

Cynulliad Cenedlaethol Cymru
Bil Awtistiaeth (Cymru) drafft
Llythyr Ymgynghori DAB26a
Ymateb gan Cymdeithas Genedlaethol
Awtistiaeth Cymru

National Assembly for Wales
Draft Autism (Wales) Bill
Consultation Letter DAB26a
Evidence from National Autistic Society
(NAS) Cymru

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

1. About National Autistic Society Cymru

The National Autistic Society Cymru (NAS Cymru) is the leading charity for people on the autism spectrum, including Asperger syndrome, and their families. Since we began more than 50 years ago, we have been pioneering new ways to support people and understand autism. We continue to learn every day from the autistic people we support. Based on our experience, and with support from our members, donors and volunteers, we provide life-changing information and advice to millions of autistic people, their families and friends. We support professionals, politicians and the public to understand autism better so that more autistic people of all ages can be understood, supported and appreciated.

NAS Cymru works across Wales alongside our 14 volunteer-led branches and members. We also provide support and specialist services for adults across Wales in a number of settings including residential care, supported living, community-based resource centres, at university and in people's own homes. Autism prevalence is estimated to be just one per cent of the UK population¹. This means that around 34,000 people in Wales are autistic. Many of this 34,000 will be undiagnosed. Together with their families and carers, they make up more than 130,000 people for whom autism is a part of their daily lives.

2. Introduction

We welcome the opportunity to respond to the consultation on the draft Autism (Wales) Bill and continue to support the need for primary legislation to improve the provision of support and services for autistic people in Wales.

We believe that legislation would show clear leadership in Wales about the importance of providing the right help for autistic people across the country. It would also put down a marker to help secure a real and long-term shift in the way we think about autism and provide assurances to autistic people and their families that their needs will continue to be considered and supported into the future. Specifically, autism legislation could put the integrated autism service on a firmer footing. For example if drafted correctly the outcomes and duties described in the legislation would have to be met beyond the current funding commitment of the integrated service to the end of this Assembly term in 2021, even if ultimately these outcomes are delivered in a different way.

¹ The NHS Information Centre, Community and Mental Health Team, Brugha, T. et al (2012). [Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey](#). Leeds: NHS Information Centre for Health and Social Care

We welcome the fact that the proposed Bill is ambitious in its scope and remit so that the wider needs of autistic people, such as their education, employment and housing needs can be met, and that they can live as independently as possible. Our key objective is to make sure that as the Bill progresses the actions set out in the subsequent Act or in the regulations or statutory guidance, published as a result of the Act, are legally binding.

Our consultation response reflects the views of our members and supporters, many of whom attended consultation events held during 2017 and 2018. We have concentrated our comments on the specific matters raised in the consultation letter and have suggested further clarity in some areas.

3. Statutory guidance and legal duties

As currently drafted, the Autism Bill contains the need to draft a strategy and to issue guidance. We have some concerns that publishing these documents alone may not be sufficient to make sure that clear duties are placed on public bodies to ensure that outcomes for autistic people are improved.

We would therefore seek assurances that that the guidance under Section 3 of the Bill is statutory. For example, in England the way that their Act is drafted means if local authorities or the NHS do not follow the statutory guidance they may be liable to judicial review or action by the Secretary of State. Our charity has experience of this being used effectively to secure services and support. For example, in Bolton, a man who was turned down for a referral for a diagnostic assessment legally challenged NHS Bolton and he was subsequently diagnosed. Moreover, as a result of the case, NHS Bolton put in place a new pathway to diagnosis for adults².

NAS Cymru has been in discussions with Welsh Government around issuing a Code of Practice on autism under sections 145, 146, 147 and 169 of the Social Services and Wellbeing Act and under sections 1 and 2 of the National Health Service Wales Act. This proposed Members Bill should consider whether incorporating issuing codes under the Social Services and Wellbeing Act and the National Health Service Wales Act into the Autism Bill for Wales would help ensure that the guidance for local authorities and the NHS would be statutory.

We would then also need to identify how to ensure that duties on other public bodies would be legally binding.

