This Explanatory Memorandum has been prepared by Paul Davies AM and is laid before the National Assembly for Wales.

Declaration of Legislative Competence

In my view, the provisions of the Autism (Wales) Bill, introduced by me on 13 July 2018 would be within the legislative competence of the National Assembly for Wales.

Paul Davies AM

Member in charge of the Bill

July 2018

Contents

Part 1: Background and purpose of the Bill

1. Introduction

1. 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 that would 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, and for connected purposes.

2. 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.

3. This Explanatory Memorandum has been prepared and laid in accordance with Standing Order 26.6. It sets out the background to the provisions and scope of the Bill.

4. The overall purpose of the Autism (Wales) 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 delivers this purpose by seeking 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 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; and
- Regularly review the strategy and guidance to ensure progress.

2. Require the Welsh Ministers to issue guidance to the relevant bodies on implementing the strategy.

3. Require the Welsh Ministers to collect suitable data to facilitate the implementation of the Bill.

4. Require the Welsh Ministers to undertake a campaign to raise awareness and understanding of ASD.

2. Legislative powers

2. 1. Introduction

5. The Assembly's Standing Orders provide for Bills to be introduced by individual Assembly Members, as well as the Welsh Government, committees and the Assembly Commission, in areas where the Assembly has legislative competence. Only the Welsh Government can introduce Bills about taxation.

2. 2. Reservations

6. Section 107 of the Government of Wales Act 2006 (GOWA) permits the Assembly to make laws for Wales known as Acts of the Assembly. Section 108A provides that "an Act of the Assembly is not law so far as any provision of the Act is outside the Assembly's legislative competence".

7. The Assembly's legislative competence is now framed by the reserved powers model. No provision in the Bill must relate to a reserved matter set out in Schedule 7A to GOWA. There are no reservations relating to health and social care that are relevant to the contents of this Bill and the Bill does not modify the law relating to a reserved matter. The Bill does not make prohibited provisions in relation to the private or criminal law.

8. In reaching this conclusion, specific consideration was given to the following reservations set out Schedule 7A:

- Reservation 140 - regulation of health professions;
- Reservation 170 – protection of personal data: and
- Reservation 187 – equal opportunities.

9. Reservation 140 - regulation of health professions: This is defined in GOWA to include various health care professions, though social care and social work professions are excluded from the reservation. The overall purpose of the Bill is to make provision for meeting the needs of children and adults with autism spectrum disorder in Wales, and protecting and promoting their rights. To help achieve this overall purpose, the purpose of the reference to training in section 2(1)(q) is to enhance and improve relevant skills by ensuring that appropriate training is made available to professionals and other staff who provide services to persons with ASD. The reference in section 2(1)(q) to training, read with the compliance provisions in section 5, would have been capable of giving rise to training obligations that might have fallen within the scope of this reservation. To avoid the risk of contravening this reservation, the words 'but not mandatory' have been included in section 2(1)(q).

10. For these reasons, the purpose of the provisions in question does not relate to Reservation 140, and is consequential upon the overall purpose of the Bill, and thus does not relate to a reserved matter for the purposes of section 108A(2)(c) of GOWA. Further, the provisions in question do not modify the law on the regulation of health professionals in contravention of paragraphs 1 and 2 of Schedule 7B to GOWA.

11. Reservation 170 – protection of personal data: No provisions in the Bill relate to or seek to amend the law, or confer additional rights, in relation to the protection of personal data. The overall purpose of the Bill is to make provision for meeting the needs of children and adults with ASD in Wales, and protecting and promoting their rights. To contribute to the achievement of this overall purpose, the purpose of the provisions in question is to ensure that the Welsh Minsters have access to anonymised data to support their functions under the Bill, including the delivery of the strategy, and for the NHS to capture and have access to relevant ASD data. The effect of these provisions will be the enhanced ability of the Welsh Ministers to deliver ASD services in Wales via the strategy and the other provisions under the Bill, resulting in a genuine improvement in the lives of persons with ASD through improved autism diagnosis, treatment and services. It has been set out variously in this Explanatory Memorandum why the data sets on the face of the Bill are required to be collected by the NHS as a minimum. The intended effect of the collection of relevant and reliable data is both to assist the NHS in delivering improved ASD services directly, and to provide anonymised data to the Welsh Ministers to assist them in the discharge of their functions under the Bill.

12. The purpose of the provision in section 6 (and note section 2(1)(o) is dependent on this) is to capture specified data, which will include the processing of personal data, solely to deliver the overall purpose of the Bill, namely delivery of the prescribed autism strategy and consequent improvement in autism care both within the NHS and generally in Wales. The provision and its effect goes no further than necessary to achieve its purpose. Expert advice was taken on the minimum necessary data categories to be included to ensure a reliable data set and data sharing was limited by imposing an anonymisation obligation.

13. The provision in section 6 of the Bill merely seeks to interact with the DPA18 in a manner already anticipated by that Act, so the effect on 'the protection of personal data' is merely consequential in this regard. Further, and more practically, the raison d'etre of the DPA18 is to set up a regime for the processing of personal data. It would be an unsustainable position if legislation could not utilise this regime to achieve a particular purpose. If that were the case, no data processing activities could ever be included in other legislation. Thus, the data collection provision in the Bill, relates in a purely consequential way to the substance of the Bill where that provision confines itself to operating within the regime prescribed by the DPA18.

14. For these reasons, the purpose of the provision in question does not relate to Reservation 170, and is consequential upon the overall purpose of the Bill, and thus does not relate to a reserved matter for the purposes of section 108A(2)(c) of GOWA.

15. Finally, the provisions in question do not modify the law on reserved matters in contravention of paragraphs 1 and 2 of Schedule 7B to GOWA. They do not seek to impose a new regime that differs from that set out in the DPA18 or the GDPR – for example they do not require the sharing of personal data in a manner outside the permissible bases set out in these enactments.

16. **Reservation 187 – equal opportunities:** There is a general reservation of equal opportunities, but with a number of exceptions applicable to it. The overall purpose of the Bill is to make provision for meeting the needs of children and adults with ASD in Wales, and protecting and promoting their rights. Two provisions in the Bill, sections 2(1)(f) and 8 have a clear connection with equal opportunities. To help achieve the overall purpose of the Bill, the purpose of the provisions in question is to seek to encourage equal opportunities in a broad sense. They only impose duties with a view to securing that the relevant functions under the Bill are carried out with due regard to the need to meet equal opportunities requirements. To the extent that this purpose relates to equal opportunities, it both falls within the exceptions to Reservation 187, and is consequential upon the overall purpose of the Bill.

17. The effect of the provisions will be to ensure that persons are not prevented from accessing ASD services due to protected characteristics, such as disability, race, etc, and other characteristics on the face of the Bill. For example, they would address particular issues highlighted in consultation relating to diagnostic issues around persons with high/low IQ, or where they are in receipt of other medical services. Also, they would promote equalities in the delivery of services, such as housing.

18. In pursuing this purpose, the provisions in question do not modify the existing law on equal opportunities in any way. They merely require that arrangements are put in place to ensure that functions are carried out in compliance with prevailing equalities law, such as the Equality Act 2010.

19. For the reasons above, the purpose of the provisions in question fall within the exceptions to reservation 187, and are consequential upon the overall purpose of the Bill, and thus do not relate to a reserved matter for the purposes of section 108A(2)(c) of GOWA.

2. 3. Welsh Public Authorities

20. Paragraphs 8 and 10 of Schedule 7B to GOWA restrict the power to legislate in relation to public authorities other than devolved Welsh authorities. The Welsh Ministers, local authorities, NHS Trusts (established under section 18 of the National Health Service (Wales) Act 2006) and local health boards (established under section 11 of the same Act) in Wales are listed as devolved Welsh authorities in Schedule 9A of GOWA.

21. Special health authorities established under section 22 of the National Health Service (Wales) Act 2006 are not listed in Schedule 9A, and therefore need to be considered individually against the more general test in section 157A of GOWA. The NHS Business Services Authority and NHS Blood and Transplant are authorities of that sort, but paragraphs 9 and 10 of Schedule 7B expressly exclude them from the restrictions on the Assembly's legislative competence.

22. Health Education and Improvement Wales was established by the Health Education and Improvement Wales (Establishment and Constitution) Order 2017 made under section 22 on 11 September 2017 (i.e. after the Wales Act 2017 received Royal Assent). For that reason it is not included in Schedule 9A, but consideration of its remit demonstrates that the body would therefore satisfy the test for devolved Welsh authorities in section 157A(2) of GOWA.

23. The NHS Litigation Authority (NHSLA) was established by the National Health Service Litigation Authority (Establishment and Constitution) Order 1995. The Order was made under the National Health Service Act 1977.

24. Following the consolidation of the enabling powers, this Order now has effect as if made under section 28 of the National Health Service Act 2006 and section 22 of the National Health Service (Wales) Act 2006, by virtue of the National Health Service (Consequential Provisions) Act 2006. It would therefore fall within the description of special health authorities if it were not specifically excluded. The consent of the Secretary of State would have been required for its inclusion.

2. 4. Jurisdiction and Compatibility

25. The Bill relates to persons in Wales with ASD. Its legal standing does not therefore extend beyond the jurisdiction of England and Wales, and it does not apply otherwise than in relation to [people in] Wales. The Bill is not incompatible with Convention Rights protected by the Human Rights Act, or with EU law.

3. Context and overall need for the Bill

26. A considerable amount of work has been undertaken in Wales in recent years to improve services for people with ASD, 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 ASD and made available a range of high quality information and resources for both service users and professionals.

27. Nevertheless, difficulties remain for people in some areas to gain access to diagnostic assessments. Getting a diagnosis of ASD can be a key milestone for people with ASD and their families, both in terms of helping them to understand ASD, and in achieving access to services. Seventy per cent of respondents to a

2015 survey[1] undertaken by the National Autistic Society Cymru said they felt relieved to get a diagnosis.

28. 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[2].

29. There was also recognition in the Strategic Action Plan that work was needed to promote employment of people with ASD 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 with ASD remain much lower than for the wider population[3] and further work is needed to address this.

30. It is therefore clear that although the Strategic Action Plan helped to improve services in many local areas and raise awareness of ASD, 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.

31. 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. 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 ASD have their needs met with high quality support wherever they live.

32. A Refreshed Strategic Action Plan 2016-20 is introducing further reforms, including improvements to diagnostic services and waiting times, the

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[1] The National Autistic Society *Act Now – An Autism Act for Wales Report*, 2016, p5

[2] Welsh Government, *Outcome evaluation of the Autism Spectrum Disorder Strategic Action Plan: Executive Summary*, 2016, p2

[3] Welsh Government, *Outcome evaluation of the Autism Spectrum Disorder Strategic Action Plan: Executive Summary*, 2016, p3

development of a National Integrated Autism Service, and measures to improve education and employment for people with autism. Developments in education support include the Additional Learning Needs and Education Tribunal (Wales) Act 2018 (the ALN Act), which gained Royal Assent in January 2018.

33. The ALN Act provides a single statutory framework for supporting children and young people with Additional Learning Needs (ALN), including ASD, throughout childhood, and up to the age of 25 where they are in further education. The ALN Act introduces statutory Individual Development Plans for all children and young people with ALN, replacing the existing system, which is based on the term "Special Educational Needs" and statements. The ALN Act 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.

34. The work undertaken by the Welsh Government in recent years is welcome, and the Autism (Wales) Bill seeks to supplement, not to replace, these measures. For example, although not specifically concerned with ASD support in educational settings, the Autism (Wales) Bill would complement the provisions in the ALN Act. The Autism (Wales) Bill would support the implementation of the ALN Act by, for example, ensuring that key staff working with people with ASD, including teachers, have access to appropriate ASD training. A significant number of staff working with people with ASD have already received training through Welsh Government led initiatives. However, legislation would:

- help to promote consistency of training standards across all regions;
- provide a 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.

