

WLGA EVIDENCE TO THE HEALTH, SOCIAL CARE & SPORT COMMITTEE'S INQUIRY INTO THE AUTISM (WALES) BILL



September 2018

About Us

The Welsh Local Government Association (WLGA) represents the 22 local authorities in Wales, and the three national park authorities and the three fire and rescue authorities are associate members.

The WLGA is a politically led cross-party organisation, with the leaders from all local authorities determining policy through the Executive Board and the wider WLGA Council. The WLGA also appoints senior members as Spokespersons and Deputy Spokespersons to provide a national lead on policy matters on behalf of local government.

The WLGA works closely with and is often advised by professional advisors and professional associations from local government, however, the WLGA is the representative body for local government and provides the collective, political voice of local government in Wales.

The WLGA, working in partnership with Public Health Wales has hosted a National Autism Spectrum Disorders (ASD) Development Team for a number of years. The team have played a key role in supporting the creation and formation of an Integrated Autism Service (IAS) for Wales and have provided a range of useful resources and advice in supporting public services in better responding to the needs of autistic people. The team are an integral part of the Welsh Government's refreshed Autistic Spectrum Disorder Strategic Action Plan.

Introduction

It is important to acknowledge the progress that has been made since the original ASD action plan was published in 2008, with one of the key achievements being the increased profile and awareness of autism in Wales. There is a wide range of information and resources available to help autistic people and their families and carers, as well as resources for professionals. This progress has been made without the need for legislation. However, we are aware that more can always be done and that some of the improvements and actions will take time to deliver. We all want to see a real

difference in the services, care and support available to autistic people, their families and carers and so it is appropriate that we take the time to consider the proposals set out in the Autism (Wales) Bill and whether legislative changes will actually bring about the desired outcomes.

We are clear that any new legislation needs to add value, make a real difference and have an impact, compared to what could be achieved without specific legislation. The reality is that ineffective legislation would only disappoint the high expectations that autistic people and their families and carers have that new and additional legislation will make meaningful changes to the services available to them.

The WLGA previously responded to the consultations on the general concept of a proposed Autism (Wales) Bill and on the draft Autism (Wales) Bill in which we highlighted our fundamental concerns about the approach of creating separate legislation for a particular condition. We believe that legislation such as the Social Services and Well-being (Wales) Act 2014, the Additional Learning Needs and Education Tribunal (Wales) Act 2018, the NHS (Wales) Act 2006 and the Equality Act 2010 should, if they are working correctly, deliver for all our citizens on the basis of need. Given the existing legislative foundations and powers that are already in place in Wales and the fact that we have previously highlighted that many of the aspects of the Bill that have been proposed would better sit within guidance / codes of practice rather than in primary legislation we remain unconvinced of the need to create this separate piece of legislation and would rather build on and use the powers and mechanisms that are already in place to strengthen the services, care and support available to autistic people, their families and carers.

We are therefore not supportive of the need for an Autism (Wales) Bill. We believe that placing a specific autism strategy in statute risks distributing resources inequitably, and without necessarily building a sustainable and strategic longer term solution that addresses the needs of autistic people. In our view, the risk is that the Bill could lead to resources and activity being governed by a narrow set of statutory processes, rather than being directed according to the delivery of improved outcomes. This could lead to particular difficulties for councils in the context of budgets that are already stretched and there is a fear that money could end up being directed away from other support services and that any benefits for autistic people could be at the expense of people with other disabilities. There is also a risk that this Bill will add complexity or duplication, for example in respect of carers.

Serious consideration also needs to be given to the implications of setting such a precedent going forward, as services for autistic people is not the only area where there is a need for service improvement for people with specific conditions. It is essential that we fully identify and consider any unintended consequences of legislating on a particular condition, and that we explore any risk that such legislation may impact on our ability to respond to others on the basis of need.

Progress to date

When considering the need for additional legislation it is vital that we consider the progress that has already been made in Wales under the existing legislative and policy arrangements, along with the planned work that is already underway, to help us weigh up what added value, if any, additional legislation would bring.

