Cynulliad Cenedlaethol Cymru Bil Awtistiaeth (Cymru) drafft Llythyr Ymgynghori DAB34b Ymateb gan Bwrdd Iechyd Prifysgol Aneurin Bevan (BIPAB) National Assembly for Wales Draft Autism (Wales) Bill Consultation Letter DAB34b Evidence from Aneurin Bevan University Health Board (ABUHB)

Please refer to questions in the **Consultation Letter**.

Question	Answer
01	We agree that the definition of autism should reflect the classification systems agreed internationally, that is the DSM 5 and the ICD 10 currently, soon to be replaced by ICD 11 that will be closely aligned with DSM5. It would be helpful if this definition was prominently displayed.
02	No. The use of Neurodevelopmental disorder is an umbrella term to include any condition such as ASD,ADHD,DCD and many others. It would not be helpful to link it with Autism strategy as it may mislead people requesting an assessment. There Is a need to consider an ND service for adults to develop a synergy with T4CYP ND pathway. Current funding does not take into account any other condition other than ASD. However based on clinical practice, there is often another co-occuring ND condition with ASD which are not catered to under current funding stream. In particular the wider definition is impossible to support and cannot possibly be agile enough to reflect the growing understanding of neurodisabilities as we progress. Do they really mean that, as sub groups, new classifications emerge then the bill would have to be amended. Currently there are lots of "diagnosis" groups unrecognised by ICD or DSM classification systems that are extremely vocal. Who will make the judgment on which categories are in or out?. We have some experience of "prescribed" categories in the mental health measure (in this case professions who could care plan and those who couldn't) that has caused significant problems with those that are "In" and those that are "out" resulting in the need for us to review the bill and are now moving to a competency based approach rather than specific job titles. I would suggest that this reinforces the need for any protection to be on the basis of need not diagnosis. Improved protection and rights for children with disabilities, physical, emotional and learning would be far more future proof and ensure those most in need get the most help, not those with the most coordinated action group
03	We agree with the list of relevant bodies. All public, voluntary and
04	private agencies would benefit from a guidance, as in a Code of Practice (in preparation) to set out the provision of service for those on the autism spectrum. At the end of the evaluation period, if there are still glaring gaps in service provision, then statutory guidance may be needed. Current legislation such as the Social Services & Well Being

	Act should be sufficient, however, accesses to services for people with ASD continue to be patchy and remain inaccessible in some areas. The Integrated Autism Service is only able to provide limited support and cannot meet the long term needs of individuals who's autism presents as a significant barrier to them achieving outcomes.
05	We have nothing to comment on the timings.
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08	IF we use NICE guidelines as a measure of good practice, then people should have an assessment started no later than 3 months after
	referral is accepted. If the NICE guideline timescales are to be followed, it must be acknowledged that more resources will be needed. IAS is not currently able to meet these timescales due to increase in number of referrals and a small clinical team in comparison. Current IAS teams are not NICE compliant as they lack the full complement of professionals as core members. To give an example there is no provision of Psychiatric input to support complex presentations and co-morbid conditions and the situation is unique to Wales. There are 3 Health Boards currently funding professionals with mental health expertise(ABUHB, C&Vale and Hywelldda). There needs to be consistency of team composition across Wales. A nurse practitioner should be a core member of the team and access to a suitably qualified dietician is also desirable for those adults with restrictive eating patterns. Again introducing a timescale of 2 months for completion of an assessment of care and support is unrealistic. IAS is not structured nor resourced to provide this. This would make service delivery impossible. Neither do IAS teams have the right skill mix to be undertaking such care and support assessments in complex cases where someone's ASD is a significant barrier to them achieving outcomes. IAS do not have resources to meet needs once they have been identified and there are not yet established pathways back into local authorities to provide this. Many individuals with ASD without a co-morbid condition, do not require a comprehensive assessment of need. Utilising an outcomes measures tool such as the Outcomes Star – Spectrum should be a robust enough and coproduced model to identify and plan to meet any support needs. Any more complex needs should be referred to local authorities or secondary services to assess and plan for.
10	Yes we do. Currently neither ND Services nor IAS team structures
11	include social work provision. This will be necessary if more comprehensive assessments of care and support are to be completed at the point of diagnosis. It is also difficult for social work practitioners

	to gain access or be accepted onto diagnostic training i.e. the DISCO.
12	It is our view that anyone referred for an assessment should be included in the single care pathway (currently used inABUHB) and receive a timely service. When it was initially rolled out IAS teams were not allowed to assess those referrals from secondary mental health services even though these needed their autism identified from their co-morbid mental health presentation and they were also denied entry into support services from IAS. In ABUHB, we have modified the pathway to be more inclusive and person centred for those complex individuals. We also support the professionals working in other services to make any necessary adjustments to their interventions. For those with additional Intellectual disability, holistic assessments are often provided by the local Teams in Learning disability services. We do see some for second opinions either regarding diagnosis or management.
13	Data Collection is crucial to inform future service planning. Whilst
14	there has been limited progress with SYML system, we hope the WICCIS would address the need to have robust, consistent and uniform data collection with similar synergies with Children's services to facilitate a seamless transition. Through the existing ND services and IAS we are already capturing a good range of data. What the IAS collect will also be subject to ongoing review as the services develop. It does not necessarily need to be specified in the draft Bill as it is likely existing services will collect over and above this naturally. We are already collecting data identified in the question but we believe that it would be useful to collect data on adaptive functioning of people referred as they often present with a variable profile of abilities. We do not have the resources to complete a physical examination and tests, we would make our recommendations to the General Practitioner.
15	We have no issues with provision of anonymised data similar to other
16	health conditions in accordance to Data protection rules.
17	WLGA and the National team have done a lot of awareness raising initiatives and valuable resources through the ASDinfoWlaes.co.uk website. There are plans to roll out ASD training to MH staff and Social care professionals but this needs to be extended to other health services such as dental services and ambulance services. The training framework developed on the Scottish Model is a good template for ongoing training initiatives. Training and continued professional development will be facilitated through the newly formed IAS practice network, a platform to share good practice and service innovations across Wales. We also feel that in order to ensure an ASD competent workforce,

	further consideration to be given around an ASD inclusive curriculum in all professional courses within higher education.
18	AS far as the impact of the strategy on various sections of the society, there is a glaring omission of the large BME population in South East Wales and the migrant population. It would be good to see this addressed at least in the Code of practice.
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