35. The Social Services and Well-being (Wales) Act 2014 promotes person centred assessment and services, and includes a power for the Welsh Ministers to issue codes (which could potentially include a code in relation to the needs of people with ASD), on the exercise of social services functions. To date, such a code has not been issued. Moreover, the needs of people with ASD extend beyond such social services functions. By contrast, the Autism (Wales) Bill would ensure that health boards and local authorities understand the particular needs of children and adults with autism and would provide an holistic range of services to meet them.

36. A key function of the Bill, therefore, is to secure consistent and continued provision of all ASD services across Wales in order to achieve the core purpose of ensuring the needs of people with ASD are met, and their rights protected and promoted. 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 for adults and children respectively. Experience there shows that legislation is needed to ensure the momentum for improvement is not lost.

37. By creating a legal requirement to publish an autism strategy the Autism (Wales) Bill would help secure a measure of permanence and sustainability in care and support services for people with ASD. It would ensure a continued, dedicated focus on the needs of people with ASD, regardless of the prevailing financial or political climate. In this way, the Bill's core purpose would be realised: to ensure the needs of children and adults with ASD in Wales are met, and to protect and promote their rights.

4. Support for the Bill and public consultation

38. Two consultation exercises have been undertaken as part of the development of the Bill: a first consultation on the principles of the Bill; and a second consultation on the text of a draft Bill.

39. The National Autistic Society Cymru has provided advice and expertise in support of the consultations and throughout the development of the Bill.

40. In addition, the expertise of Dr Dawn Wimpory, Professor Martin Knapp, Professor Tommy Mackay, Valentina Iemmi have helped to inform the content of the Bill.

4. 1. First consultation: principles of the Bill

41. A consultation on the principles of the proposed Bill was undertaken between 30 August and 20 November 2017. Eighty-five responses were received. This represents more than eighty-five individual views, as some of the eighty-five responses reported group responses or survey results.

42. The consultation sought views on key issues relating to current services, and whether and how legislation might address them.

43. Responses were received from:

- individuals with ASD;
- families and carers of people with ASD;
- organisations, including health boards, local authorities and their umbrella bodies;
- professional bodies;
- voluntary organisations (including a number of local groups);
- the Children's Commissioner for Wales; and
- the Welsh Language Commissioner

44. The views of respondents on specific issues around ASD and services for people with ASD have been incorporated into this Explanatory Memorandum in section 5 *What the Bill does and Why*. Key points arising from the consultation are summarised below.

Views on whether there is a need for a Bill

45. Most respondents to the consultation who expressed a view, 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. 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.

46. A minority of respondents (primarily statutory and professional bodies) were opposed to the introduction of legislation and to the principle of focusing on one condition (which they believed could be to the detriment of people with other conditions).

47. In general, respondents agreed that the priorities for improving ASD services identified in the consultation reflected their own, particularly issues around diagnosis, IQ and transition into adult services.

48. The Children's Commissioner noted the "people" approach of the Bill (i.e. it would apply to both adults and children). She was concerned to ensure that this approach was maintained and that the distinctive needs of children were not lost.

49. The Welsh Language Commissioner emphasised the importance of referring to the Welsh language on the face of the Bill so that guidance and subordinate legislation could elaborate on it. She pointed out that ASD services need to make an "active offer" of Welsh language services.

Whether there is a need for guidance

50. The majority of those who expressed a view on whether statutory guidance should underpin an autism strategy, agreed that it is needed. There was also broad agreement that the proposed list of duties to be included in the requirement on statutory guidance was appropriate.

51. The areas for duties to be undertaken by bodies in relation to ASD services are set out in the Bill in section 2- *Contents of the autism strategy*. The guidance to be issued by the Welsh Ministers under section 4 supports the implementation of the strategy, and section 4 sets out certain key areas explicitly, including in relation to the provision of diagnostic services and leadership of local services.

Guidance by the Welsh Ministers on these duties is deemed necessary to secure effective implementation.

Views on consultation and reviewing the autism strategy

52. There was strong support for consultation to be undertaken by the Welsh Government on the development, review and updating of an autism strategy. Responses reflected a view that people with ASD and their families and carers should be consulted on the strategy and closely involved in monitoring its implementation.

53. Respondents expressed a range of views on the frequency of review of the strategy, with a majority suggesting every 3-5 years. This is reflected in the Bill, which makes provision for review every three years.

Views on and experiences of diagnosis

54. Most responses to questions about ease of access related to difficulties obtaining a diagnosis. Long waiting times were identified as a particular concern, with some respondents describing how they had waited years for a diagnosis. Some families had paid private consultants for help with diagnosis.

55. However, some reported positive experiences in their health board areas and others believed access to diagnosis is improving as reforms begin to have an impact. Overall, the picture set out in the responses is one of inconsistency across Wales.

56. Diagnosis for adults was described as especially difficult to access, particularly for individuals without a co-existing learning disability or mental health problem.

57. When asked what they would like legislation to address, respondents frequently cited the need for quicker access to diagnosis as their main issue, followed by the need for clearer, transparent and consistent pathways to diagnosis. In addition, greater expertise in diagnosis was said to be needed, and from specialists (rather than mental health generalists, for example).

58. Other issues raised in relation to diagnosis included the need for better co-operation and communication between parts of the NHS and with local authorities. It was also felt that greater weight should be given to user/parents' views and feedback on the reasons for decisions around diagnosis.

59. Some respondents commented on a need to address the lack of Welsh medium services, particularly in relation to educational psychology. The Welsh Language Commissioner cited examples of barriers to diagnosis in Welsh.

60. There was strong support for a requirement on local authorities and NHS bodies to publish information on diagnostic pathways.

Views on the sufficiency of current services

61. The majority of respondents to the consultation believed that services for people with ASD are inadequate. Some related the battles they had had to access services, as adults or for their children.

62. Some respondents believed that services for adults are particularly poor, especially for those with no identified learning disability or mental health problem. There was a view that the differences in services for children and adults means that the transition to adulthood can result in a loss of services.

63. One consultation response reported on a 2016 Family Fund survey of people with a child with ASD. Of the 165 people relating their experiences of accessing services in the survey, nearly a quarter (23 per cent) consistently had difficulties with *all* the services they accessed. Problems included long waiting times, lack of local services and frequent changes of professionals. A further 16 per cent had problems with *many* of the services they accessed.

Views on data collection

64. Most of the respondents to the consultation who expressed a view were in favour of improved data collection on people with ASD. A small number had concerns about creating a statutory duty, whilst others were concerned that any new duties should not duplicate work that is already underway to collect data.

65. Some of those in favour of a statutory duty added provisos about gaining consent and maintaining anonymity. Others were concerned that collecting data on those with a diagnosis would exclude those who do not meet the criteria, and those who do not want a diagnosis.

66. A wide variety of suggestions for suitable data collection methods was made, although no consensus emerged. Suggestions included: collection by the NHS (for example at diagnosis or when accessing services); by schools; a census; regional registers; surveying GP patients who request a diagnosis; and general surveys of people with a diagnosis.

Views on staff training

67. The issue of staff training attracted a large number of comments. The consultation asked for views on the scope and effectiveness of current training in Wales for key staff working with people with ASD. Most respondents said that training needs to be better, although some said it has improved, or is improving.

68. The consultation also asked for views on whether legislation should specify which key staff working with people with ASD should undertake ASD training, or whether it should specify the outcomes that training should achieve.

69. Of those who expressed a view, there was more support for specifying the outcomes of training in legislation, rather than specifying which key staff should receive training. The Bill provides that the autism strategy must make provision for the identification of key professionals and provision of appropriate training to them, in order that they can most effectively support people with ASD.

70. Some respondents said that good training is available but that the challenge is to find resources to train, release staff and implement it. Some have found the training materials on www.ASDinfowales.co.uk useful.

Employment for people with ASD

71. The consultation asked for suggestions for additional action that could be taken through legislation to improve the rates of employment of people with ASD. It included reference to limitations on the ability of the National Assembly for Wales to legislate in relation to employment matters.

72. There was a wide range of views on how to improve employment rates for people with ASD, although some related to non-devolved matters. However, many of these suggestions could be progressed by increasing ASD awareness amongst employers and professionals providing employment related training and support.

Whether a definition of autism is needed in the Bill

73. The consultation asked whether a definition of ASD should appear on the face of the Bill, in the strategy, in the associated guidance or whether it should not be stated at all.

74. There was no clear consensus on where a definition of ASD should be located. The importance of using a recognised definition was emphasised, as was the need for flexibility to accommodate future modifications.

75. Most respondents believed a definition should be included in the legislation and the minority who did not were generally not in favour of legislation based on diagnosis, believing instead that it should be driven by needs rather than diagnosis.

76. Further views on a definition of ASD were sought in the second consultation, on a draft Bill.

Views on the potential costs of the Bill

77. The first consultation also asked for comments on whether the following elements of the Bill might give rise to additional costs:

- producing a national autism strategy;
- placing duties on local authorities and NHS bodies to act under guidance;
- creating and maintaining data collection practices on the numbers and needs of adults and children with autism spectrum conditions; and,
- providing training for key staff.

78. There were relatively few responses to these questions. The greatest additional costs were generally believed to be likely to arise from data collection and provision of staff training. Although some respondents believed that the Bill would generate costs in addition to those identified in the consultation, most did not identify where such costs would arise.

79. Some respondents believed longer term savings and social benefits would result from the Bill, for example if people with ASD received the most appropriate, timely and effective services. They considered that this would promote well-being and reduce the need for more intensive support (e.g. for mental health problems) later on. It was also suggested that the Bill may reduce the need for expensive specialist out of county placements, help to people gain employment, and reduce offending and reoffending where this is an issue.

80. Others were sceptical that any savings would accrue from new legislation and suggested instead that further support for the current reforms would generate economies.

81. The consultation also asked what factors should be measured to determine a cost-benefit analysis of the legislation should it become law.

82. A wide range of factors which could be measured in a cost-benefit analysis was suggested. They included:

- waiting times for diagnosis and support services;
- the quality of life, wellbeing and empowerment of people with ASD, and their parents and carers;
- current support costs and the social impact of poor support;
- increases in the number of people with ASD in employment.

83. Respondents also suggested measuring any reduction in:

- the numbers of people with ASD in the criminal justice system;
- the numbers of Looked After Children with ASD, out of county placements, and;
- the costs of medication.

Negative/unintended consequences

84. The consultation invited respondees to identify:

- any negative or unintended consequences of an Autism (Wales) Bill; and
- any solutions to such consequences.

85. Only sixteen responses were received on this question, in most cases expressing concerns about the potential ramifications of making legislation for people with ASD. No specific suggestions were made on how the Bill could be adapted to mitigate these concerns, although some suggested that a needs-based, rather than a diagnosis-based, approach would be preferable. Most (but not all) of these respondents were public or professional bodies.

86. Issues which it is believed would arise include:

- generating additional demand for a diagnosis of ASD as a gateway to services, even where it is not appropriate;
- the resource implications of the above, including diverting resources into diagnosis and away from service provision;
- an increase in appeals from people who do not receive a diagnosis;

- creating a culture of “entitlement” with legal challenges;
- undermining the needs, rather than diagnosis, based approach to care and support promoted in other recent legislation (e.g. ALN Act and the Social Services and Well-being Act);
- the risk of creating inequality and resentment from other groups and a push for further impairment-specific legislation;
- the focus of duties on statutory services which may inhibit innovation and marginalise third sector services;
- an increase in costs, both in terms of implementation and for additional services which will be required.

