

Cynulliad Cenedlaethol Cymru
Bil Awtistiaeth (Cymru) drafft
Llythyr Ymgynghori DAB04
Ymateb gan Coleg Brenhinol y
Seiciatryddion

National Assembly for Wales
Draft Autism (Wales) Bill
Consultation Letter DAB04
Evidence from Royal College of
Psychiatrists

The Royal College of Psychiatrists is a professional medical body responsible for supporting psychiatrists throughout their careers, from training through to retirement, and setting and raising standards of psychiatry in the United Kingdom.

The College was founded in 1841 and officially named the Royal College of Psychiatrists in 1971. The College has 7068 non-training workforce (consultants and staff grade doctors) according to the 2017 consensus. The College also represents the views of our members regarding mental health policy and psychiatric practice, providing advice on issues that affect both the profession and the patient.

In 2004, the College created a separate division in Wales (RCPsych in Wales) to meet the specific needs of over 550 Members working and training in the Jurisdiction. RCPsych in Wales is committed to raising awareness of issues around psychiatry, mental health and wellbeing with the National Assembly, the Welsh Government, the NHS in Wales and other public and charitable bodies.

We have welcomed the spirit in which Autism is being consulted upon. We have deemed it appropriate to share our wider thoughts as part of the process in bringing the Draft Autism (Wales) Bill to the Assembly chamber. Whilst we do hold concerns over some of the impact of legislation, we are keen to engage in the process of Assembly consultation. Accordingly, we have outlined some areas for consideration at this stage of the Bill.

Autism Spectrum Disorder (ASD) is a complex condition that presents differently in different individuals, which is in part why it is difficult to diagnose. No two persons' needs will be the same.

Similarly, there are many children with neurodevelopmental differences (ASD like traits, learning disability, ADHD) who may not meet the criteria for a diagnosis but the sum total of their difficulties is what creates the impairment and affects the quality of life. Support and treatment should be tailored through the needs of the individual through a formulation that is based on a multi factorial understanding of each case, not through their diagnosis and not prescribed through legislation.

We feel strongly that progress in this area has been made already through wider legislation and specific policies around ASD, and we would recommend that time is allowed for these policies to embed before considering introducing further legislation.

- The Social Services and Wellbeing (Wales) Act 2014¹ places a duty on public bodies to assess and address the needs of individuals. This legislation effectively covers the needs of children and adults with autism. Under the Act, Regional Partnership Boards must ensure that there are integrated care and support services to meet the need of people in their area and we understand that autism has been identified as one of their priority areas for integration. Regional Partnership Boards will provide annual progress reports to Welsh Government on their outcomes in relation to the National Integrated Autism Service.
- The Together for Children and Young People Programme², Neurodevelopmental Work stream has focussed specifically on neurodevelopmental disorders (ASD and ADHD) and has invested funding in this area. We are pleased that this investment is already resulting in improvements in the quality of service delivery and that there is now an integrated all-Wales neurodevelopmental pathway³.
- The refreshed Autistic Spectrum Disorder Strategic Action Plan⁴, and the Delivery Plan⁴ also seek to improve existing services. An Implementation Board will review the delivery of the Action Plan and produce annual reports on its progress. The Plan has also established a National Integrated Autism Service, which will see dedicated specialist teams to assess and diagnose adults and support families of children and young people in all regions in Wales by 2019. There will be an independent review of the Service.

Importantly, we question if passing legislation in this area would result in a push to legislate in other areas of health?

At this point in time, we do not believe that this should be enshrined in legislation. In Wales, we have a coherent clinical national strategy supported by the National Integrated Autism Service and T4CYP.

What we need is to ensure that mechanisms for monitoring progress are robust and there is continued financial investment to develop and strengthen services. We agree that the services are currently limited in size and function; however, with the national approach it will be possible to allow assessment of impact over time and to see where the gaps in service are, and allow sharing of good practice through the T4CYP community of practice events.

We worry that passing an Autism Act would prompt other disadvantaged groups to seek support for producing more legislation. The Social Services and Wellbeing

¹ Social Services & WellBeing Act (2014)

www.legislation.gov.uk/anaw/2014/4/pdfs/anaw_20140004_en.pdf

² Welsh Government (2016) Together for Children & Young People

³ All-Wales Integrated Neurodevelopmental Pathway

www.goodpractice.wales/SharedFiles/Download.aspx?pageid=185&mid=326&fileid=653

⁴ Welsh Government (2016) Autistic Spectrum Disorder Strategic Action Plan, & Delivery Plan
<http://gov.wales/topics/health/socialcare/asd/?lang=en>

(Wales) Act 2014, if properly implemented, should cover all individuals regardless of disability, particularly those with complex needs.

