Welsh Government - Written Evidence to Health, Social Care and Sport Committee – Autism Wales Bill

Summary

1. Since the beginning of the campaign for autism legislation the Welsh Government has carefully considered whether an Autism Act could improve services in Wales. Our conclusion is that there is little evidence to suggest that this Bill will bring any additional benefits to those service improvements that are currently being put in place. The Welsh Government has all the powers we need to deliver improvement to autism services in current legislation in the Social Services and Well-being (Wales Act) 2014, the Additional Learning Needs and Education Tribunal (Wales) Act 2018 and the NHS (Wales) Act 2006.

2. We have closely scrutinised the Bill and considered the evidence presented by other contributors. It has become clear that the Bill raises unrealistic expectations of preferential services for autistic people which will be perceived as unfair, and will disadvantage others who have significant support needs but do not have an autism diagnosis. The possibility to extend the Bill to other neurological conditions is also limited as this is likely to be beyond its purpose. Most worrying is the prospect that the Bill will artificially drive up assessment referrals, as a diagnosis is seen at a golden ticket to access services.

3. We recognise autistic people’s real concerns that progress needs to continue at pace. It is vital that we deliver on the commitments we have made and build on the areas where we are making real progress. We will achieve this through issuing a Code of Practice on the Delivery of Autism Services under existing legislation to underpin future delivery. A Code which will have more powers for Welsh Ministers to directly intervene where there is poor service delivery than this Bill currently offers.

Background

4. The Health, Social Care and Sport Committee has invited Welsh Government Ministers to provide written evidence on the merits of the Assembly Member led Autism (Wales) Bill. As requested, this is a joint submission from the Cabinet Secretary for Health and Social Services, the Minister for Children, Older People and Social Care and the Cabinet Secretary for Education. The Cabinet Secretary for Health and Social Services will be attending the Constitutional and Legislative Affairs Committee on 15 October and the Health, Social Care and Sport (HSCS) Committee on 25 October.

5. The evidence responds to written guidance provided by the HSSS Committee and reflects evidence presented by other contributors to the consultations on the Bill or who have provided committee evidence and may be attending Committee in advance of the Cabinet Secretary's attendance.

Introduction

6. The campaign for autism legislation and the introduction of the member led Wales (Autism) Bill has provided a valuable opportunity to debate autism services in Wales. In recent years it is acknowledged that significant progress has been made to address identified gaps in support, however we are all in agreement there is still more work to do. Improvements are being driven by the ASD Strategic Action Plan which was updated in 2016 and delivery is supported by the Social Services and Well-Being (Wales) Act 2014 (SSWBW) and the Additional Learning Needs and Education Tribunal (Act) 2018 (ALNET).

7. This debate has however enabled us to re-examine our plans in relation to what is needed to develop and protect autism services for the future. The ASD Strategic Action plan, backed by £13m, is delivering wide ranging improvement. At its centre is the roll out of the National Integrated Autism Service, which is open in five regions and will be available across Wales this financial year. Also since 2015 we have secured improvements to children's neurodevelopmental services, investing £2m annually. For children and young people we have introduced a 26-week waiting time standard from referral to first diagnostic assessment, in line with other paediatric waiting times. There are published referral pathways for both children and adult assessment services. We are now exploring how we can bring these two services closer together and to take a detailed look at the barriers to reducing waiting times which are complex.

8. To improve educational support for children and young people up to 25, our Additional Learning Needs reform, underpinned by the Additional Learning Needs and Education Tribunal (Wales) Act 2018, introduces a new system focused on ensuring all children and young people that require support, including those with autism, have that support properly planned for and protected, and will have a statutory plan with equal rights of appeal. The Act puts learners at the heart of the decision making process Although it extends to meet the needs of autistic children and young people it does not differentiate between different additional learning needs because it seeks to ensure that all needs are met equitably and comprehensively.

9. We are acting on feedback asking for consistency in services, rolling out the Integrated Autism Service around a national framework, which brings together health and local authority services to work collaboratively to plan and deliver services. As the service matures regions are working together to share practice, and to address continuing gaps in support. We also recognise there is more to do to re-engage with voluntary groups who can provide essential services to support the IAS, and we are exploring what more can be done to provide assistance to enable the voluntary sector to provide much needed additional services.

