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) AWB73
Ymateb gan Cardiff and Vale Integrated Autism Service
Evidence from Cardiff and Vale Integrated Autism Service

# Consultation Questions

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

The current arrangements reflect two main strategies, the IAS is an all-age approach that has been applied across Wales. There is also the National Together 4Children and Young People Neurodevelopmental (ND) Workstream, which addresses diagnostic assessment and aspects of intervention to the population under the age of 18.

Driving change directly from WG in this way, as a National IAS in conjunction with the revised WG ASD strategy has seen buy-in from Regional Partnership Boards. Representatives at Senior Management and councillor levels are committed to and leading change in their service areas for people with ASD, including monitoring the progress of the newly forming IAS.

Wales is the only country in the UK to achieve this without needing legislation to underpin responsibilities.

However, this approach has not been widely consulted and facilitated consultation with professionals involved in the service would support implementation of the new IAS. Nationally there is an emphasis on low-level awareness tools; greater emphasis on supporting professionals would be beneficial. The materials available have not been created with the input from a wide range of professionals, which could have strengthened their effectiveness.

Child ND services are not sufficiently funded to provide services to parents who require post-diagnostic support.

The Neurodevelopmental teams accept referrals of all young people presenting with needs that suggest an underlying developmental difficulty, which affects their functioning and well-being. There is huge overlap in presentation between aspects of autism, ADHD, learning difficulties, developmental trauma (ACE) emotional or mental health needs. An isolated focus on Autism with no capacity to address developmental trauma or other conditions such as ADHD will miss a clear opportunity for partnership work given the national interest in ASD, developmental trauma, Adverse child hood experiences, adult mental health, offending and antisocial behaviours.

To summarise, there are a number of existing services in Wales that support individuals with ASC both specialist and generic which promote an inclusive approach to supporting individuals with ASC.  The Cardiff and Vale ASD local action plan provides the regional partnership board with an update of areas of progress and unmet need to support a collaborative, and where possible, integrated approach to gap filling.  This in turn informs the commissioning activity to ensure the broadest offer of services to all individuals with ASC, parents and carers.

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?

No, Wales currently has a refreshed Autistic Spectrum Disorder Strategic Action Plan Wales (ASD SAP), which was first published in 2008 and revised in 2016.  This has led to significant investment into services for people with ASC from Welsh Government.  The work to create a national IAS, in addition to the revised ASD SAP and local action plan is delivering the outcomes that an Autism (Wales) Bill would promote. Regional Partnership Boards across wales have shown commitment and resources to drive forward improvement and change for individuals with Autism and some areas have already invested core funding to improve service development. The IAS and the ASD SAP provide the guidance and direction to underpin requirements

Further legislation would be costly – potentially using resources that could directly benefit people with ASDs in other ways, time consuming and bureaucratic with emphasis on legal requirements and tribunals.   This approach would be unlikely to offer additional benefits not offered by the current ASD SAP. This could affect services by impacting their input to deliver direct care and support, with the potential requirements of new legislation reducing the creativity to develop services based on needs.

The Act in England was a useful force to drive development of a strategy for implementation and was helpful for clinicians to ‘persuade’ commissioners of the gaps and the need to fund services. However, it seems that we are now beyond this point in Wales and it would be an unnecessary use of public funds. Services now need time and buy-in from partnership organisations in order to be able to deliver with an emphasis on a national agreement and quality standards to address delivery of services across Wales. This would require solid partnership working and cross-departmental government support, there would need to be a mechanism to achieve this to achieve status and prioritisation given austerity.

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

Legislation is a slow and costly process, applying too much detail would slow it down further and the strategy detail would soon become obsolete rather than being able to change over time in response to the work that is being done and the experience of people with ASC. It would potentially also remove the mechanisms for engagement in the details of adopting and updating an autism strategy.