We would urge decision makers to look at England's experience in setting this in statute. The Autism Act⁵ has been largely ignored. In addition, Think Autism has statutory authority as the current implementation guidance for the Act but this is not usually followed. On a positive note, where in England the money for health and social care is squeezed and as other services that used to cover gaps are closing, the fact that it is statutory is leading to the Act gaining more traction. Statutory bodies are now under pressure to take action.

We have outlined three areas for particular consideration.

Diagnosis & Co-Morbidity

We feel that an Autism Act will not necessarily drive good practice and could lead to a push for higher diagnosis rates rather than focus on meeting the needs of the individual. The need for diagnosis in order to push for resource will only artificially increase diagnosis rates for the wrong reasons.

Many individuals with ASD have co-morbid mental illness or substance misuse problems, which can cloud their diagnosis and complicate pathway options, with patients potentially falling between services.

We feel Local health boards and local authorities in Wales should be providing children and adults information on the pathway to diagnosis. For children, this integrated, national pathway is already publicly available. We would like to see similar for adults.

Pathways & Multi-Agency Approaches

The current arrangements are not yet fully effective in improving ASD services and provision is patchy across Wales, but autism has been seen as a priority and there have been changes in policy and law seeking to address meeting the needs of people with autism.

The Together for Children and Young People Programme (T4CYP) Programme has recognised that quality of service delivery is dependent on shared practices, joint pathways, good communication, multi-disciplinary approach supported by solid financial investment. The investment of £2m is already resulting in major improvements. The T4CYP work stream on neurodevelopmental disorders which includes children and young people with learning disabilities, has developed the all-Wales neurodevelopmental diagnostic assessment pathway with a single point of entry and quality standards for audit, a clinical peer support group and a Clinician Toolkit.⁶

⁵ Autism Act (2009) <https://www.legislation.gov.uk/ukpga/2009/15/introduction>

⁶ All-Wales Integrated Neurodevelopmental Pathway
<http://www.goodpractice.wales/SharedFiles/Download.aspx?pageid=185&mid=326&fileid=653>

There is currently ongoing work on an All-Wales Intervention Pathway to promote multi-agency working. Once these initiatives are fully adopted and applied, we believe that these arrangements will be effective in improving autism services.

Access to assessment is still patchy across Wales but there have been improvements in waiting times for assessment and in the assessment process overall. This is particularly true for children.

Multi-agency training is crucial for delivering quality services, and adequate resources must be allocated.

We remain concerned that cuts to local authority budgets have impacted on the quality of services that it provides for people with ASD. The health service restructuring and changes in provision lead to shortage in staffing and resources for diagnostic assessments and eventually delays in access to Assessments.

Consequence of Legislation

Autism Spectrum Disorder is a disorder that has gained national prominence through a strong and successful lobby of influential third sector organisations with high profile campaigns. Whilst it is welcomed that ASD gets the attention that it deserves, there are many conditions, illnesses, and diseases that hold a lower profile. If this Bill is passed, it could be argued that we should legislate for good practice in other areas, such as ADHD.

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

In response of specific questions set out in consultation:

Please refer to questions in the [Consulation Letter](#).

Question	Answer
01	We believe that a definition is best placed either in the Autism Strategy (as it currently is [2016]) or in guidance . We do not believe in legislating for Autism at this time.
08	Please see our above comments with regard co-morbidity.
09	The refreshed Autistic Spectrum Disorder Strategic Action Plan, and the Delivery Plan seek to improve existing services. An Implementation Board will review the delivery of the Action Plan and produce annual reports on its progress. The Plan has also established a National Integrated Autism Service , which will see dedicated specialist teams to assess and diagnose adults and support families of

	children and young people in all regions in Wales by 2019. There will be an independent review of the Service.
10	Multidisciplinary teams may not necessarily always need full or part representation from each of the listed professions additionally many health services do not have the capacity to have a full multiagency service.
11	There are other professions that are often necessary to a diagnostic team that have not been highlighted, notwithstanding paediatricians, educational and clinical psychologists, psychiatrists, school therapists and special needs coordinators.
13	Local Health Boards and Local Authorities are already required to collect data on the needs of their populations. We believe that if health boards and Local Authorities met the requirements of existing legislation this would address this would help to begin to address issues around data collection.
17	<p>Autism Spectrum Disorder is a disorder that has gained national prominence through a strong and successful lobby of influential third sector organisations with high profile campaigns.</p> <p>Whilst it is welcomed that ASD gets the attention that it deserves, there are many conditions, illnesses, and diseases that hold a lower profile. If this Bill is passed, it could be argued that we should legislate for good practice in many other areas.</p>