

A06

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

Ymateb gan Fwrdd Iechyd Prifysgol Hywel Dda

Response from Hywel Dda University Health Board

**Response Form
Autism (Wales) Bill**

	The general principles of the Autism (Wales) Bill and the extent to which it will make provision for <u>meeting the needs of children and adults with Autism Spectrum Disorder (ASD) in Wales and achieve the aim of protecting and promoting their rights;</u>
1.	Comments:
1.1	This response should be read in conjunction with the Health Board's responses to earlier consultations. Whilst we strongly applaud the sentiments of this endeavour, we continue to have major reservations. We are grateful that the consultation was accompanied by the explanatory memorandum.
1.2	We remain not persuaded that a legal framework will act as a driving force to achieve the aspired outcomes. We are unaware of any robust evidence that the Autism England and Northern Ireland Acts have shown enhanced outcomes for autistic people. The explanatory memorandum does not cite any positive evidence acknowledging no apparent detrimental impacts. Some of our reservations are due to the principal of legislating for specific conditions leading to many potential unintended consequences (noted below in section 3).
1.3	There are no ready incentives or enforcers within the proposed structure of the bill, except for the data collection systems. Such systems would have to be significantly enhanced and empowered to drive and ensure compliance. Obviously such infrastructure would have its own internal costs. We question the ability to effect change without incentives and enforcement eg the limited to date impact of the ASD Employment Ambassador. As in an earlier Health Board response we continue to believe regulatory bodies including Estyn, HIW and CSSIW need to be explicitly mandated within any statutory instrument.
1.4	We welcome the honesty within the memorandum of recognising autistic people are receiving both effective and unfortunately ineffective interventions. The latter lead to lack of prudence in service provision with associated, potentially inappropriate financial consequences. However, we would suggest the modelling to date does not acknowledge the significant public attitude and service changes required to bring about the aspirations voiced within the bill.
1.5	There is no mention of the Mental Health Measure within the bill or explanatory document. The latter provides a potentially invaluable example of evaluating the impact of Welsh legislation on the population. Additionally, many autistic people will have been subject to the provisions of the act due to the high rates of mental health problems in autistic people. Experiencing emotional distress, development of behavioural issues and frank mental illness often leads to seeking a diagnosis across the lifespan. More sophisticated implementation of the measure could potentially enhance diagnosis assessment and interventions for autistic people without the need for additional legislation.
1.6	There is no recognition of the impact of the act in conjunction with the Mental Health Act (MHA England and Wales). The MHA is currently within a formal consultation stage and there has been much discussion about its impact for autistic people.

<p>1.7</p> <p>1.8</p> <p>1.9</p> <p>1.10</p>	<p>Singling out autism appears to oppose the long held political and social policy endeavours to reduce concepts of disability and difference. It could potentially hinder approaches to encourage inclusiveness and acceptability.</p> <p>Whilst awareness and diagnosis are important issues, far greater is the need for skills in actually accepting and understanding different developmental and personality styles across the lifespan. If a Bill were to proceed it would need to reflect such fundamental aspirations and strategic vision including recognition of the significant changes needed in public attitudes as well as services.</p> <p>We would support continuing observation of international and UK guidance; including the use of NICE standards, however, it should be noted that expert opinion indicates diagnostic processes need to be proportionate and competent. Unfortunately the bill appears to concentrate more on the identity of different professional groups and data collection. There is no mention of the requirement for different competencies and supervision structures. For example it would be unlikely if a multi-disciplinary autism team comprised of junior inexperienced practitioners, however broad the spread of specialities, could assess the full potential range of diagnostic and assessment challenges. Additionally there is also expert opinion that no single or combination of instruments equates to automatic valid and reliable diagnosis. Instruments are helpful in aiding clinicians to gain competencies and provide consistent assessments but do not automatically translate into valid and reliable assessments. Assessments are always reliant on the clinicians experience, judgement and interpretation.</p> <p>Unfortunately autistic people are vulnerable to having a number of comorbid general and mental health conditions across the lifespan. The bill and memorandum fail to recognise the complexity of the assessment processes sometimes required. People with other neurodevelopmental conditions are similarly vulnerable to comorbidities, a consideration if the remit of the bill were broadened to cover these client groups.</p>
	<p>Any potential barriers to the implementation of the provisions and whether the Bill takes account of them;</p>
<p>2.</p> <p>2.1</p> <p>2.2</p> <p>2.3</p>	<p>Comments:</p> <p>We believe devolved educational structures need to be specifically included as relevant bodies. It is increasingly recognised skilled educational provision can ameliorate many of the disabilities associated with autism. Unfortunately, many of the comorbid social and emotional difficulties evolve during adolescence. Many autistic people do not achieve their potential educational attainment levels and particularly need the opportunities for skilled, adapted lifelong learning approaches. Additionally there is emerging evidence autistic people have an uneven pattern of abilities and impairments. Educational opportunities need to be strategically planned to acknowledge these differences.</p> <p>Recent years has seen the development in West Wales of a multi-agency board to implement the Integrated Autism Service. Unfortunately there is no mention in either the bill or the memorandum of the need for integrated strategic, operational and financial arrangements. Whilst local developments are encouraging we are aware of the fragility of such structures, especially to effect change.</p>