10. We are also committed to publish a Code of Practice on the delivery of autism Services under the Social Services and Well-being Wales Act 2014 and the NHS Act 2006, which can address all the issues identified in the Bill and can address additional concerns raised by stakeholders. The oral statement on the Updated Delivery Plan and Code of Practice made on 25th September summarises the main provisions in the Code and plans for public consultation commencing in November 2018.

    The main areas for the code correspond to the chapters in the ASD Strategic Action Plan and are:

    a. assessment and diagnosis;
    b. accessing care and support;
    c. staff training;
    d. planning; and
    e. stakeholder engagement in service planning and delivery

11. The Welsh Government has strong delivery mechanisms and a trajectory of improvement. Therefore, on the basis of the evidence presented, including from other parts of the UK which has autism legislation, we do not agree that introducing additional condition specific legislation will add value to the improvements now firmly in train. Our plans to introduce a Code of Practice on the Delivery of Autism Services under existing legislation will ensure that statutory bodies understand their duties to provide services to meet the needs of autistic people. This work will also align with the ALNET Code of Practice which we will shortly consult on and a copy will be laid before the National Assembly for Wales in 2019.

12. Notwithstanding the lack of evidence to support its likely effectiveness, legislation which promises to improve services is attractive for many people who have experienced real struggles to access the support they need. Others may believe that whilst the legislation may not have significant benefits, it will not do any harm, and may therefore be worthy of support. In this evidence paper we seek to explain why condition specific legislation is a retrograde step - it will not bring additional value or more services and is likely

to have unintentional negative impacts both for autistic people and for individuals with other often similar support needs.

13. Our plans for a Code of Practice on the Delivery of Autism services under the Social Services and Well-being (Wales) Act 2014 and the NHS (Wales) Act 2006 is more appropriate and will have more impact. It will direct statutory bodies to act and will enable Welsh Ministers to intervene in service provision directly if necessary.

Comparison with current powers

14. The Bill provides for an autism strategy to be prepared and laid before the assembly (Section 1). It also provides for guidance to be issued to 'relevant bodies' about the exercise of their functions for the purpose of securing the implementation and delivery of the autism strategy and to publish that guidance (section 4). Section 5 sets out that "relevant bodies" must comply with the autism strategy and the guidance.

15. The Bill sets out that the autism strategy must be '*laid before the National Assembly for Wales'* (section 1(4)) but is not required to undergo any Assembly scrutiny processes. There is no requirement for the guidance that is to be prepared under section 4 to be laid before or scrutinised by the Assembly. The Code will therefore undergo a higher level of scrutiny than the guidance which is provided for under the Bill.

16. The SSWBW Act 2014 already gives a power to Welsh Ministers to issue a code in relation to the exercise of social services functions. A code is in the process of being prepared under s.145 of the 2014 Act and the NHS Act 2006.

17. This draft code must be laid before the Assembly for 40 days and must not be issued if the Assembly resolves not to approve it. In accordance with section 145(3) Local Authorities must act in accordance with the relevant requirements within the Code. The Welsh Government has the ability to issue directions to Health Boards. Health Boards are under a duty to comply with directions. Therefore, the Autism Bill does not go any further in terms of placing duties on NHS boards or local authorities.

18. The Autism Bill centres on provision to meet the needs of adults and children with Autism Spectrum Disorder. This is based upon a diagnosis as opposed to a presenting needs basis. In the absence of a specific diagnosis there is a risk that persons who has ASD traits will be unable to access the help and support set out within this legislation.

The appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation

There are three specific regulation making powers contained within the Bill.

- Section 6(6)(j) – provides for The Welsh Ministers to prescribe such other categories of data that NHS bodies must collect to assist them in the diagnosis and provision of services to persons with autism spectrum disorder.

- Section 9 – Interpretation

“autism spectrum disorder” means—

(a) autism spectrum disorder as defined by the World Health Organization International Classification of Diseases from time to time; and

b) for the purpose of this Act, any other neurodevelopmental disorder prescribed by the Welsh Ministers;

“relevant body” (“*corff perthnasol”*) means a local authority, an NHS body and such other bodies as may be prescribed.

