

# Inquiry into the Autism (Wales) Bill

## Roundtable event - summary of discussion

25<sup>th</sup> October 2018

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### Health Social Care and Sport Committee

## Autism (Wales) Bill inquiry round table event 25 October 2018

### Autism Bill roundtable discussions

Sessions with parents of children with autism (involved with autism charities)

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Individuals from NAS Bridgend Support Group, NAS Cardiff and the Vale Support Group, One Life, Ebbw Vale, Chinese in Wales, NAS Bridgend Support Group and NAS Pembrokeshire Support Group took part in discussions with Members.

#### 1. Comments about autism

- Autism is a lifelong condition, it's with the person forever, short term measures aren't going to work, support needs to be funded for life.
- Even if a person has complex needs, it's the autism that's fundamental - everything else is affected by it.
- What people have to understand is the big difference between autism and other neurodevelopmental conditions is there are no drugs to manage autism.



## 2. Is the Bill necessary?

All participants said yes:

- Definitely believe a Bill is necessary.
- In complete agreement that the Bill is a must.

Reasons given included:

- It will help with accountability – staff need to be held accountable for that child’s care.
- It will mean better use of resources LSAs have no training in autism, want mandatory training.
- Can use to enforce rights - ‘I know my child has these rights under the Autism Act’.
- Rights would be enforceable and understandable under a Bill.
- Our children are being failed
- We need something statutory with accountability
- Parents are desperate for help
- We need the Assembly to stand up for parents
- We have tried other methods and they haven’t worked.
- One person said they sat on a group developing the first autism strategy 10 years ago, and said we were disappointed with the final action plan, it had no teeth and didn’t work. The autism strategy was meant to solve everything, it didn’t work, we have lost faith in it.

## 3. Comment on the Social Services and Wellbeing (Wales) Act 2014

- The Social Services and Wellbeing Act does not meet the needs of our children.
- All ‘high functioning’ people are not eligible for social services. They may have a high IQ but struggle with daily life skills.
- Social services need training in autism.
- The Bill would provide for better assessment and planning for meeting care needs - at the moment it is just not happening.
- People with ASD with a high IQ and without a co-occurring learning disability or mental health condition get missed.

## 4. Is progress being made? Have you seen improvements over recent years?

- If anything, things seem to have gone backwards.
- Restrictions on council funding mean they are using the cheapest providers who don’t necessarily provide the most appropriate service (example given of a 23 year old man who was provided with an 18 year old female carer, it wasn’t appropriate and only lasted a few days).

- Support groups like One Life and NAS Support Groups receive no funding and rely heavily on parent volunteers - “If I did not do One Life my son would not have anything.”
- Services aren’t there.
- We get statutory services referring people to us and we are volunteers!
- Ongoing support is so hit and miss.

## 5. Lack of appropriate information

- A lot of money has gone to *ASD Info Wales*<sup>1</sup> but local authorities are not obliged to use the resources. Bridgend has rejected all those resources and said we do our own, well they don’t.
- *ASD Info Wales* do not provide translated information. Chinese people have requested it, Chinese in Wales offered to translate it for them and they refused. It is an equality issue, language is very important. Interpreters also need to be autism trained and aware.

## 6. Education

- ‘Schools have always disappointed me’.
- Lack of support in schools – people seem to be facing the same issues now as I did when my son was young, he’s now 27.
- Support in mainstream education is not there.
- Local authorities do not collect data on the number of children temporarily excluded as a result of their ASD.
- Even for a ‘statemented child’, I get phone calls about once a week to pick him up.
- Teachers and support staff aren’t willing to unpick any difficult behaviour.
- We need autism awareness and understanding training in schools – it’s not understood or dealt with properly.
- Schools are expected to identify and provide a detailed report to refer on children who may have autism but schools aren’t picking them up
- Girls in particular aren’t being picked up as they present differently and are better at copying social cues. ‘We were not taken seriously and just told ‘no she’s a good girl’, and it was only when she attempted suicide that we finally got any help’.
- There’s no designated training for teachers
- We need to raise awareness and understanding, and acceptance of autism, especially in schools.
- We need clear pathways, particular issues for ‘high functioning’ girls not been identified.
- The only pathway is through the school and it’s not working. It’s very slow and delayed.
- Should be GP referrals, should be clear referral pathways in education and health.
- Schools can only make four referrals to educational psychologists per term, so it’s the disruptive children who are prioritised.

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<sup>1</sup> <https://www.asdinfowales.co.uk/home/>

## 7. Diagnosis and waiting times

One group discussed the importance of diagnosis:

- ‘Every parent has the right to understand their child’.
- Certain services aren’t available unless they have a diagnosis.
- Diagnosis also helps people to understand who they are.
- Diagnosis ‘opens so many doors’ can get advice from Careers Wales, benefits, employment support
- In Pembrokeshire they say any child should get help, whether they have a diagnosis or not, but in reality it’s not happening.

## 8. General comments:

- Health Boards are reliant on the voluntary sector, when you get a diagnosis you are given an NAS leaflet and passed over to them.
- We need timely assessments and diagnosis.
- My son was assessed after waiting 5 years for it, and we are still waiting for the outcome 5 years later.
- There are not enough autism experts on current Neurodevelopmental Disorder teams.
- The Welsh Government’s 26 week target is not being met in Pembrokeshire and other areas.
- In Pembrokeshire, Carmarthen and Ceredigion, there are 2 waiting lists, a historical one and one for new referrals – we’ve been told that by January 2019 the historical waiting list should be gone, but we were also told this 2 years ago... we’ve been in the same position for 5-6 years now.
- It is a postcode lottery, two and a half year waiting times in Pembrokeshire.
- The Bill talks a lot about diagnosis but that is only the start of the journey – it is about what happens after.
- Once you have a diagnosis there is no support. It is up to you as a parent to find out where the services are.
- Adults can now get quicker diagnosis with the IAS but there is no support afterwards.
- Long waiting lists for speech and language therapists and occupational therapists – up to a year in some cases.
- If you already have a diagnosis you do not have access to the IAS in our area.
- IAS is diagnosis based but does not provide interventions.
- One participant questioned whether the 13 week target in the Bill is long enough, and said they think it’s a sticking point in why there is opposition to the Bill.