One way of doing this would be by putting duties in the Bill on the Welsh Government to issue regulations in certain areas. We believe that regulations should be issued both to ensure that certain duties around health and care are as robust as possible, but also to ensure that there are clear duties on other public services as well. Based on consultation with autistic people and their family

² <https://www.irwinmitchell.com/client-stories/2013/july/irwin-mitchells-public-law-team-secure-autism-assessment-for-client>

members around the issues that are most difficult for them, we believe there is potential for regulations to be developed in the following areas:

- waiting times for diagnosis
- assessment of the care and support needs
- training for professionals, including those carrying out assessments
- collecting the right data to help plan services and monitor performance

Recommendations:

- Consider whether the Bill should include requirements for Codes of Practice to be issued under the Social Services and Wellbeing Act and under the National Health Service Wales Act to ensure that guidance/codes of practice issued as a result of the Bill would be legally binding on health and social care
- Consider the additional mechanisms needed to ensure that as a result of this Bill being passed there would be clear legal duties on wider public services to ensure that autistic children and adults and their families can get the help they need
- Consider using the Bill to put obligations on Welsh Government to issue regulations in key areas, such as diagnosis waiting times, assessments, training and data collection

4. Definition

We welcome the inclusion of an agreed definition of autism that is linked to the World Health Organisation definition of autism. As knowledge and understanding of autism evolves, it is appropriate to ensure that the definition of autism is able to be developed too and that any change to the WHO definition will be reflected in legislation. As such, we would caution against including any further definition or description of autism on the face of the Bill.

During our own consultation exercises, concerns were raised among our members and supporters that associated neurodevelopmental conditions may be excluded by the provisions within the Bill. We therefore welcome the provisions under Section 7 of the Bill that allows Welsh Ministers to ensure that those with associated neurodevelopmental conditions who may benefit from the rights and entitlements prescribed in the Bill are not excluded.

We would also expect that Welsh Ministers consults appropriately with the National Assembly for Wales before making changes in this area.

Recommendations:

- Defining autism should be part of the strategy and not the primary legislation so that it can be updated in line with developing thinking

- Welsh Minister to prescribe in statutory guidance or in a statutory code (whichever is deemed most appropriate) that those with associated neurodevelopmental conditions are not excluded from the rights and entitlements in this Bill

5. Timescales

We would support the timings set out in the draft bill in terms of implementing the strategy, statutory guidance and the Bill itself, set out in Sections 1 (4); 3 (2); and 9.

Our experience tells us that getting a timely diagnosis of autism and an assessment of need is key to understanding why autistic people experience difficulties. It makes it easier to make sense of the world around them and can often allow people to access services and support. Unfortunately our evidence shows that almost a third (32 per cent) of people waited more than two years for a diagnosis³.

We believe that the National Institute for Health and Clinical Excellence (NICE)⁴ is best placed to set the evidenced-based quality standards for health and social care. The NICE guidelines on the recognition, referral and diagnosis of autism state that the diagnosis assessment should be done ‘within three months of a referral.’ We would therefore support that timeframe.

On the wider point of the timescales around the assessment of care and support needs, we often hear from parents that when they are finally given a diagnosis, there’s little or no support afterwards, meaning families are left in the lurch.

We would agree that an assessment of care and support needs should be completed as soon as is reasonably practicable but we’d also welcome a clear timeline being put in place, so that autistic people know what to expect after a diagnosis and how long the wait for an assessment will be in each area. To this end, we would suggest two months to be appropriate.

As set out above, we believe that given the stress and challenges faced by autistic people and family members in waiting for a diagnostic assessment, as a result of this Bill there should be duties on the NHS around waiting times and on the wider public services around post diagnostic follow up and assessment for additional support. Putting duties on public bodies around timeframes for assessments has precedent in Wales. For example, the Education (Special Educational Needs) (Wales) Regulations 2002⁵ set out timeframes for assessments of children who may need a statement of special educational needs. In the future, the Code of Practice to be issued under the Additional Learning Needs and Education Tribunal Act will set out timeframes for assessment for an Individual Development Plan.

