

Cynulliad Cenedlaethol Cymru
 Bil Awtistiaeth (Cymru) drafft
 Llythyr Ymgynghori DAB23
 Ymateb gan Cyngorau Caerdydd a Bro
 Morgannwg

National Assembly for Wales
 Draft Autism (Wales) Bill
 Consultation Letter DAB23
 Evidence from Cardiff and Vale of
 Glamorgan Councils

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

Question	Answer
01	<p>No - the content of the Bill itself will define what is required - Autism and ASD are seen as the same. However, if Neurodevelopmental conditions are included, then this may require definition of what this is and will cover</p> <p>The bill certainly needs to define what it means by autism otherwise people will interpret and include what they want including terms such as PDA (which is not a diagnosis) and this needs to be clearly set out. There should be a definition of autism and the subcategories according to the ICD-11 (due out in May) and the DSM-V as these are the recognised diagnostic categories</p>
02	<p>No</p> <p>This approach indicates that the Bill if passed, will in future provide challenge for what is and what isn't included. Currently there is a clear notion of what Autism does and does not include, and as such services are designed around these needs to specifically meet those with the condition.</p> <p>Adding in Neurodevelopmental Disorders is a significant change in the list including as well as autism, ADHD, intellectual disability, communication disorders, motor disorders, and specific learning disorders. Whilst this is more inclusive, and supports alignment of the new ND teams and the IAS, this implies that these two services require legislation to work together across the lifespan.</p> <p>This significantly extends the bill from its original focus on autism. It also has the potential for further conditions to be added in the future making planning for need based around populations and prevalence very difficult, and could potentially increase legal challenge in the delivery of services, where definitions are not clear.</p> <p>Listing conditions also has the potential to further medicalise an approach that should be seeking to enable children, families and adults to lead fulfilled lives that support wellbeing.</p> <p>For those experiencing other neurodevelopmental disorders, including them within legislation and a more strategic approach is</p>

	<p>likely to be welcome. I don't agree with suggesting that other neuro-developmental disorders should be included at all in that I think we need to emphasise that a bill is unnecessary. However, there are a number of other identified groups which will become excluded who will not welcome the bill as a result of preferential set of legal terms which exclude these other groups which in itself is discriminatory.</p> <p>Therefore, a preferred option would be to suggest additions to the SS&WBact which could provide a specialist overview for Autism, but in its nature is an inclusive legislative all age Act.</p>
03	<p>No -</p> <p>Noting that the key aspects of the Autism Strategy include:</p> <p>Access to healthcare services; access to education; access to employment; access to housing; access to Welsh language services; access to other public services; social inclusion; and access to advocacy services</p> <p>Whilst Health and local government clearly have key roles to play in implementing the Autism Strategy and if agreed, an Autism Act, this is a wide remit covering areas that the LA and NHS will not have jurisdiction to enforce. Other partners, such as Careers Wales and the DWP oversee developments within employment and access to further education and the third sector may also have a role to play to ensure success.</p> <p>If only health and local authority are relevant bodies it is unclear how they would successfully exercise a duty in a non-devolved area such as employment. It is similarly unclear how Welsh ministers would exercise control over the DWP for example with respect to employment.</p>
04	<p>It could be suggested that 'relevant bodies' needs to be more prescriptive to include other bodies who should be directed to understand and act to undertake their responsibilities. There is a risk that wider organisations will see that an Autism Act is for Local authorities and NHS services to implement, as opposed to a broader context of change as noted within the current strategy.</p> <p>With this in mind, it would need to be made clear to Welsh Ministers who are the relevant bodies that they give direction to, should there be a requirement to exercise power over a relevant body to act.</p>
05	<p>Yes - the timeframes set out are overly optimistic and carry risk. There will be a requirement for consultation and to gain clinical input and guidance from experts in the field. In addition there needs to be</p>

