

Cynulliad Cenedlaethol Cymru Bil Awtistiaeth (Cymru) drafft Llythyr Ymgynghori DAB38 Ymateb gan Rhwydwaith Therapyddion Galwedigaethol Pediatrig Cymru Gyfan	National Assembly for Wales Draft Autism (Wales) Bill Consultation Letter DAB38 Evidence from All Wales Network for Paediatric Occupational Therapist
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I am responding on behalf of the All Wales Network for Paediatric Occupational Therapist to the Draft Autism (Wales) Bill. The network welcomes discussion which raises awareness of the needs of people with autism; however the draft Bill presents some potential dilemmas to the management of the needs of all individuals with a diagnosis affecting their participation as a full citizen within Wales. Provision of statute relating to one diagnostic group introduces inequity when considering the needs of all people with conditions resulting in disability eg those with cerebral palsy, Down's syndrome, genetic condition. This would appear to be contrary to the Equalities Act which emphasises the need to advance equality for all people with protected characteristics and to foster good relationships between groups with differing or no protected characteristics. It is unclear why the rights of individuals with Autism cannot be successfully managed under the Equality Act, precluding the need for this diagnostically focused legislation?

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

Question	Answer
01	Given the change of emphasis within the draft Bill to include individuals with neuro-developmental disorder, it would be confusing to only include autism spectrum disorder on the face of the Bill
02	We agree that reference is made to diagnostic criteria which are internationally recognised and concurrent with NICE guidelines. Whilst it is recognised that the discretionary inclusion of other neuro-developmental conditions is a direct response by the Minister to concerns raised within the initial consultation, the lack of defined boundaries to this definition will challenge the efficacy of the Bill. Diagnosed conditions which fall within neuro-developmental disorders are broad reaching and include, but are not limited to, Attention Deficit Hyperactivity Disorder, Tourette's, Developmental Coordination Disorder, Dyspraxia, Dyslexia. Furthermore, the characteristics of these disorders are experienced by individuals with other development conditions such as global developmental delay and specific speech and language disorder. The characteristics can be significantly impairing without the individual meeting the threshold for a neuro-developmental diagnosis. This emphasis on diagnosis creates a medical lens through which individuals will request assessment to meet the criteria within this Bill, rather than focusing service assessment on the removal of barrier to enable full citizen participation and wellbeing.

	<p>Whilst introduction of a Bill which focuses on a single condition is unhelpful as it potentially discriminates against other citizens without autism, expansion of the definition has the potential of making the Bill meaningless. Moreover, the protection and promotion of rights under this Bill appear dependent on the diagnostic label which could lead to challenging discussions about what conditions are 'in' or 'out' of a neuro-developmental framework.</p>
03	<p>No - whilst healthcare services and the local authority have key roles to play in the implementation of the autism strategy, other partner agencies such as third sector, employment, higher education all have a role in ensuring protection and promotion of rights for individuals with autism</p>
04	<p>Reporting to Welsh Government currently exists relating to the delivery of the Integrated Autism Service (IAS) and the ASD Strategic Action Plan (ASD-SAP). All bodies providing support to people with autism or social communication disorders should have a duty to have regard to the autism strategy and guidance; these also being embedded in the Equalities Act.</p> <p>Welsh Ministers should, in the first instance, endorse scrutiny of the current reporting via the IAS and ASD-SAP, working with local providers to ensure these measures reflect outcomes for people with autism and those undergoing diagnosis. Ministers should support local resolution of any divergence from the strategy and a power to direct should be completed as a last resort. It is important where Ministers become involved, that they consider all the actions and evidence of the relevant bodies, taking into account local complexities, before directing delivery. Training would be required to evaluate and make these often complex decisions.</p>
05	<p>From experience with ALN Tribunal Wales Act - a strategy and guidance is needed alongside the Bill, at least in first draft to give some of the context and detail to the Bill. Without this local delivery cannot be determined or impact assessment carried out accurately.</p> <p>There appear to be a number of existing strategies/guidance influencing delivery of service to people experiencing characteristics of autism and neuro-developmental disorders. The draft Bill does not make any links to these. If the expectation is for a completely new ASD Strategy to be provided with the Bill then 6 months is likely to be an unrealistic timescale. If, however, the proposal is to develop a 'scorecard' to measure the current efficacy of reporting tools against the content of the strategy in Sec 2, delivering the Strategy alongside the Bill would be more realistic</p>
06	<p>Again, this is dependent on whether Welsh Government is aiming to build on current practice, or develop new guidance. Given that Welsh Government is due to issue guidance on the implementation of the Social Services and Wellbeing Act for individuals with autism, it would</p>

