

# Financial implications of the Autism (Wales) Bill

December 2018



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# **Financial implications of the Autism (Wales) Bill**

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# About the Committee

The Committee was established on 22 June 2016. Its remit can be found at:  
[www.assembly.wales/SeneddFinance](http://www.assembly.wales/SeneddFinance)

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## Committee Chair:



**Llyr Gruffydd AM**

Plaid Cymru  
North Wales

## Current Committee membership:



**Rhun ap Iorwerth AM**

Plaid Cymru  
Ynys Mon



**Neil Hamilton AM**

UKIP Wales  
Mid and West Wales



**Mike Hedges AM**

Welsh Labour  
Swansea East



**Jane Hutt AM**

Welsh Labour  
Vale of Glamorgan



**Nick Ramsay AM**

Welsh Conservatives  
Monmouth



**David Rees AM**

Welsh Labour  
Aberavon

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The following Member was also a member of the Committee during this inquiry.



**Steffan Lewis AM**

Plaid Cymru  
South Wales East

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## Recommendations and Conclusions

**Recommendation 1.** In future, should the Assembly vote in favour of the motion tabled in accordance with Standing Order 26.91 the Committee recommends that the Welsh Government commits to providing information to ensure that costs in an explanatory memorandum are as comprehensive and detailed as possible, utilising cost information which the Welsh Government has available. .... Page 10

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**Conclusion 3.** It is difficult for the Committee to comment on the merit of a diagnosis versus needs led approach without straying into policy, but Members are uncertain whether the potential additional call on resources that this approach may result in has been fully accounted for. However, this uncertainty is based around the lack of clear information about the money spent on ASD services. .... Page 14

**Conclusion 4.** The Committee is unable to make a decision on the validity or not of this Regulatory Impact Assessment. Members have not received any substantial financial reason for the legislation not to go forward, but we have been unable to ascertain whether there is any value for money in this legislation due to the lack of financial information. .... Page 17

## 1. Background and Overview

**1.** The Autism (Wales) Bill (the Bill) was introduced on 13 July 2018 as a Member Bill by Paul Davies AM. It is intended to ensure the needs of children and adults with Autism Spectrum Disorder (ASD) in Wales are met, and to protect and promote their rights. The Bill seeks to deliver this by introducing 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 the Welsh Ministers, and local and NHS bodies can plan accordingly.
- Ensure key staff working with people with ASD are provided with appropriate ASD training.
- Regularly review the strategy and guidance to ensure progress.

**2.** The Bill also places additional responsibilities on the Welsh Ministers by requiring them to:

- Issue guidance to the relevant bodies on implementing the strategy.
- Collect suitable data to facilitate the implementation of the Bill.
- Undertake a campaign to raise awareness and understanding of ASD.

**3.** A Regulatory Impact Assessment (RIA) was included in the Explanatory Memorandum (EM) to the Bill. The RIA set out the costs for the following options:

- **Option 1:** Maintain the Welsh Government’s current approach to addressing the needs of children and adults with ASD in Wales.
- **Option 2:** Introduce legislation to ensure the needs of children and adults with ASD in Wales are identified and met.

**4.** The EM states costs and benefits associated with each option are assessed over a five-year period, as costs beyond this timeframe cannot be estimated with certainty.

## 2. Financial Implications of the Bill

### Information from the Welsh Government

**5.** Option 1 in the RIA has been estimated to cost £5.7 billion over five years, which includes:

- No costs to Welsh Government;
- £368,000 to Local Health Boards;
- £3.5 billion to public sector organisations in direct costs;
- £2.1 billion in indirect costs adjusted for employment.

**6.** Option 2 has estimated additional costs (in addition to option 1) of £7.4 million over 5 years, which includes:

- £360,000 to Welsh Government;
- £4.5 million to Local Health Boards;
- £2.5 million to public sector organisation in indirect costs.

**7.** The RIA stresses that there is no available information on the cost of providing direct services or of the indirect economic impacts of ASD in Wales. Instead, a [study of the autism spectrum](#) published in March 2018 by the Scottish Government, which was based on the latest UK and international studies, was used to determine estimates of prevalence and costs in Wales.

**8.** The study recommended that 103.5 per 10,000 population be used as the most accurate prevalence estimate available. The RIA notes there is no evidence to suggest that figures for Wales would be significantly different, nor is there recent robust evidence specific to Wales.

**9.** The RIA also used the study to estimate lifetime costs for people with ASD and their carers. It splits the costs between people with ASD with and without an Intellectual Disability (ID). It then applied the analysis in the study to the Welsh population. The methodology included:

- Applying prevalence estimates to the Welsh population to estimate the number of individuals in Wales with ASD.

- Identifying individuals with ASD by living accommodation based on previous studies.
- Applying unit costs available in the study to determine lifetime costs for people with ASD and parents.