<p>2.4</p> <p>2.5</p>	<p>In common with other rural areas, we have difficulties in recruiting staff to professional groups, such recruitment difficulties could act as powerful barriers to implantation.</p> <p>We appreciate the arrangements for professional training are not a devolved issue, however, we would suggest that without such approaches it will be difficult to bring about the changes required in this bill; and the already established autism acts/strategies in the other UK countries. We would respectfully suggest that this area is more formally explored at a strategic level between the UK Governments. We are aware there are already endeavours in the Royal College of Psychiatrists to change the training curriculum to reflect the need for enhanced competencies in neurodevelopmental conditions, including autism.</p> <p>The Health Board welcomes the targeted funding of services for children via the Together for Children and Young People Neurodevelopmental Programme and the Integrated Autism Service. However these initiatives have been associated with the funding of mainly staffing costs. Identification plus funding of staff bases and clinical settings are not included leading to challenges in new service development. Similar possible barriers to enhanced neurodevelopmental services could arise if further funding only concentrated on direct staffing costs without acknowledging the demands of vital infrastructure.</p>
<p>Whether there are any unintended consequences arising from the Bill;</p>	
<p>3.</p> <p>3.1</p> <p>3.2</p> <p>3.3</p>	<p>Comments:</p> <p>We would like to echo previous comments about the risks of a service based on a diagnostic category rather than proactive prevention of disability and meeting assessed need. The bill could result in pressures to under diagnose to act as a mechanism for rationing services and financial responsibilities. Over diagnosis could arise as a result of trying to obtain service especially in the current climate of constraints. There are real risks of services and resources being allocated disproportionately according to diagnosis rather than need. Additionally there are risks of sequential appeals and reassessments with associated distressing consequences for individuals and diversion of precious resources</p> <p>From its innovative beginning Welsh Government's strategic approaches to autism have promoted awareness and enhancing adaptations so autistic people develop fewer disabilities. These sentiments are totally in line with Wales' long standing stance trying to reduce the stigma and marginalisation of people with neurodevelopmental conditions including people with learning disabilities. Initiatives have always aimed to improve access to universal services as well as providing specialist services for those not able to have their needs successfully met even with significant adaptations.</p> <p>Whilst sometimes slow, there have been advances in universal services' competencies in supporting autistic people. Promoting single diagnosis specific teams can lead to halting of such developments if not carefully managed. The explanatory memorandum concentrates on direct diagnostic work without the balance of trying to ensure that enhanced diagnosis is also offered within generic services e.g. community mental health teams, in-patient psychiatric units, specialist learning disability services, educational and student support services, primary care.</p> <p>In the Hywel Dda area we are attempting to promote the above approaches of both offering direct services and enhancing competencies within generic services. Such duality of direct and indirect service approaches is also integral to WG's new Integrated Autism Services – due for</p>

local implementation in 2018. We are aware significant energies are needed to prevent silo formation.