	seem appropriate for guidance under an autism Bill to reflect this
07	Any gap in issuing the Bill and Strategy is likely to lead to uncertainty and risk legal challenge to service delivery under Bill, due to the absence of clear definition relating to care, support, diagnosis, IQ, appropriateness of the range of services
08	There are no current timescales for completion of diagnosis; the 26 week waiting time target for children needs to be acknowledged as a waiting time from referral to first appointment not to diagnosis. There are no current timescale noted for adults in the NICE guideline for assessment or diagnosis. Waiting time to diagnosis places an emphasis on diagnosis and not the needs of the individual or family. Multi-disciplinary team's ability to support these needs is affected by the imperative towards diagnosis. Any mandated waiting time therefore needs to account for the whole of the pathway; from initial identification to provision of proportionate care and support. Implementation of such performance indicators will aid understanding of process efficiencies and capacity demand, but should be balanced with a quality of life, outcome measurement for service users.
09	No - The process of diagnosis is critically linked to the consideration of the impact of any condition on an individual's life <sup>1</sup> . As such, diagnosis and determination of support needs should happen concurrently and be based around the individual's needs. Crucially, whether an individual is given an Autism diagnosis or not, there is a need for post-diagnostic support which acts to coproductively empower individual, offering signposting, assistance and advice. Management of assessment for care and support is currently causing great challenge due to the demand for diagnosis. More detail is required to fully consider any performance indicator associated with care and support. Additionally, the timescale for assessment of care and support within the draft Bill does not comply with that laid out in the Social Services and Wellbeing (SSWB) Act; the latter being 42 days from referral. It would seem sensible for the timescale to concur in both pieces of legislation.
10	Yes a guidance list is useful, however this is duplicitous as NICE guidelines already list professionals required to support diagnosis
11	Consultant Paediatrician isn't represented within the Autism Bill although is indicated in the NICE guideline
12	The underpinning ethos within the Bill is to ensure equitable access to diagnosis and support for all individuals with or undergoing diagnosis of autism. Services functions within eligibility criteria both to ensure a specialist delivery by trained staff and to protect resources

<sup>1</sup> World Health Organisation - International Classification of Functioning available at: <http://www.who.int/classifications/icf/en/>

	<p>for individuals with recognised characteristics. Whilst the Bill indicates the removal of IQ or other medical condition as barriers to accessing services, it does not indicate how existing services would be resourced or trained to extend their provision to meet the needs of the whole population of individuals with autism. This appears to vary from the guidance set out for the delivery of IAS.</p> <p>A diagnosis of autism cannot be seen as a gateway to services, these should be based on the individual needs and prioritisation of statutory resources to meet that need.</p>
13	<p>Yes - this would be helpful to ensure consistent data capture. It is unclear how this would coincide with the requirements under the SSWB Act to assess the needs of the population and clarity would be required from Welsh Government as to data coding and systems to collect data.</p>
14	<p>Core data sets outlined in SSWB Act and ALN Act should be adopted. It is imperative that outcome data also relates to user experience or quality of life measurement.</p> <p>It would be important for Ministers to review the current data being collected relating to SSWB Act, IAS and neuro-developmental service and look to amalgamate a dataset prior to progressing an autism Bill. The Minister should also give due consideration to appropriate data definition and data coding when issuing guidance relating to these metrics</p>
15	<p>In the guidance and potentially as a self assessment tool in the first instance.</p>
16	<p>Yes - the Minister would need to clearly define this data to ensure consistent reporting across Wales</p>
17	<p>Local services and bodies should be rolling this out on a continuous basis. This should be complemented with a tiered training approach including universal awareness for all, specialist training to services offering support to individuals with autism but not impacting their autism eg colleges, hospitals, and thereafter highly specialist training to individuals empowering individuals with autism who have complex needs.</p>
18	<ol style="list-style-type: none"> <li>a. Given the range of the impact of autism it is important that a range of materials exists for service users. All documentation should be clear and concise. Consideration should be given to the use of terminology relating to care and support within the Bill to ensure consistency with SSWB Act</li> <li>b. Direct reference is required to the relationship of this Bill with the Equality Act and SSWB Act. It is understood that Welsh Government continue to build on strategic guidance issued for other vulnerable groups, such as those with learning disability. Welsh Government guidance is also anticipated to inform</li> </ol>

	<p>delivery of services to children and young people with complex needs. The Minister may consider that development of the autism strategy and implementation guidance, comparative to Learning Disabilities guidance would provide better equity across all users groups, avoiding the potential inequity created by this Bill</p> <p>c. No comment</p> <p>d. Occupational Therapists who work with children and young people focus on the removal of barriers which are created by a diagnosis or social circumstances and which impact citizen participation. Introduction of legislation focused around a single diagnosis, creates the potential need for different eligibility criteria based on diagnosis, contrary to the philosophy of occupational therapy</p> <p>Where possible the Bill needs to align to existing legislation, namely SSWB Act and Equalities Act. Lack of clear definitions within the autism Bill will lead to duplication and ineffective resource delivery</p>
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