

<p>Cynulliad Cenedlaethol Cymru Bil Awtistiaeth (Cymru) drafft Llythyr Ymgynghori DAB19 Ymateb gan Gwasanaeth Niwroddatblygiadol Bwrdd Iechyd Prifysgol Caerdydd a'r Fro</p>	<p>National Assembly for Wales Draft Autism (Wales) Bill Consultation Letter DAB19 Evidence from Cardiff and Vale University Health Board Neurodevelopmental Service</p>
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Please refer to questions in the [Consultation Letter](#).

Question	Answer
01	This will depend on whether you include Neurodevelopmental disorders in the bill, in which case and the name of the bill and it's definitions will need changing.
02	<p>No. The Diagnostic Statistical Manual of Mental Disorders Fifth Edition (DSM-5) is used in Neurodevelopmental services across Wales, which has been agreed at an all Wales level.</p> <p>By including Neurodevelopmental Disorders in the bill, the name 'Autism Bill' will become redundant and will not represent the group of individuals that the bill refers to. However it would enable those with identified Neurodevelopmental Disorders or difficulties, who have equally significant needs to those with autism, to access the services they require.</p> <p>It will be important to specify what is meant by Neurodevelopmental Disorders. Within Wales, Neurodevelopmental Services provide assessment and intervention for autism and Attention Deficit Hyperactivity Disorder (ADHD) however DSM-5 defines Neurodevelopmental Disorders as: intellectual disabilities, communication disorders, specific learning disorder, autism spectrum disorder, ADHD and motor disorders (APA, 2013). We feel that the individuals with any of the above Neurodevelopmental Disorders should have the same legislative rights as those with autism. Including Neurodevelopmental Disorders will ensure parity for these individuals and reduce any discrimination that this Bill may cause.</p> <p>Excluding Neurodevelopmental Disorders and creating a specific bill for autism will be inequitable for the vast number of people who experience Neurodevelopmental difficulties but do not have a specific diagnosis of autism. This will also mean that services will become diagnostic led rather than needs led. The diagnosis of autism will become a gate keeper for access to services and it may lead to over-diagnosis of autism. This may result</p>
03	No. It is important that other relevant bodies including the 3rd sector need to be considered as they will also have a key role. Including only

	health and the local authority is excluding other relevant bodies that will have an important role to play in supporting people with autism (and other Neurodevelopmental Disorders).
04	As above, who the relevant bodies are would need to be made clear before making comment on this.
05	Yes. The strategy will need to be made available and out for consultation prior to the issue of the bill. The bill and the strategy will need to be published at the same time.
06	No
07	Yes. The strategy will need to be made available and out for consultation prior to the issue of the bill. It seems meaningless having a bill which comes into force if the strategy has not been developed and published.
08	<p>Firstly, we strongly feel the wording should be changed from 'diagnosis' to 'conclusion of assessment' or 'identification of needs', as many children and young people that come through the neurodevelopmental pathway will not receive 'a diagnosis' of autism yet will still have significant needs which are identified through the assessment. By using the terms 'diagnosis' we are setting unrealistic expectations for parents, who need to be prepared for the possibility that their child may not receive a diagnosis of autism.</p> <p>In a recent analysis of the data looking at the last 100 concluded assessments within Cardiff and Vale Neurodevelopmental service, only 57% of children being assessed for autism received a diagnosis of autism.</p> <p>NICE does not state a specific time limit for completion of assessment, however, some assessments are taking an unreasonable amount of time due to limited capacity and resources within our team, and many children have to wait significant lengths of time for further assessments (such as assessments from other professionals within the multi-disciplinary team, specific autism assessments such as ADOS, cognitive assessments, school observations etc). If a flexible timescale were to be provided, services would have to be appropriately resourced, with additional staff employed to manage the high number of children and young people that are being referred for assessment.</p>
09	No. This needs to be flexible and tailored to the preferences and

	needs of the individual. Any post diagnostic meetings will need to include individuals who have had an assessment for autism but do not meet criteria, as they would also require a post assessment meeting and a support plan (if appropriate), as they will still have identified needs.
10	Yes but there are key professionals that have been missed out on the list including paediatricians and relevant people within education. The role of a behavioural therapist needs clarification as this is not a role that we recognise within Neurodevelopmental services.
11	Yes. Paediatricians play a key in the assessment of autism in children and young people's services. It is also important to recognise the important role that education professionals provide in our assessment process.
12	Yes. If the Bill is passed, the Welsh Government will need to provide sufficient additional resources to meet this demand within Neurodevelopmental services as currently it will be impossible for us to begin the assessment of children and young people for autism within the specified time of three months. It would mean that those being assessed for autism would take priority if other Neurodevelopmental disorders were excluded from the bill, resulting in an inequitable and unethical service. By having a bill for autism only, Welsh Government are prioritising autism above other Neurodevelopmental disorders which may result in autism being the preferential diagnosis for individuals based on the legal rights associated with this diagnosis. This would put intense strain on Neurodevelopmental services, which are already under tremendous pressure to provide assessment and support under referral to treatment time targets.
13	Yes. It will be important to support services to set up systems which allow for the collection of important data. This data analysis will be vital in order to ensure that services are performing according to the bill, but also for Welsh Ministers to understand why under-resourced services (such as ours) are not able to meet the standards set out within the bill
14	These examples seem appropriate.
15	In the guidance.
16	Yes this is appropriate to make sure the bill is being adhered to, but I

	do not feel this needs to be included on the face of the bill but in the guidance.
17	We feel the campaign should be around awareness and understanding of Neurodevelopmental Disorders and difficulties, including autism, but not solely autism. By raising awareness of autism only, we are missing a huge group of individuals with Neurodevelopmental difficulties. Autism is one of many Neurodevelopmental Disorders and creating an autism bill alone creates disparity and potentially leaves people with
18	By including Neurodevelopmental Disorders in the bill, you are improving services for groups of people with conditions such as ADHD, whom we know are more likely to be involved in the justice system.
19	None