

# Autism (Wales) Bill Summary

January 2019

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# **Autism (Wales)**

## Bill Summary

January 2019

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**Authors:**

Amy Clifton

**Paper Overview:**

This research paper provides a summary of the Autism (Wales) Bill. It includes a summary of the main elements of the Bill and the response to it, including the views of the Welsh Government and the Health, Social Care and Sport Committee.



## 1. Introduction

On 28 March 2017, Paul Davies AM was successful in the ballot held under Standing Order 26.87 for the right to seek leave to introduce a Member Bill. His proposal was for a Bill to make provision for meeting the needs of children and adults with Autism Spectrum Disorder (ASD) in Wales, with the aim of protecting and promoting their rights.

On 14 June 2017, the National Assembly for Wales (the Assembly) agreed that Paul Davies could introduce a Bill within 13 months to give effect to the pre-ballot information he provided.

On 13 July 2018, the Bill was introduced and the Assembly's Health, Social Care and Sport Committee began the Stage 1 scrutiny process.

On 7 December 2018 the Health, Social Care and Sport Committee laid its Stage 1 report. The Finance Committee's report on the financial implications of the Bill and the Constitutional and Legislative Affairs Committee's report were also laid on this date.

## 2. Main elements of the Bill

The purpose of the Bill is to ensure the needs of children and adults with ASD in Wales are met, and to protect and promote their rights. The Bill requires Welsh Ministers to publish an autism strategy and to issue guidance to ‘relevant bodies’ responsible for its implementation; these are local authorities and NHS bodies in the Bill as drafted.

The Bill comprises twelve sections, three of which make provision for:

- publication and periodic review of an autism strategy;
- the contents of the strategy; and
- guidance on implementation of the strategy.

Other sections are concerned with a duty on “relevant bodies” to comply with the strategy, arrangements for combining assessments, data collection, a duty to undertake an autism awareness campaign, and duties on the Welsh Ministers and relevant bodies to have regard to United Nations Principles and Conventions.

The Explanatory Memorandum (EM) states that the Bill seeks to:

1. Introduce a strategy for meeting the needs of children and adults in Wales with ASD conditions which will:
  - Promote best practice in diagnosing ASD, and assessing and planning for meeting care needs;
  - Ensure a clear and consistent pathway to diagnosis of ASD in local areas;
  - Ensure that local authorities and NHS bodies take necessary action so that children and adults with ASD receive the timely diagnosis and support they need across a range of services;
  - Strengthen support for families and carers and ensure their wishes, and those of people with ASD, are taken into account;
  - Promote research, innovation and improvement in ASD Services;
  - Establish practices to enable the collection of reliable and relevant data on the numbers and needs of children and adults with ASD, so that local bodies can plan accordingly;
  - Require key staff working with people with ASD to receive ASD training;

- Ensure that local authorities and health boards publish information on the services they provide for people with ASD in their areas; and
2. Regularly review the strategy and guidance to ensure progress.
  3. Require the Welsh Ministers to issue guidance to the relevant bodies on implementing the strategy;
  4. Require the Welsh Ministers to undertake a campaign to raise awareness and understanding of ASD.

The Regulatory Impact assessment (RIA) estimates the total administrative costs of the Bill as £7,387,366. This includes:

- £359,756 costs to Welsh Government (to develop the strategy and guidance, publish data, review the strategy, and for training/awareness raising).
- £4,508,903 costs to Local Health Boards (additional staff costs of operating databases, and delivery of 13 week waiting time target).
- £2,518,708 indirect ‘opportunity costs’ of staff undertaking training.

### Summary of the Bill by section

Section 1 states that a strategy must be published and kept under review; ‘Not more than 3 years after publication (and at intervals of not more than 3 years thereafter) the Welsh Ministers must commission an independent report on its ongoing implementation and progress. The strategy must be revised to reflect any recommendations within 3 months of the publication.’

Section 2 of the Bill sets out what the autism strategy must cover including best practice models on assessment; a referral pathway; ensuring persons are not denied access to services on the grounds of IQ; access to employment; autism research; continuity of service with the transition from childhood to adult, ‘appropriate training’ for key professionals; and ‘make provision so that an appropriate range of services to deliver the autism strategy is available consistently across Wales’.

Section 3 covers combining assessments (such as those for health and social care).

