

Cynulliad Cenedlaethol Cymru
Bil Awtistiaeth (Cymru) drafft
Llythyr Ymgynghori DAB37
Ymateb gan Conffederasiwn GIG Cymru

National Assembly for Wales
Draft Autism (Wales) Bill
Consultation Letter DAB37
Evidence from Welsh NHS
Confederation

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 Draft 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.

Background

3. As highlighted in our response to Paul Davies AM's initial consultation in November 2017, current arrangements to treat autism in Wales take the form of two distinct strategies: the Integrated Autism Service (IAS), introduced across Wales from 2017 onwards with an all-age approach; and the Together 4 Children and Young People (T4CYP) neurodevelopmental workstream, introduced in February 2015, 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 (ASD) Strategic Action Plan, originally published in 2008, which established an autism infrastructure in each Local Authority area, with local co-ordinators and strategies, and a Wales national co-ordinator. The Action Plan expanded research capacity, raised awareness of autism spectrum conditions and made available a range of information and resources for people with autism, their families and professionals.
4. The 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 adults with autism in Wales.
5. The IAS has helped raise awareness of services for people with autism and is enhancing the assessment of adults. Our members report positive feedback from service users on written and online IAS resources. These materials now represent a key part of the postdiagnostic support delivered by local neurodevelopmental teams. A further success of the IAS approach has been securing the consistent engagement of Regional Partnership Boards, which were introduced as part of the Social Services and Well-being (Wales) Act 2014.
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. 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.

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

Please refer to questions in the [Consultation Letter](#).

Definition of Autism Spectrum Disorder

8. As emphasised in our previous response, a definition of autism should be included in any proposed legislation, strategy and guidance. However, to arrive at a clear definition is difficult. 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. An updated edition, ICD-11, will be published soon, informed by global collaborations and aligning closely with the latest edition of the American Diagnostic and Statistical Manual (DSM-5). Our members agree that a definition of autism spectrum disorder should appear on the face of the Bill.

9. On the issue of using the ICD-11 definition together with the power of Welsh Ministers to include other neurodevelopmental disorders, we welcome the recognition given to the prevalence of other neurological conditions, such as Tourette's and ADHD, in the Bill. However, extending the definition will lead to a significant increase in referrals, to the Integrated Autism Service (IAS) and will extend its remit too widely. The IAS is still in its infancy and such an expansion would not be feasible in the short to medium term. Children's neurodevelopmental diagnostic assessment processes have already been amalgamated and there is a need to consider a neurodevelopmental service for adults to develop synergy with the T4CYP neurodevelopmental pathway.

Range of Bodies with functions under the Bill

10. We agree that NHS organisations and Local Authorities are suitable bodies to lead on the implementation of an integrated strategy. This should include statutory and non-statutory multi-agency partners.

11. We would also suggest that public, voluntary and private agencies would benefit from guidance, for example a Code of Practice, that set out the terms of provision of services for people with autism. A decision on the need for statutory guidance could be made following a review and evaluation process, which we also alluded to in our previous response.

Duty to have regard to the autism strategy and guidance

12. All relevant bodies should have a duty to have regard to the autism strategy and guidance. Enforcement by Welsh Ministers and a power to direct should be completed only as a last resort, and health organisations should be given sufficient

time to ensure that their internal systems have regard to the autism strategy. In our members' experience, families of people with autism tend to involve Ministers and Assembly Members before communicating with the relevant body to work towards a mutually satisfactory outcome.

Timescales in the Draft Bill

13. It will be challenging to arrive at an accepted definition of autism, that is supported by designated teams across Health Boards. This is likely to impact diagnosis and treatment for patients within the system when the proposed legislation is passed. Arrangements need to be put in place to ensure that those patients continue to receive the highest possible standard of treatment and do not fall into gaps in service due to a transition period. Timescales must be realistic to allow relevant bodies to prepare for the implementation of the Bill.

