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) AWB62
Ymateb gan Di-enw | Evidence from Anonymous

Questions about getting a better way to diagnose Autism

1. What do you think about how easy it is to get an autism diagnosis where you live?

It is difficult to get a diagnosis as a child without the backing of the school unless they are having problems with the child's behaviour.

Mental Health issues and/or Learning disabilities may be diagnosed rather than Autism.

Secondary conditions which have been diagnosed and a treatment plans put in place seem to override one's ability to access services with more appropriate professionals and thus more accurate/appropriate/effective interventions. For example: it is easier to access a psychiatrist or neurologist than an Autism specific psychologist or occupational therapist. MDs override expert professionals who are not MDs. NHS and government funded bodies over ride independent opinion i.e. so even if you get to the point of having to pay for an appropriate service: it might be pushed aside. There should be an understanding that 'expert opinions' should have equal authority during diagnosis irrespective of MD or PhD.

If it's not in County: it is presented as a dead end. Obviously, if you live in a large city you have more chance of coming across an appropriate professional. York and London are far better than Cardiff and Carmarthenshire. Going out of county on a long waiting list is better than not being on anyone's waiting list.

If you've had a diagnosis as an adolescent and then become an independent adult: doctors may suggest a differential diagnosis without doing another assessment, this in turn can negatively affect interventions. Mental Health can be an inappropriate and destructive path.

Charities are relied upon for support in getting a diagnosis.

Essential developmental evidence isn't asked for early enough on in the process. It takes time to gather information and doctors are not given the opportunity to ask care givers/educators/patients prior to appointments. Thus drawing out the process and potentially effecting a correct diagnosis, this is not cost effective either.

2. What are the most difficult things about getting a diagnosis?

- Accessing appropriate professionals
- Time
- Priority Lists
- Having no prior information in order to make an effective diagnosis.
- Being sent to professionals who don't have the authority (rather than skills) to make a diagnosis and suggest interventions.

3. Do you think that the local authorities and health services should have to give out information about how to get an autism diagnosis?

YES. It would save a lot of time. Ideally, it should incorporate how long it might take – it is part of the NHS who has limited resources. For example: if people are told that it may take a year to get a diagnosis and that this doesn't mean that their issues are not been taken seriously – then suggested interim interventions can be used in the waiting period.

QUESTIONS ABOUT IMPROVING THE WAY PEOPLE GET SUPPORT SERVICES

1. Do you think services at the moment are good enough for people with autism?

NO. They are heading in the right direction.

2. Do you think the law should say that there must be guidance on how to deliver services for people with autism?

YES. It should be more defined than having to delve in Human Rights Legislation or the Equalities Act 2010 and other ethical tools.

3. I think there should be guidance. I think the guidance should say:

a. How to organise getting an autism **diagnosis**
b. Services cannot turn people with autism away because they have a high IQ
c. There should be plans for people with autism moving from child to adult services
d. How to plan for autism services
e. Who should be in charge of the organisation of autism services?

Do you agree that the guidance should say something about the things listed above?

YES

Is there anything else that you think should be in the guidance?

Point ‘b’ should be written as:

> Service cannot turn people with autism away because they have a high IQ or seem too independent. Also, something about reviewing the service’s suitability for the person rather than just how well people are doing before anything goes wrong.

4. Do you think local authorities and health services should have to collect information about people with autism so they can make better plans for services?

YES. The Welsh Assembly might have a better chance of getting appropriate information if health services handed-over the information but what the information should include must be considered. The history of the patient, such as how many doctors (including GPs)/educators prior to diagnosis they have seen, is imperative to see how effective the system has been and thus suggested changes.

6. Do you have any ideas about the best way to collect information about people with autism?

For example, information about how many people have autism and what their support needs are?

- Collect statistics from NHS/government bodies/professional organisations/peer published research, about how many people are diagnosed with ASD incorporating: local authority area (if they are ‘out of county’, their home area); which government bodies they have direct contact with and what local authority services; if they have entered the prison system; if they access ‘out of county’, location of which services and diagnostic/NHS they have passed through; what educational opportunities they have had in which area and successful completion; what employment opportunities they have had and what outcome; what voluntary employment opportunities and work placements they have had and what outcome; how many people have had sensory assessments and interventions; the challenges services have in delivering, subdivide into: public funded (including education); charities; and private practice. Their suggestions on improvements; the awareness and strategies large business have in employment; the awareness and strategies local authorities have available.

- The data can be obtained but at first glance may appear overwhelming and unrealistic. The assembly should note that this level of information gathering is constantly gathered by industries such as seen in insurance and pharmaceutical “companies”. When bids are placed for this project: the organisation should incorporate the quality of information and review past project results (customer satisfaction and how useful the information was long term) before accepting new bids. The advisements should be Autism friendly and the project should also be put out through organisation such as Keggle which are paid on results by using innervation.

