

Cynulliad Cenedlaethol Cymru
Bil Awtistiaeth (Cymru) drafft
Llythyr Ymgynghori DAB05
Ymateb gan Y Gwir Barchedig Dr Ryan
Cleminson OSB DD, Esgob Esgobaeth
Tyddewi a'r Drindod Sanctaidd (Cymru),
Esgobaeth Sanctaidd Antioch, Hen
Eglwys Gatholig Apostolaidd

National Assembly for Wales
Draft Autism (Wales) Bill
Consultation Letter DAB05
Evidence from Rt Reverend Dr Ryan
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History of Autism and The Argument

The Autism Bill (Wales) argument is something that has been a long running debate both inside The National Assembly for Wales Senedd and outside the corridors of power there have been many questions and statements raised in Senedd and it is mine and my organisations view that this time when Paul Davies brings forward his bill it may actually have a decent chance of succeeding in reaching the statute books and being passed into law, which would be great for the autistic community the length and breadth of Wales. If it replaces the broken system we currently have now then it is an absolute bonus.

I have raised the issue myself with Ministers and officials and I am happy to publish documents and emails between myself and them for the basis of this submission. In fact I may just include them in a later section of this document because no matter how many times I ask questions the answers are always something different to ones expected.

I have raised objection after objection to the Welsh Government's Strategic Action Plan and still do but my objections are constructive in mine and my organisations view we want to see a system that works for all not just for a selected few, what we want to see is a system that delivers the same services for all. Not some patchy postcode lottery based system which is what we have at present.

Now we cannot go on as we are with this broken, sketchy postcode lottery based system that we have, we need a full roll-out of what is mentioned in the Welsh Government's Strategic Action Plan, neither can we wait for the empty promises of services to be rolled out in certain areas and not others. What we and the autistic community deserve is a system that is fit for a modern society. One where waiting times are vastly reduced from years to months. The current waiting time guideline is 26 weeks but as you will see in this submission it has been met by some but not all which isn't good enough.

Although 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. This strategy has yet to provide anything positive in the way of a service yet.

In the Diocese which spans the length and breadth of Wales I deal with a lot of casework and would say a good 30 percent of that is working very closely with young people on the autistic spectrum, their family, parents, carers etc and I am hearing from many of them that access to services has become something of a postcode lottery.

We have those that live in areas with bigger health boards having access to the better services and those in smaller health boards being left with services that are very limited if any provided at all.

The Strategic Action Plan although it recognised the need for better diagnostic services for children and adults with autism spectrum conditions it did not provide this in all areas. Awareness raising led to an increase in demand for diagnosis and although it was met in some areas again it was not met in others with little or no investment being made by those who should have been making it.

A rise in demand did lead to a rise in diagnostic services being bought on stream which has to be recognised. However, in many areas there are lengthy waits for an assessment – in some cases of many years. I have heard of waiting times to be as long as up to five years and sometimes longer.

A Refreshed Strategic Action Plan 2016-20 is introducing further reforms, including improvements to diagnostic services which was supposed to 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. This hasn't and will not in the view of my organisation because there no legal duty upon the Welsh Government to monitor the roll-out of this strategy. Neither does it require the Health boards to monitor the same. I raised my concerns at the time with both ministers and civil servants and didn't receive assurances that the strategy would achieve the desired goals.

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 and also the provision of services in the 22 local health boards and 7 health trusts. I have had emails saying this has created a post code lottery which I have alluded to in my submission earlier.

Many people with autism spectrum conditions and their families still sadly do not receive the services and support they need to fulfil their potential and this after

the strategy being enacted but the Labour led Government fail to see this and continue to believe the strategy is working. Whilst good practice and responsive services are evident in some areas this is not the case in all 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 hence the reference to it being a postcode lottery. There is a need to ensure that people with autism spectrum conditions receive quality support wherever they live and this isn't the case. It is something that both my organisation and I find frustrating. I have raised the issue many times with the minister and their team but never had a satisfactory answer. It is time to stop promising and start delivering.

Although 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 despite officers telling me they remain committed to the strategic action plan and that the money will be forthcoming I and my organisation remain unconvinced. We are fearful that at any point future administrations could decide to pull the plug on this. This is one of the arguments as to why an Autism Act is needed as it would not allow such a move.

