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Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill
Ymateb gan Gwasanaeth Awtistiaeth Integredig Gogledd Cymru
Response from North Wales Integrated Autism Service

North Wales Integrated Autism Service

Autism (Wales) Bill Consultation response

September, 2018



www.ASDinfoWales.co.uk

Background to the North Wales Integrated Autism Service (NWIAS)

The IAS is jointly hosted between health and social care with strong links to education. The Strategic Board is jointly chaired by [REDACTED] Chief Officer, Social Services in Flintshire County Council and [REDACTED], Director of Operations and Service Delivery at Betsi Cadwaladr University Health Boards' Mental Health and Learning Disabilities Division.

NW IAS offers continuity of support for Autistic individuals through the various transitions in their lives, and helps people achieve the things that are important to them. The service is for individuals who do not have moderate to severe mental health or learning disability.

NW IAS Comments on areas of the Draft Autism (Wales) Bill

IAS staff and members of the Strategic and Operational groups have contributed to this response.

1. Autism Strategy

The Refreshed Autistic Spectrum Disorder Strategic Action Plan and delivery plan have already been produced with considerable research in to the needs of autistic individuals, their families and carers.

Although through the IAS and other partners, we have been to continue to gather feedback from autistic individuals, 6 months may be a short timescale for the publication of the strategy given the work needed to continue to engage with the autistic community and to develop and implement an consistent national consultation for to identify priority areas. Resources would need to be identified for this process. The North Wales IAS welcomes review of the work against any action plan or strategy as our aim is to continue to improve and develop the services we provide to meet the autistic people of North Wales' needs.

2. Contents of the Autism Strategy

Much of the work described in section 2 is already underway as a result of the development of the IAS, in particular:

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| <p>(1) The autism strategy must— (a) establish a best practice model or models for the— (i) identification and diagnostic assessment of autism spectrum disorder; (ii) assessment of the care and support needs of persons with autism spectrum disorder; and (iii) planning for and meeting the care and support needs of persons with autism spectrum disorder;</p> | <p>This is now developing with the introduction of the IAS services across Wales. In North Wales, we are in the early stages of rolling out the service across the region. We would hope that ourselves and the IAS provision across Wales would be highlighted as best practice models, although we need to continue to develop the services over time to ensure we gather the baseline evidence. We are already gathering a catalogue of case studies to show the difference the service is making. The figure quoted of £30,037 to develop the strategy seems low given the extent of public engagement needed.</p> |
| <p>b) make provision for the development of a pathway, that includes access through defined points of referral, to map the services that are available and required for persons with autism spectrum disorder;</p> | <p>Pathways events have been held with colleagues across North Wales and with autistic individuals to discuss and agree pathways in to the service. We continue to respond to feedback on this. The staff are continuing to map the services and support available.</p> |
| <p>c) provide for diagnostic assessments and any post-diagnostic meetings to 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 the National Institute for Health and Care Excellence (but this shall not prevent the provision of any other services prior to the commencement of a diagnostic assessment);</p> | <p>The service’s diagnostic assessment work will begin in full from November 2018, and will work with colleagues across the Health Board to ensure individuals will not be waiting any additional time. We will also be providing support throughout the diagnostic process. We see this as good practice. There are concerns across the IAS nationally, that the pressure imposed on services to meet the 13 week waiting time from referral to first appointment will have a detrimental effect on the support element we are able to provide. We acknowledge that waiting times are an issue, but this is also linked to a wider workforce issue in that there is a relatively small pool of professionals who can undertake them.</p> |

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| | <p>It is positive that individuals who appear to have been referred inappropriately can be advised of this and possibly redirected to other services by clinicians.</p> <p>We would require more evidence on how the figure quoted of £4,362,563 will meet this requirement across Wales. One of our 'lived experience advisors' has stated that "once there has been a diagnosis, there was a lack of professional support", and that "the diagnosis means nothing without that help and support".</p> <p>https://www.youtube.com/watch?v=Lr-vGWyzylc</p> |
| d) make provision for individual diagnostic assessments to be conducted by a multidisciplinary team of professionals; | The NWIAS has employed Psychologists, SaLT, OT, a Nurse and Social Worker to meet this requirement. |
| g) outline how the needs of persons with autism spectrum disorder are to be met by relevant bodies in respect of, but not limited to,— (i) access to healthcare services; (ii) access to education; (iii) access to employment; (iv) access to housing; (v) access to Welsh language services; (vi) access to services in other languages; (vii) access to other public services; (viii) social inclusion; and (ix) access to advocacy services; | <p>The NWIAS is making links with a number of services across the region to support them in their practice with autistic individuals.</p> <p>The ASDInfoWales website also has a number of resources aimed at a number of these sectors to ensure they can access information to help them in their work with autistic individuals, and the NWIAS can support the implementation of these alongside the ASD National Team.</p> |
| (k) place an emphasis on how families and carers of persons with autism spectrum disorder can be supported in meeting the needs of those persons; | An element of the support provided by the NWIAS will be to parents and carers of autistic individuals. |
| (l) make provision for the wishes of persons with autism spectrum disorder and of their families and carers to be taken into account; | The NWIAS ethos is centred in 'What Matters' to the individual, in line with the Social Services and Wellbeing Act (Wales) 2014. |
| p) make provision for a campaign to raise awareness and understanding of the needs of persons with autism spectrum disorder | The NWIAS continues to promote the nationally recognised 'Can You See Me' campaign with partners, Elected Members and the community. |