Since the development of the Autism Strategy in 2008 and the subsequent Refreshed ASD Strategic Action Plan in 2016, Wales has seen much progress in relation to services and support for autistic people, with awareness increasing, a range of resources being produced and training developed and rolled out. Working closely with Welsh Government (WG), local authorities and health have established, or are in the process of establishing, 7 regional IAS's. They are funded by WG through the Integrated Care Fund (ICF), based on the Health Board footprints with oversight by the 7 statutory multi agency Regional Partnership Boards focusing on integrating health and social care. The IAS's collectively contribute to what can be seen as a national service with similar and consistent standards and practice, providing advice, guidance and offering practical solutions to a range of challenges.

During 2017/2018, Cardiff and the Vale, Cwm Taf, Gwent and Powys IAS's were launched in the first phase of development and became operational, while North Wales launched in June 2018. West Wales and Western Bay continue to make progress in readiness of launching later this year and there will be an operational IAS in each region by Autumn 2018. The National ASD Development Team has supported the creation of these IAS's and continues to do so for those areas not yet fully operational.

Part of the National ASD Development Team's role is to develop and provide resources in partnership for the benefit of autistic individuals, parents and carers and professionals. Their website (www.ASDinfoWales.co.uk) is a key part of this offer and is funded by WG as part of the ASD Strategic

Action Plan for Wales. It contains a wide range of information, advice and resources for autistic people and those that support them, as well as professionals with an interest and role in autism and to ensure that the needs of autistic people are communicated to key stakeholders. The team continues to raise awareness of autism and develop training, awareness raising and supportive autism resources that can be utilised by the IAS, wider services, autistic people and all those who support them. The National ASD Development Team also support the co-ordination and delivery of training in line with the National Training Framework for Wales. The “Can You See Me?” scheme promotes awareness and acceptance in communities to improve access to community provision for autistic individuals. Specific training is available on the national website for sectors such as sports and leisure providers and housing providers (www.ASDinfoWales.co.uk/leisure-staff and www.ASDinfoWales.co.uk/housing-provider-scheme).

Some of their resources that have been developed are listed below:

Growing with Autism

The Growing with Autism resources are aimed at parents and carers of children and younger adolescents. A range of resources are available, including a guide following diagnosis, advice sheets, child personal profile builder, picture cards to structure a child’s daily activities, 5 short films which provide an overview of autism and advice on other common issues including communication planning, coping with changes and visiting health professionals.

Resources to support peers and siblings in understanding autism have also been developed. Teifi and Friends is an animation, voiced by the cast of Stella, which shows young children how to be kind and accepting to those with additional needs. Autism Superheroes is available as a story book and adventure comic strip story designed to develop understanding of autism for children of primary school age.

Learning with Autism

There are a series of resources aimed at educational settings from early years to secondary school and with a further education and work based learning programme currently in development. The Learning with Autism programmes are designed to help staff develop their knowledge and skills to support those with autism. Children and pupils are also encouraged to undertake learning with the

Teifi and Friends, Autism Superheroes and Sgilti resources. Once all staff and pupils have undertaken the appropriate training schools can apply to become an Autism Aware setting.

Living with Autism

The Living with Autism resources include a supportive guide containing tips and advice to those that have received a diagnosis of autism. Individuals are also able to search an idiom glossary and can create and download a personal profile to highlight their strengths and difficulties and ways in which others can support them.

Working with Autism

There are resources for those supporting autistic people into employment and for managers and co-workers for those working in HR. Resources to support employers include the Living with Autism film and an e-learning training. To support individuals into employment there is a CV builder, searching for work tool and a skillset builder. For co-workers and managers there is the Positive about Working with Autism scheme which includes a charter to sign, advice and a training scheme for those working in HR.

