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
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Evidence from A joint response from the monitoring groups for children and adults in Ceredigion

A joint response from the monitoring groups for children and adults in Ceredigion. The groups include representatives from adults' social services, children's social services, health services, parents and carers, people on the spectrum, service providers and third sector organisations.

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

Development of guidance has been too slow to bring about dramatic improvement.

Useful resources have been developed and are available on ASDinfoWales, but need to be in more diverse media to reach a wider audience.

Current guidance is not mandatory – it is up to each local authority and health board to interpret it. Services under pressure inevitably focus on mandatory obligations.

There is no obligation to ring-fence the funding that now goes into the RSG.

There is a lack of consistency in the way the money has been spent in different areas, which has led to inequality of access.

There are problems about the visibility of what's happening and not happening – it is difficult for parents/carers to see what has been done.

There are many good things about the work done so far; extra funding has supported training and local specialist posts but remains insufficient to meet demand.

We have not seen clear results from the money spent on training. There are various reasons, for example, lots of low level training but lack of money for specialist training; training not targeted in the right place.

Recognition of autism has improved but understanding and ability to meet people's needs has not necessarily kept pace with recognition.

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. There are mixed viewpoints within the monitoring groups. The SWWB Act underpins the rights of all individuals to access assessment and support when they need it so it can be argued that an Autism Act should not be necessary. However the overall feeling is that, despite SWWB Act, people with autism as a group still have difficulty accessing assessment, support and services.

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

The legislation should insist on specialist health provision – Occupational Therapsy, Speech and Language Therapy, Specialist Behaviour therapy, and Psychology – all the therapies – should be available within each health board. Resources should be made available to provide this. There should be equality of access across Wales and regardless of whether the autism person has a learning disability or mental ill health.

Collection of data on both diagnosis numbers and numbers provided with a service should be mandatory for adults as it is for children. We are aware that a national data base being set up within WCCIS that could capture this. We need guidance about what data to collect.

The underlying theme of the legislation should be about empowerment and in line with SSWB Act.

The legislation should insist sufficient local authority staff have specialist training to fulfil the assessment and care planning role for people with autism.

Commissioners should have qualitative assessments of providers' training.

If the detailed guidance asks for guarantees of a certain level of service, there should be a budget to ensure this is obtainable.

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 consultation but it should be careful and concise. Consultation of people on the spectrum probably needs to be issue specific. Consultation of parents and carers might take different forms and should be carried out separately. There needs to be a national team with responsibility for consultation – local monitoring and stakeholder groups don't have the capacity to do it. Consultation needs to take account of the potential for overload – people have been and are being consulted about lots of different things. Information from the extensive consultation carried out by the national development team prior to the refresh of the Welsh Government strategic action plan should be utilised diligently before any further consultation is carried out.

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. Every 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?

Data collection such as SSWB Act has required with population survey – we could capture data about autism as part of it by asking specific questions within the citizen survey.

Data about waiting lists for diagnosis, health input, and social care should be part of it and this should be public knowledge.

A register of people with a diagnosis – could be kept by GPs either at the point of diagnosis or at the point when a person on the spectrum moves into the area and registers with a GP. It would need to be clear to the individual that keeping the register is mandatory but they don't have to be on it. Anonymous data would be fine – it would still enable health and social services to plan strategically.

There is a need to record referrals *and* provision.

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

There is a clear pathway for children up to the age of 18 but paediatricians do not always take on young people after the age of 16. Waiting times are not significant at the moment. Locally we have been doing okay, but gradually we are doing less okay because resources are not keeping pace with demand.

For adults the referral process is not easy, although there is a pathway. The waiting list is about 18 months.

Diagnosis of adults in our area does not conform to NICE guidelines.

The cost of training is a concern. The timescale for training is a concern. Retention of staff who have been trained is a concern.

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

We would like to see properly resourced diagnostic assessment according to NICE guidance. A pre-diagnostic and screening consultation should be carried out within a short time of the referral being made to ensure that it is appropriate to place the individual on a waiting list. Waiting times should be limited, and the resources provided to support this.

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.

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

Varied. We are aware of some excellent services but choice is focussed in the higher populated areas of Wales. Choice in our area is severely limited due to lack of trained service providers able to meet social care packages. We often struggle to identify a provider who can meet individual assessed needs, and therefor to commission a service. Social care assessment teams are under-resourced. There is inadequate provision of therapies in Health services. Diagnostic teams are under-resources (we are aware that extra money has been put in, but too little too late).

Expectations have been raised about the IAS but it is unlikely to meet demand.