How the consultation influenced the shape of the Bill

87. The consultation responses reflected the concerns and priorities of people with ASD, their families and carers and other stakeholders. This in turn helped to shape the priorities for legislation on ASD and the initial drafting of the Bill. The following specific provisions were included in a subsequently published draft Autism (Wales) Bill as a result of the initial consultation:

- A specific reference to Welsh language on face of the draft Bill (reflecting advice from the Welsh Language Commissioner);
- Specific reference to children and young people on the face of the draft Bill (reflecting the Children’s Commissioner’s advice on the importance of ensuring that the needs of Children and Young People were given appropriate recognition in the Bill);
- A requirement to commission an independent report on the autism strategy at least every 3 years;
- A specific reference to awareness raising amongst employers on the face of the Bill (to reflect views expressed in the consultation responses on the importance of employment for adults with ASD);

88. In addition, specific questions on data collection were included in the draft Bill consultation, as a result of issues raised in the first consultation, and following discussions with experts in Wales.

4. 2. The draft Bill (second consultation)

89. A consultation on a draft Autism (Wales) Bill was undertaken between 20 February and 17 April 2018. In total, 215 responses were received; 49 by email and 166 online.

90. The views of respondents on specific issues around ASD and services for people with ASD have been incorporated into the sections of this Explanatory Memorandum on *What the Bill does and Why*. Key points arising from the consultation are summarised below.

The definition of Autism Spectrum Disorder and a power in the Bill to allow the Welsh Ministers to include other neurodevelopmental disorders.

91. Most respondents to this second consultation believed that a definition of ASD should appear on the face of the Bill. The majority also agreed that the definition of ASD should be that of the World Health Organisation International Classification of Diseases. Linking the Bill to an internationally recognised definition will ensure that it reflects current thinking and is responsive to future changes.

92. A minority of respondents expressed concerns that no single definition could accurately reflect the diverse characteristics of people with ASD. Given that research and understanding on ASD is constantly developing, such concerns clearly have merit. However, the World Health Organisation recognises the diverse characteristics of people with ASD since its definition does not seek to define a single disorder, but rather a wide ranging spectrum. As such, it is considered appropriate to refer to the definition of ASD as determined by the World Health Organisation International Classification of Diseases.

Timescales set out in the draft Bill for the strategy, guidance and commencement

93. There was support from the majority of respondents for the required timescales set out in the draft Bill regarding the implementation of its provisions. The timescales are:

- the autism strategy must be published within 6 months of the Act coming into force;
- guidance must be issued within 3 months of the publication of the strategy;

- the Act comes into force 3 months after it receives Royal Assent.

94. Some respondents, many of them statutory or professional bodies, commented that three months would be insufficient time to develop guidance. However, it is envisaged that guidance would be developed in parallel with the strategy. Work could therefore begin on the guidance as soon as the Act is passed, which would allow up to nine months for the process.

Timescale for the period from referral to diagnosis

95. Most respondents agreed that timescales for the period from referral to diagnosis should be linked to those set out in National Institute for Health and Care Excellence (NICE) guidance (i.e. currently three months), as set out in the Quality Standard for Autism Spectrum Disorder Services[4]. However, a number of consultees expressed concerns that the potential complexity of the diagnostic process could make completion within three months challenging. As such, the timescale set out in the Bill now spans referral to the start of the diagnostic process rather than completion of diagnosis.

Timescale for completion of needs assessment

96. There was strong support for the requirement in the draft Bill that an assessment of care and support needs should be completed within two months of diagnosis or any post diagnosis meeting.

97. However, a number of consultees stated that a two-month standard could - in some circumstances - mismatch with other standards. As a result, the requirement in the Bill as introduced is 42 working days (to match the performance measure for children's social services assessments).

98. Some consultees also said that some people with ASD would not have particular care and support needs, and that there should not be a presumption that a person with ASD would automatically have care and support needs. For clarity, the Bill does not make this assumption: an assessment of a person's care and support needs may conclude that a person does not have any such.

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[4] NICE Quality Standard [QS 51] Autism, Quality statement 1: Diagnostic assessment by an autism team (2014)

Example list of professionals to undertake diagnosis

99. Responses to the consultation indicated strong support for the inclusion in the Bill of an example list of professionals who should form the multidisciplinary diagnostic team.

Data collection

100. The majority of respondents believed the Bill should specify the types of data to be collected to effect implementation of the autism strategy, although there was no consensus on whether the list should appear on the face of the Bill or in guidance. Some respondents felt it important that the categories of data to be collected should appear on the face of the Bill to limit the discretion in what data is or is not collected. There was also support for the example list of categories of data to be collected (which was detailed in the associated consultation document). Respondents also agreed with a provision in the Bill allowing the Welsh Ministers to request anonymised data from relevant bodies.

Campaign to raise awareness and understanding of autism

101. In terms of the requirement in the Bill on the Welsh Ministers to raise awareness and understanding of ASD, the consultation asked for views on whether the campaign should be continuous or should operate on a regular (three-year) cycle. Respondents were strongly in favour of a continuous campaign.

Barriers to accessing services

102. The consultation asked about factors which may inappropriately prevent access to services and which could be addressed in the Bill.

103. Factors most often identified by respondents were those relating to the inability of services to respond to individual needs, and exclusion of people from services, for example on grounds of having a high IQ or mental health problems.

104. A lack of staff-training in, and awareness of, ASD was also said by some respondents to result in barriers to accessing suitable services. These issues are also highlighted in the relevant sections of this Explanatory Memorandum under *What the Bill does and Why*.

105. Other respondents believed that a lack of information and advice and insufficient resources are factors preventing access to services.

Other comments

106. The consultation asked for views about the impact of the Bill on:

- The Welsh and English languages;;
- equality, diversity and inclusion;
- the justice system; and
- costs and benefits.

107. Few comments directly addressed these issues; most expressed support for the Bill. The majority of respondents to this question felt that the Bill will have a positive impact.

108. Some respondents believed the Bill risks disadvantaging people whose condition does not fall within its scope, and some commented on the absence of references in the Bill to people from black and minority ethnic communities, and to languages other than English and Welsh.

109. Conversely, others commented that the Bill would have a positive impact in terms of fairness and that it would help to raise awareness of, and help to change attitudes towards, ASD.

110. Some comments highlighted the importance of Welsh language services, with some respondents concerned that there were too few references to Welsh language services in the draft Bill. Others felt that Welsh language issues are already addressed in other legislation. Others considered that the Bill would contribute to better Welsh language services.

111. Some respondents commented that, by raising awareness and understanding, the Bill may help to promote justice for people with ASD and other neurodevelopmental disorders who are in the criminal justice system.

112. These issues are also highlighted in the relevant sections of the EM under *What the Bill does and Why.*

How the final version of the Bill differs from the draft Bill

- The duty on relevant bodies to implement the strategy and associated guidance has been strengthened, reflecting feedback in the consultation on the draft Bill. Under section 5 of the Bill, relevant bodies must now "comply with", rather than "have regard to", the strategy and guidance.

- Following feedback in the consultation, the requirement in section 2(1)(e) for the strategy to provide for an assessment of care and support to be completed within two months has been changed to 42 working days. This aligns the timescale with the performance measure for children's social services assessments.
- In addition, responses to the consultation on the draft Bill highlighted the possibility that references in the Bill to care and support assessments are assumed only to refer to social services assessments. This Explanatory Memorandum clarifies that this is not the case and the Bill now has an additional section (section 3) which makes provision for combining assessments; those for health and social care for example.
- The Bill now includes a requirement on NHS bodies to collect specified categories of data with further categories to be prescribed by regulations. This reflects expert advice from ASD data experts in Wales, which was sought as a result of responses to both consultations.
- Following feedback in the consultation, the three month timescale requirement for referral to diagnostic assessment in section 2(1)(c) now applies to the start, rather than completion, of the assessment. This is to allow for the complexity and unpredictability of some assessments, and reflects the approach taken in NICE guidance.
- The Bill also makes explicit reference to human rights obligations of relevant bodies to reflect views expressed in both consultations. In terms of age: Section 8(3) of the Bill requires a relevant body to have due regard to Part 1 of the United Nations Convention on the Rights of the Child, and section 8(1) requires relevant bodies to have regard to the United Nations Principles for Older Persons. In terms of disability: section 8(2) requires relevant bodies to have regard for the United Nations Convention on the Rights of Persons with Disabilities.

5. What the Bill does and Why

5. 1. Introduction

113. 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 does this by requiring the Welsh Ministers to publish an autism strategy and to issue guidance to bodies responsible for its implementation; these are local authorities and NHS bodies in the Bill as drafted.

114. 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.

115. Other sections are concerned with a duty on "relevant bodies" to comply with the strategy, arrangements for combining assessments, data collection in support of autism services, 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.

5. 2. Definition of Autism Spectrum Disorder and power to prescribe other neurodevelopmental conditions

116. Section 9(1) of the Bill sets out what is meant by "autism spectrum disorder" in the context of the Bill. The Bill refers to the definition of ASD in the diagnostic manual The World Health Organisation (WHO) International Classification of Diseases, which is the most widely used diagnostic manual in the UK. The World Health Organisation (WHO) International Classification of Diseases (ICD-11) replaced an earlier version, ICD-10, in June 2018. The definition of ASD is subject to periodic refinement, reflecting emerging scientific and practice developments. Therefore, referring to the World Health Organisation (WHO) International Classification of Diseases on the face of the Bill provides in-built flexibility and ensures that the definition does not become obsolete, avoiding the need to amend the Act in the future.

117. The Welsh Government has used the WHO definition ICD-10 in its Autism Spectrum Disorder Strategic Action Plan and its refreshed Autism Spectrum

Disorder Strategic Action Plan. Referring to the updated WHO definition, in the Bill therefore provides consistency with existing autism strategies in Wales, and the benefits of UK-wide (and international) recognition of the WHO classification system. An alternative definition is provided by the Diagnostic and Statistical Manual, fifth edition (DSM-V) published by the American Psychiatric Association. However, the recently updated WHO definition, ICD-11, is closely aligned with DSM-V.

118. In addition to the ICD definition of ASD, section 9(1) of the Bill provides the Welsh Ministers with a power to prescribe other neurodevelopmental conditions as falling within the scope of the Bill, should this be deemed appropriate in the future. This could include conditions such as Attention Deficit Hyperactivity Disorder (ADHD) which in some people may be diagnosed alongside ASD.

119. The majority of respondents to the consultation on the draft Bill agreed that the WHO definition should appear on the face of the Bill, together with a power for the Welsh Minsters to include other neurodevelopmental disorders.

120. However, some respondents expressed concerns that the inclusion of other neurodevelopmental disorders might dilute the clarity and focus of the Bill and would add to its complexity. It was felt that careful thought would be needed before decisions could be made on the addition of specific additional neurodevelopmental disorders.

121. Conversely, other responses to both consultations on the Bill expressed concerns that legislation for a single category of disorders (i.e. ASD), risks disadvantaging individuals with other conditions.

122. Taking account of these different views, it is considered appropriate to include within the Bill a power for its provisions to be applied in relation to other neurodevelopmental disorders. Such a power anticipates that advances in understanding ASD and other neurodevelopmental disorders could potentially make this appropriate in the future, whilst also retaining the flexibility for the Welsh Ministers not to do so.

5. 3. Relevant bodies

123. The Bill places duties on “relevant bodies” to comply with the autism strategy and guidance issued under the Bill. A relevant body is defined in the Bill as a local authority, an NHS body and such other bodies as may be defined by the Welsh Ministers. Local authorities (across all functions) and NHS bodies are the principal providers or commissioners of services for people with ASD. However, the Bill allows scope for the inclusion of other bodies as relevant bodies, should this be deemed appropriate.

124. The majority of respondents to the consultation on the draft Bill agreed that these are the appropriate bodies to implement the autism strategy. Some suggestions for additional "relevant bodies" were made in the consultation. Education bodies were most often suggested for inclusion. As introduced, the Bill would apply to all schools and some elements of post-compulsory education, to the extent that they fall within the responsibilities of local authorities.

