



Cross-Party Autism Group

Minutes

Monday 17 April 2023, 10.30am-midday

Cledwyn meeting rooms, Bangor University / Microsoft Teams

Present: Mark Isherwood MS (chair), Chris Haines (secretary), Alice Running, Danielle Jata-Hall, Dean Clarke, Lavinia Dowling, Helen Wilson, Richard Wilson, Sioned Thomas, Kirsty Jones, Anna Story, Claire Bullock, David Evans, Steffan Davies, Dr Duncan Holthom, Sian Edwards, Emma Preece, Catherine Vaughan, Rachel Everell, Heather Lucas, Jeff Morris, John Price, Jolene Martin, Kae Fairhill, Kathryn Craine, Kyle Eldridge, Sian Delyth Lewis, Michael Williams, Aoife Prior, Kirsty Rees, Rosie Edwards, Sian Owen, Suzanne Rinvoluceri, Sam Walsh, Jeni Andrews,

Apologies: Michal Blochowiak, Simon Humphreys, Kate Thomas, Lucia Elghai, Dr Sarah Broadhurst and Christy Hoskings

1. Welcome and introduction

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

2. Minutes of previous meeting

The [minutes](#) of the previous meeting held on Thursday 19 January at Ty Hywel were agreed after being proposed and seconded as an accurate reflection.

3. Parental blame and the PDA profile of autism

Alice Running and Danielle Jata-Hall presented their research, [Parental Blame and the Pathological Demand Avoidance \(PDA\) Profile of Autism](#). The authors explained that parental blame is when a professional working with a family alleges or implies that the parent-carer is somehow causing their child's disability presentation. They said it can take the form of gaslighting, minimising, repeated criticism, raising undue safeguarding concerns and blaming parental mental health. The duo described the PDA profile of autism as driven by need for autonomous control due to anxiety, manifesting as consistent resistance to everyday demands. Raising concerns about a lack of recognition and understanding of the PDA profile, they said this impacts the support families receive and leads to parents facing safeguarding scrutiny.

The researchers found that 88% of parent-carer respondents said they had felt blamed for their autistic-PDA child's presentation. Common themes including parents being told by professionals that their parenting or mental health is causing their child's autistic presentation. The research revealed that families reporting their socio-economic, professional and marital status afforded them a degree of protection against blame by professionals. 11% of respondents had been subjected to formal safeguarding procedures, citing the parents at fault for the child's presentation. Nearly 60% were lone mothers and almost 80% were neurodivergent parents. Asked what changes they would like to see, parent-carers called for better training for professionals around demand avoidant profiles of autism, support for parents to understand their legal rights, and UK-wide recognition of the PDA profile.

Helen Wilson shared her own lived experience of parental blame. She raised the importance of training. She highlighted the case of Paula McGowan OBE who successfully campaigned for mandatory autism training in the NHS following failures which led to the death of her son, Oliver.

4. Experiences of support and services in North Wales

Dean Clarke, who has an eight-year-old autistic son, Ethan, spoke about his family's experiences of services and support in North Wales. Mr Clarke was posted to RAF Valley as community development officer and designated safeguarding lead in 2015. He told the meeting there was little support after his son was diagnosed in 2017-18, with the family advised somebody would be in touch and they may want to join some family support pages on Facebook. Despite reaching the point of crisis, he said the family only receive eight hours of respite each month and he warned that support is based on availability rather than need. He added that families are expected to fund recreational activities and some may not be able to afford it, particularly amid a cost-of-living crisis. Mr Clarke also raised concerns about the lack of wraparound support for families of disabled children in Anglesey.

Mr Clarke said his non-verbal autistic son has twice been discharged by Speech and Language Therapy (SALT) services. He highlighted a high level of vacancies in SALT with each special educational unit only getting one day per month of support. Outlining similar difficulties accessing CAMHS, he said his son has been referred twice but rejected both times without assessment. In closing, he raised concerns about a lack of collaborative working and he called for a review of support services for autistic children in North Wales.

5. Mental Health, autism and the PDA profile

Lavinia Dowling, a mental health and autism specialist nurse consultant, gave a presentation about her study on mental health, autism and the PDA profile. The founder and director of The M Word consultancy, a community interest company that specialises in mental health support, has practised as a clinician for 25 years. She told the meeting that NICE guidelines do not recognise PDA. She said 70% of children and young people with PDA cannot attend mainstream education and many parents are accused of fabricating

induced illness. LD said schools often fail to recognise autism, or assert that PDA does not exist. She added that CAMHS lack knowledge of autism and do not recognise PDA. Raising the example of mimicking eye contact, she said screening is often a tick-box exercise and professionals fail to truly understand autistic traits. She pointed out that while PDA is not recognised, unlike Oppositional Defiance Disorder (ODD) which is associated with ADHD – yet ODD has similar presentations to PDA because they both describe crippling anxiety. In closing, she raised concerns about lengthy waiting lists and limited resources, calling for a more preventative and proactive approach.

Mark Isherwood MS suggested writing to Welsh Ministers to highlight the speakers' research, asking about the Welsh Government's position on the PDA profile and raising concerns about parental blame. MI also agreed to write to Welsh Government, calling for an update on the services and support offered by Betsi Cadwaladr UHB.

6. Any other business and closing remarks

MI informed attendees that the next group meeting is provisionally scheduled for Friday 14 July. He welcomed suggestions for a venue to hold the next hybrid meeting. In closing, MI thanked all the speakers, everyone in attendance and staff at Bangor University for their help hosting the meeting.