

Cynulliad Cenedlaethol Cymru
Bil Awtistiaeth (Cymru) drafft
Llythyr Ymgynghori DAB31
Ymateb gan Coleg Brenhinol Pediatreg
ac Iechyd Plant

National Assembly for Wales
Draft Autism (Wales) Bill
Consultation Letter DAB31
Evidence from Royal College of
Paediatrics and Child Health (RCPCH)

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

About the RCPCH

The RCPCH works to transform child health through knowledge, innovation and expertise. We have over 500 members in Wales and over 17,500 worldwide. The RCPCH is responsible for training and examining paediatricians. We also advocate on behalf of members, represent their views and draw upon their expertise to inform policy development and the maintenance of professional standards.

General comments on the draft Bill

We note that the Royal College of Psychiatrists have previously stated 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”¹.

RCPCH members in Wales have expressed similar concerns. In linking resource to a particular diagnosis – whether autism, ASD or a given definition of ND disorders, there is a risk that families will feel that their best opportunity to access the support they need is by securing that particular diagnosis. This is not child-centred, because children presenting with a range of issues or symptoms that may be similar to or overlap with ASD but where ASD is not an appropriate diagnosis, may then be excluded from a pathway to receiving the appropriate care and resources.

As one RCPCH member in Wales told us, “an Autism specific Bill may improve services and provisions for children with ASD, but without further resources in all sectors, existing resources are likely to be focused on children and young adults with ASD and away from others with ND disorders or learning disabilities who may have on an individual basis a lesser or greater need.”

These issues were raised by RCPCH member Dr Cath Norton at a recent session of the Assembly’s Children, Young People and Education Committee during its inquiry into the mental and emotional health of children and young people in Wales:

“A child could have a specific learning difficulty, a child could have a specific motor problem with dyspraxia. But, functionally, that child is struggling. The problem is at the moment that maybe we are driving our resources towards

a specific diagnosis, and therefore that leads to frustration and challenge on the part of parents if they do not receive that diagnosis. They may well have got an accurate description of their child's needs, but they cannot secure the support they need or the resources they need.”²

There is a risk of creating additional (and sometimes inappropriate) demand on community paediatric services where this is seen as the ‘gateway’ to diagnosis without a commensurate increase in resource. Community paediatricians have told us that they are already struggling to meet demand. We also know that there are gaps in the community paediatric workforce and a need for more community paediatricians. Further investment would also be required into the associated services and other professions working as part of multidisciplinary teams to meet any additional requirements and would therefore be key to delivering improved ASD services without risking unintended consequences for other services.

We note that in Northern Ireland, their Autism Act of 2011 required the Department of Health, Social Services and Public Safety (DHSSPS) to develop and implement an Autism Strategy, which was done in January 2014. The only report on this to date in September 2015 found that it was “not currently possible to guarantee early intervention as outlined in the Autism Strategy, without additional funding to further develop autism specific assessment services, and to extend the portfolio of available family support”³.

Responses to specific questions

Do you agree that a definition of ‘autism spectrum disorder’ should appear on the face of the Bill?

RCPCH members in Wales rarely diagnose children with ‘pure’ or ‘classical’ Autism. Autistic spectrum disorder is the recognised diagnosis provided. Many of the diagnostic manuals used also define their classification with autistic spectrum disorder eg. ADOS.

We would therefore refer to the spectrum of diagnoses rather than Autism. It reflects not only the variation in characteristics of individuals and emphasizes the multi-professional specialism required to identify diagnostic criteria. There is not one checklist or single test that equates to one diagnosis for these individuals and for professionals making the diagnosis.

Do you agree that using the WHO ICD-11 definition in the draft Bill, together with the power for Welsh Ministers to include other neurodevelopmental disorders, is the right approach?

A concern raised with us is that ICD classifications will change and no matter how much this is emphasized in small print this may contribute to confusion for non-specialist individuals. The DSM V Criteria are perhaps the most widely used classification at present pending widespread access to ICD 11 in place of ICD10.

² <http://record.assembly.wales/Committee/4529#A40906> item 388. See also items 386 and 369.

³ <https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/autism-strategy-progress-report-2015.pdf> See items 17.1, 17.2 and 17.4

The inclusion of the term ND disorders is encouraged as this reflects the range of needs and variation that is seen on a day to day basis. However, it should be noted that further discussion and agreement would be required to define what is meant by ND in the context of the legislation - there is considerable variation among professionals and families in their use and understanding of this term.

The inclusion of the term ND would also create major challenges in terms of service delivery as it represents a change from ASD specific services – this would have significant implications that would need to be carefully considered.

Our more general concern is that if a Bill is set out to support a population with a specific diagnosis then policies must deliver in catering for individuals with that diagnosis. We are concerned at the possibility of not meeting the needs of other populations who have similar needs but a different (or no) diagnosis. RCPCH and our members believe that policy and legislation should meet the needs of all individuals with ND disorders, including those who may not fit the ICD diagnostic criteria for ASD or other ND disorders specified by Welsh Ministers (and therefore not receive a formal diagnosis) but have traits of these conditions that impair their everyday social, psychological and intellectual functioning. Otherwise we risk alienating vulnerable populations who have no formal diagnosis and therefore a weaker voice to advocate for themselves.

One example provided to us by a community paediatrician is of children with mildly impairing ASD sometimes receiving educational provision over and above that which is received in some cases by children impaired by moderate to severe learning disability or attention deficit disorder.

Do you agree that diagnosis should be completed within timescales in the relevant National Institute for Health and Care Excellence guidelines, as set out in in section 2(1)(c) of the draft Bill?

