



Dr Dai Lloyd, AM
Chair
Health, Social Care and Sport Committee

To the Chair of the Committee

Re: Consultation on the Autism Bill

We write on behalf of the Community of Practice (CoP) for adult diagnosis and Integrated Autism Service (IAS) practitioners.

The Community of Practice brings together those who are involved in adult autism diagnosis and practitioners from the IAS.

The CoP have collated a response to the proposed autism bill, which evidences our reservations and concerns regarding certain aspects of the bill. This response has previously been submitted by Wendy Thomas (National Professional Lead Autism), however, for ease I have resent with this letter so that they can be read in conjunction. In addition to this response the CoP would welcome the opportunity to present verbal evidence to the Committee.

Please also find enclosed a written response from the CoP.

We therefore kindly request an audience with the committee at their convenience. We hope this opportunity could be granted.

We thank you for your time in considering this request and we will await your reply.

Yours faithfully

On behalf of the Community of Practice for Adult Diagnosis and IAS Practitioners

Endorsed by: (PTO)

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

Community of practice (CoP) for Adult diagnosis and IAS practitioners' response to the proposed autism bill.

The Community of Practice brings together those who are involved in adult autism diagnosis and practitioners from the IASs. This CoP replaces the Adult Diagnostic Network. It is the view of the CoP that the additional legislation is not required and if implemented then it will adversely impact existing and developing services. It is our view that introducing legislation at this point in the implementation of the IAS's is unnecessary and unhelpful.

- **Strategy**

The development of an Autism strategy in 2008 was ground breaking and has already had a positive impact in Wales e.g. ASD awareness has increased, a range of resources has been developed, training has been developed and rolled out, the development of children ND services and the IASs. The impact has been evaluated and the refreshed strategy 2016 reflected the findings of that evaluation. The Integrated Autism Services have now been operational in several Health Board areas for a relatively short time but in that time they have made significant progress, recognising that service development, achieving best practice etc. takes time. It is anticipated that every health board area will have an operational IAS in place by the end of March 2019. No further legislation or policy should 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 Services should be given time to establish and embed new Pathways etc. In addition, making the strategy a statutory requirement will add no value. In England, where the development of an Adult Strategy was a requirement of the ASD Act, the NAS report 2016 and the parliamentary report 2017 actually evidence that there has been no significant improvement to the lives of autistic people.

- **Diagnostic waiting times and support**

Firstly, we wish to emphasise that for a person to receive a positive autism diagnosis is so significant and life changing that the diagnostic assessment must be robust, timely and of high quality. Having a 13-week timescale for all diagnostic assessments does not reflect a person centred approach nor the length of time required to undertake often quite complex multi-disciplinary assessments.

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 Clinician's gift.

Secondly, it must be clearly understood that the emphasis upon diagnostic waiting times will have an adverse effect upon the level and quality of support that the IASs can deliver.

There are a number of key issues and concerns with the proposed legislation:

There are considerable difficulties of achieving a target of completing a diagnostic assessment within 13 weeks from referral. We are unclear why 13 weeks has been chosen as a figure as it doesn't align with any other standards for work to commence let alone be completed. To help illustrate the difficulties with a 13 week wait we have outlined the impact for one of the IAS in Wales as follows.

The Gwent IAS, as an established service, which launched in September 2017 now have 196 Individuals on a waiting list for diagnosis, which is currently resulting in a 12 month waiting list. They

have received 100 appropriate referrals this financial year alone. They have been piloting alternative approaches to diagnostic clinics (still adhering to NICE guidelines and agreed national minimum standards through the Community of Practice), they are therefore confident that they can increase the number of diagnostic clinics going forward. However, best case scenario is that they 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, they are currently receiving referrals on a weekly basis at a higher rate than they have capacity to meet. If they cleared the waiting list they may just be able to maintain a waiting list of 13 weeks, utilising the majority of their funding to do so. They only have 3 full time equivalent diagnosing clinicians so support staff would need to replace with qualified clinicians to make this possible. There are also issues around the availability of suitable trained and qualified staff to deliver this if this was the course of action agreed.

Gwent IAS estimate that to reduce their current waiting list the costs for meeting a 13 week to completion target would be an additional one off amount of £352,800. These are additional costs above the current funding allocation. (An assessment at the Dyscovery Centre is £1800 per person so costs have been based on that). In addition, there is little evidence as to demand both current and future 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 focus on the number of diagnostic assessments that they undertake. The People and Work unit are going to be looking at demand in their evaluation.

Cardiff and the Vale IAS have considered a number of options for undertaking diagnostic assessments to maximise efficiency, whilst not compromising on quality. They have secured additional diagnostician time from other local services wishing to work jointly with the IAS, which increases their capacity for assessments. However, if a 13-week target for starting the assessment were to be introduced, this would put pressure on numbers and undoubtedly reduce the quality of the assessments being provided. It is possible that assessments could be 'started' within the proposed times but this would be a misrepresentation of the actual times for people to receive a diagnosis as they would then have to go back on a waiting list for the assessment to be completed.

As at 2017, Powys had a waiting time of 17 months and approximately 70 adults waiting for an autism diagnostic assessment. Current capacity includes 2WTE staff trained to assess for autism spectrum but their roles are wider than just diagnostic assessment. It is anticipated that the team be fully staffed by autumn 2018. To reduce the length of time that people were on diagnostic waiting list, the Dyscovery Centre were commissioned to undertake adult autism diagnosis whilst the IAS was being established. This has resulted in 32 people accessing a diagnostic assessment. In addition, a suitably trained locum has been recruited temporarily to address the backlog Powys are currently operating a 10 month waiting time. Powys has reviewed the diagnostic process to explore how best to meet the ongoing demand but even so. As a result, it is evident that even when the IAS has a full complement, a waiting time target of 13 weeks will not be achievable unless the IAS becomes exclusively a diagnostic assessment service.

