

Introduction

1. The Welsh NHS Confederation, which represents the seven Health Boards and three NHS Trusts in Wales, welcomes the opportunity to respond to Paul Davies AM's consultation on proposals for an Autism (Wales) Bill.
2. The Welsh NHS Confederation supports our members to improve health and well-being 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.

Summary

3. Current arrangements to treat Autism in Wales take the form of two distinct strategies: the Integrated Autism Service (IAS), which is an all-age approach applied across Wales; and the Together 4 Children and Young People (T4CYP) neurodevelopmental workstream, which addresses diagnostic assessment and aspects of intervention to patients under the age of 18. Both workstreams support the Welsh Government's Autism Spectrum Disorder Strategic Action Plan, originally published in 2008, which established an autism infrastructure in each Local Authority area, with local coordinators and strategies, and a Wales national co-ordinator. It expanded research capacity, raised awareness of autism spectrum conditions and made available a range of information and resources for autistic people, their families and professionals.
4. A refreshed Strategic Action Plan 2016-20 is introducing further reforms, including improvements to diagnostic services, with a view to reducing waiting times for treatment and developing measures to improve education and employment for autism patients in Wales.
5. The IAS has a strong presence in relation to awareness raising, but only very recently has the strategy become visible with regard to enhanced assessment of adults. While the impact of IAS services on the population aged under the age of 18 is less apparent in terms of direct face-to-face contact, our members report positive feedback from service users on written and online IAS resources. These materials now represent a key part of the post-

diagnostic support delivered by local neurodevelopmental teams. A further success of the IAS approach to date has been securing the consistent engagement of Regional Partnership Boards throughout the care pathway.

6. T4CYP has supported the creation of neurodevelopmental services in Health Boards across Wales. These teams work within a clinical framework with a shared assessment pathway and common standards with a focus on quality improvement and delivering services to the entire population under the age of 18. As it stands, Wales is the only UK country to achieve this – significantly, despite the absence of specific legislation in this area.
7. Our response will address the general areas of the proposed Bill rather than providing specific responses to the questions outlined in the consultation document to more accurately reflect the views of our members on these issues.

The need for an ongoing Autism strategy

8. Although the principle underpinning the drive for legislation may be beneficial, statutory guidance would likely be sufficient to support the existing Autism Spectrum Disorder Strategic Action Plan 2016–20. This strategy already covers implementation of the IAS which is being monitored by Welsh Government as part of the Intermediate Care Fund (ICF) allocation, and where children are concerned, are further supported by Together for Children and Young People. High level Welsh Government guidance on the IAS model expected of local areas, alongside a comprehensive document to support local implementation, has been issued and much consultation and evaluation has been undertaken nationally since 2015, which the IAS has responded to. Over time, it is anticipated that practice and services will evolve organically, thereby alleviating the need for specific legislation.
9. Furthermore, the legislative process involved with introducing a Bill would be costly and unnecessarily time-consuming. This could lead to services reducing/restricting their input to legislative requirements and reducing the creativity to develop services based on need or developing the robust evidence base that would be required to support such a proposal. Efforts should be devoted to developing a national agreement and quality standards to address the current delivery of services across Wales and explore opportunities for integrated styles of working, establishing co-ordinated

multidisciplinary teams, expanding the existing research landscape and facilitating opportunities for sharing best practice. Effective partnership working and cross departmental support from Welsh Government would be required to achieve these objectives – but specific legislation in this area would not.

10. Moreover, to propose a Bill that deals specifically with autism would be to misunderstand the reality of neurodevelopmental conditions, particularly at the diagnosis stage. The very earliest symptoms of autism are either similar or identical to the earliest symptoms of a wide range of other emotional and mental health needs, including attention deficit hyperactivity disorder (ADHD), learning difficulties, and developmental trauma (including, but not restricted to, adverse childhood experiences). The current neurodevelopmental pathway therefore, rather than a specific autism pathway, provides an opportunity to undertake the relevant assessments, identify the specific need and decide on the appropriate treatment option. Such a system allows professionals to maintain communication and fluidity between different services – an ‘autism-specific’ service could create the misleading perception among the public that non-autism patients are to be treated less seriously than those showing early symptoms of autism. It is worth mentioning also that autism-specific legislation would effectively ‘open the floodgates’ for a number of organisations to demand that specific legislation be introduced to target other major illnesses, including cancer, diabetes and stroke.
11. Legislation is a time-consuming and costly way to achieve an outcome that requires professionals and services with the appropriate expertise and capacity to work collaboratively with service users.
12. In terms of undertaking, developing, reviewing and updating a national autism strategy as per the consultation document, any proposed legislation must, as a minimum, engage effectively with professionals (statutory and non-statutory), family members and service users throughout the care pathway. We would recommend that any autism strategy be reviewed and updated every 3–5 years.
13. Finally, we would also welcome a review of worldwide practice in countries where ‘autism-specific’ legislation is enforced so that assessments can be made about the effectiveness of such measures. However, conclusions must be drawn in light of Wales’ current legislative framework and the extent to

