



**Proposed Autism (Wales) Bill (Member Proposed Bill)**  
**Briefing from the Royal College of Psychiatrists, Royal College of Speech and Language Therapists, Royal College of Paediatrics and Child Health (RCPCH), The Royal College of Occupational Therapists (RCOT), Royal College of General Practitioners and the Welsh NHS Confederation**

Following a ballot conducted by the Presiding Officer, the National Assembly for Wales agreed that Paul Davies AM could introduce proposals for a new law in Wales around the needs and rights of children and adults with Autism Spectrum Disorder (ASD) or Neurodevelopmental Disorders (ND).

In their responses to consultations undertaken by Paul Davies AM, organisations including medical Royal Colleges and the Welsh NHS Confederation, whilst fully supportive of the need to improve outcomes for people with ASD, raised a number of issues about whether the proposed legislation would be the most appropriate vehicle to achieve the desired outcomes. This briefing summarises these shared points for the consideration of all Assembly Members before Stage 1 Scrutiny. We also set out a very brief overview of how legislation similar to that proposed in Wales has been received elsewhere in the UK. The key areas we have highlighted are:

- 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 ND and ASD; and
- The potential implications of introducing condition-specific legislation.

**Services should be based on need be person-centred and child-centred**

Additional resource and focus on supporting people with ASD is to be welcomed but support should be on the basis of need rather than diagnosis.

Many people with ND including some with ASD-like traits, some learning disabilities and other diagnoses such as Attention Deficit Hyperactivity Disorder (ADHD) may not meet the criteria for a diagnosis of ASD (or any given definition in proposed legislation) even where their

symptoms or their needs significantly impact their quality of life. A needs-based approach means that resources and support is delivered according to need, not prioritised according to legislation or linked to receiving a diagnosis. This approach would be consistent with the ethos of existing legislation such as the Social Services and Well-being (Wales) Act 2014 and the Additional Learning Needs and Education Tribunal (Wales) Act (2018).

The Royal College of Speech and Language Therapists (RCSLT) have stated in consultation responses that *“the development of the all Wales neurodevelopmental pathway has been helpful in supporting broader thinking around diagnoses. There is currently a move away from tight diagnostic groupings to ensure that people who do not necessarily fulfil the criteria for autism but require intervention have their needs met”* (RCLT, 2017). RCSLT is concerned that this shift could potentially be undermined by legislation.

The RCPCH are similarly concerned that the proposed legislation is not child-centred, because children presenting with a range of issues or symptoms that may be similar to or overlap with ASD but where ASD is not an appropriate diagnosis, may then be excluded from a pathway to receiving the appropriate care and resources. It follows that in adult services, there is a potential risk that legislation may not be person-centred for the same reasons. The RCOT have raised this in relation to accessing Occupational Therapy services: people often present with complex needs and may not fit into neat diagnostic categories but accessing services and support should be based on need (RCOT, 2016).

### **Impact on diagnosis rates**

Clinicians are concerned that a possible unintended consequence or knock-on effect of linking resource to a particular diagnosis – whether autism, ASD or a given definition of ND disorders, is a risk that individuals or families will feel that their best opportunity to access the support they need is by securing that particular diagnosis.

The Royal College of Psychiatrists have stated that an Autism Act *“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 in order to push for resource will only artificially increase diagnosis rates for the wrong reasons”* (Royal College of Psychiatrists, 2017).

### **New and existing programmes to improve outcomes for people with ASD in Wales**

There are a range of new initiatives in Wales currently within the early stages of development, as outlined below. It may be prudent to assess the impact of the implementation of these new developments prior to the introduction of new legislation.

- 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.

### **Concerns about enacting condition-specific legislation**

The Welsh NHS Confederation has raised concerns that *“autism-specific legislation could lead to other interested parties, patient groups and third sector organisations to call for the introduction of specific legislation for other illnesses and conditions. This does not mean that proposals for an Autism Act are unwarranted, but it does mean that the evidence base for the introduction of such legislation must be extremely robust and convincing around improving patient outcomes.”* (Welsh NHS Confederation, 2017).

The Social Services and Wellbeing (Wales) Act 2014 already legislates for all individuals regardless of the extent of complexity of patient needs.

### **Experiences from other nations around the introduction of Autism legislation**

Evidence from the introduction of Autism Acts in England (2009) and Northern Ireland (2011) suggests that legislation is not leading to improved outcomes for people with ASD. The National Autistic Society Push for Action report on the implementation of the Autism Act in England in 2014 concluded that whilst the strategy has been successful in putting in place 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”* (National Autistic Society, 2014).

This is also supported by a recent detailed report by the National Autism Project (a UK wide initiative which aims to provide authoritative recommendations on autism research and practice) which stated that *“nearly a decade on (from the Autism Act) the needs of autistic people are still unmet”* (National Autism project, 2017).

Similarly in Northern Ireland, the most recent Department of Health, Social Services and Public Safety report on implementation 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”* (DHSSPS,2015).

Parliamentary scrutiny of the proposed Autism Bill in Scotland, introduced as a Members Bill in 2010, considered whether the proposed legislation would lead to improvements in services without significant extra funding for staff and resources and whether condition-specific legislation might create *“a two-tier system of strategies whereby strategies set out in legislation are seen to have “more teeth”*” (Education, Lifelong Learning and Culture Committee Report, 2010). These were highlighted as key issues in the scrutiny committee’s recommendation that the general principles of the bill should not be supported. The Autism (Scotland) Bill fell at its first stage of its parliamentary scrutiny in January 2011.

### **Further information**

This briefing was jointly produced by the following organisations, who would be glad to meet with AMs to provide further information. Please contact the following representatives to arrange further discussion.

- Royal College of General Practitioners - [REDACTED], Policy and Public Affairs Officer, [REDACTED]
- The Royal College of Occupational Therapists - [REDACTED], Policy Officer Wales, [REDACTED]
- The Royal College of Paediatrics and Child Health (RCPCH) – [REDACTED], External Affairs Manager, [REDACTED]
- The Royal College of Psychiatrists - [REDACTED], Policy Officer, [REDACTED]
- The Royal College of Speech and Language Therapists - [REDACTED], Policy Adviser, [REDACTED]
- The Welsh NHS Confederation - [REDACTED], Policy and Public Affairs Manager, [REDACTED]

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