Across Wales 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 their capacity to offer any ongoing support post diagnosis. To meet a 13-week target would require, for example in Gwent, a serious reduction in 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 other than a one appointment, drop-in sessions on a monthly basis and a post diagnostic six-week course. The impact would be similar in all the other IAS services and details can be provided if needed. It would be impossible to resource a keyworker for anyone with ASD let alone everyone with ASD, as the NICE Quality Standards recommend.

CAV IAS is very concerned that a 13-week target would seriously impact the IAS capacity to deliver all of the other support it provides. 1:1 and group intervention to adults with autism and the parents and carers of adults and children and to provide the training, consultation and support to other organisations (essential in up-skilling the wider workforce). This would mean that adults with ASD and carers/parents of children and adults with ASD would not receive the support from the IAS that is currently available to them and for which they receive extremely positive feedback. Training, advice, consultation and joint working with other services would also be greatly reduced; this is essential to ensuring that people with ASD have improved experiences in all services they access, not just the specialist services. The impact of this would be that many services who are currently motivated to learn more about how they can support people with Autism would not access IAS support to broaden their knowledge and increase their confidence in this area, reducing the possibility of these services becoming more accessible for autistic people. It is well documented that mainstream services report a lack of skills, knowledge and experience in working with adults with autism and value support in this regard.

1. Whilst CAV IAS allocate significant resources to their diagnostic clinic, they also provide many hours of individual and groups support.
2. Examples of the feedback from people accessing the non-diagnostic services of the IAS:
 1. Because this is so necessary for us and other parents of autistic adults. We feel so positive about our situation after so many years of desperation, and the stress of not knowing which way to turn.
 2. Friendly service / support worker – (staff name). Help with structuring goals. Giving me more focus for my next steps.
 3. More confident in talking to other people. I now have the building blocks to build better coping mechanism for social situations. Made friends.
3. An example of feedback from a Mental Health Team professional:

‘I wish all of our services were as pleasant and straightforward to deal with..... Replies to email queries and support on offer to patient’s as well as referral process has been invaluable.’
4. Some examples of achievements of people using our service in the last few months include:
 - Two people who have received support from the IAS this quarter are also now attending Radio Platform and several people have said that they are making friends for the first time. This is in part due to their participation in the Socialeyes group.
 - Two people with ASD are now attending university following IAS support to link in the appropriate support services.

- Two people who were not able to leave the house are now leaving the house to attend IAS appointments. Furthermore, one is being supported to use public transport to learn Bee Keeping and the other has gained the confidence to drive again, is going to places independently, and is attending the Allotment group.
- Another person with ASD had wanted to attend a gaming group and had been playing on-line for two years without the confidence to attend in person. Following their attendance in the Socialeyes group, they felt able to join the group.
- A client with significant difficulties engaging in activities and with others now meets regularly with IAS staff for intervention, and also attends the weekly Allotment group. This person has said that this the first time they feel like have had help that meets their needs.

There is also a clear flaw in the proposals. Nationally we are aiming for individuals (in the majority of cases) to be given their diagnosis the same day the assessment is completed. When this does not occur it is because 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 discussion/appointment and/or information gathering through the use of structured self-reports or observations from other professionals. Theoretically all assessment could be started in a 13 week period to meet the target but it would not lead to a more efficient process as the assessment might not be concluded for 12 months. The IAS COP 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. Gwent IAS have received very positive feedback in relation to their 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.

The established 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? There are agreed national standards and pathways for diagnosis, and support in place.

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.

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.

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.

What would be lost by focusing on Diagnostic Assessments?

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, they have already provided training courses to mental health teams, DWP, Supported Housing Providers etc. They have jointly worked around 10 cases with mental health services. They 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. NB

The financial implications

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. Each IAS would need increased funding to the cost of meeting the additional demand of the 13 week waiting time. It would be anticipated that additional funds would need to be found with this new Bill from within the Welsh Government.

The diagnostic assessment is one step in people's journey with regards to autism services and whilst it is important that people do not have to wait for a significant amount of time for a diagnostic assessment, it must be recognised that this is a very small part of what they will require from services. It is short-sighted for the focus to be on meeting diagnostic waiting times, rather than taking into account all of the other work that is delivered by specialist autism services. The services would need a significant amount of additional money to clear their waiting lists and to keep within the proposed time-scales so that they do not compromise on the other work they deliver. However,

simply providing more money will not easily solve the issue with waiting times, because it is also about a lack of suitably qualified diagnosticians. Recruitment to some autism services across Wales is problematic because of a lack of staff with the necessary skills and experience. An additional role of the IASs is about generating interest in working in autism in those who are going through training, working across others services etc. Currently the Cardiff and Vales IAS provide support and advice about how others can develop their skills and offers placement opportunities. Increased pressure on diagnostic waiting times is going to reduce the time that the IASs can offer to students etc. It will also reduce the opportunities to conduct research, which is essential given the lack of research regarding effective interventions for this client group.

- **Data**

Data sets are being developed and rolled out within the IASs and ND teams therefore, the issues around autism data will be addressed. The level of data required and collected within the bill appears to be onerous and will offer little additional relevant information to inform both planning and commissioning. It does appear to be collecting data for data's sake and how GDPR compliant would this be?

- **ASD awareness, acceptance and understanding**

There is a great deal of work already being undertaken with regard to this by the IASs, the National ASD team, key professionals and individuals in each local authority area. Legislation would not add anything to this and may, by focusing funding on waiting times, and erroneous data, actually take resources away from this essential activity.

Community of practice August 2018