There are critical interfaces with developmental trauma, ADHD, learning disability, specific learning difficulties and so forth that any ASD specific legislation could ignore to the detriment of our population. Autism legislation is too specific, it immediately creates inequity. Many families may express frustration at services if an autism diagnosis is not achieved, due to a perception that a diagnosis of autism will offer the suggested benefits of ASC specific services. This would lead to a perverse incentive to apply this diagnosis when in reality a broader description and a variety of approaches may be more constructive.

If an Autism (Wales) Bill were passed, the detail would need to be similar to that within the Social Services and Well Being Act, Prudent Health Care and the ALN Bill, which have strength in being inclusive and based on need, given the inextricable links for citizens across existing legislation. Should the content require more detail, then the advice of specialist professionals within the field must be sought to provide a robust clear set of guidelines that will stand the test of time as developments in assessment, treatment and interventions emerge within the field of ASC and other neurodevelopmental conditions.

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?

Any national strategy created without appropriate consultation will be weak and subject to challenge. Consultation should cover all the agencies and all levels, citizen engagement and specialist engagement where needed. Stakeholders should include parent carers, adults with the condition, clinicians in the field and in mental health, social care, third sector and public sector.

This should be collected in many formats and be accessible to all, including to members of minority communities and for people using alternative communication systems.

A consultation should be widely advertised, with care taken to engage the wider ASC community, including people who are most isolated and struggling to get support.

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?

Any legislative approach has the capacity to introduce timescales. If this was the agreed outcome of this process, the strategy should be overseen by an expert body with links to current research and professional practice and the capacity to combine these with population needs assessment data. However, if a renewal update interval is specified, the national strategy will only be updated at that time. The reality is that implementing other legislation should trigger a review. Any legislation should not define the review timescale, but define the conditions of when a review should be commenced. The challenge (of legislation) would be to make it responsive and current; can this be achieved with a more dynamic process, or is legislation needed because this is the only way to ring fence resource at a time of austerity and competing influence?

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?

A process of base-lining to inform the setting of accountable targets need to be undertaken – which is currently in process via the IAS in this area.

Additionally high- level outcomes to be achieved must be defined and sensible reporting mechanisms are required – these are in place now to measure the success of the IAS but it is too early to tell whether this will provide the data WG sees as sufficient in understanding how people with ASD are supported across the area.

Robust reporting of outcomes for people with autism  needs to be more than ‘numbers’ and should to include qualitative info, especially given the lack of effective evaluation measures that demonstrate change for people with autism. The inclusion of case studies in reports as well as any compliments and complaints received would support this.

A sustainable method of evaluation would be to develop links with relevant local masters and PHD courses and invite these students to carry out this qualitative work.

There are, at present two different approaches: the IAS has proposals re reporting that are at an early stage of delivery.

The Neurodevelopmental workstream under T4CYP has six standards agreed by health board teams across Wales with a new set of qualitative and quantitative measures proposed- pending discussion in next the next national ND steering group

There are many additional service measures proposed by mental health services, YOTT, WLGA relating to the many additional aspects of behaviour and adverse experiences that overlap with Neurodevelopmental conditions.

Progress on outcomes would need to be broader than an isolated autism approach, this would be challenging and require a strong partnership basis.

As a result there is a risk of duplication in reporting overlapping with the above and the Social Services and Wellbeing Act and the ALN Bill and a robust ASD Sap local area action plan could potentially provide an opportunity to measure outcomes across each region.

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

This question will be debated, there being differing perspectives- there is a clear referral process now in place for adults based on the IAS work however this is relatively new.

For adults the assessment process is simple, straightforward and accessible with support services available for those who may find this process difficult. Some clinicians have expressed concern as the process transitions from previous arrangements to the diagnostic process defined under the Integrated Autism Service guidance. Once the new process is embedded, clinicians will cease to have these concerns.

For children and young people there is a new ND diagnostic process. The demand for assessment exceeds current capacity. Accessing an assessment is now straightforward, however work is required to develop ND services further as the increased awareness raising of autism has been successful and has exposed significant demand for services. It is simple for children and young people to access a high quality assessment for diagnosis in Cardiff and Vale, however there are waiting times.

