

Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill
Ymateb gan Gymdeithas Genedlaethol Awtistiaeth Cymru
Response from The National Autistic Society Cymru



**Response to the Autism (Wales) Bill consultation by the National Autistic Society Cymru
September 2018**

Introduction

We welcome the publication of the Autism (Wales) Bill and fully support the need for specific autism legislation in Wales.

Wales has had an Autism Action Plan for ten years now and yet autistic people and their families are still being let down and not having their needs met. Autistic people in Wales continue to experience poor outcomes and it's not right that this continues. For example:

- In a report we published in 2011, some 58 per cent of respondents said they'd waited too long for a diagnosis. In a similar report published in 2016 the figure had risen to 63 per cent.
- In 2011, some 53 per cent of respondents said that getting a diagnosis was stressful. In 2016 that figure was 56 per cent.
- In 2011, some 24 per cent of respondents said that they were satisfied that the information given to them afterwards helped them get the support they needed. In 2016 that figure was 21 per cent.

It's time to ensure that key changes that will make a tangible difference in the lives of autistic people are made mandatory so that public services don't view them as 'nice to haves'. This would include training for professionals, ensuring that data is collected, and support is available wherever people live in Wales.

We believe that if passed, this Bill will show real leadership by the National Assembly for Wales and the Welsh Government. It could send a clear message to autistic people as well as public bodies in Wales that autism is a policy priority in Wales. This legislation is about giving autistic people a level playing field and getting the basic things right.

We were pleased to have contributed to the previous two consultations – both on the development of the content of the Bill and the subsequent draft Bill. This included holding a number of focus groups across the country with our members and supporters, many of whom are autistic adults themselves. The vast majority of those who took part in focus groups and who engaged in the consultation process supported autism legislation. In a report that we published in 2016, nearly 90 per cent of those who responded to our survey said that autism legislation is needed.

Meeting the needs of autistic people

We are pleased that the Bill covers both children and adults as autism is a lifelong disability. In our view the Bill is further strengthened by specifically mentioning the need to provide help during the transition between childhood into adulthood which should help ease the move between children's services and adult services.

The original Action Plan recognised the need for early diagnosis and further actions to improve waiting times through neurodevelopmental teams where announced in 2015. The refreshed action plan that was published in November 2016 introduced a new 26 week waiting time from referral to first assessment for children and young people.

However, we know that this isn't being met across Wales. According to the Hywel Dda Health Board the waiting time from referral to first assessment for the neurodevelopmental team in May 2018 was 18 months. Anecdotally, parents in Pembrokeshire in particular have told us that the actual waiting time is much longer. Furthermore one of the recommendations of the Children, Young People and Education Committee's 'Mind Over Matter' report published earlier this year was that 'the Welsh Government develop an immediate recovery plan for neurodevelopmental services in Betsi Cadwaladr to address unacceptably long waiting times faced by over a thousand children and young people.' Relevant data for the neurodevelopmental teams in the five other Health Boards is not currently available and so we do not know if the needs of autistic children and young people are being met. This is despite a commitment in the refreshed Action Plan that Health Boards should report a 26 week waiting time from referral to assessment by March 2017.

We know that getting a diagnosis can be the key that unlocks support and services for autistic people and welcome the proposal to link to the relevant Quality Standard issued by the National Institute for Health and Care Excellence (NICE). We welcome the inclusion in the Bill of the need to ensure that support is in place regardless of whether a person has a diagnosis, and that support should include wider family.

We therefore welcome the certainty in the proposed legislation gives around the diagnosis process in its entirety.

We welcome the fact that the Bill seeks to address the wider needs of autistic people including support around meeting employment and housing needs. More than half (55 per cent) of autistic people who responded to our 2016 survey said that they'd like more support around employment and only one in ten were in full time paid employment.

Recent development in services to address the needs of autistic children and adults are welcome, particularly the creation of Integrated Autism Services in each Health Board region. These teams are best placed to deliver many of the provisions contained in the Bill and therefore the legislation supports the role of these new services and is designed, we feel, to help ensure they can become embedded in local health and care services. We feel that this would be better than the Integrated Autism Service having to be reliant on short-term funding up until 2021.

