



Welsh Parliament  
**Cross-party Autism Group**

Minutes  
Monday 13 June, 10.30am-noon  
Virtual meeting

**Present:** Mark Isherwood MS, Carolyn Thomas MS, Willow Holloway, Kathryn Williams, Aimee Grant, Amy RL Hughes, Bethan Edwards, Bethan Gilson, Bill Fawcett, Carys Holt, Catherine Edevane, Catherine Vaughan, Cllr Jane Tremlett, Dave Evans, David Vittle Thomas, Steffan Davies, Debbie Shaffer, Debbie Jackson, Debra Mitchell, Ryland Doyle, Elaine Jennings, Frances Rees, Rebecca Gooch, Eleri Griffiths, Rachel Hazelwood, Heather Lucas, Helen Bucke, Keith Ingram, Janet Williams, Jo Taylor, John Price, Jolene Martin, Kieran Fraser, Kirsty Jones, Lindsay Brewis, Michael Imperato, Michael Williams, Monique Craine, Nicole Mitchell-Meredith, Paula Shoosmith, Rebecca Lydon, Dan Rose, Samantha Williams, Selina Johnson, Sheladevi Nair, Shah Shumon, Sian Owen, Siôn Edwards, Sioned Thomas, Stephane Gidon, Suzanne Rinvolucrí, Rachel Brown, Einir Price, Heledd Roberts and Chris Haines

**Apologies:** Emma Howick, Wendy Thomas, Ruth Rabet, Sarah Broadhurst, Samantha Inglis, Karen Thompson and Caroline Wright

### 1. Welcome and introduction

Mark Isherwood MS welcomed everyone to the meeting of the Senedd's Cross-party Autism Group and introduced the two speakers.

### 2. Minutes of previous meeting

The [minutes of the previous meeting](#) on Monday 7 March 2022 were agreed after being proposed and seconded as an accurate reflection by Willow Holloway and Monique Craine, respectively.

### 3. Reflections on the Autistic Women's Empowerment (AWE) project

Willow Holloway – a director and chair of the executive board of Autistic UK as well as chair of the board of directors at Disability Wales – reflected on the Autistic Women's Empowerment (AWE) project, which she officially launched seven years ago on June 13, 2015. She explained that the AWE project was launched to empower autistic women and girls by developing a network and providing peer support. She told attendees that the project was initially started to raise awareness but it has become a vehicle to campaign for recognition and acceptance. Willow also outlined her own personal journey from being virtually housebound due to anxiety and sensory overload to becoming a 'velvet bulldozer' and an expert by experience. She explained that she holds various representative roles including on Welsh Government's autism advisory

group as well as on the North Wales Integrated Autism Service's strategy board. Willow called for better recognition of the different presentation of autism in women and girls. She raised the importance of improving diagnostic pathways, pre- and post-diagnostic support to help develop a healthy self-identity, and support to overcome social barriers.

Attendees were unanimous in their praise for Willow's excellent work over many years, with Catherine Vaughan describing her as a great ambassador for the neuro-diverse community and autistic women. Frances Rees, Bethan Gilson and Kirsty Jones agreed, saying the National Autism Team is very grateful for all Willow's hard work. Janet Williams, Helen Bucke, Bill Fawcett and Suzanne Rinvoluceri offered their help with the project.

#### **4. Latest research about autistic women's experiences**

Kat Williams, a non-executive director and research involvement lead at Autistic UK, outlined research projects including a systematic review of [autistic women's experiences of infant feeding](#) – a project led by Aimee Grant at Swansea University. She also outlined a review of [autism health passports](#) – again led by Dr Grant – and a study into community-based language preferences for multiple developmental disabilities including autism, ADHD and Tourette's. Kat, a postgraduate at Cardiff University, is also researching autistic adults' unequal access to health care. Her master's project is a qualitative study into autistic adults' experiences of telehealth. This will be followed by a PhD starting in October on the role of communication in access to health care for autistic adults. She raised concerns about 'gaping chasms' in the research base and the intersectional nature of inequalities faced by autistic women. Kat highlighted low understanding of autistic people's needs, including pain reporting, sensory and communication differences. She concluded that the health experiences of autistic women need to be a research priority, with studies led by autistic people and appropriately funded.

Jolene Martin gave her personal experience, saying breastfeeding didn't work for her and she did not know she was autistic at the time. She said she felt traumatised by the health care system. Janet Williams said she felt ignored in hospital, with her first experience of breastfeeding involving too many people telling her she was doing it wrong – without considering how they were making her feel. Eleri Griffiths told the meeting she recently spent four days on a maternity ward with her daughter, saying the environment is unsuitable for anyone with sensory perception differences.

Aimee Grant said research on autistic people's pregnancy experiences showed worsening mental health was common – as was women not knowing that they were autistic at the time. Dr Grant said a shortage of midwives in the UK means that support for breastfeeding is inadequate. Frances Rees said the National Autism Team would promote the research on its website and social media channels as well as with the Integrated Autism Services across Wales. Asked how Wales can confront belligerent attitudes towards autistic women, Kat Williams raised the importance of growing the evidence base and cultivating system change.

#### **5. Developments on fair treatment of autistic women and girls**

Willow Holloway gave an update on policy developments. Looking to the future, she highlighted a quality statement for the health of women and girls, which is being developed by the Fair Treatment for the Women of Wales charity. She told the meeting that two reports would shortly be published, an AWE project report and a user-led report, entitled *Break the Bias*. In closing, Willow outlined how people can get involved with Autistic UK by becoming a sponsor, joining the mailing list, attending events or donating.

Mark Isherwood raised concerns about families in his region, often mothers, who find themselves in crisis after being treated as vexatious by public bodies which blame

parents, refuse assessments and threaten to begin Section 47 enquiries. The North Wales MS told the meeting that parents are too often refused services when minor adjustments could make a major difference to their lives. Willow said there is brilliant work going on nationally but she acknowledged that too often it does not filter through to a local level.

Jolene Martin described the difficulties she had in gaining a diagnosis. She questioned the appropriateness of services 'gatekeeping' to manage demand, raising the example of a form she had to fill in while struggling with imposter syndrome.

Frances Rees highlighted the National Autism Team's forthcoming Community of Practice about autistic women and girls on 29 June.

## **6. Any other business / closing remarks**

Chris Haines provided a brief update on an agenda item from the March meeting about a [preliminary report on the education of autistic pupils](#). He told the meeting that the Cross-party Group had written to the regional education consortia, directors of education, Estyn and the Minister for Education to highlight the report. He said he would circulate responses from the minister and HM Chief Inspector. The report's author, Steffan Davies, added that he has had positive contact with Estyn about his work which was also highlighted during a Senedd [short debate](#) led by Caerphilly MS Hefin David.

Mark Isherwood thanked everyone for attending the meeting. He told attendees that the next meeting would be held on Monday 19 September 2022 from 10.30am to noon. Chris Haines added that he hopes to hold the next meeting in North Wales with participants able to join in-person or virtually. Attendees helpfully suggested some potential venues.