

# Inquiry into the Autism (Wales) Bill - Focus Group Summary

2018

Inquiry into the Autism (Wales) Bill - Focus Group Summary

---

## Background

This report summarises the findings of focus groups held as part of the Health, Social Care and Sport Committee's inquiry into the Autism (Wales) Bill. Findings are based on 10 focus groups held in Dyserth, Bronllys, Newtown, Bridgend, Ebbw Vale, Cardiff, Swansea and Wrexham. Input from individuals who were unable to attend focus groups have also been included.

Sessions were arranged through organisations that support adults with Autism Spectrum Disorder (ASD) and their families as well as through local support groups. The views of the 95 people that took part have been summarised into key themes. Notes from individual sessions can be available on request.

Participants discussed their view of the current services and support available to them, the main issues they experience and their ideas for changes that would make a difference to them.

The purpose of these findings is to help the Committee determine the extent to which the Autism (Wales) Bill will make provision for meeting the needs of children and adults with ASD in Wales.



## Summary of Key Themes:

# What support or services are working well?

### No Support

---

A number of people within each group felt that they received no support at all.

“I pay for help at home, but can only afford 2 hours per week. I have no other support. No family input. No carer or partner. No I.A.S input. No social services. No hope” Autistic Women’s Empowerment Project (AWEP), Dyserth

“Lots of support ... but very disjointed – no networking. Very disillusioned. After 6/7 years my communication has broken down – can’t be bothered to chase them anymore... but my son is still suffering!” AWEP, Dyserth

Of those who did share positive experiences answers were largely inconsistent even within the same group. Some described having a positive experience with individual professionals such as a GP, Dentist, Teacher or Social Worker but these were seen as the exception within their profession. Others described receiving support such as direct payments, speech and language therapy, counselling, benefits and an Autism Key worker but again this was inconsistent.

Common themes that did arise include:

### Third Sector

---

Six of the groups said they received the best support through the Third Sector. Participants from Autism Spectrum Connections (ASC) said the centre offered important face to face and social support and was the only way for them to access the town. For parents, support groups were often their only source of information and support, with a number offering family sessions as well. Charities that offered breaks in holiday homes and specialist equipment was also cited as some of the best support.

“Without that safe space, I couldn’t come into town.” ASC, Cardiff

“If it wasn’t for the support group the 6 week summer holiday would drive me crazy”  
Bridgend Support Group

“The support I’ve had from charities has often been better than statutory support”  
Newtown Support Group

“The only support I get in Blaenau Gwent is from One Life project” One Life, Ebbw Vale

“Parent Support groups are available at Createasmile as well as family sessions” AWEF, Dyserth

## Schools

---

Five of the groups also described receiving some good support from schools, especially those which were specifically for children with ASD or Special Education Needs (SEN). However there were limited spaces available in these schools and parents described lengthy waiting lists or having to go to court to secure a place. Positive experiences within mainstream school included 1:1 support and some individual teachers having a good understanding of the condition. However, as will later be described in the issues section, this is largely outweighed by negative experiences.

“In school support - good understanding of child’s individual needs & making allowance for ASD (only very few schools)” AWEF, Dyserth

“Excellent support in the ASD Specific Learning Resource Base within the school” One Life, Ebbw Vale

## Integrated Autism Service (IAS)

---

Two groups described receiving support from the IAS:

“Our group does receive support from the IAS but only because I sit on the ASD steering committee and I was introduced through them” One Life, Ebbw Vale

“The IAS has worked wonders for me. With their help (as well as that of my detached support worker) I have been able to start going outside after my anxiety stopped me, and have helped me understand my own diagnosis. I would not be able to function if not for them” Bronllys

# What are the main issues you experience?

## Diagnosis

---

All groups discussed issues to do with the diagnostic process and its subsequent impact on other areas of their life including education, mental health and access to support. Issues raised included late, or no diagnosis, long waiting lists for diagnosis (3 years), misdiagnosis and schools or GPs being unclear on how to refer for a diagnosis.

---

“I lost decades of my life without knowing why.” ASC, Cardiff

“If I had been diagnosed earlier, I wouldn’t have had the problems I had.” ASC, Cardiff

“No access to diagnosis and excessive delays – i.e. can’t assess until 3yrs, then 5yrs then 7 then refuse to diagnose “AWEP, Dyserth

“It took 2 years to get diagnosis from a specialist, 6 months waiting for a report and 2 months for the official statement.” Chinese Autism Support Group, Swansea

“No diagnosis so no support given” One Life, Ebbw Vale

“I feel that professionals tried not to diagnose my daughter to avoid extra strain on the service.” Bronllys

---

## Schools

---

Frustrations around mainstream schools and their lack of understanding, knowledge and provision for children with ASD dominated the conversation in the majority of groups. Parents discussed how their children were often sent home from school making it difficult for them to work and for their children to access a full education. It was said that teaching assistants hired to give 2:1 or 1:1 support lacked training on how to support children with ASD and were often supporting multiple children at a time which impacted on the flexibility of support they could offer.