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

4. Comments:

4.1 We welcome that some financial modelling has occurred, but there is no mention of forming integrated commissioning, contracting or other financial arrangements.

4.2 We would suggest further financial modelling would be enhanced by recognising the autistic people currently within specialist education, mental health and elderly care.

4.3 West Wales has had a history of long waiting lists for neurodevelopmental disorders. When the new Health Board ASD service model commenced in November 2015, the service acquired a historic waiting list of 633 people waiting for an assessment with some waiting over 5 years. Alongside this, the ASD Service received 373 referrals since November 2015, giving a challenge of 1006 referrals in total waiting for an assessment.

In April 2017 the Welsh Assembly introduced a new 26 week performance target for Neurodevelopmental Disorders and Health Boards are expected to reach 80% compliance against this target. To date, we have received 438 new referrals since April 2017. The new 26 week Welsh Government Performance Target is set at measuring the time from when a referral is received by the ASD Team to the first face to face assessment. There have been significant improvements in ASD waiting times for children and young people and the current waiting lists report the following:

ASD	Jan-18	Feb-18	Mar-18	Apr-18	May-18	Jun-18
Patients waiting >26 Weeks	263	256	249	222	198	191

For children Welsh Government has supported via the Together for Children and Young People's Neurodevelopmental Programme initiatives which are broader than a single diagnosis via recurrent funding. For example since 2015, the small multidisciplinary Neurodevelopmental team has assessed over a 1000 referrals for ASD and thus has made significant progress in reducing the historic waiting list. Additional recent funding from IAS has enabled us to prioritise the historic waiting list and young people approaching transitional age.

We have had a small adult Autism Diagnostic Service for over 5 years. The Health Board elected to retain the service originally formed from the All Wales Adult Network. The service consists of 1 WTE practitioner and 0.4 WTE Consultant Psychiatrist. Our current pattern of adult referral includes a monthly average of 20 referrals over the first 2 quarters of 2018. Over the five years in which the Adult diagnostic service has been operational the monthly average referrals per year has consistently increased. Our waiting time from referral to the start of assessment is currently fourteen months. This includes a waiting list initiative over the past 6 months. The new Integrated Autism Service (IAS) is due to become operational locally

	<p>in early 2019 with recent recruitment of key personnel. The IAS should allow greater capacity for adult ASD diagnosis but we would predict as with other IAS teams across Wales we will experience even greater demand and have accompanying lists. To enhance diagnostic provision would require increased revenue and recruitment of skilled personnel across all age groups.</p>
	<p><u>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).</u></p>
5.	<p>Comments:</p> <p>We respectfully suggest this section is considered in conjunction with the above, especially section 1.</p>
5.1	<p>There is increasing recognition and actual diagnosis of neurodevelopmental conditions across the lifespan. Factors influencing this development include greater recognition, changes in diagnostic classification systems and genuine increases in prevalence; the latter is associated with advances in clinical genetics, increased survival of premature and very sick babies, and the increasing survival rates for people with neurodevelopmental disorders. Additionally conditions such as schizophrenia and personality disorder are being recognised as having a neurodevelopmental trajectory. In summary an increasing proportion of the population could become eligible for the rights within the bill. There would be inevitable pressure to include more categories if associated with prioritisation and rights to service</p>
5.2	<p>People with neurodevelopmental conditions including autism are at higher risk of mental health conditions. If implemented the Bill would potentially prioritise some of their clinical journey in comparison with other service users. If they were being assessed for an autism diagnosis it would not be professionally and ethically appropriate to ignore comorbid conditions. People with neurodevelopmental disorders are increasingly recognised as also having a number of physical health conditions as an integral part of the disorders eg joint problems. Inevitably such conditions would be recognised within any diagnosis and assessment framework for neurodevelopmental conditions. Thus a Bill could influence the pattern of all universal health services to allow prioritisation according to diagnosis and not based on clinical acuity and need. We would suggest energies would be better used enhancing the competency and efficacy of universal services in including people with neurodevelopmental conditions and more ably recognise the heightened morbidity associated with these conditions; this needs to include public health and wellbeing preventative as well as reactive approaches.</p>
	<p>References</p>