Timescales for diagnosis and assessment of needs

14. Using NICE guidelines as a measure of good practice, people with autism should receive an assessment within three months of referral. Assessments for care and support are undertaken collaboratively with the patient. However, it must be acknowledged that greater investment is still needed to achieve full NICE compliance. Current IAS teams are not NICE compliant as they lack the full complement of professionals as core members. For example, there is no psychiatric input to support complex presentations or co-morbid conditions. This situation is unique to Wales. Three Health Boards are currently funding professionals with mental health expertise, but greater consistency of team compositions is required across Health Boards in Wales.

15. The 26-week waiting time target for children needs to be acknowledged as a waiting time from referral to first appointment, and not a waiting time from referral to diagnosis. Whilst timescales are useful to guide smooth processes, these need to be realistic given current demand and capacity pressures on the service. If waiting times are changed dramatically, then this will impact resources (both financial and the workforce) and a team's ability to provide other services e.g. support following diagnosis, which is equally as important as the diagnosis itself. Inevitably, this would require an additional resource to meet demand. Furthermore, waiting time to diagnosis targets are only concerned with arriving at the diagnosis rather than the needs of the individual or the family. The capacity of multi-disciplinary teams to support these needs is affected by the current priority towards diagnosis.

Multi-disciplinary team

16. It would be useful to include a list of professionals who could form the multi-disciplinary team for diagnostic assessments under the new legislation. NICE CG128 and/or 142 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.

Ensuring equity of access to services

17. Access to services should be based on a patient's need and the capacity of the relevant service to deliver the best possible outcome for the patient. Access should not be dependent on a person's IQ score or the receipt of other medical services.

18. When the IAS was originally rolled out, individual Health Board teams were not allowed to assess 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 to make appropriate adjustments to patient interventions where necessary to improve patient experience and outcomes.

Data on autism spectrum disorder

19. Data collection is crucial to inform future service planning. We hope the Welsh Community Care Information System (WCCIS) will address the need to have robust, consistent and uniform data collection systems that interact with children's services to facilitate seamless transitions and effective data sharing between health and social care.

20. It is important to have prevalence estimates and data collection to gain an understanding of the proportion of people in the population that may have autism. This will also support service planning and development both locally and nationally.

21. It is also important to consider the General Data Protection Regulations (GDPR), which are coming into force on 25th May 2018. Health Boards and other organisations will have 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 type of data accessed by a NHS practitioner, clinician and service planner tend to vary, which needs to be considered during the development of a data set. This should not only take account of diagnostic information, but also include supporting activity and be focused on patient outcomes, as per the IAS reporting template. Also, the list provided in the Draft Bill fails to recognise the importance of post-diagnostic support data, which is central to informing suitable care pathways.

Campaign to raise awareness and understanding

22. 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. Plans are in place to scale-up ASD training to mental health staff and social care professionals more widely, but we recommend that ambulance staff and dental staff should also be brought within this remit. Therefore, we feel that a three-year cycle is sufficient.

23. Training and continued professional development will be facilitated through the newly formed IAS practice network, a platform to share good practice and service innovations across Wales. However, to achieve an ASD competent workforce, further consideration must be given to an ASD-inclusive curriculum in all professional courses within higher education.

Impact of this legislation

24. As emphasised in our response to the initial consultation, 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.

25. The financial pressures and the significant challenges associated with recruiting and training the required multi-disciplinary teams make it difficult to ensure effective implementation of the Bill.

Conclusion

26. Across Wales, Health Boards have made significant progress in recent years in delivering high quality services for people with autism. Our members do not believe there is sufficient evidence to say that autism-specific legislation would enhance the programme of work already being implemented and delivered across the NHS and Local Government. Areas of best practice have been achieved as a result of local teams working collaboratively and sharing ideas to meet the increasing challenges of workforce pressures and demand. We recommend exploring opportunities for scaling-up best practice, as highlighted within the Parliamentary Review of Health and Social Care in Wales, as a means of improving autism services for patients, rather than turning to legislative measures.