³ <http://www.autism.org.uk/get-involved/campaign/wales/actnow.aspx>

⁴ <https://www.nice.org.uk/>

⁵ The Education (Special Educational Needs) (Wales) Regulations 2002

Recommendation:

- Clear duties should be placed on public services around diagnosis and assessment waiting times so that autistic people and their families receive timely support, in line with NICE guidelines. We would welcome further discussion about whether this could best be achieved through regulation, statutory guidance or a statutory code.

6. Multi-disciplinary team

We recognise that getting a diagnosis is complex because autism affects each person differently and this is why it should require the input from a broad range of professionals. While we do not believe that an exhaustive list is necessary on the face of the Bill, examples of those multi-disciplinary teams might be helpful to be included in statutory guidance or a statutory code in order to support professionals and to ensure the best outcomes for autistic people.

Recommendation:

- Statutory guidance or a statutory code to include a list of suggested professionals who could be involved in making a diagnosis of autism

7. Equity of Access to Services

We are fully supportive of Section 2 (1) (f) which seeks to ensure that autistic people are not denied access to services based on a person's IQ. However, we are not sure that asking that this is made clear in a strategy is the most legally binding way of ensuring that this is made clear to public services. There should instead be a standalone duty on the face of the Bill that makes this clear. The merits of this should be considered further to ensure that this issue is addressed.

Furthermore, we want to ensure that support is also available for people who don't meet the eligibility criteria for a care and support plan under the Social Services and Well-being Act. This would include access to low-key preventative support that could avoid the need for more acute, high-cost services later on in their lives, for example, the type of support currently provided by the integrated autism service.

We know that autistic people may often have a co-morbid condition that requires bespoke, person-centred support that meets their individual needs. Autistic people with a learning disability or a mental health condition for example should have an equitable right to access the services they need and be supported by professionals who understand autism and how this may influence other health and care needs.

Recommendations:

- A duty is placed on the face of the Bill to ensure that autistic people are not denied access to services based on their person's IQ

- Local authorities must make it clear, whether through further guidance a code or legislation that there should be a plan in place in each area for the provision of preventative, low level support that autistic children and adults who do not meet the eligibility criteria for a care and support plan can access to help prevent needs from escalating.

8. Data

A key challenge for public services when trying to plan and commission services that autistic children and adults might need is that there is a lack of data on numbers of autistic people and their needs. We believe that data collection is vital to help the NHS, local authorities and other public services in the planning and provision of support and services. As a result of this Bill, this is an issue that we believe should be urgently addressed.

We know however that some autistic people also have concerns around the collection of data about them. In order to address the need to collect this data in an anonymous way, we believe that this Bill should put a duty on Welsh Ministers to issue regulations on data collection.

Recommendations:

- Duties should be placed on public services on data collection in the areas outlined below to help local services plan appropriately and monitor performance. We would welcome a further discussion on whether this would be most appropriately achieved through regulations or through statutory guidance or a statutory code.
 - i. collecting information on autism prevalence and the profile of local autistic people's needs
 - ii. the numbers of people being referred for autism diagnosis and assessment waiting times
 - iii. the numbers of autistic people with care and support plans with and without a learning disability as part of the population needs assessment under the Social Services and Wellbeing Act
 - iv. the numbers of autistic adults, young people and children receiving pre-and post-diagnostic counselling
 - v. the numbers of children and adults accessing the integrated autism service, including waiting times for support, types of support and those waiting to access the service
 - vi. the type of accommodation autistic people are living in (and, where funded by the local authority out of area, location)
 - vii. details of how this data will be used developed in consultation with autistic people and their families

9. Campaign

We support the need for an awareness campaign, to help increase public understanding of autism. The National Autistic Society has clear experience in running awareness campaigns. Notably, our *Too Much Information* campaign is a three year campaign aiming to transform public understanding of autism and make our communities more open and welcoming to autistic people and their families. Early campaign evaluations indicate that public understanding of specific challenges autistic people face has seen a significant shift amongst the general public. After the first year of the campaign, understanding that autistic people can face difficulties in public places increased by 17 per cent.

We believe that working with Welsh Government we could build on the work we have developed already on understanding to help transform autism awareness across Wales and would welcome the opportunity to work with Government and other partners to do this.

