

# **Explanatory Memorandum: The Autism (Wales) Bill**

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## **The proposed title of the Bill**

1. The proposed title of the Bill is the Autism (Wales) Bill.

## **The proposed policy objectives of the Bill<sup>1</sup>**

2. The purpose of the Bill is to make provision for meeting the needs of children and adults with autism spectrum conditions in Wales with the aim of protecting and promoting the rights of autistic children and adults in Wales.
3. The Bill would also give the condition its own statutory identity, recognising that autism is a condition in its own right.
4. The Autism (Wales) Bill would seek to:
  - Introduce a strategy for meeting the needs of children and adults in Wales with autistic spectrum disorder conditions;
  - Ensure a clear and consistent pathway to diagnosis of autism in local areas;
  - Ensure that local authorities and health boards understand and take necessary action so that children and adults with autism get the timely support they need (this might include, for example, putting duties on local authorities and health boards about the

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<sup>1</sup> As required by Standing Order 26.91B, I consider these policy objectives to be broadly consistent with those stated in my pre-ballot information. The additional information under 'The proposed policy objectives of the Bill' (compared to that included in the pre-ballot information), has been provided so that Members have a greater level of clarity on my thinking as to the need for delivering these policy objectives, and to reflect initial research and dialogue with key stakeholders, such as the National Autistic Society.

organisation of support for autistic people and their families, in their local areas);

- Establish practices, including the possible creation of a register, to enable the collection of reliable and relevant data on the numbers and needs of autistic children and adults so that local areas can plan accordingly;
- Require key staff working with people with autism to receive autism training
- Ensure that local authorities and health boards publish information on the services they provide for people with autism in their areas; and
- Regularly review the strategy and guidance to ensure progress.

5. Much work has been undertaken in recent years to improve services for people with autism, 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 the profile of autism and made available a range of high quality information and resources for both service users and professionals. Additional funding was provided to local authorities, although this was ring fenced only up to April 2015.

6. The Strategic Action Plan recognised the need for better diagnostic services for children and adults with autism. Awareness raising led to an increase in demand for diagnosis but also to lengthening waiting times for assessment. Difficulties remain for many people in gaining access to assessments in some areas.

7. There was also recognition in the Strategic Action Plan that work was needed to promote employment of people with autism and to

provide employment support to individuals. An Autism Employment Ambassador provided training and awareness on autism to employers and employment support providers up to April 2016. Nevertheless, rates of employment amongst young people remain much lower than for the general population and further work is needed to address this.

8. It is therefore clear that, although the Strategic Action Plan helped to improve services in many local areas and raise awareness of autism, problems remain. Evaluation of the Strategic Action Plan, and the work of autism task and finish groups have identified continuing gaps in services, particularly around diagnosis, transition to adulthood, employment support, and access to information on services.

9. Many people with autism and their families still do not receive the services and support they need to enable them to cope with the challenges of autism and to fulfil their potential. Whilst good practice and responsive services are evident in some areas, the local focus of the Strategic Action Plan has meant that provision has remained inconsistent across Wales. Furthermore, the voluntary nature of the local autism infrastructure means it is more effective in some areas than others. There is a need to ensure that people with autism receive quality support wherever they live.

10. A Refreshed Strategic Action Plan 2016–20 is introducing further reforms, including improvements to diagnostic services and waiting times, the development of a National Integrated Autism Service, and measures to improve education and employment for people with autism. Developments in education support include the introduction of the Additional Learning Needs and Education Tribunal (Wales) Bill. This is currently being scrutinised under the Assembly’s legislative process and, subject to Assembly Members’ approval, should receive Royal Assent towards the end of 2017. The Welsh Government is currently consulting on options for transition to the new system.

11. The Additional Learning Needs and Education Tribunal (Wales) Bill provides a single statutory framework for supporting children and young people with Additional Learning Needs (ALN), including autism, throughout childhood and up to the age of 25, where they are in further education. The ALN Bill will introduce statutory *Individual Development Plans* for all children and young people with ALN, replacing the current system which is based on the term 'Special Educational Needs' and statements. The ALN Bill aims to improve health board/local authority collaboration and to develop a fairer, more transparent and less adversarial system of support for children and young people with ALN.

