

	The Welsh NHS Confederation written response to the Health, Social Care and Sport Committee's scrutiny of the Autism (Wales) Bill.
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Introduction

1. The Welsh NHS Confederation, which represents the seven Health Boards and three NHS Trusts in Wales, welcomes the opportunity to respond to the Health, Social Care and Sport Committee's scrutiny of the Autism (Wales) Bill.
2. The Welsh NHS Confederation supports our members to improve health and wellbeing by working with them to deliver high standards of care for patients and best value for taxpayers' money. We act as a driving force for positive change through strong representation and our policy, influencing and engagement work.

Background

3. The Welsh NHS Confederation has provided written responses to Paul Davies AM's initial consultation on the need for a Draft Autism (Wales) Bill (November 2017) and the proposed Draft Autism (Wales) Bill itself (April 2018). Whilst fully supportive of the need to improve services for people with Autism Spectrum Disorder (ASD), both of our previous responses outlined a number of issues around whether the proposed legislation would be the most appropriate vehicle to achieve the desired outcomes for people with ASD.
4. Our response highlights:
 - 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
 - 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.
5. Since Paul Davies AM invited views on the Draft Autism (Wales) Bill in April 2018, the Welsh NHS Confederation has worked closely with the Royal College of Psychiatrists, the

Royal College of Speech and Language Therapists, the Royal College of Paediatrics and Child Health and the Royal College of Occupational Therapists to produce a briefing that outlines our shared position in relation to the proposed Bill. This co-produced briefing will be submitted to the Committee separately.

6. Our response will address the general principles of the proposed Bill to more accurately reflect the views of our members on these issues.

Services should be based on need and be person-centred

7. We welcome the additional resources that have been provided to support people with ASD, but support should be provided on the basis of patient need and the capacity to deliver the best possible services for the person rather than solely diagnosis. In addition, the Bill is based on the current understanding of classification of disease and disorders, which are changing and evolving. As neuro science develops this will challenge existing diagnostic categories.
8. Many people with Neurodevelopmental Disorders (ND) including some with ASD-like traits, some learning disabilities and other diagnoses such as Attention Deficit Hyperactivity Disorder (ADHD) would not (nor would it be appropriated for them to) 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.
9. 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 is consistent with existing legislation in the Social Services and Well-being (Wales) Act 2014, which already legislates for all patients regardless of the complexity of need, and the Additional Learning Needs and Education Tribunal (Wales) Act 2018. Services should not be based on diagnosis or be conditional on the receipt of other medical services.
10. When the Integrated Autism Service (IAS) was originally rolled out across Wales in 2017 with an all-age approach, individual Health Board teams were prohibited from assessing people with autism referred by secondary mental health services, regardless of the outcome of their mental health presentation at the first appointment stage. Some Health Boards have modified the pathway to be more inclusive and person-centred to address the needs of most patients, particularly those who may also have learning difficulties or other neurodevelopmental conditions. IAS teams are working collaboratively with other services, including Local Authority partners, to make appropriate adjustments to patient interventions to improve patient experience and outcomes.
11. In our joint briefing with Royal Colleges, the Royal College of Speech and Language Therapists say 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 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. Similarly, the Royal College of Paediatrics and Child Health (RCPCH) have highlighted that the impact of the proposed legislation could be to exclude children from appropriate services with no clear pathway available to ensure their needs were met. The RCPCH say that whilst this clearly indicates the legislation is not child-focused it also presents the risk that adults would be directed to inappropriate care pathways under the proposed Bill.

12. Efforts to improving services should be devoted to exploring opportunities for integrated styles of working across Health Boards and Local Authorities, establishing co-ordinated multi-disciplinary teams and facilitating opportunities for sharing best practice. It is through these channels that outcomes for patients will be improved in the future.

Impact of legislation on rates of diagnosis

13. Our members and a number of Royal Colleges are concerned that a possible unintended consequence of linking resource to a particular diagnosis, whether it is 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. This may impact on services, families and individuals in a number of ways both in the short term e.g. the duration and nature of the assessment process, and longer term with undetermined theoretical impact of a perhaps unhelpful diagnostic label that defines an individual.
14. The symptoms of autism, particularly in children, are shared by a wide range of ASD-like conditions. The proposed legislation would dictate that the best way for individuals and families to receive the support they feel they require would be to secure an autism diagnosis. The legislation could artificially increase rates of diagnosis for autism when it may be that an alternative care pathway would be more appropriate for the individual and would lead to better outcomes for them in the long-term.

Existing programmes to improve outcomes for people with ASD in Wales

15. The Welsh Government in partnership with Local Authorities is already rolling out a number of initiatives aimed at raising awareness and improving services for people with ASD in Wales. We would strongly recommend that the impact of these initiatives, which are currently in the early stages of development, be assessed prior to the introduction of new legislation. It will be especially important to understand the demand for and capacity to provide services across the age range.