Section 4 states that Welsh Ministers must issue (and publish) guidance to relevant bodies about the exercise of their functions for implementing and delivery of the strategy, no later than 3 months after publication of the strategy. Section 4(6) details what the guidance must cover including an indicative list of key professionals to be included in multi-disciplinary diagnostic assessment teams.

Section 5 covers compliance with the autism strategy and guidance by relevant bodies.

Section 6 states that the Welsh Ministers must obtain, produce and keep updated reliable data on ASD and publish it annually. Section 6(6) sets out details of the data NHS bodies must collect.

Section 7 states that the Welsh Ministers must initiate and maintain a campaign to raise awareness and understanding of the needs of persons with ASD upon publication of the strategy.

Section 8 covers duties to have regards to the relevant UN Principles and Conventions.

### 3. Rationale for the Bill

The Explanatory Memorandum (EM) states that the key function of the Bill is **to secure consistent and continued provision of all ASD services across Wales**. The EM notes that the Welsh Government is currently under no statutory obligation to provide or update its autism strategy. The original action plan was published in 2008 and refreshed in 2016. It reasons that beyond the period of the revised Autism Spectrum Disorder 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, and the EM states, “Experience there shows that legislation is needed to ensure the momentum for improvement is not lost”.

The Member in charge believes that creating a legal requirement to publish an autism strategy would help secure a measure of permanence and sustainability in care and support services for people with ASD, and ensure a continued, dedicated focus on the needs of people with ASD, regardless of the financial or political climate.

The EM explains that despite progress in recent years, difficulties remain for people in some areas to gain access to diagnostic assessments. It states ‘many people with ASD and their families still do not receive the services and support they need to enable them to cope with the challenges of ASD and to fulfil their potential’, and provides further detail including:

The Welsh Government’s Autism Spectrum Disorder Strategic Action Plan recognised the need for better diagnostic services for children and adults with ASD. However, evidence suggests that the success of the Action Plan in raising awareness of ASD led to an increase in demand for diagnosis but also to lengthening waiting times for assessment<sup>1</sup>.

<sup>1</sup> [Welsh Government, Outcome evaluation of the Autism Spectrum Disorder Strategic Action Plan: Executive Summary, 2016, p2](#)

The EM notes that 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.

Paul Davies stated in Plenary:

[...] what is clear is that the issues that were identified in the first strategy in 2008 are the same issues that remain now in 2018: diagnosis, data, support services, training, employment, housing, mental health—just to name but a few. That is what people are telling me about this issue—that those are the same issues that were actually being debated then, 10 years ago, and that is why we need primary legislation.

He also stated that ‘despite the strategy introduced 10 years ago, we are still seeing a lack of services for people with autism in certain parts of Wales’, and that this legislation ‘will make sure that there will be consistency of services throughout Wales’.

National Autistic Society (NAS) Cymru has campaigned for the legislation and supported the Member in charge in the development of the Bill. NAS Cymru states in its consultation response:

10 years of the autism Action Plan hasn’t achieved the necessary changes to the lives of autistic people in Wales. We believe that changes that will make a tangible difference are mandatory. Legislation is supported by our members and supporters and the overwhelming majority of the hundreds of responses to both the consultation on both the development and the draft autism bill. The Bill has therefore been shaped by autistic people who will be directly affected by it.

### Views from the Member in charge’s consultations

The EM reports that ‘most respondents’ to the Member in charge’s consultation on the principles of the Bill agreed that there is a need for an Autism Bill. Support for the introduction of a Bill was particularly strong amongst users of ASD services and their families and carers. The EM states there was a clear view that services for people with ASD need improving, that services are variable across Wales, and that legislation would help to drive improvement.

Long waiting times for diagnosis were identified as a particular concern, with some respondents describing how they had waited years for a diagnosis. Diagnosis and services for adults were described as particularly difficult to access, particularly for individuals without a co-existing learning disability or mental health problem. There was also a clear view that the differences in services for children and adults means that the transition to adulthood can result in a loss of services. The EM states that with this in mind, the Bill requires an autism strategy to meet the lifelong needs of people in Wales with ASD by improving the provision of services for them. It also includes a requirement that the strategy ensures continuity between child and adult services.



## 4. Response to the Bill

There are strong views on either side of the debate about the Autism (Wales) Bill.

