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Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill
Ymateb gan Fwrdd Iechyd Lleol Cwm Taf
Response from Cwm Taf Local Health Board

Response from Cwm Taf University Health Board, collated by:

██████████, Head of Planning, Children, Young People and Families.

Overview

There has been significant progress made locally, regionally and nationally across Wales since the original ASD action plan in 2008, with one of the key achievements being the increased profile and awareness of autism in Wales, as well as many others.

Through working collectively with the National ASD development team, we have seen significant developments in the wide range of information and resources available to help autistic people and their families and carers, as well as resources for professionals.

From initial consideration of the proposed Bill, it is clear that any new legislation should and need to add value to individuals, families, carers and professionals alike. It is not clear how in regard to what is proposed how specific improvements will be made without the broader consideration of the national action plans being worked to along with other key legislation currently being implemented and or drafted.

Wales currently has a refreshed Autistic Spectrum Disorder Strategic Action Plan Wales (ASD SAP), which was first published in 2008 and revised in 2016. This has led to significant investment into services for people with ASC from Welsh Government. The work to create a national IAS, in addition to the revised ASD SAP and local action plan is delivering the outcomes that an Autism (Wales) Bill would promote. Regional Partnership Boards across Wales have shown commitment and resources to drive forward improvement and change for individuals with Autism and some areas have already invested core funding to

improve service development. The IAS and the ASD SAP provide the guidance and direction to underpin requirements

Further legislation would be costly – potentially using resources that could directly benefit people with ASDs in other ways, time consuming and bureaucratic with emphasis on legal requirements and tribunals. This approach would be unlikely to offer additional benefits not offered by the current ASD SAP. This could affect services by impacting their input to deliver direct care and support, with the potential requirements of new legislation reducing the creativity to develop services based on needs.

As a UHB and region we have previously responded to the consultations on the general concept of a proposed Autism (Wales) Bill and on the draft Autism (Wales) Bill in which we highlighted our fundamental concerns about the approach of creating separate legislation for a particular condition. We believe that legislation such as the Social Services and Well-being (Wales) Act, the Additional Learning Needs and Education Tribunal (Wales) Act and the Equality Act 2010 should, if they are working correctly, deliver for all on the basis of need.

We are therefore not supportive of the need for an Autism (Wales) Bill. We believe that placing a specific autism strategy in statute risks distributing resources inequitably. As a UHB we have a duty to ensure we consider the need of all individuals referred to us for assessment, diagnosis and ongoing intervention and support in line with all other statutory responsibilities expected of our services jointly with our partners.

Serious consideration also needs to be given to the implications of setting such a precedent going forward, as services for autistic people is not the only area where there is a need for service improvement for people with specific and associated conditions. It is essential that we fully identify and consider any unintended consequences of legislating on a particular condition, and that we explore any risk that such legislation may impact on our ability to respond to others on the basis of need.

In particular, the Social Services and Well-being (Wales) Act already places a duty on both 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 Additional Learning Needs Bill also reinforces these expectations jointly across both health organisations and education authorities. In addition, the Social Services and Well-being (Wales) Act also places a statutory duty on local public sector services to establish information, advice and assistance services, including to people with autism spectrum conditions, their families and carers.

As referenced earlier, we have reservations about the approach of legislating for a particular condition, as we believe that legislation such as the Social Services and Well-being (Wales) Act 2014 and the ALN Bill, The Well-Being and Future Generations (Wales) Act currently going through the Assembly should, if they are working correctly, deliver for all our citizens on the basis of need. Consideration also needs to be given to the implications of setting such a precedent going forward, as services for people with autism is not the only area where there is a need for service improvement and as UHB's we would struggle to ensure that only priority is only given to this area of need specifically within the requirements of such a Bill when responding to other aspects of legislative guidance and statutory responsibility as outlined within this response.

The Act in England was a useful force to drive development of a strategy for implementation and was helpful for clinicians to 'persuade' commissioners of the gaps and the need to fund services.

However, it seems that we are now beyond this point in Wales and it would be an unnecessary use of public funds. Services now need time and buy-in from partnership organisations in order to be able to deliver with an emphasis on a national agreement and quality standards to address delivery of services across Wales. This would require solid partnership working and cross-departmental government support, there would need to be a mechanism to achieve this to achieve status and prioritisation given austerity.

Legislation is a slow and costly process, applying too much detail could slow it down further and the strategy detail would soon become obsolete rather than being able to change over time in response to the work that is being done and the experience of people with ASC. It would potentially also remove the mechanisms for engagement in the details of adopting and updating an autism strategy. There are critical interfaces with developmental trauma, ADHD, learning disability, specific learning difficulties and so forth that any ASD specific legislation could ignore to the detriment of our population. Autism legislation is too specific, it immediately creates inequity, and we need to ensure strong linkages with neuro-developmental disorders more widely as opposed to only concentrating on the needs of individuals on the spectrum. Many families may express frustration at services if an autism diagnosis is not achieved, due to a perception that a diagnosis of autism will offer the suggested benefits of ASC specific services. This would lead to a perverse incentive to apply this diagnosis when in reality a broader description and a variety of approaches may be more constructive.

If an Autism (Wales) Bill were passed, the detail would need to be similar to that within the Social Services and Well Being Act, Prudent Health Care and the ALN Bill and The Well-Being and Future Generations (Wales) Act, which have strength in being inclusive and based on need, given the inextricable links for citizens across existing legislation. Should the content require more detail, then the advice of specialist professionals within the field must be sought to provide a robust clear set of guidelines that will stand the test of time as developments in assessment, treatment and interventions emerge within the field of ASC and other neurodevelopmental conditions.

Comments on the proposed Bill

Below we highlight some specific comments related to the Bill as currently drafted outlining some specific areas of concern we wish to share for wider consideration:

Autism Strategy

Under 2(1)(a) the Bill identifies that the Autism Strategy must establish a best practice model or models. It seems far too restrictive to prescribe the models that must be established, it may be better to highlight pathways rather than models.

Under 2(1)(c) the Bill requires diagnostic assessments be commenced as soon as reasonably practicable following a referral, and at least within any timescales set out in the relevant Quality Standard issued by NICE (currently 13 weeks). The current Welsh Government guidance, setting a 6 month (26 week) target would cause significant lack of clarity over expectations for those with assessment and diagnostic responsibilities. Whilst it is not ideal to not have any timescales, in reality, the current blanket 26 weeks' target does not reflect the complexity of many referrals, with a 13-week timescale further challenging this and not reflecting the length of time required to undertake what are often complex assessments.

2(1)(g) identifies that the autism strategy must outline how the needs of persons with ASD are to be met by relevant bodies in respect of, but not limited to: access to healthcare services; access to education; access to employment; access to housing; access to Welsh language services; access to services in other languages; access to other public services; social inclusion; and access to advocacy services. Some of these areas are far too general, for example how will access to employment, or access to public services be covered in any meaningful way? This is not clear and would require further consideration and consideration to the ALN Bill and the expectations being outlined here.

As a UHB we wish to work in an integrated manner with partners in support of any guidance and or legislation that is put to challenge and focus our attention's on meeting the needs and improving services locally. However we feel that there is suitable and appropriate legislation and guidance already in place to push us in the right direction and challenge our vision to improve early intervention and prevention as well as timely assessment, diagnosis and support.

However as a UHB we have a collective responsibility to all children, young people adult individuals and their families with any form of additional learning and or

support needs and wish to be able to ensure we prioritise our service according to the need of all.