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

The only challenges Cardiff and Vale are experiencing at present are around the transition to the IAS which enhances the diagnostic process and the resources required to meet demand for children's diagnostic work.
Cardiff and Vale have a good process for both children and adults, including the relevant clinical skills within this process, which are underpinned by NICE guidelines, IAS guidance and strong links with the university to ensure we are continually evaluating practice and enhancing the service.

A potential gain if legislation were to be passed would be in relation to securing resource to enhance capacity and identifying the minimum expectations for people to be able to assess and diagnose, especially partner professionals outside of the IAS.

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?

Yes – this is already in place with continuous improvement in place through the regional steering group although more effective reporting would be facilitated if there was an overarching approach which included IAS, ND, CAMHS, AMH - this would be clearer for the public and more efficient for services.

j) What are your views on the sufficiency of services currently provided to meet the needs of people with autism spectrum conditions in Wales?

This is a very broad question as services currently working to meet the needs of people with autism include those specific to children or adults, diagnosis, education, information, social care, third sector, day services and residential support. A recent scoping exercise identified significant service delivery across Cardiff and the Vale for both specialist and inclusive services and further work will be required in this area to fully understand if gaps in services still remain post-commissioning.

Expectation within the population is high including demand for services; LAs and UHBs are working closely together to improve access to services for those most in need and support to community- based services, who are best placed to support people closer to their own homes.

All service areas are challenged with austerity, with those most in need being prioritised for care and support. However, resource envelopes for grant- funded projects are also shrinking with regional areas pressured to consider how best to meet the needs of the wider population.

This affects all individuals and not just those with ASC, and areas will need to consider their population needs assessment and local data to make informed decisions about how best to resource services for people with ASC.

Where possible, people with ASC should be enabled to access services that support all individuals, with specialist services being available for those most in need. The new specialist IAS service meets this need, but it is too early to state whether this will be sufficient, as the resources allocated from WG have not been based on population needs assessment.

The ND service has prioritised assessment of individuals and resources allocated to Neurodevelopment are perceived as inadequate as a direct result of services being unable to provide specialist clinical interventions.

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, does the following list cover the right areas to be included under the duties on local authorities and Local Health Boards?

i) The provision of relevant services for the purpose of diagnosing autistic spectrum conditions in children and adults.

This is already in place in our area via the IAS guidance ASD Strategy and ND pathway in our local area.

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.

Services for individuals are based on need and not IQ – an individual requesting assessment of a neurodevelopmental condition would be assessed on their presentation, not by their IQ. This is covered in the Social Services and Well Being Act.

Services post diagnostic can be accessed based on IQ (typically LD services) however this is a threshold for care and support services/health services based on the needs of those with significant learning needs, which may include a diagnosis of ASC.

iii) Planning in relation to the provision of relevant services to people with autistic spectrum conditions, as they move from being children to adults.

Guidance is required to define what constitutes a relevant service. There are many existing services. It should be considered that an individual with autism is an individual first, services will therefore need to be based on anticipated and evidenced needs – with consideration of making other services autism "accessible "

This is covered in part in the guidance for the IAS and the ASD SAP in the development of lifespan services and approaches to individuals with ASC. Planning for services for individuals with ASC is included in the popu;ation needs assessment and could be improved by legislation to put in place a register for those with ASC in order to better understand and predict existing and future care needs

Legislation could be one method of clarifying details around transition such as which agencies should work with early teens, and young adults.

iv) Other planning in relation to the provision of relevant services to children and adults with autistic spectrum conditions.

In order to answer this question, further guidance regarding what is a relevant service would be required. There are many existing services developed and delivering in our local area based on the needs of the population. These services continue to inform planning arrangement for the future via the local area plan and ASC steering group.

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

This is covered by the Regional Partnership Board in line with the recommendations within the Social Services &Well Being Act. For Cardiff and Vale, the Disability Futures Programme oversees the leadership and development of services for all children with disabilities, individuals with ASC and adults with learning disabilities.