The National ASD Development Team is also facilitating an adult diagnosis Community of Practice, bringing together health and social care professionals in order to develop consistent assessment, diagnostic and support pathways across Wales. The Community of Practice is already addressing key areas such as developing best practice in relation to: the identification and diagnosing of ASD; pathways; assessment; and planning. Many of these have already been explored, agreed and are being rolled out on a national basis through the IAS. The National ASD Development Team further facilitates a network of local authority ASD leads and IAS leads across Wales. The newly established National IAS Leads Network will work collaboratively with the team and WG to finalise reporting ICF templates for the next financial year to ensure that information collected provides information on the outcomes and impact of the services. There will be further work to align data collected in the IAS and that collected in the Neuro Developmental services. These fora are critical to sharing good practice, exchanging knowledge and maintaining a key focus on the needs of autistic individuals, parents, carers and families.

It is also worth noting that WG have already identified that they intend to introduce a Code of Practice on the delivery of autism services which will be published under the Social Services and Well-

being (Wales) Act 2014 and the NHS (Wales) Act 2006 next year. This aims to provide clarity on the support autistic people can expect to receive and will provide guidance on how services can adapt their practice to meet the individual needs of autistic people.

The Explanatory Memorandum that sits alongside the Bill makes frequent reference to the fact that the Bill builds on the existing arrangements identified above. For example:

- “build on the gains made by the Strategic Action Plan”
- “build on the current arrangements for data collection, which are currently under development”
- “build on materials already prepared for this Code of Practice [to be developed under the Social Services and Wellbeing (Wales) Act]”
- “the awareness raising campaign for this Bill will build on these existing resources [those already developed by the National ASD Development Team, such as the ‘Can You See Me?’ campaign]”
- “the Bill builds on the ambitions of the Welsh Government’s Autism Spectrum Disorder Strategic Action Plan, which originally established an autism infrastructure in each local authority area, with local co-ordinators and strategies and a Wales national co-ordinator.”

This underlines the fact that much of what the Bill sets out to do is already in train – a lot of progress has already been made and the autism specific legislative proposals being consulted upon highlight the existing rights that already exist and which can be achieved through other routes. However, we also need to recognise that much of the work that has started is still in its formative stage, such as the establishment of the regional IAS’s. Through the Strategic Action Plan and the roll out of the IAS we are now seeing significant improvements in services emerging and a renewed appetite for collaborative working across sectors. We need to focus our attention on delivering the services and support which can make a real difference to the lives of autistic people and their families by supporting the establishment of these services and allowing them time to embed new pathways rather than potentially destabilising or hindering some of this progress. The implementation of the National IAS is currently being independently reviewed, with the outcome of this review due by March 2019 and so we need to await the outcome of this review before looking to make any further changes and considering whether any changes in policy, or indeed legislation are required in order to improve services.

English and Scottish Experiences

It is also worth noting the experience in England and whether introducing specific autism legislation actually leads to improvement in services. In England the Autism Act received Royal Assent in November 2009 and placed statutory requirements on the Government to publish an adult autism strategy and associated statutory guidance for local authorities and local health bodies on supporting the needs of adults with autism. A key action from the *Think Autism* strategy was that NHS England would help improve autism diagnostic services, however in the latest Autism Self-Assessment Exercise published by Public Health England only 22% local authorities reported meeting the National Institute for Health and Care Excellence (NICE) recommended waiting times, with some areas in England reporting assessment waiting times of up to two years¹. The National Autistic Society suggested that the results from the latest progress report exposed “the autism diagnosis crisis” in England despite having legislation in this area.² This raises the question of how effective introducing new legislation is in actually improving services for autistic people and whether in fact there is a danger that the development of an Autism Bill at this stage will cut across the work already being undertaken, and in turn cause difficulty in delivery of a consistent approach.