	<p>recognition that local areas will have pre-identified commitments such as preparing for the implementation of the ALNET Act, which are ongoing and require dedicated resources.</p> <p>Rushing the development of the strategy, and subsequent publication could lead to revisions being required earlier than needed and additional work at a later stage.</p> <p>A measured and realistic timeframe which takes into account the need to implement the ALNET Act, which also allows for engagement and inclusion of those who will be leading the implementation of an ASD strategy would be more beneficial. This would support wider ownership of the strategy and any action plans that may develop as a result of this.</p>
06	<p>As above. It would be helpful to reflect on lessons learned from the implementation of the Integrated Autism Service and other time sensitive developments to understand the implications of setting timeframes which are challenging to achieve. Whilst positive change has occurred, there was a significant amount of preparation and planning time which would have benefitted the development of an integrated service.</p>
07	<p>The information provided implies that an Autism act would come into force prior to the publication of the ASD strategy or guidance. This would prove very challenging to implement as an Autism Act would have no purpose and will be challenging to govern without a code or standard to work from.</p> <p>This could lead to legal challenges and vague expectations from those who may benefit from an Act, but no guidance to work from for those who are supporting these individuals.</p> <p>There would need to be an understanding that an Autism Act may come into force before duties of responsible bodies can be governed.</p> <p>It is therefore difficult to see how these timelines could be adhered to while allowing an appropriate consultation to take place leading to the publication of a strategy and guidance that is a practical and achievable.</p> <p>As the timeline implies that the guidance cannot be finally written until the strategy which informs the guidance has been created, these seem overly optimistic and unrealistic time frames.</p>
08	<p>Do you agree that diagnosis should be completed within timescales in the relevant National Institute for Health and Care Excellence</p>

	<p>guidelines, as set out in in section 2(1)(c) of the draft Bill?</p> <p>The NICE guidelines state that a diagnostic assessment for children should be started within the first 3 months. https://www.nice.org.uk/guidance/cg128/chapter/Recommendations#local-pathway-%20for-recognition-referral-and-diagnostic-assessment-of-possible-autism</p> <p>This does not refer to completion of assessment and confirmation if appropriate of diagnosis. There are no timeframes noted within NICE guidelines for adults for either assessment waiting times, or provision of a diagnosis if appropriate.</p> <p>Within Neurodevelopment Services the 26 week diagnostic waiting time for children is from referral to first appointment, and the assessment and diagnosis process can take longer and should be bespoke to the needs of the individual but not excessively lengthy. It would be clearer to outline expectations for waiting times within an act or strategy, but with the acknowledgement of context and complexity of some cases which may require longer to assess to be able to confirm diagnosis.</p> <p>Performance indicators to ensure compliance should include waiting times for governance purposes, but allow for flexibility that accounts for a thorough needs assessment. Simply adding a target will not resolve the issue of waiting times.</p> <p>However, there is no maximum waiting time standard from referral to a final diagnosis of autism.</p> <p>This has been the subject of recent debate in parliament. http://www.normanlamb.org.uk/maximum_waiting_times_for_autism_diagnosis_needed</p> <p>It could be suggested that an Autism Act should refer to a minimum standard waiting time for adults and children, or timescales noted within NICE guidelines, whichever is shorter.</p>
09	<p>No - a proportionate assessment of needs should be carried out post diagnosis, as is consistent with the Social Services and Well Being Act. The timeframe for completion of this proportionate assessment should be consistent with the SSAWB ACT within Information, Advice and Assistance services, and where further assistance can only be delivered through the development of a care and support plan, this should also be completed under the principles of the SSWBACT. The proposed Autism Act suggests a 2 month completion timeframe, whereas the timescale for completion of the assessment within the SSWBACT is a maximum of 42 working days from the point of referral. This would require alignment to ensure all assessments are</p>

