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) AWB20
Ymateb gan Prosiect Cymorth Teulu Sir Fynwy Cymdeithas Genedlaethol Awtistiaeth Cymru – safbwyntiau'r grŵp cymorth i rieni
Evidence from National Autistic Society Cymru's Family Support Project Monmouthshire- views of parent support group

a) What are your views on the effectiveness of the current arrangements for improving autism services in Wales?

b) Do you believe Wales should have legislation requiring the Welsh Government to publish a national autism strategy for children and adults and issue guidance to local authorities and NHS bodies on implementing the strategy?

Yes, definitely.

c) To what degree of detail do you think the content of a national autism strategy should be defined in legislation?

d) What (if any) consultation do you think the Welsh Government should be required in legislation to undertake, when developing, reviewing and updating a national autism strategy?

There should be 'bottom up' consultation. Too often parents are left out of this process and services are asked to rate themselves. Parents know the effect of any changes and how effective services actually are at the sharp end.

e) Do you believe that legislation should define how often a national autism strategy should be reviewed and updated? If so, how often should it be reviewed and updated?

Yes because nothing is ever perfect. [Suggestions ranged from 3-5 years.]

f) Do you have any views on how Welsh Government should monitor what progress is being made and how public services should be held accountable for how they support autistic people and their families?

g) What are your views on how easy it is to access a diagnostic assessment where you live?

It is better since the ISCAN system came into place. However, too many GPs still don’t know how to refer and there is often a delay while we wait for information and supporting evidence from school.

h) What key challenges around how the diagnostic process works would you like legislation to address?

The need for information from schools holds things up.

Parents’ evidence is not given enough weight – we are the ones who know our children best, not schools where they are on their best behaviour/masking/keeping it together.

There should be training for parents immediately after their child has been diagnosed. Some wait months for an Early Bird or Early Bird Plus course. And there’s nothing if your child is over 8. Parents should be automatically enrolled on a training course to learn about autism as soon as their child gets a diagnosis, no matter what age the child is. We’re left in the lurch, knowing nothing.

i) Do you believe that Local Health Boards and Local Authorities in Wales should be required to publish information on the pathway to diagnosis for children and adults living in their areas?

Yes, definitely. There is a need for a lot more transparency. Why is all this information not on the internet for all to see?

j) What are your views on the sufficiency of services currently provided to meet the needs of people with autism spectrum conditions in Wales?

Patchy. Mostly lacking. Mostly not worth trying to get a referral as, even if you are seen, most professionals don’t know about autism and how it will affect your child. This is especially true of mental health services where we are told ‘it’s because he’s autistic’. That’s not true – you don’t have to have depression or anxiety or social phobia if you’re on the spectrum – it’s just because their needs haven’t been recognised and prioritised early enough.

k) The legislation I am proposing would require the Welsh Government to issue statutory guidance that would put duties on local authorities and Local Health Boards on how they should be delivering services for autistic children and adults and their families.

Do you agree that legislation should require statutory guidance? If so, does the following list cover the right areas to be included under the duties on local authorities and Local Health Boards?

i. The provision of relevant services for the purpose of diagnosing autistic spectrum conditions in children and adults.

ii. The fact that assessment of the eligibility of children and adults for relevant services cannot be denied on the grounds of the person’s IQ.

iii. Planning in relation to the provision of relevant services to people with autistic spectrum conditions, as they move from being children to adults.

This is particularly important. At the moment nobody wants to know 16 and 17 year olds and, when your child gets to 18 all support drops off a cliff. Why don’t statements of special educational needs carry on into FE college or university? Why do we have to apply and be assessed and fight all over again? We’re told that there will be ‘transition packages’ but these never seem to come to anything.

iv. Other planning in relation to the provision of relevant services to children and adults with autistic spectrum conditions.

v. Local arrangements for leadership in relation to the provision of relevant services to children and adults with such conditions.

l) Do you believe that Local Health Boards and Local Authorities in Wales should be required to establish and maintain new data collection practices around the numbers and needs of children and adults with autism spectrum conditions so that local areas can plan services accordingly?

Yes, how can you plan effectively if you don’t know how many and who you’re planning for? But ‘data’ must not include names and addresses. It must be anonymised so it’s just numbers, not identifiable people.

m) Do you have a view on how data can most effectively be gathered, on the numbers and needs of children and adults with autism spectrum conditions in different Local Health Board and Local Authority areas in Wales?

