



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 when considering the General Principles of the Autism (Wales) Bill. 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.

NHS professional’s views

For further details around the areas highlighted within this briefing please see the medical Royal Colleges evidence sessions to the Health, Social Care and Sport Committee on the [11th of October](#) and on the [25th of October](#).

Having condition specific legislation:

“I think the main concern is that by labelling services specifically for one condition there will be a number of people who require services who don’t fulfil the diagnostic category for autism who will then not get sufficient services, and we are looking at the fact that, under the Social Services and Well-being (Wales) Act 2014, patients should be assessed for their needs, and we want to ensure that these patients are assessed for their needs, rather than based on a diagnosis”.

Dr Jane Fenton-May, Royal College of General Practitioners in Wales

“Our primary concern... is for those individuals who don't meet the criteria for autism who still have significant needs... With the autism legislation, the resources will be put more into that, because they'll have targets to meet in order not to breach, and other areas of the service will be detrimentally affected. It may even be considered discriminatory.”

Julie Mullis, Royal College of Speech and Language

Clinicians having to prioritise on the basis of legal requirements rather than clinical need:

“So, children and families get referred because there’s a problem or a concern. That may or may not be autism...the risk is in part that you discriminate against those children because of the ASD specific.”

Dr Catherine Norton, Royal College of Paediatrics and Child Health, Consultant Community Paediatrician at Cardiff and Vale University Health Board (UHB)

The impact on the workforce:

"I'm going to do my clinic tomorrow. If I'm not doing that, I'm providing the sexual assault service for... for Powys, also for Gwent, also for Swansea, also for Cwm Taf, because you haven't got any other paediatricians with those skills. So, which do you want me to do? Which is more important today? The sexual assault of children and the investigation and assessment of that? Or is it autism? I'm doing autism every other week, but in the other week I'm doing actually all our special schools in Cardiff and I'm working with Amani around children with learning disability, our children with trisomy 21, with other genetic syndromes. So, actually, there are only so many ways you can cut individuals up, and does anybody have any knowledge about the evidence and the size of that workforce before we put through specific legislation that cuts into that workforce?"

Dr Catherine Norton, Royal College of Paediatrics and Child Health, Consultant Community Paediatrician at Cardiff and Vale UHB.

The risk that linking resource to diagnosis will inflate referral rates:

"With the development of the neurodevelopmental services, we have already seen that the referral rates for children and young people being referred for autism and ADHD has gone up. Linking a diagnosis with resources is probably going to make it a worse scenario, because families are going to think that the only way that they can access support, be it from education, or social services, or the third sector, or elsewhere, is going to be a diagnosis, which means that a workforce that is already stretched and trying to do their best is going to be overstretched and not be able to cope with the rate of referrals coming in."

Professor Alka Ahuja, Royal College of Psychiatrists, Aneurin Bevan UHB

"I think one of the concerns with speech and language therapists is that....they should be able to make a decision about how to use their time in the best interests of their patients and families. It may be that spending more time on interventions and training might be maybe more appropriate. We have to consider that prudent healthcare means that we should be meeting the needs of those who've got the greatest needs first, and somebody who's seeking a diagnosis but may not have a great amount of need, their needs, should they come before somebody who's got a great deal of need but hasn't quite got the diagnosis of autism?.... I think that this added pressure to have to do something in a particular way because there's legislation behind it is bound to have an effect."

Julie Mullis, Royal College of Speech and Language

Policy and legislation needing time to deliver results:

"Together for Children and Young People, the pathways, the standards, the Social Services and Well-being Act, the additional learning needs reforms. Give them a chance to settle and then see whether we need anything more to add on, rather than rushing and trying to introduce more legislation."

Professor Alka Ahuja, Royal College of Psychiatrists, Aneurin Bevan UHB

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