In Scotland the proposed Autism Bill fell at stage 1 in January 2011 after the Scottish Parliament disagreed to the general principles of the Bill. The lead Committee for the Bill was the Education, Lifelong Learning and Culture Committee who concluded that:

“legislation for a strategy for a specific disability group may create a two-tier system of strategies whereby strategies set out in legislation are seen to have “more teeth”. The Committee is also concerned that this might lead to a perception of two-tier disabilities with some disabilities thought of as being more worthy of a legislative strategy than others. The Committee does not believe this would be helpful.”

They also felt that the Bill as introduced would not overcome the barriers to service delivery nor satisfy the expectations of people with autism. They pointed to the fact that there were significant pieces of relevant legislation, similar to the situation in Wales, that had not been in force for a sufficient amount of time to evaluate their impact and so the Committee were not convinced of the

¹ <https://www.bbc.co.uk/news/uk-england-norfolk-41112597>

² <https://www.autism.org.uk/get-involved/media-centre/news/2017-07-05-autism-support-report-england.aspx>

need for additional legislation and that “resources would be better spent focusing on the implementation of existing legislation and duties”.

Comments on the proposed Bill

Whilst we have significant reservations about the approach being considered in creating new and additional legislation, below we highlight some specific comments related to the Bill as currently drafted, though overall we believe that the drafting of the Bill would need to be strengthened, with some aspects of the Bill lacking clarity around expectations.

Autism Strategy

Under 1(7) reference is made to the need to commission an “independent” report, whilst we recognise the need to review progress and report on implementation we would question the use of the word “independent”, what is meant by this and whether it needs to be placed on the face of the Bill?

Under 2(1)(a) the Bill identifies that the Autism Strategy must establish a best practice model or models. This seems far too restrictive to prescribe the models that must be established and may hinder innovation in the future, it may be better to highlight pathways rather than models.

Under 2(1)(c) the Bill requires diagnostic assessments be commenced as soon as reasonably practicable following a referral, and at least within any timescales set out in the relevant Quality Standard issued by NICE (currently 13 weeks). This differs to the current Welsh Government guidance, setting a 6 month (26 week) target. The Community of Practice for Adult diagnosis and IAS practitioners’ are responding separately to the inquiry, in their response they highlight this element of the Bill and the challenges and implications involved and we endorse their comments. Whilst it is not ideal to not have any timescales, in reality, the current blanket 26 weeks’ target does not reflect the complexity of many referrals, with a 13-week timescale further challenging this and not reflecting the length of time required to undertake what are often complex assessments. In addition, best practice dictates that diagnosis and assessment should be on a multi-agency basis and therefore, the imposition of timescales might negate or work against such an approach. Work is currently being undertaken by clinicians, practitioners, Welsh Government and the National ASD Development Team to look at diagnosis and assessment timescales as part of the ongoing work around the development

of the IAS. It is envisaged that draft guidance will be issued for consultation in the 2018/19 period. While time is a factor in conducting assessments, the quality of the assessment must take priority.

2(1)(g) identifies that the autism strategy must outline how the needs of persons with ASD are to be met by relevant bodies in respect of, but not limited to: access to healthcare services; access to education; access to employment; access to housing; access to Welsh language services; access to services in other languages; access to other public services; social inclusion; and access to advocacy services. Some of these areas are far too general, for example how will access to employment, or access to public services be covered in any meaningful way? Rather than putting these areas on the face of the Bill, they would sit better within guidance.

2(1)(l) states that the autism strategy must, “make provision for the wishes of persons with autism spectrum disorder and of their families and carers to be taken into account”, however under 4(6)(b) reference is made to “persons who are to be classed as carers for the purposes of this Act”. It is not clear what is meant by those who will be classed as carers for the purposes of this Act, how does this fit with the Social Services and Well-being Act and the definition of a carer under that legislation? Are we creating different definitions of carers under different pieces of legislation? This highlights the complexities associated with creating additional legislation for groups that are already covered under existing legislation and the need to be clear on what rights and expectations people have, ensuring that new legislation complements existing laws.