12. The work undertaken by the Welsh Government in recent years is welcome; the proposed Bill seeks to supplement, not to replace these measures. For example, although not specifically concerned with autism support in educational settings, the Autism (Wales) Bill would complement the provisions in the ALN Bill. The proposed Autism (Wales) Bill would support the implementation of the ALN Bill by, for example, ensuring that key staff working with people with autism, including teachers, receive autism training. A significant number of staff working with people with autism have already received training through Welsh Government led initiatives, but legislation would promote consistency of training standards 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.

13. This is one of the key functions of the Bill: to secure consistent and continued provision of all autism services across Wales. Beyond the period of the revised autism Strategic Action Plan 2016–20 there is no certainty of continued prioritisation of autism services. Both England and Northern Ireland have legislation requiring their governments to

publish an autism strategy for adults, and for adults and children respectively. Experience there shows that legislation is needed to ensure the momentum for improvement is not lost.

14. By creating a legal requirement to publish an autism strategy the proposed Bill would help secure a measure of permanence and sustainability in care and support services for people with autism. It would ensure a continued, dedicated focus on the needs of people with autism, regardless of the financial or political climate of the time.

15. In many areas of Wales there is also no clear and publicly available information on pathways to diagnosis. Receiving a diagnosis of autism 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 services.

16. Providing in legislation for a clear pathway in all health board areas would give people with autism and their families the clarity and reassurance they need about the process of diagnosis. It would also enable Health Boards to be accountable in law for the provision of a clear pathway.

17. Autism services are often provided through learning disability or mental health services, even though people with autism may have needs which do not fit these categories. People with autism risk falling into the gaps between services which are not responsive to their needs or which impose inappropriate criteria (such as level of IQ) for access. The ASD Adult Task and Finish Group recognised this problem and called for improved assessment tools and better training for staff working in these services.

18. The *Social Services and Wellbeing (Wales) Act 2014* promotes person centred assessment and services, and includes a power for

Welsh Ministers to issue codes (which could potentially include a code in relation to the needs of people with autism), on the exercise of social services functions. However, to date, such a code has not been issued. Moreover, the needs of people with autism extend beyond such social services functions. By contrast, the proposed Bill would ensure that health boards and local authorities understand the particular needs of children and adults with autism and would provide the holistic range of services to meet them.

19. In order to provide effective services health boards and local authorities need to know the extent of need in their areas. Under the *Social Services and Wellbeing (Wales) Act 2014* they have a duty to assess the levels of need for care and support services in their areas and the range and level of services required to meet them. One of the core themes of these population assessments is learning disability/autism. Local authorities are also expected to draw up registers of disabled people in their areas. 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, without the risk of subsuming it within learning disability. This will enable health boards and local authorities to address the gaps in local service provision.

20. The proposed Bill would place a clear requirement on health boards and local authorities to establish data collection practices around the numbers and needs of autistic children and adults so that local areas can plan services accordingly.

## Details of any support received for the Bill, including details of any consultation carried out

21. There is a significant level of public support for the Autism (Wales) Bill, illustrated through a number of public consultations carried out in recent years.

22. The National Autistic Society carried out an online survey of autistic people living in Wales, and their parents or carers, between May and June 2015. Nearly 90% of the 668 respondents said that specific autism legislation was needed in Wales.<sup>2</sup>

23. Moreover, a further 5,309 people (as of 20 April 2017) have signed a petition on the website '38 degrees' calling for the introduction of an Autism Act for Wales to:

- Ensure that children and adults with autism in Wales can get a timely diagnosis;
- Improve understanding of autism among key professionals; and
- Introduce duties so that all local authorities and health boards take action to ensure children and adults with autism get the support they need.<sup>3</sup>

24. Since my proposal was drawn in the Member Bill ballot of 28 March 2017, I have personally received support from a range of autism charities, including Creatasmiles, Autistic Women's Empowerment Project, Autism Directory, Yourspace, Autistic UK, Denbigh Mens Shed, Rainbow Biz and the National Autistic Society Cymru, and its 14 branches across Wales, including:

- [NAS Blaenau Gwent Branch](#);

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<sup>2</sup> Act Now, An Autism Act for Wales, The National Autistic Society Cymru, <http://www.autism.org.uk/get-involved/campaign/wales/act%20now.aspx>

<sup>3</sup> Act Now: We need an Autism Act for Wales, petition created by Meleri Thomas <https://you.38degrees.org.uk/petitions/act-now-we-need-an-autism-act-for-wales>

- [NAS Bridgend and District Branch](#);
- [NAS Caerphilly Branch](#);
- [NAS Cardiff and The Vale Branch](#);
- [NAS Carmarthenshire Branch](#);
- [NAS Denbighshire and Conwy Branch](#);
- [NAS Merthyr Tydfil Branch](#);
- [NAS Neath and Port Talbot Branch](#);
- [NAS Newport Branch](#);
- [NAS Pembrokeshire Branch](#);
- [NAS South Powys Branch](#);
- [NAS Swansea Branch](#);
- [NAS Wrexham Branch](#); and
- [NAS Ystradgynlais and District Branch](#).