which gaps in service provision are already covered by existing legislation and policy instruments in Wales e.g. the Social Services and Well-being (Wales) Act 2014. The Social Services and Well-being (Wales) Act already places a duty on Health Boards and social services to assess the needs for care and support services in their areas and identify the range and level of services required to meet them. The Act also places a statutory duty on Local Authorities to establish information, advice and assistance services, including to autistic people, their families and carers where appropriate.

Clarity on pathways to diagnosis

14. Local Health Boards have adopted varying approaches to achieving clarity around pathways to diagnosis and access to a diagnostic assessment. In Powys Teaching Health Board for example, the Powys Social Communication Assessment Team (SCAT) process was developed in 2005 (which was also reviewed in accordance with NICE CG128 in 2011), and an adult diagnostic assessment pathway is also fully operational locally. Access to assessments have been well communicated across the Health Board with professionals and families alike and the result is that patients experience a seamless pathway through the system. For Cardiff and Vale University Health Board (UHB) however, the development of a clear referral process for adults under the IAS has only recently been established (introduced in 2017). For children and young people, the neurodevelopmental workstream under T4CYP has transformed and streamlined the previous pathway where the majority of referrals were to community child health service or children and adolescent mental health services (CAMHS), mainly by introducing a single point of access. Over 1,000 referrals for assessments were received for young people under the age of 18 across the Health Board in the first year of the service, which functions across paediatrics and CAMHS.
15. Significant work is required to develop these services not only to meet current demand, but also to address the significant level of unmet need for services which the Health Board has exposed as a resulting of a number of successful awareness-raising initiatives. We welcome the significant progress the Health Board has made in recent months to address these challenges but recognise that further work is needed to address the increasing workforce and demand pressures.

Delivery of services

16. All service areas are challenged with austerity, with those most in need being prioritised for care and support. However, resources for grant funded projects are shrinking, with regional areas pressured to consider how best to meet the needs of the wider population that reduces the need for statutory support. It is notable that resources allocated from Welsh Government via the IAS, which seeks to ensure that those with the greatest need are treated first and supported throughout the care pathway, were not based on population needs assessments – thus it is too early to state whether the service will achieve its long term strategic objectives.
17. The suggestion in the consultation document that statutory guidance be introduced alongside any new legislation which would place duties on Local Health Boards and Local Authorities around how they should be delivering services for children and young people and their families is already covered by the IAS. Rather than introducing new legislation, emphasis should be placed on facilitating integrated styles of working to support autistic patients and their families, as well as managing the crucial transition from children’s services to adult services.
18. Effective methods of data collection and analysis are essential to enable service planning and continual improvement of service delivery. This will also support transition from children to adult services. The existing IAS implementation process includes the electronic recording of autism-related data and work is ongoing across Wales to deliver this via local teams. Likewise, the Welsh Community Care Information System (WCCIS) integrated system for Health Boards and Local Authorities supports collaboration, avoids duplication and facilitates a national approach to data collection.

Training

19. We would welcome the introduction of a set of effective training programmes, supported by a robust evidence base. We would also welcome peer reviews and governance mechanisms as key considerations for meeting training needs, but emphasise that any estimate of service capacity must take into account the time allocated to achieve such needs. There are also opportunities for joint working with Royal Colleges across Wales to establish a more collaborative training process and share best practice. Training outcomes

should be specified at the beginning of the process and minimum awareness level training should become mandatory, especially for statutory services. The National Autism Training Framework for Wales should be referenced throughout the training process.