At a local level, there is a high degree of coordination between IAS and ND services as a result of individual efforts and oversight of the disability Futures Programme. This is also occurring in other Health Boards, but is not uniform as it is dependent on individual motivation and regional governance.

This will be achieved locally by inclusion of this into the local area plan.

l) 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 autistic spectrum conditions so that local areas can plan services accordingly?

Having information on numbers of people with ASC would be unlikely to accurately capture the true figures given that many people are still undiagnosed.

Services should be planned based on national prevalence figures and population needs assessment.  Local areas, where required, should aim to make their population needs assessment more robust the inclusion of autism alongside learning disability for this purpose does not help.

Daffodil already provides numbers per area on basis of prevalence and there is already a disability index across Cardiff and the Vale, 0-18 years.  It could be seen as discriminatory to single out those with ASCs for inclusion in an ASC- specific register. There will be data collected via PARIS/ other data systems and care should be taken not to duplicate this.

The WCCIS needs to make further progress.  A focussed resource and support to deliver this will improve data collection across Wales.  Currently, there is national variation across Wales of IT and performance management systems, which can only support with effective planning based on local needs.

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?

Daffodil and the Index of children with additional needs provides numbers per area on the basis of prevalence.  The collection of data in these ways needs to be voluntary, not compulsory and should come with a function/incentive for people to want to register.

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?

The IAS has funded access to training in ADOS, DISCO and ADIR across Wales, although further access will be needed to ensure national consistency for areas which are newly or yet to roll-out their IAS.   Additionally the ASD info website have a training framework, which was taken from the Scottish one, but the material appears to be aimed at the basic level and does not cover more specialist skill sets.

There is plenty of training, which is high quality and effective, but resources to train, release staff and implement are challenging given the pressures on services to do more with less.

Training is available across all service areas both to staff and parent carers facilitated by those specialist skills in autism.  There are strong links with

Education who provide evidence based programmes and training across Cardiff and Vale.

A robust definition of “Autism Training” is needed to ensure that training resources are used effectively and support national consistency.

There has been discussion within T4CYP and TFMH of training needs analysis, the reality is that there will be local variation in needs so access to a set of evidenced and effective training programmes would be helpful. Peer review and governance mechanisms should be considered alongside training needs.

Any estimate of service capacity must take into account the time allocated to achieve training needs

Any process must be linked to evolving research and clinical practice; it would be helpful for all the IAS teams to share and develop training materials and packages and ensure that all offer similar levels of quality and content. Many of the IAS staff will already have great resources and experience in training others.

Training across agencies and different professional backgrounds would need to be considered as the teams are from multiple backgrounds.

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

We do not see this as a function of legislation, the guidance for the IAS has provided clear enough outcomes for individuals working with people with ASC. Any outcomes specified must link to monitoring and accountability, wider outcomes and the question of relevant services.

The risk is that specifying outcomes of training would reduce flexibility of delivery rather than encouraging it.

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

The range of training needs within the cohort of staff working with people with autism are vast. If the guidance states “commensurate with the role”, then that has to be defined. The published national training framework http://www.asdinfowales.co.uk/resource/Training-Framework-digital-eng.pdf contains only links to low level awareness resources on ASDinfo.

Given the prevalence of ASC within the general population all staff should be able to access training and awareness. A similar approach to the dementia friend model should be considered.

q) 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)?

No suggestions that can be achieved through legislation – difficulties can be encountered due to agencies such as DWP not being devolved.

“Positive role models” as seen in the dyslexia movement on social media could help to reduce negative impact of comorbid difficulties through appropriate support and through improving well-being and therefore functionality in a competitive work place.

The most vital elements are training, support, awareness/ understanding raising within workplaces and partnership working from specialist autism services to employment support services (both specialist and general) is essential on an ongoing basis. Also, other initiatives specifically for people with autism need to be funded which can allow for things like ‘working interviews’ etc. However, none of these would require legislation to implement.

r) 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?

Autistic spectrum disorder is defined by DSM V and ICD 10. If a definition of Autism is included in legislation there is a real risk of it becoming obsolete; diagnostic manuals get updated periodically to avoid this.