19. There would be limitations to how the regulation making power to extend the definition of “autism spectrum disorder” to any other neurodevelopmental disorder as prescribed by the Welsh Ministers could be exercised. The purpose of the Bill is to “*make provision for meeting the needs of children and adults with autism spectrum disorder”*. Therefore, if Welsh Ministers used that regulation making power to then include other neurodevelopmental disorder conditions within the definition, that would not normally have fallen within the definition of autism - this would likely fall outside of the scope of the Bill’s purpose.

Remedies

20. Whereas compliance with the Autism Bill can only be enforced by way of Judicial Review, there are already built in mechanisms within the SSWBW Act for intervention and enforcement of the Local Authority to the Code. Section.150 provides for Welsh Ministers to be able to intervene in the event that Local Authorities fail to comply with a duty that is a social services function, act unreasonably in the exercise of a social services function, or fail to perform a social services function to an adequate standard. There is then provision for a warning notice to be issued and further steps to be taken by Welsh Ministers by way of enforcement against a Local Authority.

21. Similarly, under the NHS (Wales) Act 2006, there is provision to make an intervention order and for further steps to be taken in the event that a local health board is not performing one or more of its functions adequately or at all, or that there are significant failings in the way the body is being run, and the Welsh Ministers are satisfied that it is appropriate for them to intervene

Human Rights and UN Conventions

22. The Autism Bill places a duty on relevant bodies and Welsh Ministers when exercising their functions under the Act to have due regard to the UN principles for older people and the UN convention on the Rights of Persons with disabilities. It also places a duty on relevant bodies to have due regard to the UN Convention on the Rights of the Child.

23. The Additional Learning Needs and Education Tribunal (Wales) Act 2018 ('the 2018 Act') places duties on relevant bodies to have due regard to the United Nations Convention on the Rights of a Child (UNCRC) and the United Nations Convention on the Rights of a Persons with Disabilities (UNCRPD). However, the 2018 Act states that there is no requirement for specific consideration of the conventions on each occasion that a function is exercised. This provision minimises bureaucracy and red tape by ensuring that consideration of the conventions is not required each time a decision is made for an individual. There is no similar provision in the Autism Bill.

24. Furthermore, the requirement in the 2018 Act to have due regard to the conventions is limited to local authorities, schools, further education institutions and NHS bodies who operate on a scale and have sufficient structures in place to effectively carry out these duties. The Autism Bill provides for the Welsh Ministers to be able to prescribe additional bodies within the definition of 'relevant bodies'. This would then mean that these additional bodies would have to also have due regard to the conventions when exercising their functions. This could have the potential of placing significant duties upon bodies that may not have the framework to incorporate this.

25. Both the Autism Bill and the 2018 Act make provision for the guidance (in the Bill) and the Code (in the 2018 Act) to set out what is required to discharge the duty to have due regard, and that the requirement to have due regard should be interpreted in accordance with any provisions in the guidance/code.

26. As the Bill goes further than the 2018 Act, there would be inconsistences as both an Autism Act and the 2018 Act could apply to the same individual. This would create difficulties in interpretation for bodies implementing the Acts.

General Principles of the Bill

27. If the purpose of the Bill is to improve support for autistic people then we share its ambitions. Where we differ is that we already have all the legal powers required to the deliver improvements set out in the Bill and more. We should be building on existing powers in recent legislation to support the improvements that are being put in place.

28. Whilst an Autism Strategy has been in place for some time, we acknowledge that services can still be very difficult to access for some. As Paul Davies AM also acknowledged in his evidence to the Constitutional Affairs Committee, and in the Explanatory Memorandum for the Bill, significant progress has been made in the last 12-18 months. We have considered the views of all the contributors to this debate who all want to see improved services. The overwhelming conclusion to be drawn from the facts is that there is no evidence to support the belief that autism specific legislation will add any value to the improvement we are achieving, nor can it guarantee access to particular services now or in the future.