**10.** Costs are estimated to be over £1.1 billion per year for current Welsh Government provision of the refreshed ASD Strategic Action Plan,<sup>1</sup> which was updated in September 2018. Around £700 million, or 62%, of these are direct costs (two-thirds of these direct costs relate to accommodation) and £400 million, 38%, indirect costs relating to productivity loss.

**11.** In addition, the analysis in the RIA has been informed by engagement with key stakeholders including Welsh Government, professionals within the field and third sector bodies. Two consultations have also been undertaken to allow the RIA to incorporate the views of local authorities and health boards.

**12.** The Member in Charge of the Bill, Paul Davies AM confirmed to the Committee that these estimated costs were “as accurate as possible” given the lack of available information – such as waiting times or the number of people with autism.

**13.** During the evidence session, Paul Davies AM shared correspondence he had had from the Welsh Government which stated:

“Just to confirm our conversation that, following the recent exchange of letters between the Cabinet Secretary for Health and Social Services and Paul Davies AM, the Cabinet Secretary is not minded to provide any further information at this time.”<sup>2</sup>

**14.** Paul Davies AM concluded that:

“... it was disappointing to know that the Government has failed or has refused to give us any further information”<sup>3</sup>

**15.** The Cabinet Secretary for Health and Social Services, Vaughan Gething, (the Cabinet Secretary) outlined his view that:

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<sup>1</sup> [Welsh Government Autistic Spectrum Disorder Strategic Action Plan \[accessed 26 November 2018\]](#)

<sup>2</sup> RoP, 11 October 2018, Paragraph 9

<sup>3</sup> RoP, 11 October 2018, Paragraph 10

“The costs, such as they are—that we’re investing in the service—are available. In terms of the costs for the Bill, that’s not a matter for the Government. .... Through the Bill process, there’s been an interesting conversation about how we divide up costs and how we provide those costs. Because we’re currently delivering a system based on needs, and we’re investing money in the integrated autism service to underpin the strategy we have, to then undertake an exercise to try and portion out direct costs for autism would have required us to run through a not uncomplicated process, and, really, that’s a matter for the Member in charge, as opposed to the Government undertaking work with a real cost to it. So, it’s for the Member in charge to set out from his own perspective how he assess the costs as they are and the costs of the Bill and the legislation that he seeks to introduce.”<sup>4</sup>

**16.** The Cabinet Secretary also expressed his surprise that the Member in Charge had not employed a health economist to help work through the figures. The Member in Charge subsequently wrote to the Committee on this point and set out:

“It is clear from my evidence that I sought robust expert advice on the available data. It is concerning to note the difficulties the Cabinet Secretary outlined to you in apportioning ASD specific spend from wider spend on neurological development conditions, as one would expect the government to be capturing this data as part of its existing ASD activities. Further, if this information is not readily available, I’m unsure as to how a health economist could have assisted in this instance.”<sup>5</sup>

**Conclusion 1.** The Committee is concerned that the Welsh Government did not provide costings for delivering current services to the Member in Charge of the Bill.

**Recommendation 1.** In future, should the Assembly vote in favour of the motion tabled in accordance with Standing Order 26.91 the Committee recommends that the Welsh Government commits to providing information to ensure that costs in an explanatory memorandum are as comprehensive and detailed as possible, utilising cost information which the Welsh Government has available.

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<sup>4</sup> RoP, 7 November 2018, Paragraph 254

<sup>5</sup> [Correspondence from Paul Davies AM](#)

## Methodology for calculating costs

### Option 1

**17.** Option 1 is the default option where the current status quo continues and the Welsh Government’s Autism Spectrum Disorder Strategic Action Plan would continue to be delivered across Wales in its current form.

**18.** The table below shows the summary costs for Option 1:

Body	£000s					Total
	Year 1	Year 2	Year 3	Year 4	Year 5	
Welsh Government	0	0	0	0	0	0
Local Health Boards	74	74	74	74	74	370
Public Sector Organisations (direct costs)	700,058	702,142	704,223	706,350	708,496	3,521,268
Opportunity costs adjusted for employment	424,704	425,968	427,231	428,521	429,823	2,136,248
<b>Total Costs</b>	<b>1,124,836</b>	<b>1,128,183</b>	<b>1,131,528</b>	<b>1,134,944</b>	<b>1,138,393</b>	<b>5,657,884</b>

Please note: costs have been rounded and therefore subtotals may not sum to totals.

