

A08

Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill

Ymateb gan Gwasanaeth Awtistiaeth Integredig Gwent

Response from Gwent Integrated Autism Service

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To Whom It May Concern

Re: Consultation on the Autism Bill

It is the view of the Gwent Integrated Autism Service that this additional legislation is not required and will in fact, adversely impact on the delivery of service development and the provision of support services. In fact the Autism Bill has the potential to do harm.

There is already an Autism Strategy in place. This Strategy is well under way in terms of implementation and achieving change, in time this will result in improved quality of lives for those individuals with ASD. The Integrated Autism Service has now been operational in the Aneurin Bevan Health Board area for just under 12 months and has made significant progress, recognising that service development, achieving best practice etc. take time. No further legislation or policy needs to be considered, pending the outcome of the formal review of the Implementation of the National Integrated Autism Service currently being undertaken by the People & Work Unit, completion due March 2019. The Integrated Autism Service should be given time to establish and embed new Pathways etc. There are a number of key issues and concerns with the proposed legislation:

1. There are considerable difficulties of achieving a target of completing a diagnostic assessment within 13 week from referral. We are unclear why a 13 week timescale has been proposed, it is not in accordance with any other standards for work to commence let alone be completed. As an established services, which launched in September 2017 we now have 196 Individuals on a waiting list for diagnosis, which is currently resulting in a 12 month waiting list. We have received 100 appropriate referrals this financial year alone. We have been piloting alternative approaches to diagnostic clinics (still adhering to NICE guidelines and agreed national minimum standards through the Community of Practice), we are therefore confident that we can increase the number of diagnostic clinics going forward. However, best case scenario is that we can reduce the diagnostic waiting time to nine months (this assumes there will be no DNA's, no cancellations due to sickness etc.). The impact of this will be a reduction in the time clinicians have to provide support as around 80% of their time will be committed to diagnostic clinics, MDTs, supervision, CPD, mandatory training etc. However, even with an increased number of diagnostic clinics, we are currently receiving referrals on a weekly basis at a higher rate than we have capacity to meet. If we cleared the waiting list we may just be able to maintain a waiting list of 13 weeks, utilising the

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majority of our funding to do so. We only have 3 full time equivalent diagnosing clinicians so support staff would need to be replaced with qualified clinicians to make this possible.

2. To reduce the current waiting list we anticipate the costs for meeting a 13 week to completion target would be an additional one off amount of £352,800. These are additional fees on top of the current costs. (An assessment at the Dyscovery Centre is £1800 per person Presently there is little evidence as to demand as the IASs have been operating for such a short time. However, with the current waiting times across Wales it is evident that to meet a 13 week target then all areas would have to greatly increase the number of diagnostic assessments that they undertake.
3. It is anticipated that moving the focus for IAS services to meet a diagnostic assessment completion target would undermine the action planned commitment for IAS services to organise their services to deliver 60% support and 40% diagnostic assessments. The focus on assessment would undermine our capacity to offer any ongoing support post diagnosis. To meet a 13 week target would require, for example in Gwent, a serious reduction in our support staff to recycle the funding to employ additional diagnosing clinicians. So, whilst an assessment of need could be completed the IAS would no longer be in a position to offer anything post diagnostically, other than a post diagnostic appointment, drop in sessions on a monthly basis and a post diagnostic six week course. It would be impossible to resource a keyworker for anyone with ASD let alone everyone with ASD, as the NICE Quality Standards recommend.
4. Some assessments can take longer than others depending on the complexity of the presentation, the difficulties for the person in attending and organising themselves to the assessment. A rushed assessment can lead to erroneous conclusions, therefore a fixed timescale and turnaround for completion of the assessment is not always within the Clinicians gift.
5. There is also a clear flaw in the proposals. Currently, whilst we have a significant waiting list for diagnosis, individuals are (in the majority of cases) given the diagnosis the same day the assessment is completed. At present only around 10% of individuals do not receive this, usually because a further assessment i.e. ADOS or a second opinion around a co-morbid diagnosis needs to be considered. The Bill proposes a timescale as recommended in the NICE Quality standards of : diagnostic assessment should be started within 13 weeks of receipt of referral. This is completely achievable, but is, in our view, poor practice. This will force an alternative approach where the diagnostic process will be split into a pre-diagnostic counselling appointment and/or information gathering through the use of structured self-reports or observations from other professionals. So, whilst the timescale of starting the

assessment will be met, in reality, the conclusion of the process and confirmation of diagnosis will still be 12 months in the Gwent area. We suspect many individuals pushing for this legislation are not fully appreciative of this and believe the legislation will achieve a timely diagnosis NOT a timely start of the diagnostic process. In Gwent we have received very positive feedback in relation to our diagnostic Pathway and process. It includes the following comments:

93% of individuals rated their experience as 'very good'

"It was a long wait but worth it"

"clarity of information was excellent and the support to feel ok about autism"

"I felt listened to and understood"

There is a real risk that if we have to meet a 13 week target, then this quality will be compromised.

6. The establish Community of Practice is already addressing key areas such as developing best practice in relation to the: identification and diagnosing of ASD, Pathways, assessment and planning. Many of these have already been explored, agreed and are being rolled out on a national basis through the Integrated Autism Service. - How can we develop standards if we are constrained by waiting list targets which aren't taking the broader quality issues into consideration
7. The Integrated Autism Service already ensures that diagnostic assessments are carried out using a range of multi-disciplinary professionals as required. The Integrated Autism Service also ensures that no adult falls through the gap of service eligibility criteria i.e. based on IQ. The Integrated Autism Service are also establishing strong links with the local authority ASD Leads to consider strategic/policy/commissioning issues.
8. A further complication of the Bill's focus on diagnostic assessments is that the IAS are also committed to resource other services (in both diagnostic and support work). The professionals in IAS services need time to undertaking training, joint work and offer consultation to other professionals undertaking assessments in Learning Disability or Mental Health Services. This work would be not achievable under the proposed bill. For example in Gwent, we have already provided training courses to mental health teams, DWP, Supported Housing Providers etc. We have joint worked around 10 cases with mental health services. We also provide three one hour slots a month for professionals from secondary services to discuss complex cases. All of this support would be lost if we need to hit the recommendation of the NICE Quality Standards as outlined in this Autism Bill.

9. It is also concerning that the Bill would appear to be including all other neurodevelopmental disorders in its powers. Meaning at any time, without any other consideration i.e. staff competence, funding & resource issues individuals with any other neurodevelopmental disorder would have the same entitlements. At present the IAS Services are designed, set up, funded and staffed to meet the needs of people on the Autism Spectrum as defined by the diagnostic and statistical manual (DSM5 or ICD10). This would again cause significant resources issues and further impact on the IAS ability to provide a quality service.
10. The Autism Bill could also potentially be seen as positive discrimination. No other service user group has its own specific legislation they are all bound by the Social Services & Well-Being Act and access to services assessed against an Outcomes Framework, which does not guarantee the provision of a support plan, key worker nor services. By adopting the NICE Quality Standard as the basis for legislation anyone with ASD will have an entitlement to these and a standard of service that no-one else will i.e. a named keyworker.
11. It is evident that to meet the needs of the Autism Bill and the NICE Quality standards a significantly greater level of funding is required to meet identified time scales and to ensure the ongoing provision of support.

Please also find attached an anonymised response we have received from an autistic adult who has accesses our services. This response was received as part of our service evaluation process. The individual has given consent for us to share this as part of our response the Autism Bill.

Yours faithfully

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Aneurin Bevan University Health Board

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