

Cynulliad Cenedlaethol Cymru | National Assembly for Wales

Datblygu Bil Aelod | Development of Member Bill

Y Bil Awtistiaeth (Cymru) - Datblygu'r Bil | The Autism (Wales) Bill - Bill Development

DMB(5) AWB24

Ymateb gan Di-enw | Evidence from Anonymous

The Autism Bill

At my mum's funeral only my brother & I and our partners attended. All we could say was 'She did not understand us and we did not understand her. Suppose she did her best'. Her funeral was over in 8 minutes. She was 90, I was 60 and had only realised she had Aspergers for the last year of her life.

My hope from the Autism Bill is that in future there is not just more understanding throughout society but also support to children of Autism/Asperger parents

I know Autism/Aspergers covers a wide spectrum but basic info is needed in a wide range of professions

Police and emergency workers

My cousin is a Ceredigion hill farmer. In the dark one evening she found 2 police at her farm gate. They said they were waiting in case 2 girls who had got lost in the miles of forestry up the mountain came back that way. One had autism. My cousin asked if there were any lady police officers looking for the girls. The police saw no point in the question even when my cousin tried to explain that a girl with autism who would have been told 'don't go with men you don't know & stranger danger' would take this literally.

My cousin then went around the mountain calling 'hello I'm Delyth, I am a lady farmer, I am looking for 2 little girls who may be lost, you are not in trouble.....She found them after 1 am and took them to the police.

One of the police irritably told the girls that they should not go walking.... He never got a chance to finish. The girl with autism collapsed saying 'I musn't walk, I musn't walk'. My cousin responded 'It's OK he only meant you must never walk this walk again, you can walk any other path you want, don't worry'. The police asked my cousin how she knew what to say & do with a girl with autism. Fortunately she had worked as a Teacher's Assistant and had worked with autistic children

Public Servants – Job Centre Staff

Sometime after my cousin stopped being a Teacher's Assistant, she was in Aberystwyth one day when a lad she knew who had been at Penglais school stopped her. He looked unwell and said he & his granny (with whom he lived), were hungry & had had no money for some time. Knowing he was autistic & had learning difficulties Delyth took him to the Job Centre. It was obvious the staff in the Job Centre knew him but commented that he never kept appointments he just came in stood around & went away. Delyth explained he could not read & could not tell the time and had no understanding of appointments and could not understand the way they asked complicated questions & phrased things. The staff were adamant he had to stick to appointments sent by letter. Desperate to help she offered to come back with him for an appointment. Job Centre staff responded the due to data protection she would not be allowed to be with him during their discussions with him.

Eventually Delyth gave him £50 to get food for himself & his granny as she knew that the school had given him the skills to buy food.

Then she went back and insisted on speaking to the Job Centre Manager. She asked for a home visit for the lad & his granny.

Some weeks later Delyth saw the lad in Aberystwyth, he was so grateful he & his granny had food and some money.

Health Service Staff:

It would be helpful if doctors, midwives, health visitors & nurses had more information about autism as part of training not just about children and young adults with autism, but also how it affects adults. This may help parents with autism in caring for their children.

Staff could also better assist patients with autism who have problems with interoception (the ability to know and express internal states such as hunger, tiredness, thirst, cold, pain) and alexithymia (difficulty in experiencing, expressing, and describing emotional responses)

Midwives & Health Visitors

My mother (a barrister) often said she had no clue what to do when I was born, but she remembered seeing a puppy being put in a drawer with a blanket under him, so that's what she did with me

When I was 5 I said I did not feel well. Mum asked 'What's your evidence?' Being unable to respond adequately I was packed off to school where a member of staff took my temperature. It was over 100. I was sent home (and hit)

When I was a Health Visitor I came across a few women who had no clue what a baby or child needed. It was if their child was an alien on another planet designed to stress them. Another mum who was not stupid, insisted that her 3 day old child could eat chips & brown sauce. Were these women on the spectrum?

Other health workers

My mum was completely unable to explain her symptoms or feelings
Taking mum to a consultant for back pain, she could not identify where the pain was in words or by pointing and eventually angrily told the doctor 'you should know where the pain is'. The doctor said it did not work like that. I suggested that that is how vets have to work. The doctor took this on board. Had we all known about autism we would have understood she had problems with interoception

Physiotherapy etc

Mum could not see connection between having knee replacements & the need for physio & rehab. She seemed completely disconnected from the muscles & bones in her body and seemed to have some magical interpretation of how bits of the body (muscles & bones) interrelate. If she had had more practical demo with anatomical model perhaps she could have understood & continued walking.

Safe Guarding

My mother's boyfriend's best friends were part of a sado-masochistic group that ended up in court (Regina v Brown 1993)

When I was a teenager, my mum's boyfriend tried to get into my bed naked and offered me his 'sausage & eggs'. I told mum what had happened using his words of 'sausage and eggs'. She just looked blank, told me I had always been a stupid silly little girl hit me and that was it.

Only now I understand she had Aspergers she had no clue what I was trying to convey

Support to Family

It was strange to grow up in a house where we were always waiting for a meltdown without knowing what the cause was. Eventually I learnt to just let mum to hit me as then she would calm down. Being hit was easier than wondering when I would be hit. I found it strange seeing other parents hugging their children

It was character forming but I could have done with help as for 30 years I felt as if I was carrying suppressed rage within me, like a volcano

Our family had no friends, visitors were usually sent packing, there was no social chitchat, only legal cases discussed, bizarre interpretations of other people were created as she had no understanding of other peoples' points of view, people were either OK or 'spawn of satan' and insulted to their faces.

We had to guess if she was tired, hungry, cold, hot, in pain, she was just angry Her only emotion seemed anger, if you asked what she was feeling she had no clue (alexithymia). Her reaction to music, smells, textures, requests, touch was rage

Her reaction to others being ill was rage. My dad was ill for many years and had things thrown at him. Being in hospital for months on end was probably a refuge. Her reaction to my starting periods was to hit me

School was very wary of mum. She had hit a teacher but as she was a barrister no one followed it up.

The need to be mothered

I was very lucky that when I started nursing, 2 of the other nurses in my student group said 'you need a mother' and looked after me.

A few years later when I worked as a nurse & midwife in an Oxfam Project in Kenya (providing health services for 20,000 people) some of the older local women came to see me and said 'Are you an orphan? You need a mother. We will be your mother'

I have been very lucky to have been mothered by others. That may be what other children with parents on the spectrum need

Post script,

What happens when people e.g. carers understand the issue:

The last 2 years of mum's life she was in a residential home. After a year the staff asked us to remove her as she was so vile to staff. Being a Barrister she knew how to attack and diminish people and was threatening to sue them for assault as she hated being touched but needed care and assistance with toileting, changing pads & clothes etc

I had just realised that mum had Asperger's. I explained to the staff what part of the problem was. The carers' response was kind & delightful 'Oh my grandson is autistic'. 'My nephew is autistic Ok – now we understand.' Instead of trying to reason or rationalise with her they would say 'we will come back in 10 minutes when you feel better' They let her stay in the home till she died thank goodness