



## Cross-Party Autism Group

### Minutes

Thursday 13<sup>th</sup> February 2025 ,15:00 - 16:30 pm Microsoft Teams

Present: Mark Isherwood MS (Chair), James Radcliffe (Secretary - NAS), Julian Morgan, Kate Gibson, Kara Monkiewicz, Denise Mckernan, Luke Clements, Fiona Dakin, Kerrie Hopwood, Janine Cusworth, Alex Still

**Apologies:** Llyr Gruffydd, Nigel Morgan, Amy Gray, Lee Green

#### **1. Welcome**

Mark Isherwood (MI) welcomed everyone to this meeting of the Senedd's Cross-Party Autism Group.

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

Julian Morgan (JM) proposed and Kerrie Hopwood (KH) seconded the minutes from the previous meeting as fair and accurate.

#### **3. Matters arising**

JR explained that the letter to the minister regarding mental health and autism, as agreed in the previous meeting, had been sent and we were still awaiting a response.

#### **4. Forced home education – Kate Gibson (KG)**

KG introduced herself and shared her presentation. She is a co- director of Cross Roads educational consultants, who started the business with her partner when they noticed lack of attendance from academically able children. They had noticed there was no support for those transitioning to home education, so they established

business. They now have 30 families and are currently full. 90% of families on their books have children awaiting diagnosis of autism or have it already.

There are over 6000 children home educated according to the Welsh Government (WG) with a significant portion who have ALN. The number is probably higher as people go under radar. Many don't choose it, they have it forced on them due to lack of support from services. It is not an easy choice.

KG outlined the reasons this can happen which include school avoidance (since covid), inadequate ALN support within schools, and bullying and isolation. The term is also 'forced' because many parents would rather have not been placed in this position.

The impact on those children is considerable, there is a loss of structure and routine, Parental stress is massive. There is a barrier to qualifications – in practice children who are educated at home cannot sit any WJEC exam except Maths. Whilst other exam boards are available for other subjects, this has a bigger impact on Welsh Language students. There is a lack of funding and support compared to mainstream education. Parents face financial challenge – parents move from free education to having to pay for things (eg school meals)

LEA alternative provision is not available or suitable – academically gifted introverted children are sometimes only offered places with children with behavioural issues. Further education provision that is sometimes offered is also not always suitable for 14 year olds.

Crossroads provides personalised learning including English and Maths to a range of children of all ages, with the majority in year 9 or above. The support is for families – whole families sit in and they discuss plans, the children are very independent and motivated. KG then gave examples of children they had worked with, and how their confidence had improved

They have also started looking at creating an ND friendly exam centre – trauma means many children cannot do exams in a mainstream school centre. Their proposal is to establish one (or more) centres for home educated children to do exams – with one proposal to establish one in a wildlife park as the children find that relaxing.

KG finished by calling on the group to advocate and demand better support for ALN education and those who home educate.

JM agreed on the problems identified, and pointed out that income levels of a family would often halve when home educating. He suggests that some of the allocation a LA would receive for a pupil could be a source of funding for supporting families in that situation or for funding accessible exam centres. He also then suggested using non-medical terms (such as avoiding the term 'disorder'), which MI agreed with.

DM then shared her own experience of removing her son from education. MI then noted the issues autistic pupils face and that he was still aware of pupils being excluded for behaviour resulting from autism despite that being illegal.

DM then noted the autism team in Leeds that had practitioners who went into schools to support their understanding of autism, but this was not happening in Flintshire.

JR agreed to write to the minister on the issues raised, and offered to make mutual introductions between KG and a member of staff in the children's commissioner's office he had recently met with.

## **5. Fabricated or Induced Illness – Prof Luke Clemments (LC)**

LC introduced himself and the research he had been involved in. He introduced the main subject of his presentation – fabricated or induced illness (FII) – noting it used to be called Munchausen's by proxy (MSbP). He started by noting the story of Sir Roy Meadow, and the wrongful convictions that resulted from it. FII is a wider concept than MSbP and so there are concerns that this diagnosis could result in well-meaning but over anxious parents included under the term if it is felt their concern is doing harm to a child. LC notes that the guidance produced by the Royal college of paediatrics initially warned of wrongful accusations being a possibility, but the most recent guidance (of 2021) dropped those warnings.

LC then presented figures on the estimated prevalence of FII, noting it was very rare.

LC noted that the implications of the way FII has been defined is discriminatory against parents with ND, and there is a very high danger that a mother with diagnosed/undiagnosed autism, communication difficulties and anxiety can have her behaviour misinterpreted by professionals unfamiliar with autism as FII.

Over 50% of allegations of FII are made against disabled parents (who make up 10% of the population), and over 50% of allegations of FII were made after a parent made a complaint against a public body. Autistic parents are three times more likely to be accused of FII. Yet 84% of allegations resulted in no follow up action, and 95% of cases the children remained at home.

The impact of a false accusation is traumatic to the parents, it leads to a loss of trust in public institutions (NHS/School/Social Services), and even wrongful allegations remain on DBS investigation data – which would affect employment prospects. LC then added some statistics about parents who had been blamed, with 90% of parents saying they were blamed when asking for support. LC noted this would translate into over million false positives.

LC then noted that Martha's rule (where parents have the right to a second opinion) had demonstrated that an ability to push back against professionals and seek a second opinion had saved lives.

LC said they had asked the royal college to reconsider their guidance to accept discrimination and false positives exist, but this had not happened. But until they do, LC wanted governments to accept the guidance from the association of social workers instead, which does accept this.

DM then shared her own story on this issue. She noted one issue was inexperienced social workers and too much paperwork, which led to a loss of expertise and experience of the history with MSbP.

JM then added a comment about moral panics and autism – and how there is always a reason found to blame parents for having autistic children. He noted there was precedence for ignoring royal college guidance, with the royal college of psychiatrist's guidance still referring to autism as a mental health condition but that guidance was now being ignored by governments.

LC noted he was having a more mature discussion with WG than UK government, and if the govt were to withdraw support for royal college it would have a big credibility issue for the royal college.

MI also noted that in the chat Yasmin (support staff for luke fletcher MS) wanted to work together on a motion on this issue on a cross party basis.

#### 6. Papers to note

JR proposed noting the papers that had been circulated to the group. The papers, are '*Ben Scott Violations of Autistic Individuals' Rights in the UK*' and '*Laura Ferguson and Debbie Hollingsworth, Autism and Parental Blame Project Blamed Instead of Helped*'. MI suggested asking both authors to speak at a future meeting.

#### 7. AOB

DM suggested inviting DCI Curry from North Wales Police to a future meeting on how police respond to call outs involving autistic people. JR agreed with the suggestion.

JR suggested possibly moving the time of the next meeting to enable more people to attend. It was agreed to try an earlier time for the next meeting.

The provisional date for the next meeting was agreed to be moved to 2pm on the 22<sup>nd</sup> May.