We were surprised to learn that this data isn’t collected by the NHS when children are diagnosed and when they access services. These seem the obvious points where information could be gathered. Also schools who collect data on SEN so this wouldn't be another job for them.

n) Do you have a view on the current scope and effectiveness of training in Wales for key staff working with people with autism spectrum conditions?

We are always told that schools find it difficult to find the time and/or money to train all staff. Training tends to be the SENCO or a TA who's dealing with a particular child. We think everybody who works in a school from the secretary to the dinner ladies should be trained. And SMTs must be trained too because they form policies.

o) Do you believe that legislation should specify outcomes that training should achieve, thereby providing greater flexibility around the delivery of such training?

We think that staff knowledge of ASD and their ability to apply this to correct handling of children in school, as well as physical provision (eg quiet room, sensory area, alternative eating area) should be a specific part of the ESTYN inspection. Schools can then be compared against each other and schools which are good or very good on this can mentor other schools to make them better.

p) An alternative approach would be for legislation to specify that key staff working with people with autism spectrum conditions should undertake autism training.

Not 'key staff' – all staff. If a head teacher decides that only class teachers or TAs should be trained, how is she supposed to properly decide on budgets to support ASD children in her school, or adopt an appropriate whole school support strategy?

q) Do you have any suggestions for additional action that could be taken through legislation to improve the rates of employment of people with autism spectrum conditions (bearing in mind that the National Assembly for Wales does not have the power to make changes to employment law)?

Positive discrimination / quotas. All firms of a certain size (eg 100 or more) should be obliged to employ autistic people are a rate of at least 1% (one of the lower estimates of the prevalence of ASD in the population.)

r) Do you believe that a definition of autistic spectrum disorder should:

- be included on the face of legislation (which makes it more difficult to change in the future);
- be included in an autism strategy;
- be included in guidance; or,
- not be stated at all?

s) Can you identify any possible unintended consequences which could arise as a result of this legislation? If so, what steps could be taken to deal with them?

t) Do you believe that the proposals in this consultation would give rise to any substantial costs, in addition to the cost-areas already noted in this consultation? How can such costs best be mitigated?

If this bill introduces proper support for autistic people, it will definitely give rise to costs but we believe that these should be borne in the short term for long term gains. If politicians looked over a 15-20 year time span instead of a 3-5 year one, they would see that ‘front loading’ the system and investing heavily in services for children (both health and education) will mean that there is less of a burden on the state when those children grow up in terms of unemployment benefit, impact on criminal justice system, need for supported living/housing, social services involvement etc. Also, many more autistic people would be employed and paying taxes. So costs shouldn’t be ‘mitigated’ in the short term – you should take a longer-term view.

u) What would the impact or costs be in terms of:

i. producing a national autism strategy;
ii. placing duties on local authorities and NHS bodies to act under guidance;
iii. creating and maintaining data collection practices on the numbers and needs of adults and children with autism spectrum conditions; and,
iv. providing training for key staff?

v) Do you envisage any other additional administrative and regulatory costs as a result of this legislation and if so, how can any such impacts be mitigated?

w) What factors should be measured to determine the cost-benefit analysis of this legislation should it become law?

x) Do you have any views on how savings that might arise from this legislation can most effectively be identified and calculated?

y) Do you wish to make any other comments on my proposals?

Not all parents are articulate and educated. We cannot all fight for our children or navigate the confusing systems that exist. We would like to see a kind of one-stop shop where you could go with your concerns and be told how to access all necessary services and be given support to do so if necessary. At the moment some parents have to rely on charities to help them access things which they should be able to get without help. Even a website with all this information – including who to contact and what forms are needed – would help. As it is, the system is hopelessly difficult to get to grips with and you have to have advice just to know what's out there, never mind how to get it.

Once your child has been diagnosed with ASD you should be able to self-refer to all other relevant services – eg OT, physio, Speech and Language, Mental health, dietician – without having to go back again and again to your GP or school for a referral. There is virtually nobody on the spectrum who does not have other needs [by the new diagnostic criteria all people on the autism spectrum, by definition, have sensory needs] so this should be recognised in ease of access to assessment and support. The system of 'gatekeepers' is expensive, time consuming and puts up barriers which should not be there. Parents aren't going to ask for things they don't need – we don't enjoy taking our children to appointments for the sake of it!