125. Other suggestions for relevant bodies included the police and other criminal justice providers. Although such bodies play a significant role in the lives of many people with ASD, they are non-devolved bodies, and it would therefore be outside the competence of the Assembly to make legislation imposing additional duties on them, without consent of the Secretary of State. It is envisaged, however, that criminal justice providers in Wales will be beneficiaries of awareness-raising provisions in the Bill.

126. Some respondents suggested including third and independent sector service providers as "relevant bodies". It is envisaged that NHS bodies and local authorities will discharge their duties under the Bill through third and independent sector service providers where this is appropriate (e.g. where services are commissioned from them).

5. 4. The autism strategy

Duty to publish an autism strategy

127. The principal aim of the Bill is to create a legal requirement on the Welsh Ministers to publish an autism strategy which will ensure that the needs of people with ASD are met, and their rights protected. The strategy would set out requirements on relevant bodies - NHS bodies and local authorities - on meeting the needs of children and adults with ASD. The Bill would require statutory guidance to be issued by the Welsh Ministers to relevant bodies on the exercise of their functions in implementing the autism strategy.

128. The Welsh Government published an Autism Spectrum Disorder Strategic Action Plan in 2008 and a Refreshed Strategic Action Plan in December 2016, which runs from 2016-20. The Action Plan has led to improvements in services for people with ASD and to increased awareness of ASD.

129. However, the improvements made by the non-binding voluntary strategy have been limited, and beyond the lifetime of the Action Plan there is an increased risk to the continued prioritisation of ASD. In order to secure comprehensive, consistent and high-quality services in the long term, a statutory requirement on the Welsh Ministers to publish an autism strategy is needed.

130. The Strategic Action Plan has demonstrated the importance of taking a strategic, co-ordinated approach to ASD services across Wales, rather than relying on a diversity of approaches and initiatives at the local level. The aim of the Bill is to strengthen this approach, and to reinforce and build on the gains made by the Strategic Action Plan, by creating a legislative imperative to develop and embed comprehensive and effective ASD services in all parts of Wales and provide a measure of permanence to these arrangements. The results of both consultations on the Bill show that there is broad support for this approach.

131. In order to ensure that people with ASD and their families have a voice, and to reflect their lived experiences, the Bill provides for consultation on the development of, and any significant revisions to, the autism strategy. Such consultations must include people with ASD and organisations representing their interests or providing services to them. These requirements also apply to guidance issued in relation to the strategy, including any substantially revised guidance.

132. The experience of people with ASD and their families and carers shows that, despite improvements brought about by the strategy, services for people with ASD remain inconsistent across Wales. Evaluation reports on the Autistic Spectrum Disorder Strategic Action Plan and the Integrated Autism Service, for example, both commented on the uneven and variable services for people with ASD across Wales. This view was reflected in responses to the initial consultation on the Bill, with comments indicating that there remains significant variation in services across Wales.

133. Further evidence of variability is provided by the interim report of the evaluation of the refreshed Autistic Spectrum Disorder Strategic Action Plan which noted the challenges of establishing the new Integrated Autism Service in the patchwork of existing services, which differ from region to region.[5]

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[5] Evaluation of the refreshed Autistic Spectrum Disorder Strategic Action Plan, Interim Report, Dr Duncan Holtom and Dr Sarah Lloyd Jones, 1 March 2018, Page 5.

134. Accordingly, the Bill requires (section 2(1)(h)) that an autism strategy make provision for an appropriate range of services to be available consistently across Wales, reflecting the core aim of ensuring the needs of people with ASD are met.

135. Evidence indicates that, whilst services for children with ASD are variable and often difficult to navigate, services for adults with ASD are worse in many cases, particularly for adults who have not had a diagnosis as a child. Responses to the consultation on the principles of the Bill reflect these difficulties, with respondents describing long waiting times for diagnosis, and an absence of appropriate services following diagnosis.

136. 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 is a Bill to promote the rights of both adults and children. It also includes a requirement (in Section 2(1)(j)) that the strategy ensures continuity between child and adult services.

137. The Bill makes provision for the autism strategy to be published within six months of the Act coming into force. This timescale was endorsed by the majority of respondents to the consultation on the draft Bill. The strategy, and any subsequent versions with substantial revisions, are subject to consultation and must be laid before the Assembly.

138. The Bill requires the Welsh Ministers to keep the strategy under review and to revise it, if it is deemed necessary.

139. Progress on the implementation and impact of the strategy must be the subject of an independent report, at least every 3 years. The frequency of review reflects the views of respondents to the consultation on the principles of the Bill. The independent report must be laid before the Assembly, and published. It is anticipated that Assembly Members would hold the Welsh Government to account on any issues raised in such reports. It is also anticipated that Assembly Members would consider such reports in the context of any post-legislative scrutiny conducted into the implementation of this legislation. Such scrutiny would be welcome.

Contents of the autism strategy

140. Section 2 of the Bill sets out the key issues to be addressed in an autism strategy. The Bill does not define the detail of the autism strategy; instead it sets out the matters which an autism strategy must address to ensure the needs of people with ASD are met. They reflect the priorities identified in published research/evaluation documents[6], and by National Autistic Society Cymru.[7]

141. These priorities were largely endorsed by the consultation undertaken as part of the development of the Bill. Consultees expressed specific concerns around diagnosis, IQ as a barrier to services, and transition from children's to adult services. They also expressed strong support for better data collection on people with ASDs and for improvements to training and awareness of ASD. Many of these reflect the issues and priorities in the Welsh Government's Autism Spectrum Disorder Strategic Action Plan. The Bill would provide the statutory force to secure more rapid, comprehensive and permanent improvements to these services.

142. The list of matters to be addressed in the autism strategy is not exhaustive, and it provides the Welsh Ministers with scope to include within the strategy any other matters which are considered appropriate (and which are within the competence fo the Welsh Ministers to pursue). The Bill also provides for statutory guidance to be issued to underpin the implementation of the autism strategy.

Best practice models

143. The two consultations on the Bill provided clear evidence that key areas of concern for people with ASD (and their carers and families) are diagnosis, assessment of needs, and access to services to meet needs. Overlaying these issues are the challenges of navigating a route through services and the lack of information, particularly at the local level.

144. Best practice models help promote high and consistent standards across all local authorities and health boards, and help service users to be better informed and feel confident they will receive high quality services.

145. The Bill therefore requires an autism strategy to define best practice models for the three key elements of services for people with ASD: identification and diagnostic assessment of ASD; assessment of care and support needs of people with ASD; and planning and meeting those support needs. The Bill itself is not prescriptive about the models, which can be developed and updated in the strategy according to current circumstances.

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[6] Welsh Government, *Outcome evaluation of the Autism Spectrum Disorder Strategic Action Plan: Executive Summary*, 2016, pp7-9

[7] The National Autistic Society *Act Now – An Autism Act for Wales Report*, 2016, p4

A clear pathway and map of services

146. In many areas of Wales there is no clear and publicly available information on pathways to diagnosis and services for people with ASD. Receiving a diagnosis of ASD is a critical milestone for many individuals and their families and it is the key to accessing some services. Some consultees commented that just having a diagnosis was in itself a major step forward, in terms of a person's understanding of both themselves and the world around them.

147. However, the experience of many people with ASD (and their carers and families) is of receiving a diagnosis of ASD and then being left to navigate a pathway through care and support services with little or no information and guidance. A 2015 survey[8] undertaken by National Autistic Society Cymru found that only one in five respondents were satisfied that the information they received following diagnosis helped them to access the support they needed. Clarification is needed for people with ASD - and their carers and families - about what they can expect from care and support services and how to access them.

148. The outcome evaluation of the Autism Spectrum Disorder Strategic Action Plan stated that, notwithstanding the contribution of the strategy to improvements to local information on services,

> "parents and carers consistently report that it remains difficult to identify support and services and that they experience high levels of stress and anxiety as a consequence". [9]

149. The ASD Adult Diagnostic Task and Finish Group found only patchy provision of good quality information for adults diagnosed with ASD.

150. There was strong support amongst respondents to the consultation on the principles of the Bill for a requirement on local authorities and the NHS to publish information on diagnostic pathways. Respondents commented that information is hard to obtain, particularly in relation to diagnostic pathways for adults.

151. Providing in legislation for a clear pathway to diagnosis and services in all health board areas would give people with ASD - and their families and carers - the clarity and reassurance they need about the process of diagnosis.

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[8] The National Autistic Society *Act Now – An Autism Act for Wales Report*, 2016, p5

[9] Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Final Report, Dr Duncan Holtom and Dr Sarah Lloyd-Jones, 18 February 2016, Page 9

152. Section 2(1)(b) of the Bill therefore requires the autism strategy to make provision for:

> "the development of a pathway, that includes access through defined points of referral, to map the services that are available and required…"

5. 5. Diagnosis of Autism Spectrum Disorder

Timescales for diagnostic assessments

153. The length of time taken to receive a diagnosis continues to be a major problem for people with ASD, their families and carers. Sixty per cent of respondents to a 2015 survey undertaken by National Autistic Society Cymru said they had waited more than a year for a diagnosis and thirty-two per cent had waited more than two years. Most respondents to the survey found the process too lengthy and stressful.[10]

154. Evidence suggests that the welcome increase in awareness of ASD brought about by the Welsh Government's Autism Spectrum Disorder Strategic Action led to sharply increased rates of diagnosis, particularly amongst school age children, from 0.2 per cent in 2003/04 to 1 per cent in 2012/13 but the pressure on diagnostic services increased waiting times in many parts of Wales[11] .

155. A long wait for diagnosis can mean a lack of access to services and support, during which time maintaining an ordinary life can be difficult and stressful, often leading to additional problems.

156. The ASD Adult Diagnostic Task and Finish Group found waiting times across Wales of between 2 and 18 months for access to diagnostic services for adults, although data on waiting times is incomplete.

157. A 2015 survey undertaken by the ASD National Development Lead found problems for children and their families in relation to:

- Long waiting times
- Lack of information prior to, during and following completion of the diagnostic assessment

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[10] Cited in Act Now – An Autism Act for Wales, National Autistic Society Cymru, page 5

[11] Outcome evaluation of the Autism Spectrum Disorder Strategic Action Plan: Executive Summary, Welsh Government, 2016, page 2

- Little or no provision of advice and support at point of, and immediately after diagnosis.
- The report concluded that the issues were likely to be similar for adults seeking support services.

158. Difficulties experienced around access to - and waiting times to receive - a diagnosis were reflected in responses to the consultation on the principles of the Bill, and highlighted variable provision across Wales. Quicker access to diagnosis was most often cited as the issue respondents would like legislation to address.

159. The Bill aims to address waiting times for diagnosis by requiring an autism strategy to provide for improved timeliness of initial diagnostic assessments and any post-diagnostic meetings. These must be undertaken at least within timescales set out by NICE.

160. NICE Clinical guideline 128 currently recommends a maximum timescale of 3 months for children and young people for the period from referral to start of diagnostic assessment. There is no timescale for adults in clinical guidelines but the NICE Quality Standard 51 on Autism recommends 3 months for both children and adults. It is therefore this Quality Standard to which the Bill refers.

161. The Welsh Government has introduced a 26-week (80% success) waiting time standard from referral to first assessment appointment for children which, if met, would represent a significant improvement for some individuals. A similar approach is planned for adults. However, it is still approximately double the three-month standard set by NICE. It is this latter standard to which services should adhere if people with ASD are not to be subjected to excessively long waits for diagnosis, and it is this standard which is set out in the Bill.