Similarly, while some good work has been done in the development of awareness resources and training, uptake in accessing these has in our view been too slow and is inconsistent across the country. For example, not all local authorities are taking up the 'Learning with Autism' programme for schools. And since the scheme was extended in September 2017, only three secondary schools have achieved the 'Learning with Autism Award.'

We believe that legislation should clearly set out which professionals need what levels of training to ensure that autistic people are supported by professionals who understand them.

Current initiatives recognise the importance of collecting the necessary data to plan future support and services. For example there is a requirement on Regional Partnership Boards to include autism and learning disabilities as a key theme in regional plans. However, this is difficult as very little data on autism is collected in practice and existing plans focus heavily on learning disabilities. Making the data collection mandatory through legislation will make sure that services understand that this is not just a nice to have and give strength to the hand of Regional Partnership Boards and other public services to ask for the data.

In our view, one opportunity in this legislation in ensuring that autistic people's needs are met is by offering an opportunity to embed the necessary training for relevant professionals while obtaining their initial professional qualification and through subsequent continuous professional development. The aim here is not to make things more onerous or difficult for professionals but to provide them with support and clarity, for example, through access to the right training for the right professionals. Professionals we talk to say they want this training and autistic children and adults should at the very minimum expect to be supported by professionals who understand them.

Protecting and promoting the rights of autistic people

As stated on the face of the Bill, this legislation makes provision for meeting the needs of children and adults with autism spectrum disorder in Wales and protecting and promoting their rights. This is consistent with the social model of disability. We believe that this will ensure that societal barriers faced by autistic people are removed. Training and the awareness campaigns are examples of this and we welcome the inclusion of both of these elements in the Bill. Similarly, the Bill makes provision in relation to social issues such as housing and employment. We welcome the ambition in the Bill to look at an autistic person in a holistic way throughout their lifetime as well as the needs of their families and careers.

We note the specific reference in the Bill to have regard to the UN Principles and Conventions. This would bring this piece of legislation in line with the duties on co-existing legislation including most recently the Social Services and Wellbeing Act, and the Additional Learning Needs Act.

We welcome the ambition in the legislation to enable autistic people to live as independently as possible through ensuring that relevant bodies ensure the rights of autistic people to access the provisions listed in section 2 (1) (g). While the list is not limited we particularly welcome the inclusion of social inclusion.

We know from our own research that one of the main barriers facing autistic people in particular is social isolation. For example, nearly four of every five autistic people (79 per cent) who responded to one our surveys said that they felt socially isolated.

We also note the specific mention in the Bill that autistic people should be able to access Welsh Language Services. This combined with the Welsh Government's Active Offer framework strengthens the rights of autistic people to access services in the language they choose.

Autism is a spectrum condition. All autistic people share certain difficulties, but being autistic will affect them in different ways. This Bill will ensure that where autistic people don't fit into current existing structures, local services will be under a duty to make sure there is a pathway for them to get the support they are entitled to, helping create a level playing field for autistic children and adults. Furthermore we welcome the explicit duty in the Bill that adults with autism cannot be

denied access to services because of their IQ. This will make it clear to services that the needs of autistic people across the spectrum need to be identified and met.

We recognise that the Bill links to the WHO definition of autism and NICE guidelines and Quality Standards. This means that if and when our understanding of autism improves and develops, any changes made to the WHO definition or NICE guidelines will be reflected in the interpretation of the Bill, and its subsequent guidance and we welcome its inclusion.

We are also pleased that the Bill requires an independent report on the autism strategy, including its ongoing implementation and progress. Furthermore we particularly welcome the requirement to reflect on recommendations made by the independent review. Although the Welsh Government's Action Plan has been evaluated, recommendations have not always been taken on board or implemented in the development of support. This means that many of the issues autistic people face now are exactly the same as they were when the original action plan was first developed in 2008 and which this Bill seeks to address. Examples include getting a timely diagnosis, collecting data for planning services, raising awareness, and training for practitioners.

Barriers and unintended consequences

The Bill is clear that a diagnosis shouldn't prevent support from being made available either for the autistic person themselves or their families and carers, from the point at which their needs first become apparent. Support should be available regardless of a diagnosis.

As currently written, the Bill says that the waiting time from which a referral for diagnostic assessment of autism is made and an initial diagnostic appointment should be no longer than 13 weeks. This is in line with NICE guidelines and has been developed by experts, including clinicians and commissioners, as well as autistic people, and their families.