Discussions around the support offered in ASD specific units or schools for children with learning needs was largely positive. However these were often difficult to access due to limited places or with no school provision for ASD in the county. Some parents described having to take the local authority to court in order to gain a place even when their child’s needs were severe. One parent’s child was only offered two hours a day in a SEN unit as an alternative to remaining in mainstream education.

It was also felt that there was a lack of ASD specific support available in mainstream schools. For instance, it was felt that children with a high IQ needed more emotional and social support within that setting without moving to a different school.

Adults with ASD also described numerous instances of being bullied at school by other children who lacked awareness of Autism.

“As a teacher, I had children in my classes with special needs without a diagnosis and I did not know how to help them.” AWEP, Dyserth

“The Gap between mainstream and special needs school is too wide -often our kids fit into the middle” Bridgend Support Group

“The pathway is always through schools at the moment and I’m always being told that “everything is fine”. Chinese Autism Support Group, Swansea

“The school kept sending my son home for bad behavior but he’s entitled to an education” One life, Ebbw Vale

“Bullying is bad for “Normal Children” but worse if you’re different. Teachers can be hard on kids if your mind is different” One life, Ebbw Vale

### Barriers to Accessing Support/Services

---

The majority of groups discussed barriers to accessing existing support and services. It was felt that there was a lack of clear information about what support and services were available and sometimes even misinformation about their right to access support. It was also therefore felt that there were a lack of advocates to help both parents and people with ASD to understand and access the support they need.

“It’s up to the parent to try to work it out and it’s exhausting” One Life, Ebbw Vale

“System is very confusing” One Life, Ebbw Vale

“Nobody tells you what your rights are and in the meantime your struggling emotionally and financially” Newtown Support Group

Once aware of the services and support they should receive, all groups described having to ‘fight’ to access them.

“It’s a fight to get what you can and even that’s not much – it’s soul destroying” Newtown Support Group

“Constantly fighting for support or to keep support going” One Life, Ebbw Vale

“Other parents might not be able to do this exhausting fight” Bridgend Support Group

It was also discussed how there was often a failure to make provisions or adjustments to support people with ASD to access services.

“Difficulty accessing health services – repeatedly being discharged from clinic because I am not able to organise and arrange appointments. No one thinks to check on why I have not attended” AWEP, Dyserth

“ASD is a communication and social disability, but we are denied support because we are not able to communicate our needs. This is a catch 22!” AWEF, Dyserth

“The GP surgery has changed so that you see a different GP every time you attend an appointment – with no provision made for people with ASD who find change difficult” Cross Party Group, Wrexham

“Limits on support by health i.e. can’t get sensory or pragmatic speech assessment as “not relevant” or “don’t provide this” AWEF, Dyserth

“We have never really had any support from the family doctor or from the Health visitor. As our daughter melts down each time we try to take her to the doctor the doctor refuses to help or refuses to visit her at home. She has not seen a doctor about her health since she was 2 1/2 - she is now 6. We can’t check her eye sight, we can’t check her hearing or mental or physical health. There doesn't seem to be any help with an Autistic child regarding regular checkups.” Individual, Swansea

Other issues discussed to do with barriers accessing support included:

- Criteria for accessing support too narrow

“Disregard of difficulties because of being intelligent. Classes as high functioning but not functioning at all “AWEF, Dyserth

“Self-referral to new IAS – I was emailed an 11 page form rather than taking the details as provided by my referral. Before I was able to complete the large form I received another email to say “IAS is not the service for me”. So where am I supposed to go?” AWEF, Dyserth

- Long Waiting lists

“The waiting is too long from one appointment to another. I feel lost while waiting and not knowing how to help my child.” Chinese Autism Support Group, Swansea

- Lack of social workers

“I was told that ‘Autism is not a priority’ by the council so a social worker is not assigned very quickly” One Life, Ebbw Vale

- No long-term funding

“Uncertainty for the service provider means uncertainty for the service user and for someone with ASD, this is the worst thing ever. It makes us more anxious. The system makes us sick!” ASC, Cardiff

### Transition/Adult services

---

The majority of groups also discussed the lack of support available for the transition between child and adult services, between school and college or between different year groups. The jump between child and adult services was also of particular concern, with support often ending entirely after 18, 21 or 25.