- The Social Services and Well-being (Wales) Act 2014 places a duty on public bodies in Wales to assess and address the needs of individuals. The Social Services and Well-being (Wales) Act 2014 required partnership arrangements to be made in each Local Health Board area, under the direction of a Regional Partnership Board (RPB). The RPBs have representation from Health Boards, Local Authorities and service users. These RPBs have been established for defined functions, focussed particularly on areas where successful integration between local government and health is essential

for the provision of effective support services to meet the needs of people within their localities. The Social Services and Well-being (Wales) Act 2014 and supporting statutory guidance requires joint planning, commissioning and the use of pooled budgets between health and local government. The RPBs are recognised as key drivers of transformation under the Welsh Government's long-term plan for health and social care, "A Healthier Wales".

- The Welsh Government's recently-published Autism Spectrum Disorder Action Plan Annual Reportⁱ supports this work and clearly recognises the key challenges to achieving an integrated and effective service.
- Under the Together for Children and Young People programme (T4CYP), there has been significant investment in neurodevelopmental services since its introduction in 2015. Nationally-agreed neurodevelopmental children and young people's diagnostic pathways and standards are now in place and are being adopted by all Health Boards.ⁱⁱ A new 26-week waiting time standard from referral to first appointment has also been introduced. Neurodevelopmental teams work within a clinical framework with a shared assessment pathway and common standards. They focus on quality improvement and delivering services to the entire population under the age of 18. Wales is the only UK country to achieve this without specific legislation relating to autism.
- The Welsh Government have also acknowledged that many people with ASD or similar conditions often find it difficult to find and maintain employment and have recently introduced an Employability Plan. The plan provides an individualised approach to employment support and gives advisers the autonomy and flexibility to address the needs, strengths and ambitions of the person preparing for work. The Welsh Government are also supporting the Getting Ahead 2 project, which is aimed at people between the ages of 16-25 with learning disabilities and/or ASD.
- The National Integrated Autism Service (IAS) has recently been established with the aim of creating consistent support structures for people with ASD across Wales. An interim evaluation reportⁱⁱⁱ has been published in March 2018 considering the initial development of IAS in the first four regions where it is being rolled out – Cardiff and Vale, Cwm Taf, Gwent and Powys. While the report highlights that establishing a new integrated service like the IAS is challenging it does find that *"important progress has been made in establishing an IAS in Cardiff and Vale, Cwm Taf, Gwent and Powys and this represents a considerable achievement. Stakeholders expect the service to make important improvements to the quality and timeliness of assessment, diagnosis and support"*. The final report is scheduled for January 2019 and it will explore how the IAS continues to develop and how the recommendations within the interim report have been taken forward.
- The Additional Learning Needs and Education Tribunal (Wales) Act 2018 has recently been given Royal Assent and implementation will begin in 2020. The Act will introduce a new system of supporting children and young people with ASD through by

supporting early identification of additional learning needs and targeted, needs-based interventions in the education of children and young people.

16. In terms of existing programmes and engagement networks, Health Boards across Wales are working collaboratively with Local Authorities to raise awareness of IAS initiatives and provide valuable support resources through the ASD Info Wales website.^{iv} Plans are in place to scale-up ASD training to mental health staff and social care professionals more widely, but we recommend that ambulance and dental staff also be brought within this remit.
17. The changes in waiting time targets as envisaged by the Bill, would have a significant impact on resources (both financial and workforce) as well as a team's capacity to provide other services such as follow-up support, which is as important as the treatment itself. Furthermore, waiting time to diagnosis targets are only concerned with arriving at the diagnosis rather than assessing the needs of the individual or the family. The current priority towards diagnosis rather than need also inhibits a multi-disciplinary team's capacity to deliver the required services in an effective and timely manner. As our briefing "Autism (Wales) Bill: A look at autism strategies and legislation in England, Northern Ireland and Scotland", submitted with this written response, highlights there does not appear to be any current evidence to demonstrate that the provision of ASD specific legislation has improved services for people with ASD.

Multi-disciplinary teams

18. In our previous response to the Draft Bill we said it would be helpful, if legislation is taken forward, to include a list of professionals who could form the multi-disciplinary teams that would be required for diagnostic assessments. NICE CG128^v and/or 142^{vi} should be referenced with an explicit list of multi-agency, multi-disciplinary professionals. In particular, a nurse practitioner and a suitably qualified dietician for those with restrictive eating patterns would be key components of an effective IAS team, and clarity on what professions can administer autism diagnostic assessment tools would also be essential.