29. The Bill seeks to make the Autism Strategy statutory, and is seeking to ensure there are diagnostic pathways. We renewed the Strategy in 2016 and in September 2018 published an updated Delivery Plan, which confirmed our commitment to a statutory Code of Practice on the Delivery of Autism Services. The Bill seeks to improve access to social care services, but these are improvements we must achieve for everyone irrespective of their condition or group.

30. We will continue to deliver our autism commitments through existing legislation, notably the SSWBW Act 2014 and the ALNET 2018. We need time for new legislation and services being developed to be rolled out and embedded and we need to learn lessons from the evaluation of their implementation before we consider if any further legislation is required.

31. In written evidence submitted by the Children's Commissioner, she refers to her 2018 *Don't Hold Back Report* noting that there was a strong legislative framework in place to plan for and provide person centred support services, and this extends to autistic people. We agree with her view that existing

legislation could be used more effectively, and that is why we have committed to deliver a Code of Practice.

32. In relation to other duties in the Bill, it seeks to encourage staff training amongst professionals; we are already improving awareness through encouraging the use of the Autism Training Framework for Wales, to assess training needs which will be promoted through the Code of Practice on Autism. The Bill does not mandate professional training.

33. The National ASD Development Team has produced a wide range of highly regarded resources and training materials. For example the *Can You See Me* video aimed at raising awareness amongst health and education professionals. Through partnership working with Cardiff University this resource has been translated in four other European countries – Spain, Italy, Lithuania and Latvia. This and other resources can be found on the dedicated website for delivery of the Autism Strategy. www.asdinfowales.co.uk.

34. The Integrated Autism Service has attracted a wide range of experienced and specialist staff, which offer training to other specialisms such as mental health and learning disability to ensure their expert knowledge is shared. Workforce development is also a critical part of the Additional Learning Needs Transformation Programme. Working with our 5 ALN transformation leads we are delivering an extensive package of training and core skills development for all practitioners, which will include autism training.

Legislation in other parts of the UK

35. In his evidence Paul Davies AM refers to a report by Lemmi, Knappe and Ragan (2017) – the Autism Dividend, stating that without legislation an autism strategy will not have statutory force. The evidence from other UK countries where an Autism Act is in place clearly shows that where legislation in force, even with additional statutory guidance it has not brought the benefits anticipated. It is important to highlight that similar autism legislation made in other parts of the UK was enacted nearly a decade ago, before the introduction of modern legislation which places the individual at the heart of decision making, is person focussed and most significantly requires services to be provided on the basis of need.

36. As other contributors have also demonstrated there is little evidence to show that progress in England nearly a decade after the Autism Act was passed in 2009. The National Autistic Society claims there is a '*national diagnosis crisis'*

as evidence published by Public Health England shows that only 22% of local authorities in England are meeting recommended waiting times. There are reports of waiting times of up to two years in some areas.

37. Similarly, in Northern Ireland the most recent Department of Health, Social Services and Public Safety report on implementation of the Act found that it was "*not currently possible to guarantee early intervention as outlined in the Autism Strategy without additional funding to further develop autism-specific assessment services, and to extend the portfolio of available family support*."

38. The Scottish Parliament considered the need for autism legislation in 2010. It concluded a Bill would not overcome the barriers to service delivery nor satisfy the expectations of people with autism. It stated that passing more legislation is not an appropriate response to the poor implementation of existing legislation and more time was needed to evaluate the impact of other relevant recent legislation. Concerns were also raised about creating 'two tiers' of strategies.

The Impact on Existing Legislation and Welsh Government Policy Development

39. It is our view and that of many other contributors to the debate that we can deliver the improvements to autism services through existing legislation. Paul Davies AM states that the Bill will support and underpin current legislation, however we would strongly argue that diagnosis or condition led law would be directly at odds with the delivery of modern legislation, which bases service provision on the basis of individual assessed need not on a specific diagnosis.

40. The Explanatory Memorandum states a key function of the Bill is to *secure consistent and continued provision of all ASD services across Wales.* As the Children's Commissioner agreed in her evidence, if the aim is to secure permanence to autism services then this will be achieved through plans to issue a Code of Practice on the Delivery of Autism Services under existing legislation.