Guidance by the Welsh Ministers

4(2) identifies that guidance must be issued within 3 months of the publication of the strategy. Our previous consultation responses raised concerns with this timescale as the work to develop guidance needs to be progressed collectively and so appropriate time needs to be given to allow for this approach. We therefore still question whether the three-month period set out in the Bill would be sufficient and suggest more time needs to be allowed for.

Under 6(f) the Bill states that “guidance issued under this section must in particular include guidance about local arrangements for leadership in relation to the provision of services”. It is not clear what is meant by this clause, nor what it seeks to achieve and so further clarification is needed.

Data on autism spectrum disorder

Further clarity is needed on what the data will be collected for, how and for what purpose it will be used and why are certain types of data identified but not others? For example, why is gender identified, but not other protected characteristics? It would also be helpful to identify timescales involved and consider how manageable over time some of the expectations will be on the data identified as needing to be collected.

Financial Implications

In our evidence in response to the development of the Social Services and Well-being (Wales) Act we consistently highlighted the resource implications for implementing that piece of legislation and the same is true of this Autism Bill. Many authorities are having to juggle a number of unfunded pressures with unprecedented reductions in funding. We believe that there should be full and early engagement with all stakeholders in the formulation of legislation and that the financial impacts should not be assessed in isolation but part of the whole programme. It is vital that any new duties and burdens created are identified and fully funded. Any legislation that is enacted also needs to be assessed after it has been implemented independently of government. The reality is that if the true costs of implementing this proposed legislation and guidance are not identified, then its introduction could result in resources being directed away from other support services in order to provide the relevant services for autistic people.

The Explanatory Memorandum identifies additional costs of over £7 million, this is a significant resource requirement that would need to be fully funded and supported, with ongoing monitoring of these costs to ensure that the additional responsibilities continue to be fully funded. Whilst the Memorandum argues that there is evidence that the Bill will result in considerable benefits, both direct and indirect, it fails to identify what these are, stating that, “these are not possible to quantify and hence unknown.” The biggest costs attributed to the Bill are in relation to the cost of meeting the additional demand of the 13 week waiting time. As identified by the Community of Practice for Adult diagnosis and IAS practitioners’ response the diagnostic assessment is just one step in people’s journey in relation to autism services and whilst it is important that people are not just left waiting for a diagnostic assessment this is a very small part of what they will require from services. The focus should not just be on meeting waiting times, but has to take into account all of the other work that is delivered by specialist autism services. Significant amounts of additional funding are needed to be able to clear existing waiting lists and to then be able to keep within the proposed time-scales so that they do not compromise on the other work they deliver. There is also a need to ensure that there is

appropriate post diagnostic support available, which also requires additional investment in order to be able to meet the extra demands being placed on services.

However, simply providing more money will not easily solve the issue with waiting times, because it is also about a lack of suitably qualified diagnosticians, with recruitment to some autism services across Wales being problematic because of a lack of staff with the necessary skills and experience.

Conclusion

Significant progress has been made in Wales in recent years in improving services and support for autistic people, with awareness increasing and a range of resources being produced and rolled out. This progress has been made without the need for additional legislation. Existing legislation in Wales such as the Social Services and Well-being (Wales) Act, the Additional Learning Needs and Education Tribunal (Wales) Act 2018, the NHS (Wales) Act 2006 and the Equalities Act 2010 are already in place and provide existing rights to autistic people, which if working correctly will deliver for all of our citizens on the basis of need and can be used to meet the ambitions of the proposed Bill. There are also implications of setting such a precedent going forward of introducing condition-specific legislation which could lead to other calls for the introduction of specific legislation for other illnesses and conditions without robust evidence being available.

There is evidence to suggest that where autism specific legislation has been introduced, such as in England, it has not led to improved outcomes for autistic people and has not brought about the benefits originally envisaged. We firmly believe that the focus in Wales should be on using the resources available to focus on the implementation of existing legislation and duties, concentrating on the work that is already in train, which the Bill seeks to build on, focussing our attention on delivering the services and support already in development which can make a real difference to the lives of autistic people, their families and carers.