

Question 1

<p>Consultation response no:</p>	<p>Do you agree that a definition of 'autism spectrum disorder' should appear on the face of the Bill?</p>
<p>1.</p> <p>2.</p>	<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><b>The act as introduced</b> added the phrase <i>(b) for the purpose of this Act</i>, This has the potential to add to confusion as it implies that an alternative neurodevelopmental condition may be considered as autism only for the purpose of this act and not with respect to other statutory instruments which would be unchanged.</p>

Question 2

<p>Consultation response no:</p>	<p>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?</p>
<p>1.</p>	<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</p>

2.	<p>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 because 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&amp;WB Act, which could provide a specialist overview for autism, but in its nature is an inclusive legislative all age Act.</p> <p><b><u>The act as introduced</u></b> retained this section providing a power for Welsh ministers to introduce other conditions if necessary. This continues to be a section with the potential to lose the focus and purpose of the proposed Bill turning it into a pan-disability piece of legislation, which is effectively what the Social Services and Well Being Act is.</p>
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### Question 3

Consultation response no:	Are the “relevant bodies” in section 7 of the draft Bill the appropriate bodies to implement the autism strategy?
1.	<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>Health and local government clearly have key roles to play in implementing the Autism Strategy and, if agreed, an Autism Act, but 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>
2.	<p><b><u>The act as introduced</u></b> does not change this section and the memorandum of understanding (Explanatory Memorandum) comments <i>“it is outside the competence of the Assembly to make legislation imposing additional duties on them”</i>. The outcome is that other than provision of autism training the only aspects that this Act could influence would be those that are delivered by devolved functions.</p>

#### Question 4

Consultation response no:	Should the duty on relevant bodies to have regard to the autism strategy and guidance be reinforced by providing Welsh Ministers with a power of direction over relevant bodies?
1.	<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>
2.	<p><b><u>The act as introduced</u></b> changes wording from “<i>duty to have regard to</i>” to “<i>compliance with</i>”. It is unclear if this indicates a broad power of direction over local authorities and health boards, with respect to compliance with this Bill, if passed. It also unclear whether this has potential to conflict with existing legislation that would lead to confusion.</p>

Question 5

Consultation response no:	Do you have any views about the timing set out in section 1(4) of the draft Bill for the publication of the Autism Strategy?
1.	<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 Additional Learning Needs and Education Tribunal (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 that 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>
2.	<p><b>The act as introduced</b> is unchanged in wording it is unclear from the memorandum of understanding how this could be achieved in such a short time scale particularly considering the level of consultation with stakeholders that would be required.</p>

### Question 6

<p>Consultation response no:</p>	<p>Do you have any views about the timing set out in section 3(2) for issuing guidance under the Bill?</p>
<p>1.</p> <p>2.</p>	<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 that 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> <p><b><u>The act as introduced</u></b> is unchanged the memorandum of understanding envisages that guidance would be developed in parallel with the strategy. Work could therefore begin on the guidance as soon as the Act is passed, which would allow up to nine months for the process. This implies that the guidance can be written before the strategy has been written and consulted on which is poor practice.</p>

### Question 7

<p>Consultation response no:</p>	<p>Do you have any views about the timing set out in section 9 for when the Act comes into force?</p>
<p>1.</p>	<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</p>

2.	<p>would have no purpose and will be challenging to govern without a code or standard as a basis to work undertaken. 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. 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. As the timeline implies that the guidance cannot be finally written until the strategy that informs the guidance has been created, these seem overly optimistic and unrealistic time frames.</p> <p><b>The act as introduced</b> is unchanged, there are no notes in the memorandum and all concerns previously highlighted remain.</p>
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#### Question 8

Consultation response no:	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?
1.	<p>The NICE guidelines state that a diagnostic assessment for children should be started within the first 3 months. <a href="https://www.nice.org.uk/guidance/cg128/chapter/Recommendations#local-pathway-for-recognition-referral-and-diagnostic-assessment-of-possible-autism">https://www.nice.org.uk/guidance/cg128/chapter/Recommendations#local-pathway-for-recognition-referral-and-diagnostic-assessment-of-possible-autism</a></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.</p>

2.	<p>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 that 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. This has been the subject of recent debate in parliament. <a href="http://www.normanlamb.org.uk/maximum_waiting_times_for_autism_diagnosis_needed">http://www.normanlamb.org.uk/maximum_waiting_times_for_autism_diagnosis_needed</a></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> <p><b>The act as introduced</b> changes the wording from “completed” to “commenced”. While this is positive and notes in the memorandum acknowledge that the potential complexity of the diagnostic process could make completion within three months challenging, it is doubtful if families and individuals would find this completely satisfactory.</p> <p>Commenced is the start of the diagnostic process and that can be simple steps such as a first telephone call or an initial screening questionnaire.</p> <p>Adding this target is not helpful to families and individuals and will not have the effect of resolving the issue of waiting times.</p> <p>It would be more helpful to define what “commenced” means for the purposes of this Bill as that will give consistency across families and service areas of expected waiting times.</p>
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## Question 9

Consultation response no:	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)?
1.	<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 SS&amp;WB 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 SS&amp;WB Act. The proposed Autism Act suggests a 2-month completion timeframe, whereas the timescale for completion of the assessment within the SS&amp;WB Act 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 that 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&amp;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 could 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 SS&amp;WB Act.</p>
2.	<p><b>The act as introduced</b> changes the time scale from 2 months to 42 working days. The memorandum clarifies that this change provides alignment with social services assessments for children.</p> <p>The memorandum provides some further clarification stating that some people with ASD would not have particular care and support needs, and that there should not be a presumption that a person with ASD would automatically have care and support needs.</p>

