

Cynulliad Cenedlaethol Cymru
Bil Awtistiaeth (Cymru) drafft
Llythyr Ymgynghori DAB40
Ymateb gan Cymdeithas Llywodraeth
Leol Cymru (CLILC)

National Assembly for Wales
Draft Autism (Wales) Bill
Consultation Letter DAB40
Evidence from Welsh Local Government
Association (WLGA)

About Us

The Welsh Local Government Association (WLGA) represents the 22 local authorities in Wales, and the three national park authorities and the three fire and rescue authorities are associate members.

The WLGA is a politically led cross-party organisation, with the leaders from all local authorities determining policy through the Executive Board and the wider WLGA Council. The WLGA also appoints senior members as Spokespersons and Deputy Spokespersons to provide a national lead on policy matters on behalf of local government.

The WLGA works closely with and is often advised by professional advisors and professional associations from local government, however, the WLGA is the representative body for local government and provides the collective, political voice of local government in Wales.

Introduction

The WLGA has hosted the National Autism Spectrum Disorders (ASD) Development Team for a number of years who have provided a range of useful resources and advice in supporting public services in better responding to the needs of autistic people. The team are an integral part of the Welsh Government's refreshed Autistic Spectrum Disorder Strategic Action Plan. The National ASD Development Team are currently supporting and coordinating the development and implementation of an Integrated Autism Service for Wales.

It is important to acknowledge the progress that has been made since the original ASD action plan in 2008 and one of the key achievements has been the increased profile and awareness of autism. There is a wide range of information and resources available to help autistic people and their families and carers, as well as resources for professionals. However, we are aware that more can always be done and that some of the improvements and actions will take time to deliver. We all want to see a real difference in the services, care and support available to autistic people and so it is appropriate that we take the time to consider the proposals set out in the draft Autism (Wales) Bill and whether legislative changes will bring the desired outcomes.

Response

The WLGA previously responded to the consultation on the general concept of a proposed Autism (Wales) Bill in which we highlighted our reservations about the approach of legislating for a particular condition. We believe that legislation such

as the Social Services and Well-being (Wales) Act 2014 and the Additional Learning Needs and Education Tribunal (Wales) Act should, if they are working correctly, deliver for all our citizens on the basis of need. Serious consideration needs to be given to the implications of setting such a precedent going forward, as services for autistic people is not the only area where there is a need for service improvement for people with specific conditions. It is essential that we fully identify and consider any unintended consequences of legislating on a particular condition, and that we explore any risk that such legislation may impact on our ability to respond to others on the basis of need.

Although we have significant reservations about the approach of legislating, below are our responses to the specific questions asked in relation to the draft bill.

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

Question	Answer
01	We agree with the use of the definition of 'autism spectrum disorder' in the forthcoming World Health Organization International Classification of Diseases, however believe that if a Bill is to be put forward then any definition would be better included in statutory guidance / regulations rather than being on the face of the Bill so it can be updated and amended if necessary without recourse to a lengthy legal process of changing the Bill / Act.
02	Whilst we agree with the WHO definition being proposed we need to give serious consideration to the impact of neurodevelopmental disorders being included in the Bill. Whilst it would be a 'power' to include other neurodevelopmental disorders (i.e. neurodevelopmental disorders other than autism spectrum disorder) this is potentially considerable and the implications of defining the scope of neurodevelopmental disorders requires careful review and consideration before being included in the definition, or indeed in the Bill. At this point we do not support the inclusion of other neurodevelopmental disorders in the Bill.
03	We would suggest that it would make sense that the relevant bodies be the same as those impacted under the Well-being of Future Generations (Wales) Act, the Social Services and Well-Being (Wales) Act and the Equality Act, with a need to explicitly reference education settings and providers.
04	Welsh Ministers already have a number of existing powers of direction, for example, under the Social Services and Wellbeing (Wales) Act. We do not believe that are any deficiencies with current powers that would require further power of direction being necessary and suggest that the creation of a further power of direction would be too prescriptive and unnecessary.
05	It is important to recognise that there is already an existing Refreshed