162. The Bill refers to the NICE Quality Standard [QS 51] on waiting times from referral to start of assessment. Initially it was proposed to set a maximum waiting time from referral to completion of assessment. Such a position was supported by the majority of respondents to the draft Bill. However, concerns were also expressed that such a timescale did not take appropriate account of the diversity of people with ASD and their needs, and the complexity of the assessment process for some. Therefore, the timescale in the Bill now applies to the period from referral to the start of assessment, in line with the NICE Quality Standard.

163. Aligning the timescale from referral to start of diagnosis with the NICE standard also provides flexibility. The legislation will be responsive to changes in

NICE standards, which remain evidence based and are developed with expert and service user input.

Multi-disciplinary diagnostic assessments

164. Multi-disciplinary diagnostic assessment teams help to ensure a balanced and holistic approach to diagnostic assessment, which produces a comprehensive, well-informed and rounded picture of the person being assessed.

165. The NICE Clinical Guideline for adults[12] recommends that diagnostic assessment be undertaken by professionals who are trained and competent and who are team-based and draw on a range of professions and skills. For children, the Clinical Guideline[13] recommends that core members of such a team should include a paediatrician and/or child and adolescent psychiatrist; a speech and language therapist; and a clinical and/or educational psychologist. The team should also include, or have regular access to, a range of other professionals.

166. The report of the ASD Adult Diagnostic Task and Finish Group identified variations across health boards in the skills mix of diagnosing professionals (para 15). It highlighted a lack of guidance (and therefore consistency) in relation to who should undertake diagnostic assessment.

167. Section 4 of the Bill, on guidance for implementing the autism strategy, includes an example list of key professionals for inclusion in multidisciplinary diagnostic assessment teams. The list comprises: clinical psychologist, psychiatrist, speech and language therapist, occupational therapist, behavioural therapist, social worker.

168. It is important to note that the list is advisory; there is no intention to set out a prescriptive list of professionals in the Bill, as introduced. Individual characteristics and needs differ; for example, the diagnostic team for a child may include a paediatrician and educational professionals but these may not be appropriate for diagnosing an adult. The composition of multidisciplinary teams should reflect individual differences.

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[12] NICE Clinical Guideline [CG 142] Autism spectrum disorder in adults: diagnosis and management para 1.2.5, (2012)

[13] NICE Clinical Guideline [CG 128] Autism spectrum disorder in under 19s: recognition, referral and diagnosis paras1.1.3-1.1.4

5. 6. Timescales for needs assessments

169. Many people diagnosed with ASD will not require care and support following diagnosis and conversely, having a diagnosis is not a prerequisite for receiving care and support. Where an assessment is necessary, however, it should be undertaken within a reasonable timescale following diagnosis. The Bill provides that needs assessments should be undertaken within 42 working days of a diagnosis or any post diagnostic meeting.

170. Although the Bill does not refer specifically to social services assessments, since healthcare assessments may also be undertaken, responses to the consultation on the Bill highlighted the importance of aligning any timescale in the Bill with those applicable to social services assessments. In the case of social services assessments for children, these must be completed within 42 working days.

171. The Bill also makes provision in section 3 for combining assessments (for example for health and social care) to avoid the need for multiple assessments and duplication of effort.

5. 7. Accessibility of services

172. In general terms, section 2 of the Bill requires a strategy to make provision for a range of services to be available and accessible to all users, to deliver the strategy across Wales. In particular, section 2(1)(i) requires the strategy to ensure that services are “accessible to each person”. This means responding to individual needs, for example in terms of gender, sexual orientation, ethnicity and language (whether this is English, Welsh, or another language).

173. The strategy must outline how the needs of people with ASD should be met by relevant bodies by access to the range of public services. This should encompass (but is not limited to) needs around healthcare, education, employment, housing, Welsh language services, social inclusion and advocacy.

174. Health and social care services in Wales are subject to the public sector equality duty under which they must ensure that equality considerations are built into the design of policies and the delivery of services and that they are kept under review. Such duties are applicable to people with protected characteristics, as set out in the Equality Act 2010.

175. Issues were raised in the consultation on the draft Bill around the specific challenges facing people with ASD and their families from black and minority ethnic communities, and for women and girls. This highlights the importance of ensuring that all services, including information and advice, diagnosis, care and support, and awareness raising, are responsive to the needs of every person with ASD.

176. The provisions in the Bill for improving understanding and awareness of ASD will help to improve individual experience of services, including for people from black and minority ethnic communities, and women and girls. Further information is included in the *Equality Impact Assessment*, detailed in this Explanatory Memorandum.

177. In addition to provision in the Bill for accessible ASD services, the requirements for improved data collection will support the development of services which are better able to respond to the range of attributes and needs and of people with ASD in Wales.

5. 8. Welsh language provision

178. Under the Welsh Government's strategic framework for Welsh language services in health, social services and social care, organisations have a responsibility to recognise and to respond to language need as an integral element of care. They must make an 'Active Offer' of Welsh language services, rather than expecting patients and recipients of care services to ask for them.

179. The consultation on the principles of the Bill highlighted some issues around Welsh language provision. The Welsh Language Commissioner cited examples of barriers to diagnosis of ASD in Welsh, for example because of a lack of validated tests and poor workforce planning. She emphasised the need to take every opportunity to address Welsh language issues in legislation.

180. Several other respondents to both consultations on the Bill referred to a need to develop the Welsh language speaking workforce and to improve Welsh language provision in assessment and service provision, including in educational psychology.

181. Services for people with ASD and their families and carers need to be available in Welsh. Accordingly, the Bill requires an autism strategy to outline how the needs of people with ASD should be met by relevant bodies in respect of access to Welsh language services. Guidance about the implementation of the strategy issued under the Bill could be used to supplement the provisions in the Bill around Welsh medium services.

5. 9. Inappropriate access criteria

182. There is evidence that ASD services in some areas place additional and inappropriate criteria on access to support, which prevent some individuals from receiving the services they need. This may occur, for example, in areas where responsibility for providing support to people with ASD falls within services which are not specifically designed for people with ASD.

183. ASD 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. 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. Nevertheless, where local services are configured in this way, some people with ASD 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.

184. The way that services have historically been configured should not preclude some individuals from accessing services. Despite provisions in the 2008 Autism Spectrum Disorder Strategic Action Plan to address this, its outcome evaluation reported that:

> ”there has been little change in a situation where most adults with ASD and a learning disability can access a statutory service, while those without a learning disability cannot.”[14]

185. In addition, the ASD Adult Diagnostic Task and Finish Group found inequality of access to diagnostic services in some areas where, for example, individuals had no learning disability or mental health problem.

186. These findings were reflected in responses to the consultation on the principles of the Bill. When asked to identify factors which may inappropriately prevent access to services and which should be addressed by the Bill, the largest category of responses highlighted characteristics such as high IQ or mental health problems which exclude people from services or force them into inappropriate provision.

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[14] Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Final Report, Dr Duncan Holtom and Dr Sarah Lloyd-Jones, February 2016, Paragraph (Para) 11

187. Section 2(1)(f) of the Bill therefore requires the autism strategy and associated guidance to ensure that access to services for people with ASD is not dependent on IQ.

188. Section 2(1)(f) also seeks to ensure that access to support for persons with ASD is not denied to a person on the grounds that he or she is receiving support for another health condition, for example a mental health problem.

5. 10. Transition to adult services

189. The transition from children's to adult services can cause considerable difficulties for young people with ASD. The Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Final Report found that high thresholds of eligibility for adult services and a lack of specialist services for those who do not also have a learning disability can result in withdrawal or significant reduction in support, making the transition to employment and independent living difficult. The Outcome Evaluation also highlighted a failure of the Strategic Action Plan to implement national standards and guidance around transitions.

190. The problems experienced by young people moving from children's to adult services were reflected in responses to the consultation on the principles of the Bill. Individuals commented on high referral criteria for adult services, the sudden loss of support at 18 years and the ineffectiveness of transition packages. The Children's Commissioner highlighted the frequent contacts she receives on ASD services, which include issues around transitions in social services.

191. The Bill seeks to ensure that this key issue is addressed. Section 2(1)(j) requires an autism strategy to ensure a continuity of service for young people with ASD to "reflect and facilitate the transition from childhood to adulthood".

5. 11. Staff training

192. Professionals in contact with people with ASD need a sound understanding of ASD if services are to improve. The absence of knowledge and skills needed to identify characteristics and behaviour as possible indicators of ASD can lead to inappropriate responses on an individual level and a failure to provide the necessary support to enable individuals to develop and achieve their potential. Without adequate training key signs are missed, behaviours misinterpreted and unsuitable services are not modified.

193. The need for better staff training in awareness of ASD, and skills in supporting people with ASD, has long been acknowledged. Improvements to levels of knowledge and awareness have been, and remain, priorities for the ASD Strategic Action Plan and the refreshed Strategic Action Plan, including the resources available on www.ASDinfoWales.co.uk.

194. Nevertheless, there remains a widely held view amongst people with ASD, and their families and carers, that many professionals they encounter have a poor understanding of ASD. A National Autistic Society Cymru survey[15], for example, reported that about half of adults who responded believed there was a lack of understanding of ASD among professionals. There is a need to ensure that children and adults with ASD are supported by professionals who understand them.

195. Although significant gains have been made in staff training, following the implementation of the Autism Spectrum Disorder Strategic Action Plan, progress has been variable. A key finding of the 2016 Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Final Report in relation to training and awareness was that:

> "A wide range and large number of services and people have been reached and the improved training and awareness is reported to have had positive outcomes. Nevertheless, coverage has been uneven across services and groups and more work is needed."[16]

196. The report stated that a key challenge for a refreshed Strategic Action Planwould be integrating ASD awareness and support into mainstream policy and practice in such areas as education, mental health, social care and employment services.

197. The Evaluation of the Integrated Autism Service and Autistic Spectrum Disorder Strategic Action Plan Interim Report (2018) highlights that:

> "The understanding of autism and the lack of skills and confidence of many staff within existing services has been identified as a key barrier to services adapting to meet the needs of adults with autism…[and]… the needs of children with autism and their families."[17]

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[15] The National Autistic Society *Act Now – An Autism Act for Wales Report* 2016, p7.

[16] Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Final Report, Dr Duncan Holtom and Dr Sarah Lloyd-Jones, February 2016, Para 6

[17] The Evaluation of the Integrated Autism Service and Autistic Spectrum Disorder Strategic Action Plan Interim Report, Dr Duncan Holtom and Dr Sarah Lloyd Jones, March 2018, Pages 44 and 47

198. The issue of staff training attracted a large number of comments in the consultation on the principles of the Bill. Most responses said that training needs to be better, although some said it has improved, or is improving. There was strong support for better staff training and awareness raising across education, health and social services in particular, to enable staff to identify the symptoms and needs of people with ASD and to know when to refer people on for assessment. Respondents said that ASD awareness is also important for other staff in the public sector such as housing workers, JobCentre Plus staff, and police/emergency workers.

199. Section 2(1)(q) of the Bill would ensure that key staff working with people with ASD can access appropriate autism training. It would require an autism strategy to identify key professionals and such appropriate training to enable them to support people with ASD. Further detail must be set out in guidance.

200. A significant number of staff working with people with ASD have already received training through Welsh Government led initiatives, but the Bill would:

- promote consistency of training availability across all professions in all regions;
- provide a clear means by which implementation and maintenance of appropriate training can be monitored, and;
- secure the delivery of such training on an ongoing and permanent basis.

201. In addition, other service improvements and reforms, for example those introduced in the ALN Act, would be underpinned by a better trained education workforce.

202. The Bill envisages a tailored approach, depending on the specific professional roles of individuals. The relevant professional groups and the training they require would be identified in the process of drawing up the strategy and further developed in the accompanying guidance.