Enacting condition-specific legislation

19. Autism-specific legislation could lead to people with other neurodevelopmental disorders and challenges receiving inequitable services. Through introducing Autism-specific legislation there is a risk of excluding and disadvantaging other groups with neurodevelopmental conditions such as hyperkinetic disorder, learning disabilities, tic disorders, sensory impairments etc. It could also lead to other interested parties, patient groups and third sector organisations to call for the introduction of specific legislation for other illnesses and conditions to ensure they also given equal status and provision. This does not mean that proposals for an Autism Act are entirely 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. At present, this is not the case. Moreover, the financial pressures and significant challenges associated with recruiting and training the required multi-disciplinary teams that would be required to

deliver services as envisaged by the Bill would make it difficult to ensure effective implementation.

Data on autism spectrum disorder

20. Effective methods of data collection and analysis are essential to continual improvement of service delivery and it is positive that the Committee has recognised this in its terms of reference for this work.
21. The existing IAS implementation process includes the electronic recording of autism-related data and work is ongoing across Wales to deliver this through local teams. Likewise, the existing Welsh Community Care Information System (WCCIS) will support collaboration and facilitates a national approach to data collection. That said, we would emphasise that more work needs to be done to ensure that these systems interact with children's services more effectively to facilitate seamless transitions and continual data sharing between health and social care.
22. It is important to have prevalence estimates and data collection to gain an understanding of the proportion of people in the population that may be living with autism. This will also support service planning and development both on a local and a national level.
23. It is also important to consider the General Data Protection Regulations (GDPR), which have been in force since May 2018. The Regulations place a legal obligation on Health Boards and other public bodies to be fully transparent about what data they collect, their methods of collecting it, and how it will be used. Currently, IAS services across Wales are reviewing data items to inform service planning and development. The types of data accessed by NHS practitioners, clinicians and service planners tend to vary, which needs to be considered during the development of a data set as per the proposed Bill. This should not only take account of diagnostic information, but also include supporting activity and be focused on patient outcomes. Also, the list provided in the Draft Bill does not recognise the importance of post-diagnostic support data, which is central to informing suitable care pathways after diagnosis. The ND services are currently developing a data set for the collection of both qualitative and quantitative information.

Experiences from other nations around the introduction of Autism legislation

24. Evidence from the introduction of Autism Acts in England in 2009^{vii} and Northern Ireland^{viii} in 2011 suggests that legislation is not leading to improved outcomes for people with ASD.
25. The National Autistic Society report *Push for Action*,^{ix} which was published in 2013 and 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*". This is also supported by a recent detailed report by the National Autism Project^x (a UK-wide initiative which aims to provide authoritative recommendations on autism research and practice) which stated that "*nearly a decade*

on the needs of autistic people are still unmet and the expected economic dividend has never materialised”.

26. Similarly, 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”*.^{xi}
27. 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”*.^{xii} These were highlighted as key issues in the Committee’s recommendation that the general principles of the Bill should not be supported. The Committee also 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.

Conclusion

28. Health Boards and Trusts across Wales have made significant progress in recent years to deliver high quality services to people with autism. In many areas, Health Boards have reconfigured their services to improve quality and access. This progress and improvement has been made possible thanks to closer collaboration between NHS Wales organisations and Local Government. Areas of best practice have recognised that achieving the best possible outcome for the patient must be the key priority of NHS services above all else.
29. Integrated working has also allowed individuals and teams across health and social care to come together and share ideas to tackle the increasing workforce and financial challenges. Against this background, it is our view that NHS Wales can develop and improve its services for people with autism further by looking more closely at ways to scale-up examples of best practice and drive transformation, as set out in the Parliamentary Review of Health and Social Care^{xiii} and included within the Welsh Governments recently published “A Healthier Wales” Plan, rather than introducing legislation.

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

ⁱⁱ <http://www.1000livesplus.wales.nhs.uk/neurodevelopmental-services>

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

^{iv} www.asdinfo.wales.co.uk

^v NICE, Clinical guideline CG128. Published date: September 2011. Autism spectrum disorder in under 19s: recognition, referral and diagnosis <https://www.nice.org.uk/Guidance/CG128>

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- ^{vi} NICE, Clinical guideline CG142. Published date: June 2012. Autism spectrum disorder in adults: diagnosis and management. <https://www.nice.org.uk/guidance/CG142>
- ^{vii} [Autism Act 2009](#)
- ^{viii} [Autism Act \(Northern Ireland\) 2011](#)
- ^{ix} [The National Autistic Society, 2013. 'Push for Action campaign – Turning the Autism Act into action'](#)
- ^x [National Autism Project, January 2017. The Autism Dividend: Reaping the rewards of better investment.](#)
- ^{xi} [Department for Health, Social Services and Public Safety of Northern Ireland, 2015. 'The Autism Strategy \(2013 – 2020\) Action Plan \(2013 – 2016\) Progress Report](#)
- ^{xii} [The National Autistic Society, 2013. Push for Action campaign – Turning the Autism Act into action](#)
- ^{xiii} [Parliamentary Review of Health and Social Care in Wales, January 2018. Parliamentary Review final report – A revolution from within: Transforming health and care in Wales.](#)