“Adult services are non-existent – my son went from having 2:1 support in school to no support after the age of 19/20. It’s as if they they’re saying ‘You’re cured!’ It’s putting a huge strain on the family” CPG, Wrexham

“Something needs to be done to bridge the gap between child and adult services.”  
ASC, Cardiff

“Services being cut after 25 and inconsistency in services – there’s no recognition that Autism won’t go away” CPG, Wrexham

“As soon as he turned 18 they washed their hands of him” One Life, Ebbw Vale

### Lack of professional knowledge and understanding

---

Most groups felt that there was a lack of understanding about ASD even among professionals such as teachers, social workers, educational psychologists, council staff and dentists. Participants described instances where they were signposted to inappropriate support or were given incorrect assessments. They also said there was a there was a lack of understanding about the differences between male/female presentations of autism and wider strains of the condition such as Pathological Demand Avoidance (PDA). Parents felt they sometimes had a better understanding of the condition but were often not believed by professionals.

“Police treat victims badly – fail to refer to experts for info on vulnerability, failure to follow Advocate’s Gateway Guidance on how to get best evidence from autistic person” AWEF, Dyserth

“It’s obvious that the people who are supposed to understand, don’t ”ASC, Cardiff

“Parents and carers are the lead on this and they should be listened to. But as parents we are ignored” Bridgend support group

“The health professional at my tribunal for child DLA had no understanding of ASD”  
Newtown Support Group

“My GP looked at me and said “you haven’t got autism” when I asked to be assessed.”  
Bronllys

“My Doctor did not know who to make the referral to when I asked for an Autism  
Diagnosis.” Bronllys

## Lack of Public Awareness

---

Most groups described how there was a general lack of awareness of ASD among the public, with people not understanding its spectrum of disorders and people with ASD often being underestimated. Some felt there was a stigma around ASD.

“There is a lack of awareness re: Autism amongst some which is very frustrating. It is like a wall that you can’t break through.” Chinese autism support group

“People say that my child does not look Autistic” One life, Ebbw Vale

“People underestimate a child’s ability to achieve when the child has autism” One Life, Ebbw Vale

“80/90% of people will talk to my daughter but 10% look away.” Bronllys

“General ignorance of Autism the stigma, isolation and mistreatment that comes from the rest of society.” Bronllys

“A staggering amount of ignorance from classmates, relatives and staff. Also, a lack of (simplified) information on Autism and it’s spectrum of disorders, and many places (banks & doctors in particular) being ill equipped to deal with Autistic people.”  
Bronllys

## Financial

---

Some of the groups discussed how gaining employment could be difficult for people with ASD due to no support to access it and reduced options. Some also described difficulty with the benefits system due to having no support to fill out the forms and being ineligible for Personal Independence Payment or Employment Support Allowance. Another issue was that medical evidence over three years old was often not accepted despite ASD being a lifelong condition.

Parents described losing out financially due to being unable to work full-time, with some mentioning how Carers Allowance was less than Job Seekers Allowance.



“I really want to get into a job. If I get back into employment and become a tax-payer, I’ll be a member of society again. But I need help to get out of the system.”  
ASC, Cardiff

“Working environments are, I hope unintentionally, typically hostile towards those with ASD. For me personally, issues such as being forced to work in physically uncomfortable environments such as open plan offices (tacit implication - do so or leave), and dealing with daily lack of precision and clarity on the part of neurotypical people.” Individual, Newtown

### Lack of co-ordination between services

---

Some groups were frustrated about the lack of communication between services and the need to have numerous meetings to repeat the same information to different services.

“My self-referral to IAS was declined because they ‘don’t do crisis intervention’, but this did not trigger referral to social services or any other support. Is there no safeguarding provision if my ‘normal’ is seen as a ‘crisis?’” AWEF, Dyserth

“Health services will tell you that you should be getting certain support from social services but social services will say ‘They shouldn’t have told you that’” Newtown

### Lack of Support for families

---

The lack of support available for families and its impact was an issue discussed in most groups. Issues centred around how there was no post diagnosis support to help families come to terms with diagnosis, no clear signposting for support or services and a constant need to fight for services. A lack of respite was also a common problem even when a need had been identified, with this being especially difficult during the school holidays. Parents supporting adult children described how they didn’t have any time during the week for themselves because their children didn’t have access to a support worker.

“I am very lost and very stressed.” Chinese Autism Support, Swansea

“During the summer holidays I’m pulling my hair out” Powys

There was often a distrust in social services, with parents describing how they were given contradictory information about how best to support their children. They also described how support wasn’t offered unless they said they couldn’t cope, which as a parent is something they don’t want to admit.

“A parent will never say ‘I am unable to cope’ because they are genuinely scared of the care system” Bridgend Support Group

Another issue discussed by some groups was how services often failed to safeguard families against the violence they experience. One parent described how she was called to the school to collect her son as four members of staff were unable to restrain him. When she arrived they put her son in the car and held the door handle shut until she could pull away – with no consideration of how she’d be able to get home safely. Another parent described how she was told she was lucky that her son only had to wait two months for an appointment for his severely ingrown toenail- even though she was facing violence at home because of the pain her son was in.

