

Cynulliad Cenedlaethol Cymru | National Assembly for Wales
Datblygu Bil Aelod | Development of Member Bill
Y Bil Awtistiaeth (Cymru) - Datblygu'r Bil | The Autism (Wales) Bill - Bill Development
DMB(5) AWB67
Ymateb gan Cymdeithas Seicolegol Prydain
Evidence from British Psychological Society

About the Society

The British Psychological Society, incorporated by Royal Charter, is the learned and professional body for psychologists in the United Kingdom. We are a registered charity with a total membership of just over 50,000 and are over 1,500 members in Wales.

Under its Royal Charter, the objective of the British Psychological Society is "to promote the advancement and diffusion of the knowledge of psychology pure and applied and especially to promote the efficiency and usefulness of members by setting up a high standard of professional education and knowledge". We are committed to providing and disseminating evidence-based expertise and advice, engaging with policy and decision makers, and promoting the highest standards in learning and teaching, professional practice and research.

The British Psychological Society is an examining body granting certificates and diplomas in specialist areas of professional applied psychology.

About this Response

This response was jointly led for the British Psychological Society by:

Dr Dougal Hare CPsychol AFBPsS, Division of Clinical Psychology and BPS Autism Task and Finish Group

With contributions from:

Dr Graeme Karger CPsychol, Division of Clinical Psychology

Dr Vaughan Price CPsychol, Division of Clinical Psychology

Dr Rebecca Saltmarsh CPsychol, Division of Clinical Psychology

Alison Clarke

Chair, BPS Professional Practice Board

Dr Paul Hutchings CPsychol AFBPsS

Chair, Welsh Branch

British Psychological Society response to the National Assembly for Wales Development of the Autism (Wales) Bill

Introduction

This consultation document outlines some of the key issues that my Bill will seek to address. Throughout the document there are a number of consultation questions posed to all interested parties. For clarity, all of the questions are also listed at the end of this document.

You can answer all, or some of the questions.

Background

Much work has been undertaken in recent years to improve the services and support for people with autism spectrum conditions, their families and carers. The Welsh Government's ground-breaking Autism Spectrum Disorder Strategic Action Plan, published in 2008, established an autism infrastructure in each local authority area, with local co-ordinators and strategies, and a Wales national co-ordinator. It expanded research capacity, raised awareness of autism spectrum conditions and made available a range of information and resources for both autistic people, their families and professionals. Additional funding was provided to all local authorities, although this was ring fenced only up to April 2015.

The Strategic Action Plan also recognised the need for better diagnostic services for children and adults with autism spectrum conditions. Awareness raising led to an increase in demand for diagnosis. However, in many areas there are lengthy waits for an assessment – in some cases of many years.

A Refreshed Strategic Action Plan 2016–20 is introducing further reforms, including improvements to diagnostic services which should lead to shorter waiting times, the development of a National integrated Autism Service, and measures to improve education and employment for people with autism spectrum conditions.

However, although the Strategic Action Plan has helped raise awareness of autism, implementation has been patchy and problems remain. Independent evaluation of the Strategic Action Plan, and the work of autism task and finish groups identified continuing gaps in services, particularly around diagnosis, transition to adulthood, employment support, and access to information on services.

Many people with autism spectrum conditions and their families still do not receive

the services and support they need to fulfil their potential. Whilst good practice and responsive services are evident in some areas, the local focus of the Strategic Action Plan has meant that provision has remained inconsistent across Wales. Furthermore, the voluntary nature of the local autism infrastructure means it is more effective in some areas than others. There is a need to ensure that people with autism spectrum conditions receive quality support wherever they live.

The need for an ongoing Autism strategy

The Welsh Government's Strategic Action Plan has made, and continues to make welcome improvements to autism services in Wales. Nevertheless, ongoing improvement is needed, and beyond the period of the revised autism Strategic Action Plan (2016–20) there is an increased risk to the continued prioritisation of autism.

In my experience ensuring that there are legal duties on public services and mandatory reporting on how well they are doing is essential to ensure:

- that services understand what actions they should be taking to support autistic children and adults effectively;
- that the momentum for improvement is not lost; and,
- that there is accountability on services to improve.

Both England and Northern Ireland have legislation requiring their governments to publish an autism strategy and guidance for adults, and for adults and children respectively. The Republic of Ireland is currently considering its own autism legislation.

I believe legislation should require the Welsh Government to develop, publish and review a national autism strategy on a periodic basis, in consultation not only with relevant public bodies, but also with people with autism spectrum conditions and others affected by it such as parents, other family members and carers. This would help secure a measure of permanence and sustainability in care and support services for people with autism spectrum conditions and ensure a continued, dedicated focus on their needs regardless of the financial or political climate of the time.

