

Pwyllgor Iechyd, Gwasanaethau Cymdeithasol a Chwaraeon

Health, Social Care and Sport Committee

HSCS(5)-26-18 Papur 3 / Paper 3

Autism Bill Consultation response from Dr Dawn Wimpory, Consultant Clinical Psychologist – Lead for ASD (BCUHB) and Lecturer (Bangor University)

I have held an autism-specific clinical and research joint post for the last 3 decades and have been invited to present evidence to the scrutiny committee for this bill on 3.10.18. (I was also asked by the Division of Clinical Psychology, for the British Psychological Society, to represent them in their response to this bill but had to decline as I shall be abroad on the date that my presence was required for that.)

- 1) The general principles of the Autism (Wales) Bill and the extent to which it will make provision for meeting the needs of children and adults with Autism Spectrum Disorder (ASD) in Wales and achieve the aim of protecting and promoting their rights

I think the general principles of the bill are sound and that they will help Wales to meet the needs of children and adults with ASDs, and achieve the aim of protecting and promoting their rights, more than previous strategies have been able to do. I was on the original strategic group for the first ASD action plan and have seen the level of impact of this and subsequent action plans over the last decade; as a result I think it is appropriate to bring in legislation to address the issues of concern.

- 2) Any potential barriers to the implementation of the provisions and whether the Bill takes account of them

I think that staffing and their organisation may represent potential barriers to the implementation of the provisions in the Bill in relation to waiting list times. Specifically this may include initial difficulty with commencing ASD assessments within 3 months of referral. However, I think it is inappropriate that Wales should have guidance of 26wk maximum Waiting List (WL) time (e.g. for children) whilst NICE guidelines from England specify 3months for adults and children. It seems appropriate that any ASD legislation for Wales at least matches NICE-issued guidelines. I think it is positive that individuals who appear inappropriate referrals can be advised of this promptly and possibly redirected to other services by clinicians.

I am concerned that discussions of the this Bill have been erroneously representing the 13 wks until *commencement* of assessment as 13 wks until a *diagnosis* should be made (this appeared to be how it was represented by the new WLGA national ASD Lead at a recent regional IAS strategic meeting and subsequent written communication reflected this misunderstanding). These are very different in terms of the implications/resources required for each and

I would be very disappointed if confusion around this issue influences receptiveness to the bill on a larger scale.

Currently, waiting lists, e.g. in children's ND services, are being clogged by inappropriate referrals that tend to be held there for too long. After such cases have waited for an unreasonable amount of time, there is a tendency to feel that they are 'owed' an ASD assessment even when other indicators show that this is not the most appropriate use of resources. I think that removing such cases from ASD WLs early on, as advocated in the bill, will ultimately reduce pressure on WLs and therefore proved helpful. Of course additional resources may well be necessary, especially initially, in order to assist in this reorganisation of how services/WLs are organised.

I also think it is important that clinicians can focus half their efforts on supporting families of clients with ASD, rather than be consumed by assessment work - I am not yet certain that the bill addresses the need to protect intervention time within services for these clients.

I welcome the bill's position in requiring services to record ASD diagnoses. Under my own direction, BCUHB has successfully collected and collated such diagnostic information for children over the last 6yrs and is therefore unique in Wales in being able to identify accurately whether or not research-supported internationally-recognised prevalence rates are being adhered to, or exceeded or failing to be reached. BCUHB's Autism Module enables examination of such figures within each of the 3 constituent areas of BCUHB and over the HB as a whole. Such figures are absolutely essential in Wales being able to identify whether diagnoses are being made at appropriate levels.

It is both inappropriate for ASD diagnoses to be missed and for people without ASD to be erroneously diagnosed as having ASD. These are real dangers and can only be addressed through accurate data recording and analysis in a constant manner. BCUHB's database, conceived originally by WG, as a pilot for the whole of Wales, has demonstrated that such data can be efficiently and routinely recorded/analysed. I understand concerns from other services that this may be an impossible task but 6yr's experience with our ASD database proves otherwise. Software for this database, via CCH2000's database system of electronic records, already exists throughout NHS Wales. CCH2000 is currently migrating to an upgraded system, CYPRIS. ABHB are the first Health Board to use the Autism Database Module on CYPRIS.

3) Whether there are any unintended consequences arising from the Bill

My experience of successive ASD all-Wales strategies is that they have not drawn attention away from, eg, ADHD, so I do not envisage this as an unintended consequence of the Autism Bill. However, IF diagnoses of ASD were to proceed without prevalence levels being checked (as the Bill sets out to avoid through the data collection referred to above) then there might be a

risk that resources are not allocated appropriately to the correct service users. But the latter risk already exists without the Autism Bill anyway.

It would seem essential that the bill is applied to private services as well as to statutory services so that the former adhere to standards required of the latter; this is particularly important to help address any over-diagnosis of ASD in private provision, possibly through less thorough assessment strategies.

4) The financial implications of the Bill (as set out in Part 2 of the Explanatory Memorandum)

My understanding of the bill is that it has been supported through appropriate research and reviewing of available information, including financial elements; I particularly welcome the involvement of Professor Martin Knapp at LSE as appropriate international expert in this aspect of ASD. The data collection/analysis elements of the bill are based on experience of 6yrs piloting an ASD Database Module that was piloted by WG in anticipation of All Wales roll out.

5) The appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation (as set out in Chapter 6 of Part 1 of the Explanatory Memorandum)

Unlike NICE guidelines that advocate both ICD-10 and DSM5, the Bill employs just DSM5, this seems regrettable as there have been some criticism of this system (e.g. that it may be too influenced by insurance issues in US). It seems surprising, and perhaps too bold, that ministers will be able to extend the client group to whom the Autism Bill applies, in addition to ASD in the future.

I welcome a bill that identifies the unique difficulties and challenges presented by autism to services and their uses. It seems too wide that ministers might expand the neuro-developmental conception of service users to whom the bill might apply in the future. As a related example, the current strategic inclusion of ADHD child referrals along with those for ASD has been not been helpful in my experience. This is because approximately half of those children with diagnosed with ADHD have an emotional or environmental basis for their diagnosis (as outlined by Dr. Elspeth Webb, Consultant Paediatrician, ND national presentation), whereas this is not the basis of ASD. Clinicians working with each group of children therefore require a different skill set and, in my experience, services for children with ASD can be slowed down by the contrasting needs and challenges presented by those with ADHD.

Hopefully ministers would not be defining the boundaries of ASD. Instead it seems appropriate that research-informed leaders of the ASD clinical field should take that responsibility, with research-evidenced prevalence figures in mind. As a disability, even in high functioning individuals, ASD should only be

diagnosed (through the NHS or private services) where there is a level of impairment that warrants clinical recognition.

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