5. 12. Awareness raising

203. A major contribution of the ASD Strategic Action Plan has been to raise awareness of ASD, not least through the resources provided on the ASD website www.ASDinfoWales.co.uk.. This was acknowledged by stakeholders, as reported in the Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan:

Final Report.[18] It remains a key priority for the refreshed ASD Strategic Action Plan. However, according to the 2016 Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Final Report, coverage across services and groups is uneven, and more work is needed.

204. Responses to the consultations on the Bill reflected the importance to people with ASD- and their families and carers- of better public awareness. There was a belief that some of the challenges they face could be alleviated by greater understanding from the public and from service providers; misunderstandings and potential conflict could be greatly reduced. Some respondents expressed frustration at the lack of understanding and awareness of ASD and how it impacts on behaviour, which can leave individuals and those close to them feeling isolated and misunderstood.

205. A key area for awareness raising identified by respondents to consultations on the Bill has been amongst employers.

206. .Employment for people with ASD has been, and remains, an area of significant concern. More than one third of respondents to the initial consultation on the Bill made suggestions about how to improve employment rates for people with ASD. Many of these could be taken forward by increasing ASD awareness amongst employers and professionals providing employment related training and support. There was a feeling that much could be achieved by educating employers about autism, including the positive aspects and the contribution people with ASD can make. Support could be offered on how to match individuals to suitable jobs and make “reasonable adjustments” for a person with ASD.

207. During the implementation the first ASD Strategic Action Plan from 2008 the Welsh Government supported the role of an Autism Employment Ambassador who helped raise awareness of autism with employers and providers of employment support. Links were also developed with JobCentre Plus and Careers Wales, which enabled local staff to develop knowledge and skills to support people with autism into employment.

208. However, the Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Final Report found that, despite better support for moving into and maintaining employment,

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[18] Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Final Report, Dr Duncan Holtom and Dr Sarah Lloyd-Jones, February 2016, Page 9.

> "adults with ASD still struggle to access effective support to find employment, and employment rates remain low."[19] (p9)

209. In acknowledging the significance of employment issues for people with ASD, which were highlighted in the initial consultation, the provisions in the Bill concerned with raising awareness make specific reference to employers. Section 7 of the Bill requires the Welsh Ministers to initiate and maintain an ASD awareness raising campaign. The campaign must enhance the understanding of the needs of people with ASD by "members of the public, employers and those providing services".

210. Section 7 of the Bill provides for the awareness campaign to be rolled out on a continuous basis. This approach was endorsed by respondents to the consultation on the draft Bill.

5. 13. Support for families and carers.

211. Families and carers often feel unsupported following a diagnosis of ASD; there are issues about post-diagnostic information and advice, with many individuals and their families left to manage the challenges of ASD alone.

212. Respondents to the consultation on the principles of the Bill described being left with insufficient information and support, following the diagnosis of a relative with ASD. Some commented that voluntary organisations are the best source of support. Some felt they were not listened to by professionals, despite having expertise and experience of caring for a person with ASD.

213. Section 2(1)(k) of the Bill requires an autism strategy to place an emphasis on how families and carers can be supported in meeting the needs of a person with ASD. In addition, a strategy should ensure that the wishes of people with ASD and their families and carers are taken into account.

5. 14. Research, innovation and service improvement

214. Developing better services for people with ASD requires more than reforms to organisation and delivery. Advances in neuroscience, innovations in education, care and support and new approaches to empowering people with ASD - and their carers and families - all contribute to enhanced understanding and better

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[19] Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Final Report, Dr Duncan Holtom and Dr Sarah Lloyd-Jones, February 2016, Page 9

life experiences for people with ASD. It is essential to take a long-term view and develop research capacity, and to incorporate policy and practice innovations into mainstream services.

215. The Bill offers flexibility in the development and review of the autism strategy and the provision of guidance. This will allow the strategy to be updated in light of advances in understanding of ASD and service improvements, and to respond to the needs and views of people with ASD and their families and carers.

216. The Bill recognises the importance of scientific and service development by requiring (in section 2(1)(m)) an autism strategy to place an emphasis on innovation and improvement in the commissioning and delivery of ASD services, and to make provision for the commissioning of research into ASD.

5. 15. Local infrastructure

217. The Welsh Government's 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 ASD and made available a range of high quality information and resources for both service users and professionals.

218. However, the voluntary nature of the local autism infrastructure means it has been more effective in some areas than others. Additional funding has been provided to local authorities, although this was ring fenced only up to April 2015. A more robust approach is needed.

219. The ASD strategic action plan put in place a local ASD infrastructure which included ASD leads and coordinating groups in each local authority. However, the Outcome Evaluation of the ASD SAP reported that weak governance and accountability structures contributed to an uneven impact across Wales, "so that the strategy helped create "islands" of good practice across Wales but struggled to create systemic change".[20]

220. Providing for a local autism infrastructure in legislation will help to promote improvements in services and support and ensure that high quality provision for people with ASD is available across Wales. The Bill requires an autism strategy to establish the necessary infrastructure and leadership to monitor and promote

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[20] Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Final Report, Dr Duncan Holtom and Dr Sarah Lloyd-Jones, February 2016, Page 10.

implementation of the strategy. By setting out clear responsibilities for promoting the strategy, real service improvements can be secured.

5. 16. Data on autism spectrum disorder

221. Evidence shows that better information is needed on the number of people in Wales with a diagnosis of ASD and their needs[21]. Although Betsi Cadwaladr University Health Board collects data on children diagnosed with ASD, using the Community Child Health 2000/CypRIS database, there is currently no systematic collection of information across Wales on people with ASD and the services they need. The paucity of data makes the task of planning sufficient and effective services difficult.

222. The Social Services and Well-being (Wales) Act 2014 requires regional partnerships to undertake population assessments for their areas, in order to determine the services required to meet their needs. They must then plan services accordingly. The Welsh Government has identified priority groups for the initial assessments, which includes people with learning disability and ASD.

223. However, data for ASD needs to be clearly and separately identified, if meaningful information on the numbers of people and their needs is to be achieved. It is important that any population assessment identifies and recognises the distinctive needs of people with ASD, without subsuming it within learning disability. This will enable NHS bodies and local authorities to address the gaps in local service provision.

224. The first population assessments published by regional partnerships in 2017 under the Social Services and Well-being (Wales) Act 2014 illustrate the lack of information on people with ASD and their needs across Wales.

225. Local authorities are expected to draw up registers of disabled people in their areas but the registration is voluntary: individuals can decide whether they wish to be included. Such registers are therefore unlikely to provide a comprehensive picture of the numbers and needs of people with ASD in local authority areas.

226. The lack of data on people with ASD was identified as a significant issue in the consultation on the principles of the Bill. The vast majority of comments on this issue expressed strong support for improved data collection on people with

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[21] Outcome evaluation of the Autism Spectrum Disorder Strategic Action Plan, Welsh Government, 2016, page 31

ASD, although there was no consensus on the best method for achieving this. There was likewise no consensus in the consultation on the draft Bill on whether the categories of data should be specified on the face of the Bill or in guidance. In their interest of transparency and clarity, key data categories are set out on the face of the Bill, and provision is made for further categories to be prescribed by the Welsh Ministers.

227. The Bill would place a clear requirement on NHS bodies to collect specified categories of data (as set out in section 6(6) of the Bill), to establish the numbers and needs of children and adults with ASD, and about the process and methods of diagnostic assessment. This will enable better planning of services, monitoring of trends in diagnosis and evaluation, and improve diagnostic processes both locally and across Wales as a whole. Other issues around data collection may be addressed in the guidance to be issued under the Bill, at the discretion of the Welsh Ministers.

228. The Bill sets out the key categories of data to be collected. The list has been compiled with advice from experts in data collection, and clinical practice in ASD services. The categories in the Bill are judged to meet the minimum requirements for satisfying the functions of diagnosis, service planning and development. This data is needed from all parts of Wales; consistency in data collection will facilitate a strategic approach to service planning.

229. The Bill also allows the Welsh Ministers to request anonymised data from relevant bodies, a provision that was strongly endorsed by respondents to the consultation on the draft Bill. Such data is likely to prove invaluable for research purposes, as well as assisting with service improvement.

230. The Bill seeks to build on the current arrangements for data collection, which are currently under development using the Community Child Health 2000/CypRIS database, and not to replace them.

231. It may be noted that the database will build valuable data for research purposes, and that there will be potential for this information to be used for research both on the impact of policies and services, tracking ASD across areas, and highlighting potential inconsistencies between diagnoses in different areas.

5. 17. Guidance on implementation and delivery of the autism strategy

232. The Bill includes, in section 4, a duty on the Welsh Ministers to issue guidance to relevant bodies on the implementation and delivery of the autism strategy. This will allow the Welsh Government to ensure effective delivery of the strategy. It therefore underpins the core aim of the Bill to ensure the needs of people with ASD are met.

233. Section 4 sets out a number of specific issues which are required to be included in the guidance on the implementation and delivery of the strategy. These are deemed to be of sufficient importance to warrant guidance, and these must therefore be included. The guidance may refer to other aspects of the autism strategy at the discretion of the Welsh Ministers.

234. The Bill requires guidance issued by the Welsh Ministers to include the following:

- The identification of persons with ASD.
- Persons who are to be classed as carers for the purposes of this Act.
- The provision of diagnostic and needs assessment services.

These are the bedrock of ASD services and areas of major concern for people with ASD, their families and carers. Guidance on diagnosis and needs assessment in support of an ASD strategy will help to secure greater quality and consistency in these services.

- The inclusion of key professionals in multi-disciplinary diagnostic assessment teams.

Section 4(6) includes an example list of key professionals for inclusion in multidisciplinary diagnostic assessment teams. The list comprises: clinical psychologist, psychiatrist, speech and language therapist, occupational therapist, behavioural therapist, social worker.

- The training of staff who provide services.

The pressing need to improve staff training in recognition of ASD and skills to support people with ASD makes this a vital component of the strategy. Guidance for relevant bodies is needed in order to achieve significant and comprehensive improvements to staff training and consistent outcomes of such training across Wales.

- Local leadership.

The Bill aims to improve ASD services across all parts of Wales; to facilitate this, localities need clear direction and leadership. The Bill requires guidance to be produced on how this can be put in place in all localities, to secure accountability for implementation and delivery of the ASD strategy.

235. Section 4 requires guidance to be published within three months of the publication of the autism strategy.

236. Publication of the guidance and any subsequent revised versions must be the subject of consultation with relevant bodies and other persons considered appropriate, including persons with ASD and organisations representing their interests or providing services to them.

237. The Welsh Ministers are required to keep the guidance under review. In reviewing the guidance, the Welsh Ministers are required to consider how effective it has been in implementing the strategy.

238. The Welsh Ministers may also revise the guidance, and where this occurs, publish a revised version as soon as is reasonably practicable. They must consider whether any revisions to the autism strategy require revisions to the guidance.

239. Section 4 of the Bill also provides that work undertaken by the Welsh Ministers prior to this provision coming into force (for example in developing guidance on an autism strategy, to the extent that it meets the criteria set out in the Bill) is construed as meeting the requirements of the Bill. This will help to avoid duplicating work previously undertaken.

6. Power to make subordinate legislation

240. The Bill contains provisions to make subordinate legislation. Table 1 sets out in relation to these:

> (i).the person upon whom, or the body upon which, the power is conferred;
>
> (ii).the form in which the power is to be exercised;
>
> (iii).the appropriateness of the delegated power;
>
> (iv).the applied procedure; that is, whether it is “affirmative”, “negative”, or “no procedure”, together with reasons why it is considered appropriate.

241. The Welsh Government can be expected (in line with its usual practice) to consult on the content of the subordinate legislation where it is considered appropriate to do so. The precise nature of the consultation (if any) will be decided when the proposals have been formalised.