The Health, Social Care and Sport Committee heard from individuals with ASD and their families, and charities representing them such as NAS Cymru, that it is often extremely difficult to access support, with long waits for diagnosis, and clear gaps in service provision, including employment support for adults with ASD, particularly those with a high IQ and without a learning disability or mental health condition. The Committee received evidence that the autism strategies and current legislation such as the Social Services and Wellbeing (Wales) Act 2014 have failed to deliver people with ASD, and views that the Integrated Autism Service will not provide the level of frontline support services which are urgently needed.

The Committee also heard from Health and Social Services representatives, Royal Colleges of health professionals, and the Welsh Government about their concerns that the Bill is ‘diagnosis-led’ rather than ‘needs-based’, and could lead to autism diagnosis being prioritised over other conditions and services, and therefore have a negative impact on other neurodevelopmental conditions and people who do not reach the diagnosis threshold. Some also felt that time should be allowed to enable new policies and legislation to ‘bed-in’ including the Additional Learning Needs and Educational Tribunal (Wales) Act 2018, the Integrated Autism Service which has not yet been rolled out in all areas, and the Welsh Government’s new Code of Practice.

### The Welsh Government’s position

The Welsh Government does not support the legislation.

The Cabinet Secretary made a statement on 25 September 2018 announcing he has published an [updated Autistic Spectrum Disorder Strategy Delivery Plan](#), reflecting ‘important new commitments which will improve services’.

The Welsh Government also issued a [public consultation on 30 November 2018 on a new Code of Practice on the delivery of autism services](#), which it has stated “can address all the issues identified in the Bill and can address additional concerns raised by stakeholders”.

The Welsh Government states it has re-affirmed its commitment to improve the lives of people with ASD by publishing the latest Autistic Spectrum Disorder Strategic Action Plan, backed by a £13 million pounds of investment in new services

(the Integrated Autism Service). The Welsh Government’s view is that recent developments like the new Integrated Autism Service will deliver the required improvements given time.

The Welsh Government believes it already has all the powers required to deliver improvement to autism services in current legislation in the Social Services and Wellbeing (Wales) Act 2014, the Additional Learning Needs and Education Tribunal (Wales) Act 2018 and the NHS (Wales) Act 2006. The Welsh Government also believes that the Bill will 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.

Two key elements of the Bill which the Welsh Government disagree with are the introduction of a new waiting time for diagnostic assessment and new data collection provisions.

The Bill adopts the NICE quality standard target which states that children and adults should not wait more than three months from referral to a first diagnostic appointment. The Member in charge and supporters of the Bill argue that this is necessary to ensure that people receive a timely diagnostic assessment, and address the issue of current long delays. The Welsh Government introduced a commitment to a 26 week waiting time standard for referral to first assessment for children in its refreshed autism Action Plan published in November 2016, and have since committed to extend this standard to adults. The Welsh Government believe the proposed shorter waiting time in the Bill would force services to focus limited resources on meeting the Bill’s duties; funnelling more people through diagnostic assessment at the expense of providing pre- and post-diagnostic support.

The Bill includes new data collection requirements for health bodies, with supporters arguing that this will help to monitor effectiveness, and identify whether diagnoses are being made at appropriate levels. The Welsh Government isn’t in favour of the provisions, stating that the level of data required in the Bill is ‘onerous and adds little additional relevant information to both planning and commissioning’.

## The Health, Social Care, and Sport Committee's view

The Committee unanimously agreed that the current struggle people with ASD and their families regularly face when trying to access support is unacceptable and must be addressed. Members said the message has clearly come through in evidence that more support services are urgently needed for people with ASD.

The Committee was unable to reach consensus on whether this legislation, at this particular time, is the most appropriate way of achieving these much needed improvements.

Some Members support the introduction of this Bill, believing that it is both timely and necessary to put services on a statutory footing to deliver improvement where previous strategies have failed to do so, and achieve the change required for people with ASD and their families.

Other Members feel that more time is needed for existing initiatives and legislation to take effect. Some were also concerned about the focus of the Bill (which some believe is diagnosis rather than needs-led) and the potential consequences on people who will not receive an ASD diagnosis, and/or have other neurological conditions.

However the Committee stressed that they are in agreement that there is a pressing need to improve support services for people with ASD and their families across Wales, and believe this must be addressed as a matter of priority. They made a number of recommendations to the Welsh Government to this effect.