There may be confounding variables that need to be addressed before being able to accurately assess for ASD, for example whether or not there are co-morbid mental health factors or environmental factors such as family dysfunction or adverse childhood experiences that all currently present (sometimes inappropriately) through the ND pathways.

There may be a requirement to address these needs before completing the assessment of ASD. Some assessments are completed with the minimum number of clinical encounters and diagnostic assessments, whereas others may be extended over a longer period whilst other diagnoses are being explored.

A timely description that facilitates access to resources and support to meet identified needs is perhaps a more helpful way to consider the timescale issue. This would prioritise a child-centred approach over the goal of a diagnosis.

NICE guidance provides relevant guidance that should be cross referenced as should emerging guidance within the ALN Bill.

Do you agree that an assessment of care and support needs should be completed within 2 months of a diagnosis of autism spectrum disorder or any post-diagnostic meeting, as set out in section 2(1)(e)?

Once a diagnosis has been made of any ND disorder or at the conclusion of the assessments, whether a person has a formal diagnosis or has identified additional needs but not a formal diagnosis, a timely multiagency commitment must be established to ensure that these children and their carers have their concerns addressed and support initiated.

This is a practical approach that would require enhanced collaborative working. The resources to support identified needs do not rest with the diagnostic teams. This has implications for both children's social care and education in addition to health services. Key interfaces with both ALN and HSCWB require consideration.

Do you agree that it is useful to include in the draft Bill a list of professionals who may form the multi-disciplinary team for diagnostic assessment?

This would strive for a best practice approach although it is important to note that multidisciplinary teams may not necessarily always need representation from each of the listed professions.

It is also important to note that many health services do not have the capacity to have a full multiagency service inclusive of educational and clinical psychologists, paediatricians, psychiatrists, school therapists and special needs coordinators and so will struggle to meet a minimum standard if this list becomes too specific. There are CAMHS and paediatricians diagnosing children with varying practices depending on factors including the team available and the allocated time.

The skills required to address key aspects of the diagnostic process that are already outlined in NICE guidance should be considered. The opportunity to refer back to Together 4 Children and Young People (T4CYP) national standards and peer review should be considered to ensure that the process is of a high quality and fit for purpose.

If so, are there any other disciplines that you think should be listed as possible members of such a multi-disciplinary team?

Paediatricians are often pivotal members of the diagnostic team yet not referenced in the draft bill. Colleagues in education provide significant input to the diagnostic process.

Are there any other factors or individual circumstances which may inappropriately prevent access to services and which should be set out in the Bill?

Waiting lists to access assessments. Due regard needs to be placed on the increasing demand to diagnose children with autism. Many referrals are not appropriate and this needs to be addressed with education for referrers on what the other potential solutions or diagnoses could be other than autism. Waiting times could be reduced if mental health and community paediatric services were

accessed appropriately, consistently.

Increased resource in other areas such as administration responsibilities and shared care services with general practitioners would release time to allow paediatricians and psychiatrists to increase clinical capacity.

Children and young people presenting for ND assessment may be identified to have experienced significant developmental trauma that may be felt to be the major factor contributing to their behavioural presentation. Whilst a comorbid diagnosis of a ND condition may be possible and may warrant consideration it must be noted that the interface with developmental trauma is a complex issue. There is an opportunity for further discussion and collaborative work to be undertaken between the ND services and the trauma informed services that include the ACES Hub etc. The focus should be on meeting the needs of the child however this interface with trauma informed services needs to be considered very carefully - it could both hinder and overload access to a ND assessment.

Should the draft Bill specify the types of data to be collected by Welsh Ministers to enable them to carry out functions under the Bill?

Detailed consultation with the professionals diagnosing autistic spectrum disorders alongside other neurodevelopmental disorders (primarily paediatricians and CAMHS professionals) would provide the opportunity to understand the types of data that could be collected, how this might be achieved and what obstacles there are to doing so.

We do not currently have numbers for children of various ages being diagnosed with ASD or other ND disorders or the prevalence throughout the UK. This would be useful for further research into the process of diagnosis and providing educational and social services for this population.

The ND Workstream within T4CYP has completed an extensive project with clinicians across Wales to agree a quantitative and qualitative data set that has the intention of retaining clinical validity and generating a coherent data set that will impact on the quality of services across Wales. It is intended to allow "Like for Like" comparisons and to provide a greater depth of information, as simple "referral to assessment" data is of limited value in terms of service improvement.

Any process of data collection will require resource and enhanced administration and IT management if it is not to distract teams from their key purpose of providing assessment and support to families.

If so, do you have any views about the types of data which should be collected? Examples of types of data which should be collected might include: age, age at diagnosis, gender, health board/local authority area, time from assessment to diagnosis, profession(s) of diagnosing staff and service in which based, diagnostic assessment tool(s) used, use of a scored assessment, the diagnosing clinician's estimate of intelligence level, communicative development, whether testing for phenylketonuria (PKU) was carried out.

PKU is tested for in all children through the newborn Guthrie card. Paediatricians

would not routinely perform any diagnostic blood testing for ASD unless associated with developmental delay.

If there is any evidence or suggestion that a child has a learning disability, this is a neurodevelopmental ICD/ DSM classification in its own right. An educational psychologist would be able to provide a thorough assessment and IQ score, but they are increasingly burdened with workload.

It may be useful to register whether children have co-morbid conditions but again the spectrum and degree to which this impacts their functioning would be difficult to quantify and how this data would be used to inform policy would require careful consideration. For example, individuals with a learning disability may require different or additional opportunities to access support.

This is a complex issue that is superficially simple – we would encourage consideration of the extensive work that underpins the new standards and guidance on ND conditions issued by the T4CYP workstream. This has been developed by clinicians and academics across Wales. Please contact us if you do not have this guidance or to hear from specialists working on this.