Information and awareness

41. The Bill raises an important issue in terms of information and awareness raising about existing rights and services. The Welsh Local Government Association National Development Team, has a strong record in raising awareness, as evidenced in their annual report published in June, and is

delivering dedicated awareness programmes this year, with a national autism conference for autistic people next April.

42. In the forthcoming consultation on Code of Practice on the Delivery of Autism we will be asking autistic people and their parents and carers how access to the right information and advice can be improved.

Data Collection

43. Since the introduction of the first ASD Strategy we have considered the value and the benefits of gathering data balanced with the resources required to ensure it is collected consistently and is robust.

44. The detailed person specific data requirement in this Bill does not tell us about the impact of services, only the individual characteristics of those with a diagnosis. As the Community of Practice for Adult Diagnosis and IAS Clinicians points out in their evidence, the level of data required in the Bill is onerous and adds little additional relevant information to both planning and commissioning. It does appear to be collecting for data's sake and there is a need to ensure it will be GDPR compliant.

45. Some of the responses to the consultation on the Bill were uncomfortable about the level of personal information to be collected. Collecting and analysing detailed personal information through an NHS number may be useful for research, but we would question whether it is necessary and would provide the information needed for service planning.

46. The People in Work Unit, which is evaluating our ASD Strategy, in their evidence are of the view that accepted prevalence rates are an adequate measure of the numbers of autistic people. They do state that there is a strong argument for collecting outcome focussed qualitative data about experiences of autism and of using services, and this is an approach that is currently being developed.

47. To give a clearer picture of the numbers of autistic people and to raise awareness of their needs, we are introducing a GP autism register of the numbers of patients diagnosed. Through the Integrated Autism Service and the children's Neurodevelopmental Service we are also working in partnership to establish quality based measures which can provide evidence of distance travelled and the benefits of services to individuals.

48. Under existing duties in the SSWBW Act, we are extending the core themes for Mandatory Population Needs Assessments to include autism as a stand

alone theme. These assessments are undertaken jointly by health and local authorities through Regional Partnership Boards.

49. Establishing new data collections is a complex process to ensure the data is comparable across services, is reliable and consistent. We are currently piloting the 26-week diagnostic waiting time standard and this approach has taken substantial discussion and review to ensure the data being collected is of sufficient quality for publication. As part of the pilot this data will be available on the Stats Wales website if it is of sufficient quality.

Unintended Consequences

50. Our greatest concern is that the Bill continues to raise high expectations that autistic people can expect preferential access to services and the legislation will result in more services becoming available. As the Children's Commissioner stated the Bill may not result in anything more than the current provision.

51. Many may view the prospect of legislation as attractive, but in addition to evidence provided by statutory bodies and the Royal Colleges on its weaknesses, there were also responses from parent groups and autistic people to the consultation on the Bill that were realistic in their views that this Bill will not deliver on its intention.

52. We understand there is frustration amongst Primary Care practitioners that they cannot refer into local authority services, and we will look at how the Integrated Autism Service is bridging this perceived gap between health and social care. It must be emphasised again that an Autism Bill cannot require specific services to be available.

53. Supporters of the Bill believe that legislation is required to compel authorities to deliver the services autistic people and their families want to see. The Constitutional and Legislative Affairs Committee has already heard evidence from Paul Davies AM about remedies under the proposed legislation. There are no specific remedies proposed other than the opportunity to pursue a judicial review, as is the case for other Welsh legislation. We are not aware of any evidence that autism legislation has seen a marked increase in judicial review in England, despite the lack of progress being seen. This is in contrast to the remedies available through a Code of Practice on autism which is stronger as it enables Welsh Ministers to intervene in service delivery. The ALNET Act also brings a right of appeal to education tribunal.

Needs Based Services

54. Another widely held concern we share with many of our delivery partners and practitioners is that the spirit of this legislation is completely at odds with our modern legislative approach as set out in the Social Services and Well-being (Wales) Act 2014 and the Additional Learning Needs and Education Tribunal (Wales) Act 2018. This legislation may undermine our programme of Additional Learning Needs reform, to be rolled out from 2020 which is needs based, by creating an environment where an autism diagnosis could give preferential treatment to support and services.