	<p>prioritised based on needs and not diagnosis.</p> <p>Using the term care and support needs implies that all individuals diagnosed with autism have needs which can only be met through the provision of care and support services. This is simply not the case, with many individuals diagnosed with Autism never requiring This is simply not the case, with many individuals diagnosed with Autism never requiring</p> <p>There are however a number of individuals who may have care and support needs, which are unrelated to their diagnosis of ASD but need local authority intervention.</p> <p>As within the SS&WB Act it would need to be clear who would have a duty of care to complete assessments. An analysis of current capacity and demand within services would be required to ensure the resource implications for implementing this approach can be fully understood.</p> <p>A diagnosis of ASD should not be a trigger for care and support, but is an appropriate trigger in the requirement to assess and it would be expected that those assessing would be as outlined within the SSWBACT.</p>
10	<p>No - The NICE guidelines outline the key individuals that can support a diagnostic assessment.</p>
11	<p>As above (Q10)</p>
12	<p>No - Specific services have eligibility criteria's to enable delivery to vulnerable groups (LD, MH services, Phys Dis etc)</p> <p>There would be resource implications if these services were to include ASD without associated LD,MH.PD etc and these service areas are already delivering to a growing population of eligible citizens.</p> <p>SS&WBA provides care and support based on need not diagnoses.</p> <p>Equipping services to be able to assess based on need rather than diagnosis to ensure those in need of care and support have access to services which are able to best meet these needs.</p> <p>There should not be an expectation that a diagnosis of ASD is a gateway to services, this should be based on needs of an individual and prioritisation of resources to meet these needs. Perhaps emphasising further that if an ASD diagnosis results in priority to services over other groups then there will be even more pressure on</p>

	<p>diagnostic services as people will feel they need it to get support. An innovative approach to these things would indeed be needs' led services.</p>
<p>13</p>	<p>Any personal data collected must comply with Data protection legislation (GDPR)</p> <p>In order to be consistent the population needs assessment, as identified in the SSWB Act, should determine what data is collected.</p> <p>Currently ASD data is aggregated within LD and separating that data to clearly delineate the two conditions and the differences between the two population needs would be informative. Lumping autism generally in with LD is incorrect and unhelpful and creates an expectation among families and individuals that will not be fulfilled.</p>
<p>14</p>	<p>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.</p> <p>Data gathered should be limited to that necessary in order to satisfy the requirements of data protection and what is required within the Population Needs Assessment to understand regional need.</p> <p>Any other data for 'interest' purposes should be done via research units only. Collecting and processing data should not be to an extent which is significantly beyond that collected for other similar conditions. To do so risks marginalising this population for study purposes. Were this being done for in a research setting it would be accompanied by extensive work around consent and ethics and involve a clear understanding by the individuals as to exactly how the data will be used and processed.</p> <p>Very clear reasons would need to be given regarding why each piece of data is being collected and what the purpose of its use would be. It could be argue that much of the data that is being proposed is available elsewhere, for example, the information gathered as a result of the assessment of the Autism Act in England and also through very comprehensive Nice Guidelines relating to autism.</p> <p>An 'estimate' of intelligence should never be made and it would be neither reliable or valid. Experienced clinicians can indicate whether they think an individual requires a comprehensive assessment of</p>

	<p>their IQ if there is some concern that an individual has a learning disability but this is already currently done in order to ensure people are accessing the appropriate services.</p>
15	<p>If at all, in the guidance</p>
16	<p>If at all in the guidance.</p>
17	<p>Both – this is a proven success and should be continue. The campaign should be around awareness and understanding of Autism - including those individuals with particular needs. Not all individuals with ASD will see themselves as having needs.</p>
18A	<p>Individuals with a diagnosis of autism have impairments in their ability to communicate. Feedback from individuals has indicated that information should be provided in a clear and concise manner.</p> <p>Bi-lingual documents can be confusing for individuals who already have challenges with communication. Some exceptions within the Welsh Language act for services to be able to take the individuals lead in language preference which takes into account their communication methods would be helpful.</p>
18B	<p>Reduce negative effects by aligning closely with the SSAWB ACT to reduce impact on groups not represented within this draft bill. Other disabling conditions have no Bill to support them, and refer to the new Social Services and Well Being Act, and ALNET Act to support assessment of need and delivery of services. Moving away from the SSAWB ACT for a specific group will create an equality issue for those living without Autism who will be less well supported, and may lead to an increase in people seeking a diagnosis to access support where previously they did not need to. It would be helpful to see a copy of the Equality Impact Assessment completed on this.</p>
18C	<p>Would it be worth putting something in here about potential positive benefits to people with ASD if there was an onus on the ‘justice system’ to increase their knowledge and understanding of autism and how to support autistic people? I am not sure if this is what they are asking though?</p>
18D	<p>Where possible the draft bill should seek close alignment with existing legislation to reduce cost implications. Where additional responsibilities are outlined which are not met within current regional strategic action planning these should be resourced accordingly. This would enable regional areas to meet the standards</p>

	set out which are above and beyond current duties.
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