

Cynulliad Cenedlaethol Cymru
 Bil Awtistiaeth (Cymru) drafft
 Llythyr Ymgynghori DAB35
 Ymateb gan Gwasanaethau Plant
 Caerdydd a Bro Morgannwg

National Assembly for Wales
 Draft Autism (Wales) Bill
 Consultation Letter DAB35
 Evidence from Cardiff and Vale of
 Glamorgan Children's services

Please refer to questions in the [Consultation 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>
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, pathological demand avoidance etc. 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 likely to be welcome.</p> <p>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: 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. In addition there needs to be 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</p>

	<p>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. 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>The NICE guidelines state that a diagnostic assessment for children should be started within the first 3 months.</p> <p>https://www.nice.org.uk/guidance/cg128/chapter/Recommendations#local-pathway-for-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.</p> <p>http://www.normanlamb.org.uk/maximum_waiting_times_for_autism</p>

	<p>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 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 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 any further support post diagnosis.</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	No - The NICE guidelines outline the key individuals that can support a diagnostic assessment.
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