At this stage I do not believe that legislation should necessarily define the detail of such a strategy beyond the objectives I have set out for it, but that it should allow

sufficient flexibility to accommodate future needs.

I believe legislation should also require Welsh Ministers to issue, and periodically review, statutory guidance to local authorities and NHS bodies on their duties around the implementation of the strategy and arrangements for local services. The Bill should include some key areas and issues that the guidance will cover, although this list should not be exhaustive. Local authorities and NHS bodies should be required to act under the statutory guidance.

a. What are your views on the effectiveness of the current arrangements for improving autism services in Wales?

The Society welcomes the emphasis on initial assessment. However, we believe that there is an over-emphasis on this aspect of service provision at the expense of longer-term post-assessment rather than post-assessment support / intervention.

The existing Autism Strategy, Neuro-developmental Disorders work stream (*Together for Children and Young People (T4CYP) Welsh Government 2015*) and the Integrated Autism Service plan are likely to ensure the development of appropriate pathways to diagnosis for children and adults with ASD but it is not clear at present whether these services will develop to support people who have ASD following diagnosis and throughout their lives.

b. Do you believe Wales should have legislation requiring the Welsh Government to publish a national autism strategy for children and adults and issue guidance to local authorities and NHS bodies on implementing the strategy?

The Society believes that this should be in the form of clear and simple guidance for clinicians and it is not necessarily the case that legislation is necessary for this to be provided.

c. To what degree of detail do you think the content of a national autism strategy should be defined in legislation?

The Society believes that the proposed legislation should not define the content of the strategy as this should be done as a separate propose consultation with all interested parties.

d. What (if any) consultation do you think the Welsh Government should be required in legislation to undertake, when developing, reviewing and updating a national autism strategy?

Adults and children with Autism Spectrum Disorder (ASD), their families, charities who support them and professionals who work with them should all be consulted. However, it is essential that the strategy is evidence-based with reference to current best practice (NICE, 2015)

We believe that it should be clearer as to how the proposed legislation would facilitate this process.

e. Do you believe that legislation should define how often a national autism strategy should be reviewed and updated? If so, how often should it be reviewed and updated?

There is no current evidence or framework for determining how often a national autism strategy should be reviewed and updated.

f. Do you have any views on how Welsh Government should monitor what progress is being made and how public services should be held accountable for how they support autistic people and their families?

The Society would welcome the development of a monitoring programme and believes that the primary indices for progress should be the quality of life and well-being of both the person with ASD and their family.

Clarity on pathways to diagnosis

In many areas of Wales there is no clear pathway to diagnosis. Receiving a diagnosis of an autism spectrum condition provides many individuals and their families with a measure of certainty and greater insight into the difficulties they experience. It is also the key to accessing appropriate services.

I believe that establishing in legislation the necessity of a clear pathway to diagnosis, for each local health board area and local authority would make sure that regardless of where you live and what age you are, you could access a diagnostic assessment in a timely way. This would also enable health boards and local authorities to be accountable in law for the provision of a clear pathway.

g. What are your views on how easy it is to access a diagnostic assessment where you live?

Access to diagnostic assessment services is currently via referrals from medical practitioners, primarily paediatricians, and the current process is often lengthy.

The current neuro-developmental disorders work stream is working with agencies across Wales to develop pathways to diagnosis that are as consistent as possible

across the country (Neurodevelopment Diagnostic Assessment Pathway – T4CYP, 2015) and in the short-term, this work may be contributing to the long wait for diagnostic assessment.

It is hoped that access to diagnostic assessments will become easier, quicker and more consistent once the current Neuro Developmental Delay (NDD) work streams initiatives have been implemented.

h. What key challenges around how the diagnostic process works would you like legislation to address?

The Society believes that there needs to be recognition that not all diagnostic assessment result in a clear diagnosis of ASD and assessment services need to be aware of further assessment and intervention services / pathways as appropriate, both within the NHS and social services.

A significant issue relating to assessment and diagnosis is not a lack of legislation but the chronic under-resourcing for existing diagnostic services, which is exacerbated by locating diagnostic provision within under-resourced CAMHS teams. A consequence of this is that clinicians find it difficult to prioritise NDD diagnosis over working with young people with major mental health difficulties.

The new NDD work stream should begin to address this difficulty as their function will be to carry out diagnosis and post-diagnostic work with children with ASD and other NDD.