A campaign on a three year cycle, in line with the proposed independent review of the strategy, would allow Welsh Ministers to raise awareness of the key issues relating to the aims of the autism strategy.

Recommendations:

- NAS Cymru to work with Welsh Government and other partners on an awareness campaign
- Welsh Ministers to review the autism strategy once every three years concentrating on the key issues relating to the strategy

Other comments

We welcome the inclusion in the draft Bill under Section 2 (1) (q) that requires the statutory guidance to identify key professionals who should receive training. As set out above, we do need to ensure that this guidance is statutory and so that training developed as a result of the Bill is mandatory. When looking at professionals across health and social care sectors, especially priority groups like GPs and community care assessors, we would like to know whether if training these groups were covered under Codes issued under the Social Services and Wellbeing Act and NHS legislation, this would mean that the training was mandatory.

Outside of health and social care, teacher training in autism is another clear area of priority. There are more than an estimated 6,000 children and young people of school age on the autism spectrum in Wales. Every teacher can expect to teach children and young people on the autism spectrum during their career and school staff who come into contact with autistic pupils should have an understanding of the condition. There should be legal duties to ensure that trainee teachers and teachers who have already qualified but who have not received autism training access training in autism.

In terms of delivery of training of teachers, in England, there is a model of continued professional development that exists for teachers. The Autism Education Trust [AET] is supported by the Department for Education and provides three levels of training for teachers at school, with the basic training provided free of charge. A similar model could work in Wales.

Recommendations:

- Duties should be placed on public services stipulating mandatory training for key professionals
- Duties should be placed on public services setting out which professionals require what level of training
- We would welcome a further discussion on the best way to ensure that the duties around training were as legally binding as possible

Conclusion

We are very pleased to see the publication of this draft Autism Bill, a decade on from the publication of the Welsh Government's first autism strategy. We must be sure that the Bill is as strong and binding as possible, in order to ensure the best results for autistic people in Wales.

Summary of recommendations:

- Consider whether the Bill should include requirements for Codes of Practice to be issued under the Social Services and Wellbeing Act and under the National Health Service Wales Act to ensure that guidance/codes of practice issued as a result of the Bill would be legally binding on health and social care
- Consider the additional mechanisms needed to ensure that as a result of this Bill being passed there would be clear legal duties on wider public services to ensure that autistic children and adults and their families can get the help they need
- Use the Bill to put obligations on Welsh Government to issue regulations in key areas, such as diagnosis waiting times, assessments, training and data collection
- Defining autism should be part of the strategy and not the primary legislation so that it can be updated in line with developing thinking
- Welsh Minister to prescribe in statutory guidance that those with associated neurodevelopmental conditions are not excluded from the rights and entitlements in this Bill
- Clear duties should be placed on public services around diagnosis and assessment waiting times so that autistic people and their families receive timely support, in line with NICE guidelines

- Statutory guidance includes a list of suggested professionals who could be involved in making a diagnosis of autism
- A duty is placed on the face of the Bill to ensure that autistic people are not denied access to services based on their person's IQ
- Statutory guidance makes it clear that autistic people who do not meet the eligibility criteria for a care and support plan can access support
- Regulations should include data collection in the following areas:
 - i. collecting information on autism prevalence and the profile of local autistic people's needs
 - ii. diagnosis and assessment waiting times
 - iii. the numbers of autistic people with care and support plans with and without a learning disability as part of the population needs assessment under the Social Services and Wellbeing Act
 - iv. the numbers of autistic adults, young people and children receiving pre-and post-diagnostic counselling
 - v. the numbers of children and adults accessing the integrated service, including waiting times for support, types of support and those waiting to access the service
 - vi. the type of accommodation autistic people are living in (and, where funded by the local authority out of area, location)
 - vii. details of how this data will be used
- NAS Cymru to work with Welsh Government and other partners on an awareness campaign
- Welsh Ministers to review the autism strategy once every three years concentrating on the key issues relating to the strategy
- Statutory guidance should stipulate mandatory training for key professionals
- Statutory guidance should set out which professionals require what level of training