## 9. Training for key staff

- There is still stigma around the condition – we need to promote awareness and understanding of autism.
- ‘Without the Bill this training won’t happen’.
- Training in autism should be mandatory for all statutory services, especially social services, schools, and GPs.

## 10. Financial implications

- Early intervention would save money in the longer term.

## 11. Is anything missing?

- Involvement with the police and criminal justice system is an omission.

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## Session with adults with ASD at Autism Spectrum Connections Cymru (ASCC)

Six adults with ASD at the session, the mother of one of the participants and Gareth Morgan from ASCC took part in discussions with Members.

### Integrated Autism Service (IAS)

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The group first of all expressed concerns over the Integrated Autism Service and felt that the voices of those with ASD were missing from the way the policy had been developed.

One participant felt there was a gap in the support given by the IAS at the lower end of the spectrum following diagnosis. They felt that IAS had provided some help but in trying to get back into work, there was a gap in support. IAS had signposted to the Citizen’s Advice and the Job Centre, but no appropriate support had been offered. They felt that they were not cognitively disadvantaged enough to benefit from the courses on offer, but could have used support with other things such as benefits they are entitled to.

ASCC staff said the WLGA say they are upskilling people within places such as benefits offices but this had not been the experience of the group. They felt they have to start again everywhere they go as there is no awareness of what Autism is and no understanding of the adjustments that would help them. Job Centres and GP surgeries were examples of challenging situations mentioned by the group with no option to meet in a quiet space as opposed to open plan, noisy environments.

Participants also said that IAS meetings were held on Monday mornings in Cardiff Library – a very noisy environment which is not welcoming for individuals with ASD. They didn’t feel they were there to help high functioning adults with ASD and most of

the participants had been sent on training that was not appropriate for them. One participant said it felt like a tick box exercise to say something had been offered and that the post diagnostic courses offered through ASC were much more focused on the spectrum condition and much more beneficial.

Gareth Morgan provided some context on the courses offered by ASC which have been recognised by the wider Autism community across the UK in moving people on to greater independence but he felt is being ignored by the IAS. There was also a frustration that IAS signpost individuals to the support offered by ASCC but no support is offered from the WG funding to deliver these services as those who access the support are not classed as 'critical'.

Participants felt that the IAS are very clear in what they can and can't do, which is primarily signpost not support. This does not work for individuals with ASD. The support they need is personal and needs to be flexible.

The group felt there is a disconnect in what the Welsh Government are saying they are delivering and what is actually being delivered.

There was frustration with knowing that £13m has been allocated to Autism services but they were still not getting the support they need. Participants felt the services at ASCC worked well for them and was a cost effective service but due to lack of funding, those services were being cut and they weren't able to access them elsewhere. A suggestion was made that the third sector be given some of the funding to continue to deliver services that worked well for them already.

The group did however feel that the diagnostic service needs to be retained. However, they noted that in Cardiff there is a waiting list of up to 12 months and the Welsh Government don't seem to know how many they have diagnosed.

## The Bill

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Many in the group felt the Bill was a positive step but there was a missing section relating to adults with ASD who are not 'critical'. They felt they are an invisible group in the Autism community as they don't fall into the category of children or adults who need day to day care and they are not affecting employability and disability statistics. They felt they are qualified individuals with the potential to be high tax paying, but without the support they are unable to give back to society.

The group talked about the online courses mentioned in the Bill to increase awareness and understanding for those who are likely to support people with ASD and didn't feel this was a good enough proposal. One participant said their family still don't fully understand their needs so an online course would not be sufficient.

The group identified that support in completing forms was a need for adults with ASD and this needed to come from an independent centre like ASC or family. They didn't feel this level of support was possible with upskilling staff alone.

"The idea that you can make other people 'aware' to make things better is not enough."

In discussing whether the Social Services and Well-being Act covered the support needed by the group, they felt strongly that no needs were being met by this legislation. They said the IAS were struggling with assessment referrals as the tools are not right to assess individuals with Autism as the criteria is based on mobility and ability to wash and dress. Many in the group also weren't aware they were entitled to an assessment as Citizen's Advice and Social Services hadn't communicated this. Some only knew about their entitlement through ASC.

The group supported the idea of the Bill but felt strongly that it means nothing if the services they need are not put into place. They felt that services like job support, university support, and help with benefits forms, need to be embedded in order to make a difference to them.

They felt the Bill will strengthen the need for Autism services and support and provide a structure. They felt there needed to be stricter guidelines and scrutiny of the £13m allocated to Autism support as they do not feel the money is being spent where it is needed.

The group felt a Bill was required to provide a clear definition and framework for the services on offer and how they are being delivered. Participants also felt strongly that individuals with ASD should be involved in developing that framework.

Many felt the Bill is a great idea but that it is too vague in what it will deliver so it could pass and not much would change. There needs to be ringfenced money to deliver services and a commitment that if the system doesn't work, it will be changed.

#### Additional points

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The group felt they have to fight for everything and one participant said they didn't think that complaints processes should be the way they get their needs met.

They didn't feel there is any understanding of how difficult it is to have conversations, send emails, go somewhere for the first time.