It is not clear at this stage whether new legislation is required for these developments to be sustained into the future and it would be appropriate to examine the situation in England and Northern Ireland to assess how useful legislation is in ensuring that effective diagnostic processes are developed and sustained when funding for public services is tightly constrained.

i. Do you believe that Local Health Boards and Local Authorities in Wales should be required to publish information on the pathway to diagnosis for children and adults living in their areas?

The Society believes that this information should be readily accessible.

Delivery of services

Historically, because of the way local services are organised into teams, autistic people are likely to come into contact with either a learning disability team or a mental health team if they go to local health or care services to ask for support.

However, while many autistic adults also have a learning disability or frequently experience mental ill health, autism itself is not a learning disability or mental health problem. Therefore frequently autistic adults, particularly those who don't also have a learning disability or mental health problem, are turned away from services or sent from one team to the other with no team taking responsibility for assessing and meeting needs. This can often mean that while their level of need means that they are eligible for support, local service structures stop them from accessing help. As part of addressing this issue, I would want to make it absolutely clear to local services that screening people out of support on the basis of their IQ must not happen.

My intention is that the Autism (Wales) Bill would ensure that boards and local authorities understand the particular needs of children and adults with autism spectrum conditions and provide a holistic range of services to meet them.

In order to provide effective services, health boards and local authorities need to know the extent of need in their areas. Under the Social Services and Wellbeing (Wales) Act 2014 they have a duty to assess the levels of need for care and support services in their areas and identify the range and level of services required to meet them. One of the core themes of these population assessments is learning disability/autism. Local authorities must draw up registers of children with disabilities in their areas and may do so for adults too.

However, anecdotal evidence suggests that there is currently significant variation in the scope and accuracy of information gathered. It is important that any population assessment identifies and recognises the distinctive needs of people with autism spectrum conditions. There is already a misconception among local authority social services that those autistic people who need help will also have a learning disability. Therefore without autism being recorded separately, there is a risk that the needs of those on the spectrum who don't have a learning disability will be overlooked. I want to ensure this doesn't happen and enable health boards and local authorities to address the gaps in local service provision.

I intend for this Bill to place a requirement on health boards and local authorities to establish data collection practices around the numbers and needs of children and adults with autism spectrum conditions so that local areas can plan services accordingly.

j. What are your views on the sufficiency of services currently provided to

meet the needs of people with autism spectrum conditions in Wales?

The Society welcomes the focus on improving diagnostic services but there is currently very little post-diagnostic provision to support children and their families after throughout their childhood and the transition to adult services.

In child services, there is a lack of clarity regarding in which service the needs of children with ASD and their families are best met (i.e. in Child Health or CAMHS). For example, the Tier 3 CISS service in Cardiff and Vale will not see children with ASD who do not also have ID, but the Tier 2 equivalent service will. The nett result is a lack of parity and equity in service provision.

In adult services, there are still problems for people with ASD but no significant intellectual disabilities who are routinely barred from ID services that continue to be allocated primarily on the basis of low IQ score rather than individual needs relating to specific developmental disorders such as ASD (DCP, 2015).

k. The legislation I am proposing would require the Welsh Government to issue statutory guidance that would put duties on local authorities and Local Health Boards on how they should be delivering services for autistic children and adults and their families.

Do you agree that legislation should require statutory guidance?

If so, I would like to know your views on which requirements the guidance should place on local authorities and Local Health Boards.

The following is a list of the areas which I believe should be included in the statutory guidance for local authorities and Local Health Boards. Please indicate:

- whether you agree that these should be included, and,
- any other areas that should be included.
 - i. The provision of relevant services for the purpose of diagnosing autistic spectrum conditions in children and adults.
 - ii. The fact that assessment of the eligibility of children and adults for relevant services cannot be denied on the grounds of the person's IQ.
 - iii. Planning in relation to the provision of relevant services to people with autistic spectrum conditions, as they move from being children to adults.
 - iv. Other planning in relation to the provision of relevant services to

children and adults with autistic spectrum conditions.

- v. Local arrangements for leadership in relation to the provision of relevant services to children and adults with such conditions.

The Society believes that all of the above should be included with particular emphasis on the eligibility of children and adults for relevant services cannot be denied on the grounds of the person's IQ.

I. Do you believe that Local Health Boards and Local Authorities in Wales should be required to establish and maintain new data collection practices around the numbers and needs of children and adults with autism spectrum conditions so that local areas can plan services accordingly?

The Society would welcome the collection of such data and believes that mandatory data collection could be extended to for children who are referred for assessment but who do not meet the criteria for ASD diagnosis.

m. Do you have a view on how data can most effectively be gathered, on the numbers and needs of children and adults with autism spectrum conditions in different Local Health Board and Local Authority areas in Wales?

