

Cynulliad Cenedlaethol Cymru  
 Bil Awtistiaeth (Cymru) drafft  
 Llythyr Ymgynghori DAB39  
 Ymateb gan Gwasanaeth Awtistiaeth  
 Integredig (GAI)

National Assembly for Wales  
 Draft Autism (Wales) Bill  
 Consultation Letter DAB39  
 Evidence from Integrated Autism  
 Service (IAS)

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

Question	Answer
01	Yes. It is essential that the scope of any legislation is carefully considered. It is critical that broader neurodevelopmental and focused ASD is integrated.
02	<p>WHO ICD-11 / DSM definition should be used given it is a health diagnosis.</p> <p>The long term approach should be considered to include all neurodevelopmental (ND) conditions. ND conditions are highly diverse ranging from Developmental Attachment disorders to Autism Spectrum. The Integrated Autism Service (IAS) will likely be overwhelmed by extending their service and in addition, the skills required for the range of conditions is vast. The IAS is still in its infancy and this would not be feasible in the short to medium term. Children's ND diagnostic assessment processes have already been amalgamated. Much planning is required for the adult sector and should not commence until the IAS is fully operational across Wales. Whilst the recognition that there are other neurological conditions is welcomed the Bill is autism exclusive as the title suggests.</p>
03	Yes. The NHS and LA are the relevant bodies to lead on the implementation of such strategy offering an integrated approach as that of the IAS. This should include statutory and non statutory multi agency partners.
04	The ASD Strategic Action Plan (SAP) and IAS WG Guidance is currently the focus for relevant bodies and they should have a duty to deliver the strategy.
05	<p>The ASD SAP was originally published 2008 and refreshed late 2016. To supplement this strategy, the IAS Guidance was produced to offer parity across Wales. We assume the ASD SAP will be the basis of any strategy given the extensive local and national consultation undertaken to inform its development.</p> <p>The timelines for introducing should be realistic.</p>
06	As above.
07	Timescales should be realistic to allow relevant bodies to prepare accordingly.
08	Timescales should be realistic. NICE states, "evidence of local arrangement to ensure that people with possible autism referred for a diagnostic assessment by an autism team have the assessment

	<p>started within 3 months of their referral". There are no current waiting time targets set for adult autism diagnostic services and they would require sufficient time to prepare for such a target. Demand, capacity, backlog and activity will need to be reviewed given the impact this will have on services.</p> <p>We risk the IAS becoming a diagnostic assessment service only if we are not given adequate time and resources to address this area AND offer the post diagnostic support required.</p> <p>The waiting time target should be measured from the point at which the referral is accepted to the first assessment appointment and NOT the date it was received. Diagnostic services are reliant upon screening tool, supporting information/reports and consent prior to acceptance.</p> <p>Current capacity would need to be increased to avoid breaching waiting time targets or it will become unrealistic in current circumstances.</p>
09	<p>Not all clients receiving a diagnosis will require an assessment of need. Assessment might require their own timescales similar to that of diagnostic assessments so client can access the right service at the right time post diagnostically.</p> <p>If an assessment of need is required, 2 months would seem reasonable. However, it does not specify what service/s are responsible for completing this assessment. Continuity of care is essential. The IAS is in development and this timescale would therefore be challenging. A timescale to introduce this standard would be helpful.</p>
10	<p>Yes – NICE CG128 or 142 should be referenced. An explicit list of multi agency, multi disciplinary professionals should be provided. Clarity on what professions can administer autism diagnostic assessment tools essential, and on who holds clinical responsibility for giving a diagnosis.</p>
11	<ul style="list-style-type: none"> <li>- Consultant Paediatrician</li> <li>- Educational Psychology</li> <li>- Specialist Teachers</li> <li>- Learning Disability Specialist Nurse</li> <li>- CAMHS and adult MH clinicians</li> </ul> <p>NB Teachers do not have the relevant clinical training to be involved in the assessment of adults.</p> <p>Q - Why would a behavioural specialist be required in a mainstream non Learning Disability service?</p>
12	<p>The current model of the IAS across Wales is that they do not offer a direct service to those clients with a "moderate to severe learning disability or known moderate to severe mental health (MH) difficulty". How will the proposal impact on this?</p> <p>Similarly, some social care team work on this basis and some autistic</p>

	<p>client denied access on the grounds of IQ.</p> <p>It would be helpful to support the idea of services offering joint consultation/working in partnership where there are co occurring issues such as MH and ASD. Also, recognition of issues rural areas face is crucial</p>
13	YES
14	<p>It is important to have prevalence estimates and data collection to gain an understanding of the proportion of people in the population that may have autism. This will also support service planning and development both locally and nationally.</p> <p>It is important in light of the new General Data Protection Regulation (GDPR) that will apply from 25<sup>th</sup> May 2018. We must be clear on the information to be collected and how it will be used. As present IAS services across Wales are reviewing what data items to inform service planning and development. The data required by a practitioner, clinician and service planners can be different so this should be factored in accordingly in terms of a data set. This should not only take account of diagnostic information but include support activity and be outcome focused (as per the IAS reporting template).</p>
15	Yes to ensure parity across Wales. The IAS Community of Practice has been established and are reviewing / developing a data set.
16	Yes – to support a national approach and to inform service delivery for Wales. The information can be used to monitor, evaluate and improve provision nationally.
17	The IAS across Powys in collaboration with the LA lead on the continual awareness raising of autism since the publication of the ASD SAP in 2008. This happens in varying forms from training to tiered services to the ASD friend communities initiative. Therefore, a national position on this on a regular basis may complement this.
18	<p>We would always aspire to have an inclusive society where everyone can participate and be valued for who they are. It will be cost financially to implement change and will take time and resources to introduce. From public sector perspective it will cost organisations more than they are resourced for but that does not mean it should not be considered or progressed.</p> <p>A Bill is not necessary, progress of the ASD SAP and IAS implementation is being made, and moment is building in terms of these developments. How will the Bill enrich the programme of work already in place. Would better communication to professionals and the public on the work already been and being undertaken be sufficient.</p>
19	On balance, awaiting the learning from the ASD SAP inclusive of the IAS and to fully evaluate this before legislation is put forward.