- People with Autism can be found throughout society and it could be found that some of the employers/educators/services are already using cost effective strategies which could be shared: the Welsh Assembly should actively seeks them and the information through a variety of mediums and not just one.

- The data can be analysed with the use of relativity simple techniques that reports can be written from and universal guidelines developed.

- The use of an annual consensus over a five year period is an option.

- Although it is polite to ask people to handover the information: telling them they have to hand it over or there will be consequences, will work better (government bodies do this all the time).

- Development Companies such as the Welsh Assembly’s preferred ‘Tribal’, would be, for many reason: an inappropriate costly route.

QUESTION ABOUT AUTISM TRAINING FOR STAFF

1. Do you have any views about the autism training that staff working with people with autism already get?

In my experience: it depends on who you work with and who you work for. The consistency is poor and training can be expensive.

Healthcare professionals vary from person to person, it seems to be about their ability to communicate in an Autism specific way (when it comes to general health) and the attitude of the person towards any patient’s support needs rather than working knowledge of Autism delivered through training.

GPs don't seem to have training or direction on where to send people, to my knowledge, they direct straight to Mental Health who intern have to redirect. There needs to be training and guidance here, also to my understanding: when they put into their software about which consultant to send someone too (depending on their specific condition) – they are presently being directed in inappropriate direction.

In my personal experience, Social Services on the whole tend to be poor unless you have access to a social worker who is willing to look beyond the end of their nose. Their understanding of social imagination differences in Autism (integral to their job) is poor. Do they have any training on how to appropriately interact and co-ordinate in an Autism friendly style, I suspect not? Do they have any training on Autism friendly transitioning (beyond it being structured and the use of visual information), I think not? If they do have training: it is inappropriate.

The managers seem not to have the training and knowledge to support their staff this includes the NHS.

Knowing my rights and an education on how best to deal with Social Services is what saw me through. It is me who has had the training and it is key people in the National Autistic Society which provided that.

In my professional experience, I have come across many social workers. Their ability seems to depend on their personal ethics and ability to adapt – these are the minority. The majority need training on how to do their specific job in relation to Autism Specific rather than just a course /leaflet/ conference on Autism. The training should be cost effective. Appropriate Autism specific charities should be given the opportunity to develop this as they are already do it for their staff.

In my experience, Cardiff University Hospital, which has more students than most: has left out essential education on how adapt to the differences they face when nursing and treating patients with Autism for non-Autism related issues and general health. Again, a learning tool that is specific to their job is what is required. For example: you wouldn't tell a visually impaired person to monitor their own health on their visual observations, and one' should not ask a person with Autism to monitor theirs without telling them the boundaries and what to do with the information. It is not difficult, it is different.

I have found that Autism specific charities which provide care packages seem to have support staff who have a better working knowledge than other providers. The Assembly should look at recommending suitable training recommendation lists. CSIW should incorporate this during inspections.

Overall, the relevance of the training should be suitable and task specific e.g. a social workers needs training on how to communicate with people with Autism and have the knowledge to direct care providers on what specific training should be given.

Human Research Departments tend to get information after things have gone wrong and small business probably can't even afford it. Learning Strategies which include tools such as: 'How my Autism Effects Me and Others' – could be cost effective and a step in the right direction.

There needs to be easily accessible employer specific guidance and resources available for employers. There are schemes such as 'Disability Confidant' but they are voluntary and too expensive for small businesses to implement. People with Autism require a network of people and thus training should involve those from all aspect of the hierarchy.

All training should include the dimension of how some of the 'negative' aspects of a person's Autism can actually be positive rather than just changed or got around. For example: limited theory of mind can bring about a very obvious extreme sense of fair-play.

People working at job centres need training on many aspects of Autism. The current format of "hand-holding" for seeking jobs on a computer and course on CV writing and job interviews are inappropriate. They are not Autism specific and rely on Social imagination and social communication. For all the well-meaning staff: they need training and opportunities to access facilities/programs which focus on the influences Autism has on getting a job. It is not uncommon to hear people with Autism having difficulty getting past an interview but when they do: are loyal effective workers. Also, places like Tesco who have (maybe still do) offer work experience with no opportunity for a job at the end are possibly a false opportunity. Giving small business a quick and easy opportunity to offer work-placements to people with ASD – could be a good way for people to build a reputation. Industries which insist on ridgety in order to have consistency should be contacted. For example: Starbucks trains all its staff on how to deal with grumpy pre-coffee customers i.e structured social skills. The local charity shop and corner news agents require more social understanding skills and have less ridgety, so maybe not appropriate for people with Autism. Everyone is different but the present system seems to be geared towards the majority: non-Autistic people.

18. QUESTIONS ABOUT THE DEFINITION OF AUTISM

Where do you think the definition should be written? Please tick 1:

☒ On the Bill

☐ In the plan for autism

☐ In the guidance

☐ I don’t think it should be included