Table 1: Summary of powers to make subordinate legislation in the provisions of the Autism (Wales) Bill:

Section	Power conferred on	Form	Appropriateness of delegated power	Procedure	Reason for procedure
6(6)(j)	Welsh Ministers	Regulations	The regulation-making powers in this section allow the Welsh Ministers to make regulations, which prescribe additional categories of data to be captured by NHS bodies.	Affirmative	The affirmative procedure is appropriate given that any additional categories of data prescribed may include personal data.
9(1) – found under the definition of “autism spectrum disorder”	Welsh Ministers	Regulations	The regulation-making powers in this section allow the Welsh Ministers to make regulations, by which include, for the purposes of this Bill only, other neurodevelopmental disorders in addition to the WHO International Classification of Diseases definition of ‘autism spectrum disorder’.	Affirmative	The affirmative procedure is appropriate given that these regulations may significantly extend the scope of the disorders to which the Bill will apply.
9(1) - found under the definition of “relevant body”	Welsh Ministers	Regulations	The regulation-making powers in this section allow the Welsh Ministers to make regulations, which extend the definition of ‘relevant body’ for the purposes of the Bill beyond the local authorities and NHS bodies already included as relevant bodies.	Affirmative	The affirmative procedure is appropriate given that these regulations will extend the range of bodies that will be required to comply with the autism strategy and accompanying guidance.

Part 2: Regulatory Impact Assessment

This Regulatory Impact Assessment (RIA) considers the options available in respect of the main provisions within the Bill, and analyses how far each of these would meet Paul Davies AM's desired policy objectives. In doing so, it considers the associated risks, costs and benefits of each option.

242. The RIA also explores the potential for unintended consequences and includes equality considerations. The costs and benefits associated with each option have been produced using the best information available at the time.

243. This information has been prepared through discussion with key stakeholders, including: the Welsh Government, professionals within the field, and third sector bodies. In addition, two consultations have been undertaken to allow the RIA to incorporate the views of local authorities and health boards.

244. The costs and benefits associated with each option have been assessed over a five-year period, as costs beyond this timeframe cannot be estimated with certainty., Recurring costs that are expected to last beyond this period being identified in the text.

245. The HM Treasury central discount rate of 3.5%[22] has been used throughout this analysis to calculate the present value of the preferred option.

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

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[22] https://www.gov.uk/government/publications/the-green-book-appraisal-and-evaluation-in-central-governent

7. Summary of RIA

Autism (Wales) Bill
Current costs: £1.1 billion a year. While the Welsh Government is currently providing direction in terms of autism strategy, code of practice, guidance, training and developing databases. The costs of providing such is unknown and there is no legislative requirement to take these forward, these costs have therefore been estimated as zero. Funding has been provided to meet the 26 week waiting times target for children, it is assumed that this funding remains in place, The amount of funding that has been provided is unknown, as this funding is assumed to be maintained, to avoid confusion the costs are unknown so shown as zero. Compliance and enforcement costs are minimal and part of existing NHS monitoring so shown as zero. Direct incremental costs of ASD are estimated as £3.5 billion over 5 years and indirect costs, relating to productivity loss, £2.1 billion over 5 years. While UK Benefit costs are estimated at £270 million, these costs do not fall on Welsh Government or devolved bodies. **Preferred option:** introduce and pass Autism (Wales) Bill.

Stage:	Appraisal period: 5 years	Price base year: 2017
Total cost Total:**£7,387,366** Present Value: **£6,863,575**	Total benefits Total: Not possible to quantify. Present Value: unknown	Net Present Value (NPV): £6,863,575

Administrative costs

Total Costs:£7,387,366 Direct costs: Transitional costs: Welsh Government: £144,888 Health boards: £4,488,413 (over 3 years) Ongoing costs: Welsh Government: £214,868 (not evenly spread over years) Health boards: £20,490 (on top of Option 1 database, reporting and monitoring costs) Indirect costs: Training (time)

Transitional costs: NHS staff: £956,752 Local government: Social care staff £241,740 Local government: Education staff £815,271 **Ongoing costs:** NHS staff: £230,238 (over 3 years) Local government: Social care staff £172,775 over 3 years Local government: Education staff £101,933 over 3 years			
Transition: £6,647,063	Recurrent: £740,303	Total: £7,387,366	PV: £6,863,575
Cost savings:£unknown Ongoing savings:£ unknown One-off saving:£ unknown			
Transition: £ unknown	Recurrent: £ unknown	Total: £ unknown	PV: £ unknown
Net administrative cost:£7,387,366			

Compliance costs

There are no additional enforcement costs estimated for this Bill.			
Transition: £0	Recurrent: £0	Total:£0	PV: £0

Other costs

Common costs to Option 1: Direct incremental costs of ASD estimated as £3.5 billion over 5 years and indirect costs, relating to productivity loss of £2.1 billion over 5 years.			
Transition: £0	Recurrent: £5,657,516,576	Total: £5,657,516,576	PV: £5,107,745,065

Unquantified costs and dis-benefits

There are a number of benefits, disbenefits and risks associated with introducing the Bill, which it has not been possible to quantify and the impact and subsequent potential costs are unknown. These are set out by provision and by organisation raised throughout the Explanatory Memorandum and regulatory impact assessment.

Benefits

Uncertainties around numbers of people diagnosed, on waiting lists and undiagnosed, along with lack of information on services received by those with or without ASD diagnosis mean there is insufficient information to quantify the benefits of this Bill.

Unquantified benefits

The early reduction in numbers of people waiting for a first assessment meeting and better information in relation to people diagnosed with ASD will lead to more impact from scarce resources, less likelihood that services are provided to undiagnosed or unrecognised ASD that may do more harm than good and better information for research. Improved training will improve care, services and diagnosis.

Key evidence, assumptions and uncertainties

The key evidence, assumptions and uncertainties are set out in the introduction. More detail can be found in the discussion on the costs and benefits of the two options.

7. 1. Options considered

247. The two primary options considered were:

- to maintain the Welsh Government's current approach to addressing the needs of children and adults with ASD in Wales, and
- to introduce legislation to ensure the needs of children and adults with ASD in Wales are identified and met.

248. As previously noted, a considerable amount of work has been undertaken in Wales in recent years to improve services for people with ASD, their families and carers. The Welsh Government's Autism Spectrum Disorder Strategic Action Plan recognised the need for better diagnostic services for children and adults with ASD.

249. Nevertheless, difficulties remain for people in some areas to gain access to diagnostic assessments.

250. 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. 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.

251. The second main option considered was to introduce the Autism (Wales) Bill, which seeks to supplement, not to replace, the existing actions being undertaken by the Welsh Government. This is the preferred option.

252. A key function of the Bill, therefore, is to secure consistent and continued provision of all ASD services across Wales in order to achieve the core purpose of ensuring the needs of people with ASD are met, and their rights protected and promoted. Beyond the period of the revised Autism Spectrum Disorder Strategic Action Plan 2016-20 there is no certainty of continued prioritisation of autism services. By creating a legal requirement to publish an autism strategy the Autism (Wales) Bill would help secure a measure of permanence and sustainability in care and support services for people with ASD.

8. Option 1: Continue with the Welsh Government's future plans

Table 2: Summary of costs for option 1

Cost	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Welsh Government						
Developing an autism strategy	Currently provided but no requirement to keep updated strategy - £0					0
Developing guidance to implement the strategy	Currently provided but no requirement to keep updated guidance - £0					0
Making data publicly available	No specific commitment to make data public - £0					0
Independent review of autism strategy	Currently provided but no requirement to keep updated strategy - £0					0
Training development / Awareness raising	Funding provided but unknown.					0
Total costs to Welsh Government	0	0	0	0	0	0
Local Health Boards						
Costs of operating existing database	73, 579	73, 579	73, 579	73, 579	73, 579	367,895
Development costs of children's and adult databases	Funding provided but unknown.					0
Delivery of 26 week waiting time target	Funding provided to meet 26 week target for children.					0
Compliance / enforcement costs	Part of NHS performance reporting and monitoring - £0					0

Cost	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Total costs to Local Health Boards	73, 579	73, 579	73, 579	73, 579	73, 579	367,895
Total additional direct costs of Bill	73, 579	73, 579	73, 579	73, 579	73, 579	367,895
Public sector organisations						
Direct costs: accommodation	475,581,162	476,996,673	478,410,820	479,855,417	481,313,648	2,392,157,720
Direct costs: education	143,432,339	143,859,248	144,285,746	144,721,427	145,161,220	721,459,980
Direct costs: health and social care	118,936,651	119,290,652	119,644,312	120,005,587	120,370,271	598,247,473
Direct costs: Total	737,950,152	740,146,573	742,340,878	744,582,431	746,845,139	3,711,865,173
Direct costs: Total incremental	**700,057,908**	**702,141,547**	**704,223,179**	**706,349,633**	**708,496,156**	**3,521,268,423**
Total direct costs	**700,131,487**	**702,215,126**	**704,296,758**	**706,423,212**	**708,569,735**	**3,521,636,318**
Indirect costs individual productivity loss	524,450,068	526,011,031	527,570,491	529,163,529	530,771,602	2,637,966,721
Indirect costs parents productivity loss	54,165,978	54,327,197	54,488,260	54,652,791	54,818,875	272,453,101
Total indirect costs	578,616,046	580,338,228	582,058,751	583,816,320	585,590,477	2,910,419,822
Total indirect costs, adjusted for employment	**424,704,178**	**425,968,260**	**427,231,124**	**428,521,180**	**429,823,411**	**2,136,248,153**
Indirect opportunity costs of staff undertaking training	Training and funding currently provided but no requirement to continue.					0
Total costs	**1,124,835,665**	**1,128,183,386**	**1,131,527,882**	**1,134,944,392**	**1,138,393,146**	**5,657,884,471**
Total admin costs	**1,124,909,244**	**1,128,256,965**	**1,131,601,461**	**1,135,017,971**	**1,138,466,725**	**5,658,252,366**
Total savings	**Insufficient information to form robust savings estimates**					
Note: UK Benefits (not included in totals)	**53,740,037**	53,899,988	54,059,785	54,223,022	54,387,800	270,310,632

253. Current costs of ASD services are included under the heading "Public sector organisations". These are divided between service areas rather than organisations. This demonstrates how services are received by people, rather than the bodies that fund or deliver these services. Services in each of these areas could be delivered by local authority, health, voluntary or other organisation. Table 5, which shows how these costs are estimated, gives an idea of the range of services included in each heading.

8. 1. General comment on estimating costs

254. There is very little information available in the public domain to estimate the cost of current provision and future plans with regard to both the administrative costs of supporting the Welsh Government's ASD policies and the wider costs of providing services to people with ASD, and to their carers. Where investment is being made these investments are not broken down to a level of detail to inform this impact assessment. The Welsh Government were unable to provide specific information regarding the cost of the status quo position. Where possible, estimated costs associated with delivering similar actions in Explanatory Memorandums laid alongside Welsh Government Bills in the last five years have been used.

8. 2. Updating and assessing the current autism strategy

255. The Welsh Government's Autism Spectrum Disorder Strategic Action Plan[23] was published in 2016. An independent evaluation of the plan published its interim report in March 2018,[24] with a final report due for completion by January 2019. The Welsh Government also has committed to publishing an annual report on the Autism Spectrum Disorder Strategic Action Plan.

256. 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.

257. The cost and timing of producing a revised ASD Strategic Action Plan is currently unknown. If the Welsh Government were to update or revise its ASD Strategic Action Plan it is envisaged that this would be in line with the costs estimated in Section 9 (*Option 2: Produce a Bill*) of this Explanatory

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[23] Welsh Government, **Autism Spectrum Disorder Strategic Action Plan**

[24] People and Work for Welsh Government, **Evaluation of the Integrated Autism Service (IAS) and Autistic Spectrum Disorder Strategic Action Plan (ASD SAP)**

Memorandum. It is therefore estimated that a revised action plan would cost in the region of £30,000. This includes one month of an Executive Band 2 member of the Welsh Government staff's time, and six months of a Management Band 2 member of staff's time. This is based on the MB2 civil servant working on the strategy full time, with supervision and sign-off from the EB2 civil servant. These costs also include costs around design, typesetting, translation and proof-reading for a document approximately 8,500 words in length.

