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) AWB04
Ymateb gan Di-enw | Evidence from Anonymous

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

Poor and not fit for purpose.

The arrangements are inadequate and leave individuals on the autistic spectrum without the needed support. I am blessed to be a mother to two adults on the autistic spectrum. Both have been denied any support and my son has been refused twice based on his IQ being over 70. Recently he was referred by the GP, his ticks and movements have increased and he has had additional diagnosis of ADHD, Dyspraxia and possible Tourettes. He recently received a letter from SS saying he does qualify for the LD team, with a suggestion he gets in touch with some charities. No new diagnosis, just dismissed based on an IQ assessment for over 4 years ago. If I died he would not be able to manage his money, or life but it seems that in Wales there is no support for people like my son. I have personally met many autistic adults in England whose IQ is over 70, they receive support. I believe this is due to the autism act in England. My son and daughter both have mental health issues in addition to their autism, but the criteria for mental health support seems to be you have to have been under secondary care. This leaves them without support.

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. I am concerned that guidance wouldn’t be strong enough, I would like to see laws that enforce the strategy.

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

I think it should have a strong emphasis on being supported by the law, guidance and advice is easy to ignore.

Can’t refuse services based in IQ alone, need to really look at functioning. There is a tendency to only look at one aspect, eg LD rather than how the all different factors affect an individual. I would like to see autism teams set up across Wales. I also would like to see the teams working together, my daughter has a physical disability as well as autism and mental health problems. I also believe the impact of caring for more than one person should be looked at. Autism seems to occur in families, yet any assessment looks at the individual in isolation.

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?

The Welsh Government should consult widely and really listen to families and autistic individuals.

The use of qualitative and quantitative consultation. The personal stories need to be heard. The use of open questions that allow for a wide variety of responses rather than closed questions that can produce a specific response.

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. The strategy could be reviewed every 5 years. Too often uses money that could be used providing support for individuals.

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?

I think the Welsh Government should provide a tribunal for families and individuals on the spectrum. With fines for public services who don't comply. In terms of diagnosis the professional should be up to date with current diagnosis. This means professionals demonstrating their competency.

The service user and those on the spectrum should be consulted. I local autism group run by the LA is too open to being controlled.

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

I find it disturbing that where I live is very poorly served. I have been told that it's a two year wait for an adult to see a Psychiatrist. I also believe that the NHS and schools should have to accept a diagnosis that has been provided privately by a credible clinician. In my area the NHS refuses to accept a diagnosis from an Educational Psychologist that they pay to do some of their NHS diagnosis. This is just playing games, particularly when people go privately because of the long wait on the NHS.

It is very difficult and often GP's don't really know who to refer to.

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

I would like to see a clear pathway with laid out time frames and more clinical staff employed.

A clear laid out pathway, self referral is possible, access to experts in autism. Often the mental health teams who are a gateway to a diagnostic referral are generalists. This means that women and those with ‘less obvious’ autism are denied a diagnosis.

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, posters in GP practices and hospitals. Yes because this holds them accountable.

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

Not sufficient, there are not enough clinicians.

Very poor and inadequate. There is a big push to use the voluntary sector, however this ignores the fact that often those most in need can’t access this. I have observed that the same few people access a lot of different services, this enables the charity to claim success, but the people who are really on need are at home, unable to leave the house without support. They are denied this support because they have too high an IQ.

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? Yes

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.
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 at the moment children who move into adulthood fall off a cliff and are lost to local authority knowledge. Children who had a statement and attended a special school are deemed to need no support as an adult. You don't grow out of autism, how can this be justified?

Yes I agree, I also feel that the hospital traffic light scheme should be extended to all those on the autistic spectrum. My daughter has a high IQ and has a lot of medical difficulties due to EDS and Pots. She becomes very anxious in hospital and Dr appointments. I feel that it would be helpful to have her difficulties written on the system.

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?

A local authority database that is joined with the NHS, every person who is diagnosed is placed on the list. GP's should also keep a database and have health checks to see how the person is getting on. This happens with Learning Disabilities.

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?

I think it should be provided by autistic adults.

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

There is a need for all staff to receive training and it should be part of their CPD.

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

I feel that the support for employment throughout Wales has been limited to certain areas. In North Wales there is a lack of support into employment. Transport training is also an issue.

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)?

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?

I feel that the definition of autism should not be attempted in the legislation, I would prefer to see wording around a diagnosis of autism that is provided by qualified professionals and is keeping to the diagnostic criteria as set on in the DSM V or ICD10.

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?

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?

The financial costs of leaving an individual to reach crisis point before providing low level support. My brother took his own life last year, he had sought help on many occasions, but the support wasn’t there. He spent 6 weeks in intensive care suffering with a hypoxic brain injury. The financial costs could have been avoided had he been given the right support. That is not even mentioning the cost of a lost life that is not measurable.

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

The cost of some support can lead to a person gaining and keeping employment. There is also the issue of including everyone in society and making them feel useful. This reduces stress on the NHS and the person can move to pay taxes.

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?