I and my organisation are in agreement with Paul Davies the Assembly member for Preseli and Pembrokeshire when he says,

- 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 myself and my organisation believe that Wales should have the same legislative equivalent with the same requirements and not just the strategic action plan that could be replaced with any consultation. Like Paul Davies I and my organisation 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.

Furthermore it is our strong believe that any legislation should also place a binding requirement on 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 and if they fall short of their legislative responsibilities then they should questioned as to why they have done so.

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. It is the belief of mine and my organisation 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. We feel this key to make sure that services are delivered in the best way possible.

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.

So why do we support an Autism Act

We believe 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. We also believe that it would have the legal duties as set out in the submission above. We also believe it goes further and above that of the current Strategic Action Plan with a longer term commitment set up with a statutory footing creating it as primary legislation and not merely a promise. However we do recognise that money has been ring fenced for the current strategic action plan but under the current system the ring fencing can be removed very easily. We may be accused of scaremongering but seriously we aren't

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.

The intention 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 and provide services that are actually needed and not what the Officials think is needed. Myself and my organisation think the provision of services should be subject to a Wales wide consultation so that the right services are offered in the right places. We further believe that services should not be a one size fits all approach as set out in the Additional Learning Needs Bill. A separate Autism Act is required to make sure the right provisions are in place in respect of education and also health.

Training

We think that the intended Autism (Wales) Bill should ensure that key staff working with people with autism spectrum conditions, receive appropriate autism awareness training where the current strategy does not require this.

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

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

Nevertheless, myself and my organisation 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 and my organisation are 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.

We also feel that money should be forthcoming to provide this training to those that require it and this should be enshrined into the bill and ring fenced not just simply promised like money has been before.

If there were to a statutory time written into Mr Davies's bill myself and my organisation are unsure as to what this should be but it should not be more than 3 months ideally.

One member of the Assembly that has made most of the statements and held the Welsh Government to account is Mark Isherwood and he has kindly allowed me to quote from his press releases and statements on autism, we are greatly appreciative that Mark has allowed us to use his material as it makes our submission even more evidence based. I have also submitted questions to Bethan Jenkins one of my local Assembly members and her office. I have also raised the issue with Hugh Iwan Davies the new cabinet secretary who's portfolio covers autism. I have included his response and also other responses I have had for accuracy and transparency as well.

Following an email to the Welsh Government on February 2nd I am going to quote the Government's position of the current strategic action plan as it gives a very firm commitment to a timescale, but its whether that timescale has actually been met.

"Our Autistic Spectrum Disorder Strategic Action Plan published in November 2016 was accompanied by a delivery plan which sets out the specific actions that will be taken to improve services for autistic people. An Implementation Advisory Group, which includes people with autism and parent/carer representatives has been set up to monitor delivery and an annual report will be published to provide an update on the progress made. The first report will be published in the summer.

Some of the improvements and actions in our Strategic Action Plan will though take time to deliver. We are establishing a national all age Integrated Autism Service, which will be delivering several of the actions in the plan. It has been rolled out in Cardiff and the Vale, Gwent and Powys and will be open in every region in Wales by the end of this year. I am presently visiting each of the regions to talk about the implementation of their service and to encourage collaborative working to ensure the service is consistent across Wales.

We do recognise the importance of a timely diagnosis of autism and have invested £2m to develop multidisciplinary neuro-developmental teams in each health board to provide assessment, diagnosis and support for young people with autism and ADHD. This work has been supported by the NHS led Together for Children and Young People Programme which has a

specific work-stream examining neuro developmental conditions. The work stream has established a single neuro developmental care pathway for adoption by health boards to ensure consistency of provision and a 26 week waiting time for referral to assessment has been introduced.”

Further to above response I have also submitted a question via the offices of Bethan Jenkins asking the following:

Is there currently a benchmark or minimum time frame that health boards have to meet for Autism Diagnosis. So from the point of GP referral to first appointment.

Would appreciate any feedback on this as I am wanting to quote this in my submission I am writing on Autism. Also does the Welsh Government hold figures of waiting times in each health board area if so would these figures be available for public release.

This I hope will be fruitful in showing that the Welsh Governments position on their current Strategic Action Plan is flawed in that it isn't delivering the 26 week waiting times it had hoped for and that it is indeed a postcode lottery.

