



## Introduction

The Royal College of Psychiatrists in Wales (RCPsych in Wales) welcomes the opportunity to provide further written evidence to the National Assembly of Wales' Health, Social Care & Sport Committee.

Autism Spectrum Disorder (ASD) is a complex, co-morbid disorder, that presents differently in different individuals and demographic groups.

ASD and other Neurological Disorders (ND) that will be impacted by the proposed legislation sit across a range of specialisms that accordingly sit across specialist faculties of the College.

RCPsych in Wales have consulted opinion from its own faculties throughout the development of the proposed legislation.

- The Faculty of Child & Adolescent Psychiatry
- The Faculty of Intellectual Disability Psychiatry.

Whilst fully supportive of the need to improve outcomes for people with ASD, RCPsych in Wales members have expressed concerns over whether legislation would be the most appropriate vehicle to achieve the ambitions set out in the purpose of the bill. We would ask the committee to consider the following:

- That services should be based on need and be person-centred and child-centred;
- The potential for increased rates of inaccurate or inappropriate diagnosis;
- The need to consider the impact on and evaluation of existing programmes of work in Wales relating to Neurodevelopmental Disorders (ND) and ASD;
- The potential implications of introducing condition-specific legislation; and that
- There is currently insufficient evidence to show that autism-specific legislation would enhance the services already being delivered across NHS Wales and local government and will lead to improvements in the support being provided to people with ASD.

## Background

In addition to presenting our own view, we have also worked with royal colleges across the sector in considering the proposed legislation. Accordingly, we have co-produced a briefing that outlines our shared position in relation to the proposed legislation alongside:

- Welsh NHS Confederation,
- Royal College of Speech and Language Therapists,
- Royal College of General Practitioners,
- Royal College of Paediatrics and Child Health, and the
- Royal College of Occupational Therapists.

### **General principles of the Autism (Wales) Bill and the extent to which it will make provision for meeting the needs of children and adults with Autism Spectrum Disorder (ASD) in Wales and achieve the aim of protecting and promoting their rights;**

We feel it important that the committee consider experience from other parts of the UK with regard the introduction of ASD legislation.

Evidence from the Autism Acts in England (2009) and Northern Ireland (2011) suggest that legislation is not leading to improved outcomes for people with ASD. Whilst in Scotland, the Autism (Scotland) Bill fell at the first stage of parliamentary scrutiny (2011).

We would ask the committee to consider the detailed joint briefing produced with the NHS confederation and royal colleges from across the sector that looks specifically at this issue. *Autism (Wales) Bill: A look at autism strategies and legislation in England, Northern Ireland and Scotland*

For ease, we have highlighted a few considerations from this briefing.

- The National Autistic Society report *Push for Action* (2013) focused on the implementation of the Autism Act (2009) in England, concluded that whilst the strategy has been successful in establishing the building blocks for better planning and commissioning of services, “*for the most part, adults with autism and their families are still waiting for the support they need*”.

- In consideration of the Autism Act (2009) in England, The National Autism Project further stated that *“nearly a decade on the needs of autistic people are still unmet and the expected economic dividend has never materialised”*.
- In Northern Ireland the most recent Department of Health, Social Services and Public Safety report on implementation of the Act found that it was *“not currently possible to guarantee early intervention as outlined in the Autism Strategy without additional funding to further develop autism-specific assessment services, and to extend the portfolio of available family support”*
- Parliamentary scrutiny of the proposed Autism Bill in Scotland, which was also introduced as a Members’ Bill in 2010, considered whether the proposed legislation would lead to improvements in services without significant additional funding for staff and resources. Scrutiny of the Bill also considered whether autism-specific legislation might create a two-tier system of strategies whereby strategies set out in legislation are seen to have *“more teeth”*. These were highlighted as key issues in the Committee’s recommendation that the general principles of the Bill should not be supported.

In Wales, there are currently a number of initiatives aimed to improve services for people with ASD in Wales. We would recommend that these initiatives be assessed as they are at an early stage of development.

- The Social Services and Well-being (Wales) Act 2014 places a duty on public bodies to assess and address the needs of individuals. Regional Partnership Boards established under the Act are responsible for ensuring that there are integrated care and support services to meet the need of people in their area. Autism has been identified as one of their priority areas for integration (Welsh Government, 2016 and Welsh Government, 2018). We understand that a code of practice on the delivery of Autism services will be published under the Social Services and Well-being Act in 2019.
- Under the Together for Children and Young People programme, launched in February 2015, there has been significant investment in neurodevelopmental services. Nationally agreed neurodevelopmental children and young people’s diagnostic pathways and standards are

now in place and have been adopted by all Health Boards. A new 26 week waiting time standard from referral to first assessment appointment has also been introduced (Welsh Government, 2018).