20. We feel that the role and involvement of Welsh Ambulance staff is not fully recognised in sufficient detail under the proposed Bill, particularly in relation to caring for and engaging with people with autism spectrum conditions.
21. For WAST operational staff, it may be difficult to identify immediately whether an individual has autism, especially as symptoms tend to manifest themselves differently depending on the age of the patient and the circumstances of the incident. Operational staff therefore rely to a great extent on the ability of the patient (or a carer/family member) to communicate clearly and provide as much information as possible regarding the nature of their call, their current physical and mental condition, their medical history, etc. For autism patients, it is often the case that their sensory processing often results in difficulty interpreting temperature, pain and their current predicament – all of which makes it more difficult for WAST operational staff to respond to the situation, particularly given the lack of specific training exercises currently available for staff members.
22. WAST also recognise that where an individual has communication difficulties, their sensory abilities and capacity to communicate clearly with operational staff may be strained by emergency lights, loud sirens and the feeling of being surrounded by strangers, as well as the requirement to physically touch a patient to carry out basic medical examinations such as temperature and blood pressure readings. This can lead to significant patient distress and further hinders the patients' ability to communicate clearly and effectively with operational staff and makes a comprehensive patient assessment increasingly challenging. Under any proposed legislation therefore, we feel that any reference to workforce training ought to be extended to support members of WAST operational staff in delivering the best possible standard of care, while allowing the patient to remain as calm as possible.
23. In terms of suggestions for additional action that could be taken through legislation to improve the rates of employment of people with autism spectrum conditions in Wales, bearing in mind that the National Assembly does not have the power to make changes to employment law, we would

welcome greater support of ASD Info Wales. Among its many aims, ASD Info Wales seeks to provide effective training opportunities for people with autism and mechanisms for integrating people living with autism into the employment market.

Definition of Autism

24. A definition of autism would have to be included in any proposed legislation, strategy and guidance. However, to arrive at a clear definition is difficult enough a challenge in itself. Currently, the most commonly-used definitions are those offered by the International Classification of Diseases (10th edition) (ICD-10) manual, which provides a series of definitions for childhood autism, atypical autism and other autism profiles such as Asperger's syndrome. A revised edition of ICD-10 is expected in 2018, which according to the National Autistic Societyⁱⁱ, is likely to closely align with the latest edition of the American Diagnostic and Statistical Manual (DSM-5).
25. The diagnostic criteria under DSM-5 is clearer and includes sensory behaviours, which is particularly significant for autism patients given that such differences tend to manifest themselves at an early stage of the treatment process. The DSM-5 general definition also includes the additional point that the effect of the pattern of behaviour in question must be to the extent that it "limits and impairs everyday functioning" if the condition is to be diagnosed as autism.
26. To arrive at an unanimously accepted definition of autism, supported by designated teams across Local Health Boards, would pose a significant challenge therefore, particularly given the likely impact on diagnosis and treatment this would have on patients within the system at the precise time any proposed legislation was passed. While we welcome the general principle of arriving at a useful definition for autism, this is not to be achieved through legislation.

Unintended consequences

27. Unintended consequences of introducing specific legislation may include increased costs and a marked change in the attitude of professionals to policymakers. If the Bill is developed further, we would recommend that a detailed consultation with autism patients, their families and professionals is

undertaken, as well as a review and evaluation process, and possibly a 'sunset' clause with a defined expiry date to enable Welsh Government to consider its success after a fixed period.

Costs

28. The introduction of a new law to enforce the Bill would incur significant financial cost to Health Boards and Local Authorities unless additional monies were made available to support the implementation process. Delivery on any additional activity will require resources that if not provided, will come either from areas of service provision or through a reorganisation of an existing service.

Savings

29. Our members would support a detailed cost-benefit analysis of progress to explore some of the ways in which any potential financial savings that come from the new legislation could be identified and calculated most effectively. However, new legislation will not see cost benefits initially, so immediate progress would be difficult to quantify. Over the long term, it would be reasonable to expect cost benefits through early intervention and prevention to avoid escalation.

Conclusion

30. Across Wales, Health Boards and Trusts have made significant progress in recent years in delivering high quality services for autism patients. What is apparent however is that the areas of best practice have been achieved as a result of local teams working collaboratively and sharing best practice to meet the increasing challenges of workforce pressures and demand. These initiatives need to be supported to enable them to be scaled-up and allowed to develop organically rather through legislation.

ⁱ <http://www.asdinfowales.co.uk/home/>

ⁱⁱ <http://www.autism.org.uk/about/diagnosis/criteria-changes.aspx>