25. The need for an Autism Bill was also identified in the Fourth Assembly by the Cross Party Autism Group. On 19 November 2014, the group discussed the need for such a Bill, having heard evidence from NAS Cymru branch representatives, Merthyr Tydfil Autism Support Group, and the parent of a person with autism. The meeting's minutes record that the nine Assembly Members' vote "was unanimous in favour of calling for an Act."<sup>4</sup>

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<sup>4</sup> Cross Party Autism Group National Assembly for Wales, 19 November 2014, <http://www.senedd.assembly.wales/documents/s35180/Minutes%20of%2019%20November%202014-e.pdf>

## **An initial assessment of any costs and/or savings arising from the Bill**

26. Under Standing Order 26.91A (iv) there is a requirement for an initial assessment of any costs and/or savings arising from the Bill. I have set out the main options that I will consider in terms of how this Bill will be developed, but my intention would be to minimise the cost impacts of the Bill while ensuring that it achieves its stated intentions.

27. It will be important as part of developing this Bill to gain a better understanding of the number of adults and children who could benefit from this Bill and how best to organise services to diagnose and ensure pathways are conjoined and resourced. Therefore, I will work on researching the extent of people who would benefit from this Bill and involving local government and NHS bodies as to how these people will be identified and diagnosed to inform the impact assessment for introduction with this Bill if the leave to proceed vote is successful.

28. The main potential areas where costs and benefits will fall on the introduction of such a Bill are around:

- writing strategy and issuing guidance and communicating changes to legislation;
- additional duties for local authorities and NHS bodies to act under guidance;
- creating and maintaining practices to enable the collection of data on the numbers and needs of adults and children with autism;
- training for local authority and NHS staff;
- There will be savings due to the effective identification and support of individuals with autism.

### ***Autism strategy and issuing guidance.***

29. The Bill requires Welsh Ministers to publish a national autism strategy and to issue guidance to local authorities and NHS bodies on the implementation of that strategy. There will be costs borne by Welsh Government associated with the preparation and consultation to inform the strategy but it is not expected that these costs will be significantly above the current costs. For the Autism Scotland Bill, costs were prepared in 2010 for consulting on and publishing a national autism strategy in Scotland and issuing guidance, which was estimated at no more than £5,000 (£5,400 at current prices) to be incurred by the Scottish Government.<sup>5</sup> Considering the work already undertaken by the Welsh Government on their own autism strategy, the costs should not be above this figure. One of the main issues that has been identified to me is that there is a need to ensure there is consistency across Wales in terms of the awareness of families of services that are available to them and where they can go to find this information. These would be transitional costs. It would be expected that the strategy would need to be revised periodically, as is currently the case with the Welsh Government's existing strategy.

### ***Duty for local authorities and NHS bodies to act under guidance.***

30. The contents of the strategy and the guidance will be determined by the Welsh Ministers after consultation. As part of developing this Bill, I will work on researching the extent of people who would benefit from this Bill. In particular, I will consult with local government and NHS bodies as to how people may best be identified and diagnosed to inform an impact assessment, to accompany the Bill on introduction. Monitoring should be able to be designed to fit into existing NHS and

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<sup>5</sup> Autism (Scotland) Bill, Explanatory Notes, 24 May 2010, [http://www.parliament.scot/S3\\_Bills/Autism%20\(Scotland\)%20Bill/b44s3-intro-en.pdf](http://www.parliament.scot/S3_Bills/Autism%20(Scotland)%20Bill/b44s3-intro-en.pdf)

local authority regular accountability meetings and requirements. Until the number of people impacted upon and the contents of the strategy and guidance documents are known, it is not possible to estimate the costs which local authorities and NHS bodies will incur relating to the strategy and the guidance in exercising the relevant functions or the benefits that such investment would achieve.<sup>6</sup> However, I will work with stakeholders and the Welsh Government to ensure the legislation builds on and backs existing Welsh Government policy and considers how on-going costs can be minimised and benefits maximised.