- The National Integrated Autism Service has recently been established with the aim of creating consistent support for people with ASD across Wales. An interim evaluation report with recommendations has been published and the full evaluation report is scheduled for January 2019 (Dr Duncan Holtom and Dr Sarah Lloyd Jones, 2018).
- The Additional Learning Needs and Education Tribunal (Wales) Act 2018 has recently been given Royal Assent and implementation will begin in 2020. It is hoped that the new system will bring tangible benefits to children and young people with ASD by supporting early identification of additional learning needs and effective interventions to support these needs throughout a child and young person's education.

### **Unintended consequences arising from the Bill**

As highlighted at introduction, Autism Spectrum Disorder (ASD) is a complex condition that presents differently in different individuals, which is in part why it is difficult to diagnose. No two persons' needs will be the same. Similarly, there are many children with neurodevelopmental differences (ASD like traits, learning disability, ADHD) who may not meet the criteria for a diagnosis, but the sum total of their difficulties is what creates the impairment and affects the quality of life.

We believe support and treatment should be tailored through the needs of the individual through a formulation that is based on a multi factorial understanding of each case, not through their diagnosis and not prescribed through legislation.

We believe Autism legislation will not necessarily drive good practice and could lead to a push for higher diagnosis rates rather than focus on meeting the needs of the individual. The need for diagnosis to push for resource will only artificially increase diagnosis rates for the wrong reasons.

We would agree with the Royal College of Speech and Language Therapists, that the development of the all-Wales neurodevelopmental pathway, which has focussed on need rather than solely diagnosis, has been helpful in supporting a move towards person and needs led assessments and interventions. This has been particularly beneficial for vulnerable people, for example, those with ADHD or those who do not meet the threshold for diagnosis to ensure they and their families also have access to equitable and appropriate services, despite not necessarily meeting the criteria for autism that would be required under the proposed Bill.

### **Potential barriers to the implementation of the provisions and whether the Bill takes account of them**

We are concerned that the financial pressures and significant challenges associated in recruitment and education to enable multi-disciplinary teams to deliver services as envisaged by the Bill would make it difficult to ensure effective implementation. The changes in waiting time targets as envisaged by the proposed legislation, would also have a significant impact on capacity against the current resource for multi-disciplinary teams.

We would also reaffirm the findings of the Parliamentary scrutiny of the proposed Autism Bill in Scotland, which was also introduced as a Members' Bill in 2010. The Committee felt that NHS organisations and Local Authorities would face significant costs relating to the restructuring processes that would need to be implemented across Scotland to allow for the necessary enforcement measures to take effect. The knock-on effect of such a proposal would have been to place greater demand on other services which were already working at or near capacity. In light of these concerns, the Autism (Scotland) Bill fell at the first stage of parliamentary scrutiny in January 2011.

Lastly, we are concerned that disability specific legislation could lead to people with other neurodevelopmental disorders and challenges receiving inequitable services. It could also lead to an increase in calls for the introduction of specific legislation for other illnesses and conditions to ensure they also given equal status and provision.

## References

[Welsh Government, June 2018. Autism Spectrum Disorder Strategic Action Plan](#)

[Welsh Government, March 2018. Evaluation of the Integrated Autism Service and Autistic Spectrum Disorder Strategic Action Plan. Interim Report.](#)

[Autism Act \(England\) 2009](#)

[Autism Act \(Northern Ireland\) 2011](#)

[The National Autistic Society, 2013. 'Push for Action campaign – Turning the Autism Act into action'](#)

[National Autism Project, January 2017. The Autism Dividend: Reaping the rewards of better investment.](#)

[Department for Health, Social Services and Public Safety of Northern Ireland, 2015. 'The Autism Strategy \(2013 – 2020\) Action Plan \(2013 – 2016\) Progress Report](#)

[The National Autistic Society, 2013. Push for Action campaign – Turning the Autism Act into action](#)

<http://www.senedd.assembly.wales/documents/s69972/AWB81%20Royal%20College%20of%20Speech%20and%20Language%20Therapists.pdf>

[NICE, Clinical guideline CG128. Published date: September 2011. Autism spectrum disorder in under 19s: recognition, referral and diagnosis](#)

[NICE, Clinical guideline CG142. Published date: June 2012. Autism spectrum disorder in adults: diagnosis and management.](#)