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) AWB27
Ymateb gan Coleg Brenhinol yr Ymarferwyr Cyffredinol Cymru
Evidence from Royal College Of General Practitioners Wales)

RCGP Wales welcomes the opportunity to respond to the consultation on proposed Autism (Wales) Bill Consultation. RCGP Wales is a member's organisation of GP and doctors training to be GPs in Wales.

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

We are concerned that provision of patchy assessments and services may still be based on a diagnosis rather than needs of the individual or child. Autistic Spectrum Disorder has a broad range of presentations, which can mean that a diagnosis is difficult particularly for girls who may present more subtly. As the document states affected individuals may and still do fall between mental health and learning disability. The Spectrum may be part of a physical disability and this may mean patients do not get either learning disability or mental health support. Those who are not diagnosed until they are adults may have greater problems accessing support and services. There are less services for adults and some preclude those adults who were not diagnosed as children even those who moved into an area. We welcome the increase in awareness and information of Autistic Spectrum Disorder and having a nationally co-ordinated service enabled particularly for families and carers. We would welcome that the Bill provided for ongoing ring-fenced funding. The Bill should also ensure that families and carers should receive support for their own needs as carers and resources such as parenting courses. We are aware that in some areas the teams both in health and social services that support and diagnoses those with Autistic Spectrum Disorder (ASD) are very stretched and access may be difficult e.g. Child and Adolescent Mental Health (CAMHS). We would like to see these services being better supported not just for those with ASD or suspected ASD diagnosis, but for all those with a need.

We would welcome improved education, training, and employment support for all those with additional needs including those with ASD. Sadly, the employment support is patchy and limited and improving employment advisors and support would improve the wellbeing of both those with additional needs but also their carers and families. There is a lack of grants offered to companies to employ disabled people.

We would agree with the findings of the Task and Finish Group and would welcome improved access to a diagnosis for Autistic Spectrum Disorder and enhanced transition services, support for employment and information about services for those with additional needs as well as those with ASD.

We agree that services are patchy particularly in rural parts of Wales but also in some Valleys areas. We agree that these should be increased based on need not just based on a diagnosis of ASD as otherwise those who have borderline conditions are excluded. Support is also required for those family and carers.

We welcome the need for quality improvement and to this needs to be added quality assurance.

We would support the need for legislation by Welsh Government to develop, publish, consult (particularly with professionals, service users, families and carers) and review the national strategy for autistic spectrum conditions but we would caution on making definitions too tight and being based on diagnosis rather than needs for this automatically excludes many who need 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, as long as it does not result in others in need without a diagnosis being less well supported.

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

We would support flexibility in the legislation to allow for future needs developments.

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?

Stakeholder consultation

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- 5 yearly

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?

Survey of providers and service users

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

Patchy services across Wales. Patients as discussed in; a) often fall between services

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

We would like need rather than diagnosis to be the criteria for care and support

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, but not just for autism

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

We feel that they are patchy. There are particular problems with transfer of care from paediatric to adult services with patients falling out of services as there are often no equivalent services with family and carers having to pick up the pieces with no support.

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.

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.

We agree with these proposals. There should not be a bar on patients who move into an area. Movement between services should be easy as some services may be more appropriate to people's needs at different stages.

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, and this should be a combined data collection.

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 do not think it should be the responsibility of GPs to collect or hold this register.

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 have no comment on training provision, but there should be training for all staff available particularly reception and similar staff across the NHS and LA to help them support these people and their families. This could be in the form of e learning.

Increased awareness of adult autism is required. There should also be increased public awareness of autism and similar problem.

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

No

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

No this would be difficult to assess and monitor

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)?

No comment.

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

i. be included on the face of legislation (which makes it more difficult to change in the future);

ii. be included in an autism strategy;

iii. be included in guidance; or,

iv. not be stated at all?

Legislation should look at need not diagnostic labels.

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?

We feel that making legislation dependent of diagnostic labels will exclude people. We need services to address individual's needs not their diagnosis.

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?

Combining services across health and social care may have start-up costs but should reduce costs long term. Supporting people better potentially may save costs in other parts of health and social care. I think it's important to combine services across health and social care, but in the case of children, education too. The whole child approach as part of education is important not just for the child to keep them in school in order not to disrupt their day for therapies and allow them to settle back into learning more quickly. The mental health of parent carers who might be struggling with time off from work, or even allow them to work is important and this would facilitate it. Could also save costs if the therapies could be given as a class, multi child group, allowing the school to incorporate into the lessons. Such early intervention is proven to improve outcomes, but this kind of approach is patchy across Wales.

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?

No comment

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?

No comment

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

No comment

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

No comment

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

We are very concerned that introducing specific legislation and pathways for Autism means that those with need will receive poorer services and this will create a further service which is ring fenced. rather than becoming people centred and supportive.