**19.** The Welsh Government agreed that it was broadly happy with the methodology used for calculating the costs of option 1, but it did raise a number of technical issues on the figures used for calculation in subsequent correspondence, for example:

“Costs are presented to the nearest pound. This makes some of the tables, for example Table 7, unnecessarily difficult to read. More importantly it suggests an implausible level of accuracy in the analysis which may in turn give an impression of confidence in the calculations.”<sup>6</sup>

<sup>6</sup> [Correspondence from the Cabinet Secretary](#)

## Option 2

**20.** Option 2 sets out costs to introduce legislation to ensure the needs of children and adults with ASD in Wales are identified and met. This is the preferred option for the Bill.

**21.** The table below shows the total additional costs for delivering legislation introduced by the Bill over 5 years

Body	£000s					Total
	Year 1	Year 2	Year 3	Year 4	Year 5	
Welsh Government	145	20	45	129	20	360
Local Health Boards	1,584	1,458	1,458	4	4	4,509
Public Sector Organisations	0	2,014	168	168	168	2,519
<b>Total Costs</b>	<b>1,729</b>	<b>3,492</b>	<b>1,672</b>	<b>301</b>	<b>193</b>	<b>7,387</b>

Please note: costs have been rounded and therefore subtotals may not sum to totals.

**22.** A Welsh Government Official set out some concerns with the methodology for option 2:

“...looking into option 2, the methodology that’s been taken is to look at the current population of the waiting list, and to gross that up using a figure of £2,500, which would be the private sector rate for an assessment process for diagnosis. The Member has costed up the waiting list. The RIA is silent on what would happen beyond that waiting list being eradicated. So, it says nothing about future demand, nor does it say anything about the increased demand that may well come through the system through an approach such as this, which is diagnosis-based.”<sup>7</sup>

**23.** This was a view which Paul Davies refuted, setting out that the RIA has:

“assumed diagnoses will be above the prevalence rate to allow for some growth in demand.”<sup>8</sup>

<sup>7</sup> RoP, 7 November 2018, Paragraph 268

<sup>8</sup> [Correspondence from Paul Davies AM](#)

**Conclusion 2.** The Committee has been unable to fully consider the value for money of options one and two as there is little information about the current Welsh Government costs to inform such considerations.

## Miscalculation in the RIA

**24.** The Member in charge wrote to the Committee to clarify a miscalculation in the RIA. He set out that:

“...whilst it has not been possible to provide an accurate figure for the total costs of autism in Wales, the estimated figure included in the RIA is £1.1 billion per year. The RIA refers to a reduction of 1% in autism spend resulting in a saving of £1million annually, a figure I also referred to in my evidence to the Finance Committee. However, this is an under estimation of the potential savings as, based on a total cost of £1.1 billion, a 1% reduction in autism spend would actually result in annual savings of £11 million.”<sup>9</sup>

**Recommendation 2.** The Committee notes the miscalculation in the Regulatory Impact Assessment and recommends this is addressed, should the Bill proceed to stage 2.

## Increase in Service Demand

**25.** The Bill places a greater focus on diagnostic assessments. The Committee explored whether this would impact on support services for ASD as additional resources would be redirected to diagnostics.

**26.** The RIA states:

“The maximum additional cost would be the full cost of providing services to people with ASD receiving an early diagnosis for 13 weeks. An assumption has been made that the diagnosis will be completed on average 13 weeks earlier than is currently the case. The numbers included are the estimate of those currently waiting over 13 weeks, and 400 additional diagnoses annually. The cost of providing services to people with ASD who would not otherwise have received a diagnosis, is estimated at £9.5 million direct costs, plus £3.9 million productivity loss.”<sup>10</sup>

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<sup>9</sup> Correspondence from Paul Davies AM

<sup>10</sup> RIA

**27.** The Member in Charge stated that he would like to:

“...refute the view continuously expressed by the Cabinet Secretary that the sole focus of this legislation is to achieve a diagnosis of ASD. ...instead it puts forward an overarching regime that seeks to address all the needs of a person with ASD, both pre and post diagnosis.”<sup>11</sup>

**28.** In response to concerns about the risk of ASD support service capacity being undermined as a result of the extra resources required for diagnosis Paul Davies AM acknowledged that:

“... there’s a possibility that, obviously, by passing legislation, you will see an increase in demand, but I’d like to think that the costings that we’ve put forward with this Bill will, of course, absorb that demand as well.”<sup>12</sup>

**29.** The Cabinet Secretary set out that:

“If you have a diagnosis-led approach, then you’ll have pressure on diagnostic services. Don’t take my word for it—it’s something that the Children’s Commissioner for Wales refers to in her evidence as well. So, you’ll drive pressure there, so you’ll drive resources there as well. That either means that you’re saying that a diagnosis-led approach, not a needs-led approach, is the right thing. That’s a significant departure from the way we provide services now across health and social care, and certainly the scheme set out in the social services and well-being Act, but it also then means that you’re taking resource away from delivering against those needs. The RIA sets that out itself, actually; it recognises that that’s a risk.”<sup>13</sup>

**Conclusion 3.** It is difficult for the Committee to comment on the merit of a diagnosis versus needs led approach without straying into policy, but Members are uncertain whether the potential additional call on resources that this approach may result in has been fully accounted for. However, this uncertainty is based around the lack of clear information about the money spent on ASD services.