Retention of staff in different teams and services is a problem specifically for people on the spectrum and their families/carers because they are having to continually get used to people who are there for a short period of time.

Provision of suitable education is patchy across Wales.

Coordination between all disciplines including education needs to improve – this coordination needs to include different departments at government level. The act should under-pin this.

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, I would like to know your views on which requirements the guidance should place on local authorities and Local Health Boards.

The following is a list of the areas which I believe should be included in the statutory guidance for local authorities and Local Health Boards. Please indicate:

- whether you agree that these should be included, and,
- any other areas that should be included.

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

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. **Yes**

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

iv. Other planning in relation to the provision of relevant services to children and adults with autistic spectrum conditions. **Don't know – the question is too vague and open to interpretation.**

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

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.

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?

GPs – because almost everybody has one and sees them at some point in their life time – it is the one consistent point of access.

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?

The training resources on ASD info Wales website are good but are at quite low level. It is dependent on individuals to access them and make the time. We believe that staff and supporters of autistic people also need to attend training where they can ask questions and have discussions in order to progress and develop their practice.

We are aware of the National Autism Training Framework for Wales, which is useful as a general guide but relies heavily on the online resources at ASDinfoWales.

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

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

Training should be needs led. We agree that there should be guidance about minimum requirements but this would depend on the level of need/complexity of support. An advisory service available for people, including parents/carers, employers, support staff that enable them to ask specific questions and receive expert advice would be useful. (we are aware of the NAS helpline but also aware of autistic people and families in our area who have not found it supportive or useful)

p) 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)?

Incentives for employers are needed, for example seed funding to encourage employers to take on individuals on the spectrum. Low level information is available on the ASD info Wales website but employers are not likely to know about this unless signposted to it. The Employment Ambassador post funded by Welsh Government has not made a difference in our area.

Continuity in services that already provide employment support (Shaw Trust, Workways Plus, DEAs at JCP) is very important.

Build capacity in the third sector to provide mentoring and support for people in employment.

Good support is available from job centre but only for people on specific benefits.

q) 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?

There is a definition in the current autism strategy but our view is that a definition should not be laid down in the act. An overview of strengths and needs commonly experienced by individuals on the spectrum would be more useful. In the guidance do not specify one definition but instead state that the current diagnostic criteria as defined by versions of DSM and ICD current at the time should be used.

r) 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?

Please explain your answer if possible.

Cost shunting if mandatory functions are not resourced. Increased funding will be needed and this should be ring fenced.

There will be increased pressure on existing staff because duties will increase.

Potential service breakdown if legislative requirements are not resourced.

It is possible that if there is clear benefit in having a diagnosis following the act there will be an increase in requests for diagnostic assessment.

It is possible that the act might define people with autism as a group of people with a negative image – to avoid this care must be taken to ensure that it is an empowering document and it is important that it is written in a way that the community views it as an empowering document.

It is possible that it will create resentment among other groups.

This act will not capture the needs of children and adults with other developmental disabilities.

It is possible that the Act might be used to exclude people who have an unusual presentation of autism, or who have complex other issues in addition to autism that prevent them from obtaining a diagnosis.

The act needs to reference the SSWB act and link strongly to existing legislation in recognition that people with autism as a group have struggled to get services and fallen through gaps. It should ensure that in the future, people's rights under SSWB act are met.

s) 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?

Yes. We think that if an autism act is to be effective there will be significant extra cost. We believe that the significant extra cost will arise from ensuring that people with autism have access to service provision. However there will be reduced costs in other areas if we are able to prevent escalating need (for example in-patient mental health services, criminal justice system) by providing appropriate support services. Reference SSWB act and The National Autism Project Report. Preventative services should be cost saving in the long run.

The act must channel money into direct support for individuals on the spectrum and their parents/carers.

t) 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?

It is not possible for us to answer this question – a response would require considerable research by a range of parties.

u) 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?

Yes. Collecting and reporting data takes time and expertise – this would need to be a specific role and responsibility.

IT systems between health, education and social care need to be compatible and there needs to be a requirement to develop information sharing protocols, with guidance about how to do it.

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

Quality of life for individuals on the spectrum, parents and carers. Improved well-being, including reductions in parent and carer stress. Empowerment of individuals who are on the spectrum.

Reduced waiting lists.

Increased employment.

Reduced use of forensic services.

Reduction in the number of people with autism in the CJS.

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

Measure/record of the number of people with autism in the CJS, unemployed, and in MH services now (in comparison to general population) to get a starting point/ base-line against which to measure possible cost reduction over time.

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

We want to stress that if and Autism Act is introduced, it must place an emphasis on redirection to the SSWB act.