55. Evidence presented by the NHS Confederation and the Royal Colleges of Psychiatry, Speech and Language Therapy and Occupational Therapists makes the case that a system weighted by diagnosis would drive up referrals and pressure to provide an autism diagnosis, because this is seen as the best gateway to access services. The need for a diagnosis to push for resource is likely to artificially increase diagnosis rates for the wrong reasons. The Children's Commissioner also refers to autism becoming a perceived '*golden ticket'* to accessing services, when in reality other groups of children such as those with mental health needs and learning difficulties can also have challenges in accessing the right services for them.

56. The Bill will undermine the significant progress achieved in the development of neurodevelopmental assessment and diagnostic services. Separating autism from other neurodevelopmental conditions will create barriers to access services for many, it will prevent needs based services, particularly where individuals have co-existing conditions or not easily diagnosable conditions. It will lead to gaps in provision for some people who do not meet the diagnostic criteria. An added unintended consequence of added pressure to diagnose is that this could lead to inappropriate diagnosis, particularly for children, who in later life may not want to carry a diagnosis through their lives if it was not appropriate when made.

57. Feedback from practitioners and evidence from the independent evaluators of the ASD Strategy around the proposed 13-week waiting time targets is that this duty is likely force services to focus limited resources on meeting the duties in the Bill. That is funnelling more people through diagnostic assessment at the expense of providing much needed pre- and post-diagnostic support. The evaluation has found that service providers are already concerned about future capacity to meet demand for diagnosis, this will be exacerbated by legislation focussing services on a single diagnosis.

58. Introducing waiting times targets without a rationale or means to achieve this, will not achieve the desired results. The proposed new duties would require

health boards to signal a child’s assessment has started by 13 weeks, however there is no explanation on what this means in practice. It could means as little as the referral being accepted or a letter sent to this effect. We are extending the current evaluation of the autism action plan to investigate the stubborn barriers to reducing diagnostic waiting times, despite the significant additional investment since 2015 and will seek to identify where further action can be taken.

59. The Bill is creating a perception that autistic people will receive preferential services, and this can only mean that resources will be diverted from other services, creating an inequity of support for other individuals who have other substantial support needs, such as people with learning disabilities or sensory impairments. Also within autism services, providers may be forced to divert resources away from evidence based interventions to meet the demands of legislation. In this case resources moved into diagnosis and out of post diagnostic services.

60. We do not accept the argument presented that requiring services for one condition will by default improve services for others. As well as funding concerns there is absence of suitably qualified staff that can be recruited to deliver support. If autism is mandated then that is where services will have to be focused.

61. We also question whether it is possible to extend the Bill to other neurodevelopmental conditions, as is proposed, as explained earlier this is likely to be outside the purposes of the legislation. In his evidence Paul Davies AM is clear that this a Bill for autistic people only. This will immediately disadvantage those with other neurodevelopmental conditions, those who do not fit neatly into diagnostic categories and those who have other significant support needs but do not meet diagnostic criteria.

Regulatory Impact Assessment

62. It is clear that there are very real economic and social costs associated with Autism Spectrum Disorder both to the individual and their parent(s)/carer(s) and to wider society.

63. As with all Regulatory Impact Assessments (RIAs) there is an element of uncertainty in the analysis, but the broad methodological approach appears to be similar to that followed by Welsh Government when developing an RIA. However, there are elements to the RIA which require further explanation to be able to test the robustness of the calculations and areas where additional evidence to support the analysis would be useful.

64. A number of the provisions of the Bill place a duty on Welsh Government to do things that are already being done. For example, Welsh Government already has an autism strategy in place, a Code of Practice is being developed, an awareness raising campaign has already been launched and a training programme is in place for healthcare and education professionals. It is therefore questionable whether the costs identified in the RIA for these activities are additional to the baseline

65. It is difficult to determine what the additional costs and benefits of the Bill will be. The evidence around the potential benefits of the Bill is relatively weak. It is suggested that a 1% reduction in the direct and indirect costs associated with ASD will save £1m per annum but there is little evidence to indicate how the Bill might achieve this saving. Given the estimated direct and indirect cost of ASD in Wales each year is estimated to be £1.1bn, a 1% reduction in this cost would represent an £11m saving and not £1m as reported in the RIA.

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