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<sup>11</sup> [Correspondence from Paul Davies AM](#)

<sup>12</sup> RoP, 11 October 2018, Paragraph 103

<sup>13</sup> RoP, 7 November 2018, Paragraph 271

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## Code of Practice

**30.** In September 2018 the Cabinet Secretary published an updated autistic spectrum disorder strategy delivery plan, which he believed reflected new commitments<sup>14</sup> to improve services:

- issuing a **Code of Practice** on the delivery of autism services under the Social Services and Well-being (Wales) Act 2014 and the National Health Service Act 2006.
- issuing a **Code of Practice** on the Additional Learning Needs and Education Tribunal (Wales) Act 2018 and roll-out of the new ALN system from 2020.
- updating and expanding Welsh Government **autism guidance** for **housing providers**.
- **improving data collection** through developing GP autism registers.
- consulting on making **autism a stand-alone theme** for future population needs assessments.
- raising awareness by **improving engagement and involvement** of autistic people in **policy development**.
- **expanding the independent evaluation** to look at the alignment between children’s neurodevelopmental and wider autism services and to **address the continuing barriers** to reducing diagnostic waiting times.

**31.** When Paul Davies AM gave evidence to Committee, he noted that “many of the issues that the Welsh Government is planning to address in this particular code are the same as those in my Bill”. He further commented that when he asked the Cabinet Secretary about the cost of Welsh Government’s updated Code of Practice in Plenary, he did not receive a direct answer.<sup>15</sup>

**32.** The Cabinet Secretary set out in written correspondence that:

“The purpose of the Code of Practice, about which I will publish a consultation document at the end of this month, will be to underpin and strengthen the delivery of the existing ASD Strategic Action Plan. This plan is supported by annual costs of some £730k to deliver the

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<sup>14</sup> Plenary, 25 September 2018

<sup>15</sup> RoP, 11 October 2018, Paragraph 34

work programme, £13m to deliver the Integrated Autism Service up to March 2021 and £2m annually to support improvements in children's neurodevelopmental services.

The code will reinforce existing duties placed on Local Authorities and Local Health Boards under the Social Services and Well-being (Wales) Act and the NHS (Act). I do not envisage there being any additional funding required for services to be shaped in a way that is consistent with the code. There may however be a risk to the future delivery of the Strategic Action Plan should the Bill pass into legislation."<sup>16</sup>

**33.** This is symptomatic of the difficulties the Committee has experienced with scrutinising the financial information related to this Bill. The Code has a cost which is budgeted for within the current envelope for ASD services, but there is no clarity as to what the actual cost will be.

## Committee View

**34.** The Committee has a number of concerns relating to the Welsh Government interaction with this Bill.

**35.** The Cabinet Secretary for Health and Social Services was technically correct in his assertion that the Member in Charge of the Bill is responsible for producing and costing the RIA for the Bill. However, the Committee would expect that there would be greater co-operation from the Welsh Government in terms of ensuring available data is provided to any Member proposing legislation.

**36.** The Committee believe that scrutiny of this Bill would have been enhanced if we'd had the Cabinet Secretary's paper in advance of his evidence session. The correspondence received afterwards begins to challenge some of the assertions within the RIA and Members would have been able to explore these further had the information been provided in advance.

**37.** There are many areas that the Committee is unable to comment on due to the lack of financial information about the present spend on ASD. For example, as stated earlier Members are uncertain that the potential additional call on resources that this Bill may result in has been fully accounted for. However, this uncertainty in part is based around the lack of clear information about the money spent on ASD services

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<sup>16</sup> [Correspondence from the Cabinet Secretary](#)

**38.** The Committee believes that the Welsh Government has a responsibility to provide AMs producing Member led legislation with financial information, as the Government is, in most instances, the main source of such information. The Committee is disappointed at the lack of engagement from the Cabinet Secretary with the Member in Charge in this regard.

**39.** The lack of financial information provided by the Welsh Government on the cost of ASD services, means the Committee was unable to scrutinise the figures presented by the Member in Charge. The success of legislation relies on accurate information, and the failure of providing the information had hindered the process of scrutiny and potential of this legislation. This is a worrying precedent.

**Conclusion 4.** The Committee is unable to make a decision on the validity or not of this Regulatory Impact Assessment. Members have not received any substantial financial reason for the legislation not to go forward, but we have been unable to ascertain whether there is any value for money in this legislation due to the lack of financial information.