Welsh Government already base many of their guidelines for autism provision on NICE standards, such as the use of multi-disciplinary teams. This suggests that they are already content with the NICE evidence base. This Bill seeks to ensure full compliance with the NICE recommended timeframe.

This isn't about taking up resources to focus only on diagnosis at the risk of not being able to provide other pre and post diagnostic support. The Bill is clear that a diagnosis shouldn't prevent support from being made available either for the autistic person themselves or their families and carers, from the point at which their needs first become apparent. Support should be available regardless of a diagnosis.

The Welsh Government has had an autism Action Plan in place for the past ten years. There is no evidence to suggest that these provisions have privileged autism above other conditions or are responsible for demands for other condition-specific policy.

Autism legislation already exists in Northern Ireland and in England. There have been specific challenges in implementing the Northern Ireland Act and the suspension of the Assembly and wider political issues have also had an impact on the legislation. In addition, the Act hasn't made as much impact as we would have liked because it didn't result in legally binding duties for local delivery bodies in the same way as the England Act.

Where the England Act has made significant impact has been around making sure that there is a pathway to diagnosis in every area. In 2016, a survey of local authorities found that only three local

authorities reported not having an adult diagnostic pathway. This simply wasn't the case before the Act and one of the reasons we argued for it.

Before the Act, our autism services directory could only identify 14 NHS teams/individuals who diagnosed adults in the whole of England. There is also clearer 'infrastructure' at local level in terms of local leadership and local planning, including an autism lead in more than 90 per cent of local authorities.

It is also important to remember that we are not suggesting taking the England Act and the Northern Ireland Act and implementing them in Wales. From the Northern Ireland Act, we learn that we need clear duties on local public services to deliver. In terms of the England Act we want to make sure that the Wales Act is all ages.

Notably, despite the England and NI Act being in force since 2009 and 2011 respectively, there hasn't been a recognised link between this and campaigns for other condition-specific legislation.

As mentioned above we welcome the proposal in the legislation to address the barriers facing autistic adults in accessing services because of their IQ.

Financial implications

The Explanatory Memorandum is clear in where costs would occur. A net initial cost of around £7million is estimated. However, this needs to be measured against the cost effectiveness of current provision, resource and policy. It is also anticipated that there will be longer term savings due to the effective identification and support of individuals with autism.

The Explanatory Memorandum also states that 'There is little information in the public domain to estimate the current provision and future plans with regard to both the administrative costs of providing services to people with ASD... The Welsh Government was unable to provide specific information regarding the cost of the status quo.' It's therefore difficult to estimate the current costs of provision in its entirety due to a lack of reliable data, which is something the Bill seeks to address.

While we recognise that there will be some cost involved in introducing and implementing legislation, we believe that introducing autism legislation will not result in significant burdens. This must also be balanced against the cost of not intervening and the economic impact of having to access acute services.

Economic modelling in England by the National Audit Office showed that identifying and supporting a relatively small number of autistic adults would bring about significant cost savings to the public purse. In their model, they suggested that if just a 14 per cent of the autistic adult population were identified and supported, the savings that could be made would be £5,000 per 1,000 working age population. In Wales, this could mean that a 14 per cent identification and support rate would save £10 million a year to the public purse in Wales. These figures from the NAO are from 2009 and need refreshing and updating for a Welsh context, but do indicate that significant savings can be made from the proper identification and support for autistic adults.

Subordinate legislation

We are content with the affirmative procedures to make subordinate legislation in the three areas listed in Part 2 of the Explanatory Memorandum.

Conclusion

As mentioned above, 10 years of the autism Action Plan hasn't achieved the necessary changes to the lives of autistic people in Wales. We believe that changes that will make a tangible difference are mandatory. Legislation is supported by our members and supporters and the overwhelming majority of the hundreds of responses to both the consultation on both the development and the draft autism bill. The Bill has therefore been shaped by autistic people who will be directly affected by it. We believe that legislation will give autism support parity with other existing support provided to those with learning disabilities and mental health, whilst ensuring better outcomes for autistic children and adults.

In drafting our comments we have done so based on the experience of learning from what works and what hasn't worked so well in other countries that have implemented autism-specific legislation. It's also important to note that this is a Wales bill and should be fit for purpose for the benefits of autistic people in Wales.