A discussion about differing views/ opinions/ labels etc. would be essential in any guidance as it is a challenge to give one clear definition.

Use of the term Neurodevelopmental disorder is broader and reflects the way people present with a range of needs, it also allows for what we see in clinical practice- that comorbidity and overlap of conditions is the rule rather than the exception.

s) 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?

Implementing legislation for a specific outcome creates a risk of adhering only to the legislation and reducing creativity and innovation. Potential to design and deliver creative services is negated if legislation for just one condition, autism, progresses. Other services, such as diagnosis, are moving towards a neurodevelopmental approach. Children and adults often have comorbid conditions. Having a single piece of legislation for a single condition may reduce innovation, flexibility and the opportunity to respond to local need. People should have the right for their needs to be met by the services and professionals best qualified to do so and allocating resources and services according to diagnostic labels will exclude others.

Legislation may create reasons for services to introduce eligibility criteria/ exclusions whereas, at present services are designed and delivered based primarily on presenting need.

t) 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?

u) 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?

We would anticipate this would incur more cost similar to those incurred as a result of the Social Services and Well Being Act and ALN Bill and the resource intensive process of embedding new legislation. We would question whether this is the best use of resource at a time of austerity when significant resource has been invested in setting up the new IAS service and existing resources are invested into maintaining and reviewing the ASD strategy.

We have already outlined the need to address capacity in the system, unless more resources are made available through WG, then LA and UHBs will be limited in their response to legislation. It may be more prudent to direct resources towards existing services.

Further information as to the aims of this act would be required to offer a fuller response in terms of whether costs are acceptable and commensurate. Particular guidance would be needed about monitoring and accountability, relevant services and training in order to fully estimate costs.

If a long term view is considered then an initial cost due to legislation could pay off in the future if individuals with autism are able to live independently, work, stay well, and engage in their communities like everyone else – reductions in support costs, benefits, reduced sickness and absence, better physical health outcomes.

However, it cannot be stated that legislation is the only method of achieving these positive outcomes.

v) 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?

Yes – experience shows that legislation is costly. These costs are not mitigated, rather they are absorbed and acknowledged that with legislation comes more monitoring and associated administration. We know that our population want access to more services, and WG would need to advise local areas on how to respond to citizen should they choose to invest resource into legislation and the resource requirements to maintain this.

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

There are no cost benefits as £13m has already been invested into improving services for people with ASC. Imposing legislation would undermine the intention this investment is making by stating that legislation is still required. Lessons learnt from England show that irrespective of legislation, services have to work within the resources they have available, taking into account the population of people who need support most. The best cost benefit would be from investing in the workable model already in place rather than in a process to legislate for it.

If legislation were to be passed, then definitions of terms like “relevant services” would be required before any cost-benefit measures could be considered.

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

It is unlikely that savings will be achieved through the implementation of legislation. Any benefits that could potentially be achieved may not be felt by the Welsh Government, but rather by Central Government. For example, providing a service to support adults into employment is very positive and has the potential to provide a saving, as fewer benefits would be paid to individuals with ASC but that saving would be felt in Westminster not Wales.

Savings will be achieved in the implementation of the Social Services and Well Being Act and the ALN Bill (of which both are inclusive of people with ASC) and regional areas should be given the time to demonstrate the financial benefits of working together.

The coordinated delivery of services in a lifespan model that addresses co-morbidity and functionality would theoretically reduce costs and improve outcomes.

y) Do you wish to make any other comments on my proposals?

The timing of this request is challenging. At a time where WG have made significant investment into ASD, it has to be questioned what additional benefits legislation would provide us at this time. If in 3 years the services developed prove to be unsuccessful or there are still areas of unmet need then this could be revisited.

It is wasteful to seek to implement this at a time where there is so much positive improvement across Wales, with the opportunity to showcase to other countries the developmental possibilities without the need for expensive and lengthy distraction of legislation which could undermine and weaken this approach.