q) make provision for the identification of key professionals and provision of appropriate (but not mandatory) training for them in relation to supporting persons with autism spectrum disorder; and

Through the NWIAS mapping of services, we are identifying partners who wish to undertake training, not only to raise awareness, but improve the standard of their practice to meet the needs of autistic individuals. We are also working with partners to identify Autism Champions as part of their service to act as a key point of contact. The IAS staff are being trained to deliver the resources and campaigns available, for free, on the ASDInfoWales site. The NWIAS have committed funding to the roll out of ASD training to CMHTs through 'Aspects', alongside other IAS in Wales.

4. Guidance by the Welsh Ministers

We would welcome more information on how the Welsh Ministers will be informed and advised of the changes needed to any future legislation, and by whom. We would seek reassurance that alongside the 'relevant bodies' and those who represent groups of autistic individuals, that a pledge is made nationally to gather the views of those who are more isolated, and more in need of the services offered.

Will the definition of carers (6b) be in line with the definition of carers in the Social Services and Well-being (Wales) Act 2014? For consistency and clarity of services to all carers, we believe this definition should remain.

"A person who provides or intends to provide care for an adult or disabled child."

6. Data on Autism Spectrum Disorder

We welcome the Bill's position in requiring services to record ASD diagnoses. 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 accurately identify whether or not research-supported internationally recognised prevalence rates are being adhered to, or exceeded or failing to be reached, within each of the 3 constituent areas of BCUHB and over the HB as a whole. These figures are absolutely essential in Wales being able to identify whether diagnoses are being made at appropriate levels.

It is inappropriate for ASD diagnoses to be missed and it is inappropriate for people without ASD to be 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, has demonstrated that such data can be efficiently and routinely recorded/analysed.

If diagnoses were to proceed without prevalence levels of comorbid conditions 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.

7. Awareness Campaign

The NWIAS feel that there is already an awareness campaign in existence through the nationally recognised 'Can You See Me?' campaign available for free, and bilingually, via the ADInfoWales website. The promotion of this is part of the NWIAS work plan and a change to this may be counterproductive at this stage. However, additional resource to further develop this campaign would be welcome.

In conclusion

Given the work that has already taken place, we feel it is not the time to introduce specific legislation on ASD, and to continue with Option 1 due to the following reasons:

- The Social Services and Wellbeing (Wales) Act MUST continue to be the primary piece of legislation for the wellbeing of ALL citizens in Wales. We must collectively promote new ways of working, person centred thinking and outcome based solutions based on the needs of individuals as part of our daily working practices for ALL people in Wales, regardless of condition. To make specific legislation based around one condition may dilute this work, and the emphasis on any comorbid conditions the individual may have.
- The links to comorbid conditions is not sufficiently referenced or clarified within the Explanatory Memorandum. Although it states this has been included in costings, further information is needed.
- There is a risk that the focus on waiting times will dominate the support element of services. Support functions will ultimately provide better value in the long term and ease pressure on other services, but more importantly give the autistic individuals, their families and carers access to the information, advice and assistance needed to build resilience, preventing crisis. It is important that clinicians can focus half their efforts on supporting families of clients with ASD, rather than be consumed by assessment work. Further information is needed on whether the Bill addresses the need to protect intervention time within services for these clients.
- The Bill and the Explanatory Memorandum make reference to building on that which already exists, such as the 'Can you see me?' campaign and Code of Practice. We feel that the existing work is currently meeting much of the requirements of the Bill. We acknowledge that areas need strengthening, and if any additional funding could be channelled in to these areas, improvements will be forthcoming.
- Further information is needed on the details outlined in the Explanatory Memorandum on the finance and where the funding will be sourced from. Will this work be at the expense of existing services?

- Services have often been criticised for the short term view on funding. The IAS across Wales need time to establish and deliver the outcomes they are designed for, and will be able to achieve. The NWIAS was formally launched in June 2018, with diagnostic elements beginning in November. We believe we can achieve great things with the support of our partners, lived experience advisors and staff, but need the time to be able to develop a service that works for the people of North Wales.

Recommendation

We recommend that we continue of the current timescales (**Option 1**) of funding and the review work Welsh Government have already commissioned before any large scale redesign of ASD services are considered.