Data on both pre-assessment referrals and post-assessment outcomes could be usefully collected, preferably with standardised assessments and metrics for the whole of Wales.

It would be useful to look at similar mechanisms in England and Northern Ireland.

Although an example from adult mental health provision, the use of standardised assessments is undertaken in the IAPT service in England and demonstrates the feasibility and utility of a centrally-administered assessment and data collection (NHS Digital, 2017)

Training

I intend that the Autism (Wales) Bill will ensure that key staff working with people with autism spectrum conditions, receive appropriate autism awareness training.

I recognise that a significant number of staff working with people with autism spectrum conditions have already received training through Welsh Government led initiatives.

I also recognise that there is a need for flexibility around the content of the training.

Nevertheless, I believe that legislation could promote consistency of training outcomes across all regions; provide a clear means by which implementation and maintenance of such standards can be monitored; and secure the delivery of such training on an ongoing and permanent basis.

I am minded to take an outcomes based approach in guidance on training requirements to allow flexibility on how training is provided while securing better awareness of autism amongst relevant staff.

n. Do you have a view on the current scope and effectiveness of training in Wales for key staff working with people with autism spectrum conditions?

There are two Clinical Psychology training programmes in Wales based at Cardiff University and Bangor University and they are an important resource in terms of both the training of senior clinicians to implement assessment and diagnosis of ASD and to support wider workforce development. Both programmes currently have an increasing emphasis on intellectual and developmental disorders, including ASD.

The Society strongly recommends that the current funding arrangements for clinical psychology training in Wales should be retained in order to give stability and facilitate continued professional training.

o. Do you believe that legislation should specify outcomes that training should achieve, thereby providing greater flexibility around the delivery of such training?

An alternative approach would be for legislation to specify that key staff working with people with autism spectrum conditions should undertake autism training

Please explain your answers if possible.

The Society believes that key staff should receive appropriate training and the role of clinical psychologists in training and developing of the ASD workforce should be acknowledged and developed.

Employment

The Welsh Government's Strategic Action Plan recognised that work was needed to promote employment of people with autism spectrum conditions and to provide employment support to individuals. An Autism Employment Ambassador provided training and awareness on autism to employers and employment support providers up to April 2016.

Nevertheless, rates of employment amongst young people and adults with autism spectrum conditions remain much lower than for the general population and further work is needed to address this.

The Welsh Government's Refreshed Strategic Action Plan 2016–20 is introducing further reforms around improving education and employment for people with autism spectrum conditions. These include work on the Getting Ahead employment support programme for young people, action to make the Welsh Government an autism friendly employer, and work with employers and support staff to raise awareness of autism.

p. Do you have any suggestions for additional action that could be taken through legislation to improve the rates of employment of people with autism spectrum conditions (bearing in mind that the National Assembly for Wales does not have the power to make changes to employment law)?

Please explain your answer if possible.

The Society believes that legislation should be drafted to acknowledge the role of appropriate ASD-specific mental health service provision in supporting people with ASD enter and maintain meaningful employment.

Definition of autism

I intend that this Bill would address a wide spectrum of needs of people with autism spectrum conditions in Wales. Existing legislation in other parts of the UK has taken varying approaches to providing a definition of autism: in some cases it is set out on the face of the Act, in others it is in a strategy, or guidance. My approach would be to require a definition of autism to be included in the autism strategy, as it is at present, and for this to be updated from time to time as necessary.

q. Do you believe that a definition of autistic spectrum disorder should:

- be included on the face of legislation (which makes it more difficult to change in the future);
- be included in an autism strategy;
- be included in guidance; or,
- not be stated at all?

Please explain your answer if possible.

Given that the definition of ASD has changed (For example, from DSM IV to DSM V) in the light of emerging scientific findings, The Society recommends that the

legislation refers to 'current definition of ASD' rather than including the current definition.

The inclusion of current DSM-V definition of ASD in the autism strategy is appropriate and is to be recommended.

Unintended consequences

I will carry out a range of impact assessments on my proposals as I develop the Bill to make sure that it does not adversely affect people with autism spectrum conditions, people who aren't on the autism spectrum, staff involved in the delivery of autism services, organisations or other areas disproportionately.

r. Can you identify any possible unintended consequences which could arise as a result of this legislation? If so, what steps could be taken to deal with them?

Please explain your answer if possible.