	<p>Although the memorandum clarifies that the Bill does not make this assumption it still assumes that an assessment of a person's care and support needs should take place, which may conclude that a person does not have any such needs.</p> <p>This still has resource implications because of current capacity and demand which implementing these additional assessments, albeit with no support needs will require.</p> <p>Under the SS&amp;WB Act, an individual should be assessed at presentation of need for care and support. This Act as introduced has the potential to deny an individual access to assessment until a diagnosis has been made, thereby denying them access to care and service based on need. With this in mind, this piece of legislation will undermine the principles within the SS&amp;WB Act.</p>
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#### Question 10

<p>Consultation response no:</p>	<p>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?</p>
<p>1.</p>	<p>No – The NICE guidelines outline the key individuals that can support a diagnostic assessment.</p>
<p>2.</p>	<p><b>The act as introduced</b> does not change this list the memorandum notes that the list is advisory; there is no intention to set out a prescriptive list of professionals in the Bill, as introduced. Obvious gaps as noted in the memorandum are paediatrician and educational professionals. This section remains unnecessary, as the NICE guidelines should be the standard adhered to for both children and adults.</p>

Question 11

Consultation response no:	If so, are there any other disciplines that you think should be listed as possible members of such a multi-disciplinary team?
1 and 2.	As above (Q10)

Question 12

Consultation response no:	Are there any other factors or individual circumstances which may inappropriately prevent access to services and which should be set out in the Bill?
1.	<p>No - Specific services have eligibility criteria's to enable delivery to vulnerable groups (LD, MH services, Phys Dis etc)            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.            SS&amp;WB Act provides care and support based on need not diagnoses.            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 that 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.</p>
2.	<p><b>The act as introduced</b> does not change the wording. The memorandum does note that a lack of staff training in and awareness of, ASD was also said by some respondents to result in barriers to accessing suitable services.            This is more relevant and addressable than attempting to fit a person with an ASD diagnosis into an inappropriate team simply because that team happens to exist.            Please also refer to response in question 9 regarding access to care and support based on need and not diagnosis.</p>

Question 13

<p>Consultation response no:</p>	<p>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?</p>
<p>1.</p>	<p>Any personal data collected must comply with Data protection legislation (GDPR)          In order to be consistent the population needs assessment, as identified in the SS&amp;WB Act, should determine what data is collected.          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>2.</p>	<p><b>The act as introduced</b> has extensive additions in this area saying NHS bodies must collect the following data to assist them in the diagnosis and provision of services to persons with autism spectrum disorder          The data requested is only diagnostic in nature and will not inform or assist in the provision of services. It is not consistent with the population needs assessment as identified in the SS&amp;WB Act.          The data listed indicates that this Bill is extensively clinical in nature and concentrates on the single event of diagnosis to the detriment of the wider needs of families and individuals.</p>

Question 14

Consultation response no:	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 <sup>1</sup> , communicative development, whether testing for phenylketonuria (PKU) was carried out.
1.	<p>Data gathered should be limited to that necessary in order to satisfy the requirements of data protection and requirements 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 that 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>
2.	<p><b>The act as introduced</b> has extensive additions to data which is generally of the for 'interest' category. While it may be interesting for the purposes of research to gather extensive data around ASD diagnosis, it is not appropriate to include that in a statutory instrument.</p>

### Question 15

Consultation response no:	Should the types of data be specified on the face of the Bill or in guidance?
1.	If at all, in the guidance
2.	<b>The act as introduced</b> with extensive additions to data should be transferred to the guidance where it can form part of reporting on diagnosis. Having data in guidance, not the Bill allows for additions, deletions and adjustments much more easily than the face of the Bill.

### Question 16

Consultation response no:	Do you agree that: <ul style="list-style-type: none"><li>- the provision in section 5(2) to allow Welsh Ministers to request anonymised data from relevant bodies is appropriate, and</li><li>- it should be included on the face of the Bill?</li></ul>
1.	If at all, this should be included in the guidance.
2.	<b><u>The act as introduced</u></b> with extensive additions to data should be transferred to the guidance. Ministers can then decide based on circumstance and evidence accumulated what data to request much more easily than the face of the Bill.

### Question 17

<p>Consultation response no:</p>	<p>Should a campaign to raise understanding and awareness of the needs of persons with autism spectrum disorder be rolled out on a continuous basis, or on a regular (three-year) cycle?</p>
<p>1 and 2.          2.</p>	<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. The responses based on the Memorandum Of Understanding suggest a continuous campaign. This is not required within an Act but would be better situated within guidance if at all. Each Local Authority area has an ASD lead role who would lead on information and awareness raising, amongst other planned activities.</p>

### Question 18

<p>Consultation response no:</p>	<p>Giving reasons for your answer, could any of the proposals in the draft Bill be reformulated so as to increase its positive effects or reduce its possible adverse effects, in relation to:</p> <ul style="list-style-type: none"> <li>a. the Assembly's official languages (Welsh and English);</li> <li>b. equality, diversity and inclusion;</li> <li>c. the justice system in England and Wales; or</li> <li>d. costs and benefits to you or your organisation</li> </ul>
<p>1 and 2</p>	<ul style="list-style-type: none"> <li>a. 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. Bilingual 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.</li> </ul>

1 and 2	<p>b. Reduce negative effects by aligning closely with the SS &amp;WB 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 SS&amp;WB 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>
1 and 2	<p>c. 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 set out which are above and beyond current duties.</p>
1 and 2	<p>d. 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 set out which are above and beyond current duties.</p>