“I’ve been left with bitemarks all over my arm and have had to barricade myself in my room at night to keep safe. It’s how they communicate -they need you to feel the pain that they are in in order to communicate it to you.” Bridgend Support Group

“They rang me to check if I’d got home ok – how I never got killed I will not know”  
Bridgend Support Group

“The violence is not spoken about” Bridgend Support Group

Groups described how this lack of support often resulted in marriage breakdown and had a negative impact on the mental health of the parent.

## Have you seen an improvement in services/support in the last two years?

The majority of people within each group felt they hadn’t seen an improvement in services and most of the issues discussed throughout the sessions had happened in that time. Concerns were raised about the Integrated Autism Service (IAS) being more of a signposting service and online support rather than offering the practical support people wanted. It was also felt that the IAS had not advertised its services widely enough.

Some participants did share positive experiences of the IAS and felt it had made a difference to their life in this time.

## What changes would make a difference to your life?

After discussing their view of the current services and support available for people with ASD and their families participants were asked to share their ideas for improvements. Participants shared a variety of ideas relating to what would improve services as a whole as well as what support would help them day to day. Due to the breadth of answers, ideas have been bulleted and summarised into key themes:

### Training

---

- More training for professionals that support people with ASD e.g. teachers, medical staff, social workers, dentists which is measured
- Training to include difference between male/female presentations
- Compulsory and ongoing training on ASD as part of teacher training

### Diagnosis

---

- Quicker and earlier
- Clearer pathways
- Quicker to receive support after diagnosis
- Automatic screening for those diagnosed with anxiety or depression
- Private diagnosis not to be dismissed

### School

---

- More co-ordination with supply teachers
- More understanding from teachers
- Nurture groups and mindfulness
- Autism specific training in schools on male/female presentations
- School environment to support sensory needs (chill out areas)
- Minister or Estyn to act immediately if Local Education Authority has failed to educate a child that's missed 15 days education in total per academic year.
- 1:1 support to mean 1:1 support -make it part of Estyn's school inspection
- Autism awareness lessons for children

- Lessons taught in autism friendly manner
- Support regardless of diagnosis

### More support for families

---

- More access to restbite
- Counselling for the family after diagnosis
- Regular contact from professionals
- Parents to be believed and not judged

### Clear information

---

- Better signposting to services available
- Rights acknowledged without parent having to fight for them
- Information about support and services available given face to face

### Advocates

---

- More advocates
- Authorisation for people to deal with advocates, power of attorney etc

### Social support

---

- Peer to peer autistic groups, post-diagnostic groups, youth and holiday clubs.
- A Buddy to give 'social support' or social groups
- More inclusive activities such as exercises classes

### Employment

---

- Subsidies for employers that hire people with ASD
- Support to get access to employment or higher education
- More in-employment support
- Work experience
- More recognition of untapped talents

### Transition

---

- More support for transition
- Transition support to start earlier

## More awareness of ASD

---

- Awareness raising to the public
- Services to be more accessible by making adjustments for people with ASD (quiet times in banks, Autism friendly staff in hospitals, dentists, high street shops, supermarkets)

## Integrated Services

---

- One stop shop (health, education, social)
- Interagency communication
- Cross-county communication
- A book that you can take to all services which keeps a log of what each service is doing.

## Practical Support

---

- More practical support rather than just advice or signposting
- Help to fill in forms

## More access to support

---

- More access to therapy dogs and autism dogs to have the same rights as guide dogs
- Autism Safe Spaces in towns
- Access to Autistic friendly therapies; DBT, Sensory Therapy, music, Art Therapy & mental health/crisis toolkits.
- Access to sign language, ACC, Makaton, Pecs & other ways of communication.
- Support regardless of whether you have accompanying mental health or learning need
- More adult services
- More access to appropriate transport
- Legal support
- Services to be consistent and funded long-term

## Annex

### Format

---

Participants were asked the following questions:

- What support/services are working well?
- What are the main issues you experience?
- Have you seen any improvement in services/support in the last two years?
- What changes would make a difference to your life

Participants were given post it notes to write down their answers and then had an opportunity to discuss with the rest of the group. They were told they could write as much or as little as they wanted and that they didn't have to answer every question.

### Focus Group Participants:

---

1. Adults that access support from Autism Spectrum Connections, Cardiff
2. National Autistic Society Parents Support Group, Bridgend
3. Members of the Autistic Women's Empowerment Project, Dyserth (three groups)
4. Chinese in Wales Parents Support Group, Swansea
5. Cross-Party Group on Autism, Wrexham
6. Members from a Facebook Support group for Parents, Newtown
7. One life Autism Support Group, Ebbw Vale
8. Adults that access support from Powys Integrated Autism Service and parents invited through PAVO, Bronllys
9. Parent, Swansea
10. Adult with ASD, Newtown