



Welsh Parliament
Cross-party Autism Group

Minutes – Annual General Meeting
Monday 24 October 2022, 10.30am-noon
Well-being Hub, Wrexham / Microsoft Teams

Present: Mark Isherwood MS, Carolyn Thomas MS, Dr Duncan Holtom, Julie Annetts, Dr Alberto Salmoiraghi, Andrea Hughes, Ioan Bellin, Catie Parry, Ceri Low, Christy Hoskings, David Fox, Steffan Davies, Keith Ingram, Jan Thomas, Karen Shepherd, Kathleen Eley; Katie Hiscox, Kirsty Jones, Kyle Jamie Eldridge, Lee Green, Liz Fletcher, Lynette Hibbert; Monique Craine, Nicole Mitchell-Meredith, Liz Ponting, Kirsty Rees, Rosie Edwards, Ruth Rabet, Samantha Lambert-Worgan, Sian Owen, Steffan Phillips, Sioned Thomas, Stephane Guidon, Stephanie Shobiye, Alexander Still, Sue Evans, Suzanne Rinvulcri, Vaughn Price, Gareth Williams, Willow Holloway, Yvonne Odukwe. Catherine Vaughan, Eleri Griffiths, Shelly Godfrey-Coles, Katherine Wyke, Heather Lucas, Chris Haines, Elaine Jennings, David Jennings, Gillian Brokeley, Bethan Kendall, Rachel Hancocks, Justin Hurst and Helen Wilson

Apologies: Hefin David MS, Alun Davies MS, Tanya Kleinhans, Dr Elin Walker Jones, Elizabeth Naylor, Simon Humphreys and Dr Sarah Broadhurst

1. Welcome and introduction

Mark Isherwood MS welcomed everyone to the meeting of the Cross-Party Autism Group – the first to be held in north Wales since 2019 and the first in-person meeting since 2020.

2. Minutes of previous meeting

The [minutes of the previous meeting](#) were agreed. Karen Shepherd proposed the minutes as an accurate reflection of discussions on 13 June.

3. Election of officers

Mark Isherwood MS was re-elected as group chair after being proposed by Carolyn Thomas MS, while Chris Haines was re-elected as secretary. No other nominations were received.

4. Annual report

Mark Isherwood MS informed attendees that the group's annual report and financial statement would be published on the [Senedd website](#) in the coming weeks.

5. Findings of the review of neurodevelopmental services

Dr Duncan Holtom, Head of Research at People & Work, provided an overview of the findings of the [review of the demand, capacity and design of neurodevelopmental \(ND\) services](#). He told the meeting that despite investment in children's ND services and the Integrated Autism Services, which have made Wales a pioneer, long waiting lists have developed. DH said for every two children or adults referred for diagnosis, only one was undertaken. He added that capacity is constrained by the small size of teams which leaves services particularly vulnerable to recruitment and retention problems. DH said the working group identified three key goals: swifter access to early help and support, swifter access to specialist assessment, and equity of access to services and support. He told members that this should be underpinned by a 'no wrong door' whole systems approach, which is more person-centred and provides support based on need rather than diagnosis. DH also stressed the need for increasing awareness and understanding of neurodiversity.

Karen Shepherd drew on her family's experiences, raising concerns about transitions from further education into employment. Steffan Phillips agreed and argued that support tends to drop off for autistic adults. He emphasised the importance of training, particularly for learning disability and mental health services. Attendees stressed the importance of diagnosis for understanding, physical and mental well-being and access to support. DH agreed that there is still a place for diagnostic assessments but said it is important to look at what early support can be provided without requiring one.

Monique Craine welcomed the review's 'joined up' approach, saying it is important to take a holistic view. While Elaine Jennings agreed with many of the recommendations, she described her family's experience of neurodevelopmental services as 'shambolic'. Raising concerns about parent blaming by services, Helen Wilson told the meeting that her family has been repeatedly mistreated as she argued that the system has been broken for decades. DH stressed the importance of trying to strengthen existing services first. He cautioned that establishing new services can be difficult and complex in practice.

6. Welsh Government response to the independent review

Julie Annetts, head of the neurodevelopmental policy team, outlined Welsh Government's response to the review. She highlighted the [Deputy Minister's announcement](#) of an additional £12m investment to March 2025. JA also pointed to the role of the new neurodevelopmental conditions ministerial advisory group. She explained that the new three-year improvement programme will have three work streams. The first is taking immediate action to provide additional support to reduce the 'here-and-now' pressures on assessment services and put in place much-needed support for parents and families. The second will co-produce and test models to reform ND services in the longer term. The third will focus on cross-cutting priorities, such as a workforce strategy and improved data collection. JA added that the National Autism Team will become the National ND Team, with Donna Sharland leading the transformation. She highlighted [engagement events](#) taking place across Wales which will help shape the ND conditions improvement programme.

Mark Isherwood MS stressed the importance of monitoring and evaluation as well as involving those with lived experience in this. He told the meeting that it is crucial to move from awareness of autism towards understanding, acceptance and – most importantly – empowerment.

Yvonne Odukwe, from Autism's Hidden Voices, a Newport-based charity, highlighted her work supporting harder-to-reach families in the community who may not want to seek help or pursue a diagnostic assessment. She also raised concerns about transitions, saying she has had to act as a go-between physically taking records from children to adult services.

Samantha Lambert-Worgan raised concerns about her daughter's difficulties accessing support through CAMHS which told her "we know nothing about autism". Suzanne Rinvoluceri questioned the accessibility of services for parents who are often neurodivergent themselves.

David Fox pointed to studies that have shown an association between socio-economic status and lower rates of diagnosis. This point was challenged by other attendees. He also raised the importance of supporting those who do not meet the diagnostic threshold. While he supported the principle of a needs-led approach, he cautioned that some autistic adults can have difficulty identifying their needs.

7. Any other business / Closing remarks

Mark Isherwood MS said the group hopes to hold the next meeting at the Senedd in Cardiff on Monday 23 January from 10.30am to midday, with members again able to join virtually or in person.

The following provisional dates have been set for other meetings in 2023:

- 24 April at Bangor University
- 14 July and 16 October at venues to be confirmed.

In closing, the chair thanked the two speakers, everyone in attendance and the staff at the Well-being Hub for hosting the meeting.