06	<p>Autistic Spectrum Disorder Action Plan along with a delivery plan and so further clarification is needed on the status of these as any strategy or guidance is developed.</p> <p>The work to develop guidance needs to be progressed collectively and so appropriate time needs to be given to allow for this approach, we would question whether the three-month period set out in the Bill would be sufficient and suggest more time needs to be allowed for.</p>
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08	<p>Whilst it is not ideal to not have any timescales, in reality, a blanket 26 weeks' target does not reflect the complexity of many referrals. In addition, best practice dictates that diagnosis and assessment should be on a multi-agency basis and therefore, the imposition of timescales might negate or work against such an approach. Work is currently being undertaken by clinicians, practitioners, Welsh Government and the National ASD team to look at diagnosis and assessment timescales as part of the ongoing work around the development of the IAS. It is envisaged that draft guidance will be issued for consultation in the 2018/19 period. While time is a factor in conducting assessments, the quality of the assessment must take priority.</p> <p>Whilst it is essential that everyone receives the appropriate post diagnostic support it should not be just through a care and support plan. There are a range of assessment and planning tools available. On that basis, whichever tool is the most appropriate should be used to assess and plan with an individual or family. The Social Services and Well-being (Wales) Act reinforces the belief that people should not have to access statutory services to have their needs met and the emphasis upon a Care and Support Plan contradicts this. Therefore a broader approach to meeting support needs should be undertaken based on what is important to the autistic individual, their carers and family.</p>
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10	<p>NICE guidance, which sets out good practice, already dictates that diagnosis should be undertaken and delivered on a multi-agency basis, so whilst it may be helpful to re-emphasise this, this would sit best within guidance rather than being on the face of the Bill.</p> <p>It is important that an educational element is also included in any list, especially for under 18's - e.g. Educational Psychologist, Specialist ASD Teacher etc.</p>
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12	<p>Autistic people often fail to access appropriate support as it is only offered on a group basis, for example primary mental health interventions, where an autistic person may prefer one on one support and might not cope with, or may be put off by group based therapies. Consideration needs to be given as to how services can be more flexible in meeting diverse needs, though this may be better considered for guidance rather than needing to be set out in the Bill.</p> <p>The Equality Act already provides protections against discrimination</p>

	<p>and prevention of access to services so it is important not to restate powers that already exist under existing legislation.</p> <p>It is also important to recognise that services need to adhere to the Welsh Language measure requirements.</p>
13	<p>We do not believe that the Bill should specify the types of data to be collected, as this would be too prescriptive and restrictive to be able to change. This is an area that requires further consideration and discussion and would be better placed in guidance rather than on the face of the Bill. Systems are already under development, with appropriate data sets being captured and so it will be important to build on this existing work. It is vital that whatever data is collected and collated must be useful and for a purpose, with an emphasis on outcomes for people. Whilst the data listed is interesting there is also a need to consider other types of data such as: impact of the disability upon the individual; the specific needs of the individual; any suggested interventions; and the outcomes.</p>
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16	<p>We agree that Welsh Minister's should be able to request anonymised data from relevant bodies, though further clarity and guidance is needed as to how this will work in practice and the data that would be requested.</p> <p>This should be in guidance rather than on the face of the Bill.</p>
17	<p>It is important to raise understanding and awareness of autistic people and this needs to be done on a continual basis rather than on a regular cycle. This is work that the National ASD team have already, and continue to undertake as well as other organisations such as the National Autistic Society. A wealth of resources has been developed by the National ASD team which are available on the ASDinfoWales website (http://www.asdinfo.wales.co.uk/home/), the national site for Autism Spectrum Disorders (ASD). Specific campaigns, for example: the autism awareness scheme 'Can you see me?' (http://www.asdinfo.wales.co.uk/can-you-see-me) has already been developed which aims to promote understanding and acceptance, amongst communities in Wales in order to improve access to facilities and reduce the stigma that many autistic individuals and their parents and carers experience; the 'Working with Autism' Scheme (http://www.asdinfo.wales.co.uk/employment) which aims to increase knowledge and awareness of the needs of individuals with autism amongst those who are supporting them to secure employment; and the 'Learning with Autism' programmes that covers settings from Early Years to Secondary schools.</p> <p>We need to recognise the amount of work that has already been undertaken and build on this, helping to ensure that there is consistency across Wales, with key partners working with the National ASD Team together to ensure there is a coordinated response.</p>

18	We have already highlighted our reservations to the creation of a separate piece of legislation for a particular condition and that we believe that legislation such as the Social Services and Well-being (Wales) Act 2014, the Additional Learning Needs and Education Tribunal (Wales) Act and Equality Act should, if they are working correctly, deliver for all our citizens on the basis of need. Given the existing legislative foundations and powers that are already in place in Wales and the fact that we have highlighted that many of the aspects of the Bill being proposed would better sit within guidance / codes of practice rather than in primary legislation we remain unconvinced of the need to create this separate piece of legislation and would rather build on and use the powers and mechanisms that are already in place to strengthen the services, care and support available to autistic people.
19	<p>In our evidence in response to the development of the Social Services and Well-being (Wales) Act we consistently highlighted the resource implications for implementing this piece of legislation and the same is true of this Autism Bill. Many authorities are having to juggle a number of unfunded pressures with unprecedented reductions in funding. We believe that there should be full and early engagement with all stakeholders in the formulation of legislation and that the financial impacts should not be assessed in isolation but part of the whole programme. It is vital that any new duties and burdens created are identified and fully funded. Any legislation that is enacted also needs to be assessed after it has been implemented independently of government.</p> <p>The current ICF guidance identifies that the Integrated Autism Service will be supported throughout the duration of the Integrated Care Fund programme, however the underpinning of the Integrated Autism Service across Wales will require further investment beyond 2021 and so there would need to be a long term commitment to meet specific requirements on any Bill / Act.</p> <p>References to the criminal justice system also need to acknowledge the major resource and logistical requirements associated with addressing the needs of those in the secure estate across Wales and the challenges associated with engaging, reaching and meeting the needs of autistic people. The criminal justice and secure estates issues are so large that a great deal of extra work and research needs to be undertaken before this can be addressed.</p>