

Minutes / Cofnodion Cross Party Autism Group Medi 10 September 2014 Prifysgol Bangor University 10:30-12:30

1 WELCOME / CROESO

Chair of CPAG, Mark Isherwood welcomed everyone to the North Wales meeting. Fellow AM Alun Ffred Jones also attended the meeting.

2 PRESENTATIONS / CYFLWYNIADAU

- 2.1 Delyth Lloyd-Williams, whose 19 year old daughter has an ASD diagnosis, spoke about 'disabling' and 'enabling' experiences of the journey her daughter has taken to college. Delyth detailed various moments that enabled her daughter's success, from break-through moments to exceptional quality of care. Delyth also spoke of other incidents where her daughter was 'disabled' by those who didn't understand the support she needed. After visiting multiple colleges, reaching out to councillors, AMs, MPs and ultimately, refusing to let anyone 'disable' her daughter, Delyth showed photos of her daughter's ongoing success in college.
- 2.2 Dr. Ceri Christian-Jones, research officer for a family based study into *Sexuality, Autism and Young People* outlined her ongoing research into the issue and presented some of her early findings. Ceri spoke about the importance of acknowledging the rights of people with autism to form intimate relationships and on creating opportunities for people with autism to access information. The initial findings suggested that parents recognised that these issues needed to be addressed and that schools should support sexual education by tailoring it to the pupils' needs.
- 2.3 Rod Morris, having just completed his Masters in Autism, discussed the nature of his academic work in the field and spoke about how assessments can only recognise or identify autism rather than 'diagnose' the underlying cause. Rod questioned why research and assessment was formulated by the perceptions of 'neuro-typical professionals' rather than based on the 'autistic person's expression of their processes'. Rod presented the idea of assessment based on a 'deficit model' being unfair and suggested autism can only be seen as a deficit when it is misunderstood.

3 ISSUES RAISED

- 3.1 The case of Claire Dyer being moved from Swansea to Brighton to access appropriate services, highlighting a gap in adult service provision in the area, was raised. CPAG has written to the Health Minister on this issue and is awaiting a response.
- 3.2 Concerns were raised over the support in Flintshire, in particular for families where there are multiple individuals with different needs. Similarly, adults are struggling to get appropriate diagnosis in the first instance.
- 3.3 Comments were made about professionals who didn't seem to have comprehensive understanding of autism. Audience members shared concerns regarding adult diagnosis and subsequent service availability, as well as an imbalance between services for autism and services for other health issues with similar symptoms.
- 3.5 The last point raised was from someone previously in the stakeholder group in Wrexham, who questioned where money committed to autism services was spent when Wrexham and Flintshire ASD groups merged.

4. ACTIONS

- 4.1. CPAG to write to Robin Moulster, BASW Cymru Manager to propose that social workers are sufficiently trained about autism.
- 4.2 CPAG to write to Deputy Minister for Health to raise concerns over the importance of long term investment in autism and ASD funding in Wrexham and Flintshire

5. ANY OTHER BUSINESS

Date and location of the next CPAG meeting: National Assembly for Wales, 19th November 2013 12:00-13:15