The Society believes that the existence of specific legislation relating to ASD might exacerbate the current situation in which parents of children with other forms of intellectual disabilities, particularly those associated with co-morbid with ASD / autistic traits, for example Fragile X Syndrome (cf Hall et al 2010)), will perceive that their children's needs are not considered to be as important as those of children with ASD. This can result in such parents seeking an additional diagnosis of ASD in the belief that this will result in additional services and support that is otherwise unavailable except for children with ASD.

Costs

Most legislation will bring with it costs of some kind. I believe the main potential areas of costs for this Bill are likely to be around:

- gathering relevant information and developing a national autism strategy;
- periodically reviewing the strategy and issuing guidance and communicating changes to legislation;
- additional duties for local authorities and NHS bodies to act under guidance;
- creating and maintaining practices to enable the collection of data on the numbers and needs of adults and children with autism spectrum conditions; and, training for key staff.

The Social Services and Well-being (Wales) Act 2014 already places a statutory duty on local authorities to establish information, advice and assistance services, including to people with autism spectrum conditions, their families and carers. I believe that this could be extended to publishing information on services specifically for people with autism spectrum conditions in local authority areas at little or no additional cost. The Refreshed Autistic Spectrum Disorder Strategic Delivery Plan 2016–2020 also says that Local Health Boards provide advice and support for all people with autism including family and carers as part of the new Integrated Autism Service.¹ Again, I believe that this could be extended by the Bill to include awareness-raising by local health boards at little or no additional cost.

s. Do you believe that the proposals in this consultation would give rise to any substantial costs, in addition to the cost-areas already noted in this consultation? How can such costs best be mitigated?

The Society believes that assurances are required that the costs incurred in preparing, passing and compliance with the proposed legislation will not result in reduced spending and services, whether extant or proposed, for people with ASD.

t. What would the impact or costs be in terms of:

- i. producing a national autism strategy;
- ii. placing duties on local authorities and NHS bodies to act under guidance;
- iii. creating and maintaining data collection practices on the numbers and needs of adults and children with autism spectrum conditions; and,
- iv. providing training for key staff?

The Society has no comment to make.

u. Do you envisage any other additional administrative and regulatory costs as a result of this legislation and if so, how can any such impacts be mitigated?

The Society has no comment to make.

v. What factors should be measured to determine the cost-benefit analysis of this legislation should it become law?

Please explain your answers if possible.

The Society recommends relevant health economic analyses that examine the life time cost-benefit of implementing pro-active services for people with autism (Knapp, Romeo & Beecham, 2009) and it is recommended that these should be

consulted.

Savings

Legislation can also give rise to financial savings.

The National Audit Office in its publication “Supporting people with autism through adulthood”, emphasised that if services identified and supported four per cent of adults with what it describes as “high functioning” autism spectrum conditions in the local area, then the outlay would be cost neutral over time in England.

Identification of six per cent and eight per cent could lead to potential savings in England of £38 million and £67 million per year respectively. This provides evidence that savings could be made based on effective identification and support of individuals with high functioning autism.

w. Do you have any views on how savings that might arise from this legislation can most effectively be identified and calculated?

While investing in early assessment, diagnostic and intervention services is likely to save money in the long run (Knapp, Romeo, Beecham 2009), the link between such investment and legislation is unknown and The Society would recommend examining whether similar legislation has led to improved outcomes and long-term cost savings in England and Northern Ireland.

Other issues

This consultation is the beginning of a process of engagement with stakeholders as I develop my Bill. I welcome comments on any issues that I have not raised here that may be relevant.

x. Do you wish to make any other comments on my proposals?

The Society has no comment to make.

References

Division of Clinical Psychology, Faculty for Intellectual Disabilities (2015) Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood.

Leicester, British Psychological Society

Hall S.S., Lightbody A.A., Hirt M., Rezvani A. & Reiss A.L. (2010) Autism in Fragile X Syndrome: A Category Mistake? *Journal of the American Academy of Child and Adolescent Psychiatry* 49(9) 921–933

Knapp M., Romeo R. & Beecham J. (2009) Economic cost of autism in the UK
Autism 13(3) 317 – 336 DOI org/10.1177/1362361309104246

Neurodevelopment Diagnostic Assessment Pathway (T4CYP) (2015)

<http://www.asdinfo.wales.co.uk/children-diagnostic-pathway>

Improving Access to Psychological Therapies (IAPT) Data Set (2017) NHS Digital

<http://content.digital.nhs.uk/iapt>

Together for Children and Young People (T4CYP) (2015) Welsh Government

[http://www.wales.nhs.uk/documents/Framework For Action.pdf](http://www.wales.nhs.uk/documents/Framework%20For%20Action.pdf)

Quality Standard – Autism [QS51] (2015) NICE

<https://www.nice.org.uk/guidance/qs51>