31. The Social Services and Well-being (Wales) Act 2014 already places a statutory duty on local authorities to establish information, advice and assistance services to support people with autism, their families and carers. This could be extended to publishing information on services specifically for people with autism in the local authority region with little or no additional costs. The [Refreshed Autistic Spectrum Disorder Strategic Delivery Plan 2016-2020](#) requires local health boards to provide advice and support for all people with autism including family and carers.<sup>7</sup> This could also be extended to include awareness-raising by local health boards in the Bill at little or no additional cost.

### ***Data collection on the numbers and needs of adults and children with autism.***

32. Statistics show that 1 in 100 people may be on the autism spectrum in the UK.<sup>8</sup> If we take the total population of Wales as 3.1

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<sup>6</sup> As also reflected in the Autism (Scotland) Bill Explanatory Notes, 24 May 2010, [http://www.parliament.scot/S3\\_Bills/Autism%20\(Scotland\)%20Bill/b44s3-introden.pdf](http://www.parliament.scot/S3_Bills/Autism%20(Scotland)%20Bill/b44s3-introden.pdf)

<sup>7</sup> Refreshed Autistic Spectrum Disorder Strategic Delivery Plan 2016-2020, Welsh Government, <http://www.asdinfo.wales.co.uk/resource/161130ASD-deliveryplanen.pdf>

<sup>8</sup> Autism Facts and History, National Autistic Society, <http://www.autism.org.uk/about/what-is/myths-facts-stats.aspx>

million then this equates to 31,000 people on the autism spectrum in Wales.

***Training for local authority and NHS staff.***

33. The proposed Autism (Wales) Bill would support the implementation of the ALN Bill by, for example, ensuring that key staff working with people with autism, including teachers, receive autism training. A significant number of staff working with people with autism have already received training through Welsh Government led initiatives, but legislation would promote consistency of training standards 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. Part of the development process of this Bill will be to take a view on whether the current provision of training being implemented is sufficient. If the outcome was that further training needed to be mandated, then the cost of this would be calculated as part of the impact assessment with the Draft Bill.

34. The main cost to local authorities is the cost of additional resource to initially set up data collection and management practices. Once these have been established the resource required to maintain the data is expected to reduce and there would be an expectation that part of the identification process would include adding the person to this database. It would be anticipated that it would be possible to form an initial database from existing schools and NHS databases, which could then be added to over time. The cost of such an approach would be fairly minimal in the first instance and could be added to annually as people are diagnosed and added to the database as part of the requirements of this Bill.

35. I have assumed that staff involved in developing the database will be public sector administrative officials. The provisional ASHE data for 2016 shows the median gross hourly earnings in Wales in 2016 for administrative occupations: government and related organisations is £10.94.<sup>9</sup> Adding on costs of approximately 20%, gives a total hourly cost of £13.12.

36. The worst case scenario would be assuming setting-up a database from scratch and that 1% of people in Wales are identified as autistic in Wales. I have assumed that it would take an individual on average 20 minutes to enter one person on the database (dependent on the information required by Welsh Ministers). Then the total cost for local authorities in Wales is estimated at around £135,000 (31,000 x £13.12 cost per hour / 3 entries per hour). In reality, I know that only a proportion of the people in the autistic spectrum in Wales have been diagnosed and also there is likely to be existing information that can be used to populate the database. For example, there is potential for other developments in terms of data collection, such as NICE in England are currently considering requiring autism registers in GP practices. Also, additions to databases will be incremental as more people are diagnosed, so I would expect costs to be considerably lower and spread over a longer period.

### *Savings.*

37. The National Audit Office in its publication "[Supporting people with autism through adulthood](#)" emphasised that if services identified and supported four per cent of adults with high functioning autism in the local area then the outlay would be cost neutral over time in

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<sup>9</sup> As reflected in Para 8.24, Trade Union (Wales) Bill Explanatory Memorandum, January 2017, <http://www.assembly.wales/laid%20documents/pri-ld10895-em/pri-ld10895-em-e.pdf>

England.<sup>10</sup> Identification of six per cent and eight per cent could lead to potential savings of £38 million and £67 million per year respectively. This provides evidence that savings could be made based on effective identification and support of individuals with high functioning autism. However, it is not currently possible to calculate for Wales given the uncertainty surrounding the identification rate resulting from the strategy.

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<sup>10</sup> Supporting people with Autism through adulthood, National Audit Office, 5 June 2009, <https://www.nao.org.uk/wp-content/uploads/2009/06/0809556.pdf>