and suggested sending a letter to the Deputy Minister.

Following this, attendees discussed inadequate training of education staff and continuing issues with teachers' understanding of autism and neurodivergence.

Many attendees agreed there is a lack of accountability regarding the issues raised. A local authority that several participants identified as of issue was Flintshire County Council. Some attendees stated they would like to see an independent inquiry into the standards of practice in Flintshire.

One attendee had a question about NAS Outreach Services in Cardiff. TN said he would find out more information and email them directly.

## **7. Any other business and closing remarks**

Tim Nicholls outlined actions arising from the meeting. This included corresponding with the Deputy Minister about a possible inquiry into practices in Flintshire and a further meeting for those with shared experiences.

Julie Annetts confirmed the Deputy Minister will be issuing a written response to the issues mentioned during the meeting. TN highlighted the points raised about local accountability and asked for that to be flagged in the response.

MI concluded by thanking all who attended and assured members the issues raised will continue to be taken forward.