The next piece of evidence we need to consider in my submission is the level of funding that is behind this action plan. At the moment they are committing a sum of £2 million pounds but this is only to Cardiff & Vale, Gwent and Powys health boards. They are going to require far greater sums of money than the figure stated above.

Answers to questions submitted via Bethan Jenkins Office:

Is there a minimum time health boards have, to meet autism diagnosis, from GP referral to first appointment?

Does the WG hold waiting times for autism referral?

The Welsh Government's [Refreshed Autism Spectrum Disorder Strategic Action Plan](#), which was launched 30 November 2016, introduced a **26-week waiting time target** for health boards from referral to first appointment for children with autism. A subsequent Written Assembly Question to Rebecca Evans stated that the target applies to both children and adults (see below).

Health boards are expected to collect data on waiting times and report on delivery of the 26 week target. However there does not appear to be any published information on waiting times, except in a BBC news article from 24 January 2018 (see below).

The Refreshed Autism Spectrum Disorder Strategic Action Plan states:

We are already improving diagnosis for children and young people with autism and ADHD, through the Together for Children and Young People Programme. We have developed a nationally agreed neurodevelopmental diagnostic assessment pathway so there is a consistent approach across Wales.

The pathway will help families understand how the referral and assessment process works, what happens at each stage and what support they can expect when a decision about diagnosis is made. Once a child is accepted for assessment services they should not wait more than 26 weeks from referral to first assessment appointment. The time taken for a decision on diagnosis to be made will be dependent on the individual circumstances of the child.

Further clarification was provided in answers to two Written Assembly Questions in 2017.

Janet Finch Saunders to Rebecca Evans, Minister for Social Services and Public Health ([WAQ72999](#)) answered 21/2/17:

We are setting health boards a new waiting time target of 26 weeks from referral to first assessment appointment for both children and adults and will be collecting this data from the summer.

Nick Ramsay to Vaughan Gething, Cabinet Secretary for Health, Wellbeing and Sport ([WAQ73822](#)), answered 12/7/17:

Nick Ramsay: How many children are waiting under, and over the 26-week waiting time target from referral to first appointment to access autism services?

Vaughan Gething: The Welsh Government does not yet routinely collect this information from health boards. As part of our £2m investment to establish new neurodevelopmental services we have informed health boards that we expect them to work towards meeting a 26 week waiting time standard, from referral to assessment. We are currently working with health boards and NHS informatics leads to put in place the necessary administrative, data collection and governance arrangements to ensure the information can be reported accurately and consistently across Wales for this new service. Health boards anticipate being in a position to commence reporting the data later in 2017.

In latest management information we received from LHBs, both Cwm Taf and Cardiff and Vale University Health Boards anticipated meeting the 26 week target by March 2017, whilst Abertawe Bro Morgannwg anticipated meeting it from July 2017; with other health boards reporting being on track to meet the new target later in 2017. However, it should be noted that until a standard definition has been introduced health boards are continuing to use local definitions which vary across each area, so it is not yet possible to make comparisons. Also, some health boards have also taken the decision that it is in the best interests of the young person to maintain some historic referrals for neurodevelopmental conditions, which predate establishment of the new services, within specialist CAMHS.

A recent BBC news article [Autism assessment delay concerns across Wales](#) from 24/1/18 includes information on waiting times for an autism assessment in each health board which was obtained through Freedom of Information requests. The information appears to relate to waiting times for children. Average waiting times for assessments ranged from 107 weeks, 6 days in Hywel Dda UHB to 13 weeks, 2

days in Powys THB. Abertawe Bro Morgannwg UHB did not provide data but average waiting times in the remaining health boards are provided in the article.

Health Board Area	Waiting Time	Target	Outside Target
Hywel Dda	107 weeks 6 Days	26 Weeks	81.6
Betsi Cadwaladr	39 Weeks	26 Weeks	13
Cardiff Vale	27 Weeks	26 Weeks	1
Cwm Taf	26 Weeks	26 Weeks	0
Aneurin Bevan	18 Weeks	26 Weeks	8
Powys	13 Weeks 2 Days	26 Weeks	12.8

The Welsh Government [website states](#) that an Evaluation of the Integrated Autism Service (IAS) and Autistic Spectrum Disorder Strategic Action Plan (ASD SAP) is due to published on 1 March 2018.

So to conclude my submission we support Paul Davies's Autism Act and we will be backing it as it will tidy up a fractured and patchy postcode lottery of a system that exists under the current system.