258. While there are no estimates of the current cost of investment in ASD services in Wales, the Welsh Government have made announcements relating to specific funding initiatives recently. The Welsh Government announced the intention to provide £13 million of funding for the National Integrated Autism Service over the period 2016-17 to 2020-21. £6 million of funding was initially announced in March 2016[25] by the then Minister for Health and Social Services over a three-year period. This was supplemented by £7 million over the period 2017-18 to 2020-21 announced in March 2017[26] by the then Minister for Social Services and Public Health. Section 8.5 takes a different approach of using the latest academic research to estimate the costs of ASD as a whole in Wales.

259. The National Integrated Autism Service was launched in 2016 and was a key element of the Welsh Government's refreshed ASD Strategic Action Plan. Funding was designed to support delivery of the Action Plan and included commitments to develop improved autism resources.

260. Following the Minister's announcement, in March 2016, funding has been delivered through the Integrated Care Fund (ICF). ICF funding for 2016-17 and to support the development of Integrated Autism Service purposes (allocated to Regional Partnership Boards, the Welsh Local Government Association (WLGA) and Welsh Government) included;

- £188,000 allocated to Powys,
- £204,000 to Cardiff and Vale,
- £204,000 to Cwm Taf; and
- £249,000 to Gwent.

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[25] Welsh Government, 'New autism service for Wales to be established' (March 2016)

[26] Welsh Government, 'Extra £7 million for innovative all-Wales autism services' (March 2017)

261. Funding for Regional Partnership Boards in 2017-18 totalled £2,674,400, with a further £80,000 for the WLGA and £245,600 retained by the Welsh Government.[27] For 2018-19 total funding available within the Integrated Care Fund is £3,000,000 with £2,977,000 for Regional Partnership Boards.[28]

8. 3. Produce a Code of Practice

262. During the development of this Bill, the Welsh Government indicated that it intends to issue a Code of Practice[29] on the delivery of ASD services under sections 145 and 169 of the Social Services and Well-being (Wales) Act 2014 and sections 1 and 2 of the National Health Service (Wales) Act 2006.

263. There is no information to enable the estimation of the cost of producing this Code of Practice. This Code of Practice may also be partly completed or in place when this Bill is enacted. Therefore, these costs are unknown and have not been included as part of theses cost estimates.

264. The correspondence from the Cabinet Secretary for Health and Social Services indicated that local authorities will be required to act in accordance with the requirements of the guidance when exercising social services functions. Local Health Boards will be required to have regard to the guidance.

265. The correspondence from the Cabinet Secretary also indicated that the draft Code of Practice will cover a number of areas, although the outline produced by the Welsh Government did not clearly set out the extent to which this will meet the Bill's requirements.

266. The correspondence from the Cabinet Secretary also indicated that the draft Code of Practice will provide guidance on the following arrangements[30]:

- accessing social care assessment and services;
- how the needs of persons with ASD should be met by relevant bodies;
- undertaking an assessment of ASD training needs for staff working in health and social care;

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[27] Welsh Government, 'Integrated Care Fund Guidance' (Effective: 1 April 2017)

[28] Welsh Government, 'Integrated Care Fund Guidance' (Effective: 1 April 2018)

[29] Letter from Cabinet Secretary for Health and Social Services to Paul Davies AM, 29 March 2018

[30] Letter from Cabinet Secretary for Health and Social Services to Paul Davies AM, 29 March 2018

- ensuring staff have access to training to meet their identified training need;
- the development and publication of assessment and diagnostic pathways for children and adults, taking into account NICE guidance;
- reviewing and maintaining diagnostic pathways for children and adults;
- diagnostic assessments and post diagnostic meetings;
- regional autism lead role;
- local stakeholder involvement in planning and delivery of ASD services;
- promoting innovation and improvement in the commissioning of ASD services;
- undertaking population needs assessment for people with ASD and the publication of area plans;
- monitoring the delivery of ASD services;
- health and social care services provided to children and adults who are detained in the secure estate;
- the provision of mental health services for children and adults with ASD; and
- services for children and adults with ASD with co-occuring conditions.

8. 4. Existing costs of training

267. Various training resources are available on the website www.ASDInfoWales.co.uk,[31] for education, health and social care professionals. These include e-learning, toolkits, certification schemes, and training videos.

268. Additionally, several organisations provide training on ASD to the public, private and third sectors.

269. During 2017-18, the ASD Info Wales team delivered a number and range of training courses in support of their work. These courses:

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[31] ASD Info Wales, **Professionals**

- raised awareness of ASD and the specific needs of people with ASD; and
- supported and assisted organisations in:
  - using the resources developed by the Team; and
  - arranging the commissioning and delivery of training by external bodies in support of improved service delivery, including by the Integrated Autism Service.

270. Using the 'Learning with Autism' resources, and awareness raising sessions to highlight the programme and its resources (e.g. presentations to ALN coordinators and educational psychologists) the following training has been delivered by the National Autism Development team:

- Learning with Autism:
  - Early Years: In total 25 training sessions across Early Years settings across Wales
  - Primary Schools – 4 training sessions, including 3 super schools across Wales
  - Secondary Schools - 9 training sessions have been undertaken this year.
- Up to 10 sessions have been held across Wales for Flying Start managers focusing on the Health & Social Care for children training package, also received Early Years training and have committed to continue to support the roll out of the training in local settings.
- 6 training sessions for Health Visitors in Abertawe Bro Morgannwg University Health Board as part of Health Visitors Skills Day (a series of sessions) focusing on the Health & Social Care for children training package.
- HR training was provided during April 2017 to staff at the Welsh Government's Merthyr office and a further session for staff at ONS, Newport.
- 10 leisure training session were facilitated in SE Wales, including train the trainer session for staff within Disability Sports Wales, as mentioned above.

- There have also been several generic ASD awareness sessions held for business networks, local events and conferences.
- Working with Autism training delivered for Workways Wales in Neath Port Talbot and Pembrokeshire

271. During the development of the Bill, the National Autism Development Team advised that this training had been well received across all areas and requests were being received on regular basis.

272. The website **www.ASDinfoWales.co.uk** is managed by the National Autism Development Team. Over 24,200 people have undertaken the general ASD Aware scheme. During the development of this Bill, the National Autism Development Team outlined that they are continuing to develop and enhance the www.ASDinfoWales.co.uk website. They outlined that the following additional resources have been added:

- **ASD Planner app** – had been redeveloped, but the Team were working on compliance with GDPR regulations before launch.
- **Birthday Party film**[32] launched in June 2017. The film is a partnership project between the WLGA, Cardiff University, Aston University and clinical psychology partners, and has been funded by the Economic and Social Research Council and Welsh Government. The film's aim is to improve front-line professionals' understanding and awareness of ASD in children.
- **Leisure Scheme** was launched at the beginning of 2017. Using a 'train the trainer' approach, Disability Sports Wales officers have been trained to deliver ongoing training. The Leisure Scheme aims to increase knowledge and awareness of the needs of individuals with ASD within the leisure industry.[33]
- **8 Regional events** took place across Wales between April/May 2017. There were two sessions per day, one for professionals and another for parents. The aim of these events was to raise awareness of the work of the Team, their resources and to provide further information regarding

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[32] Further information can be found at https://www.asdinfowales.co.uk/news/wlga-press-release-film-collaboration-aiming-to-increase-awareness-of-autism-signs-in-children

[33] Further information can be found at **www.ASDinfoWales.co.uk/leisure-staff**

the Integrated Autism Service and also advising participants about new schemes, such as the “Can You See Me” scheme.

- An **emergency services training film** has been completed. This arose from repeated requests for emergency services training from various sources and in response to a scoping exercise identifying the need and desire for developing an emergency services programme,. A training package to accompany the film is being developed in 2018-19.
- A **mental health and social care training package** has been completed and the Team have commissioned Aspects - Adult Autism Psychology Ltd to deliver the training across Local Authorities and Health Boards in Wales. The aim of the one-day course is to raise awareness and understanding of ASD across specialist health and social care practitioners and provide information on how to adapt practice.
- **Idiom Glossary** - In response to the issue that many autistic individuals may have problems understanding some of the most common idioms used as part of everyday language, the Team has developed an on-line idiom dictionary[34] in English and Welsh.
- A **Housing Scheme**[35] was developed and is available on the www.ASDinfoWales.co.uk website. The scheme was developed and piloted with Merthyr Housing Association and will be part of the development of updated guidance in the 2018-19 work programme.

273. The National Autism Development Team also reported that at the end of 2017-18:

- 24,200 people had completed the general ASD Aware scheme;
- 1,194 people had completed I know about autism;
- 1,010 people had completed Working with autism;
- 7,512 teachers have completed Learning with autism; and
- 882 health and social care staff had been involved on other schemes.

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[34] Further information can be found at https://www.asdinfowales.co.uk/idioms-glossary

[35] Further information can be found at https://www.asdinfowales.co.uk/housing-provider-scheme

274. These figures did not include the videos provided by the Team that have been viewed.

275. Therefore, there is on-going investment into the production and delivery of training in relation to ASD. There is insufficient information to be able to estimate the cost of producing and delivering this training and also no statutory commitment for the Welsh Government to do so. Therefore, an attempt to cost the design and delivery of training has not been made. However, the numbers specified above have fed into calculations of staff training requirements in Option 2.

8. 5. Costs of existing data collection on Autism Spectrum Disorder

276. There are a number of projects across Wales that collect data on ASD, which is mainly available for child diagnoses rather than for people diagnosed as adults.

277. Almost all diagnoses are made within health services so it would be appropriate to use the ASD module within the Child Community Health 2000/CYPRIS database for the purpose of data collection for child diagnoses.[36]

278. The ASD module is currently used by Betsi Cadwaladr University Health Board[37] and has collected data across North Wales since 2012. This development is compatible with a pilot being undertaken in Aneurin Bevan University Health Board using the CYPRIS database.

279. Additionally, Powys Teaching Health Board is piloting cross-agency development of the Wales Community Care Information System (WCCIS) to collect data on ASD and neurodevelopment disorders.

280. Betsi Cadwaladr University Health Board have advised that the Monitoring their child ASD module requires:

- 1 day a week of a NHS Wales Band 8D FTE;
- 2.5 days per week of a NHS Wales Band 5 FTE;
- 2 days a week of a Grade 7 researcher employed by a university; and

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[36] Dr Dawn Wimpory, Autism (Wales) Bill consultation response 28

[37] Dr Dawn Wimpory, Autism (Wales) Bill consultation response AWB72

- 2.5 days per week of a Grade 6 research project support officer employed by a university.

281. In 2017-18, the midpoint annual salary for a full-time equivalent member of NHS Wales staff on pay scale Band 8D was £76,329.[38] Using the estimate of on-costs being 25% of salary that is used by the NHS,[39] this would give an annual FTE cost of £95,411. If the staff member works on the database for an average of 1 day per week, this would give an annual cost of £19,082.

282. In 2017-18, the midpoint annual salary for a member of NHS Wales staff on pay band 5 was £25,551.[40] Estimating that on-costs represent 25% of salary,[41] this would give an annual FTE cost of £31,939. If the staff member works on this area for an average of 2.5 days per week, this would give an annual cost of £15,969.

283. For a grade 7 research officer at a university, the midpoint annual salary is £38,833.[42] On-costs for university staff in this section have been calculated taking into account the current Universities Superannuation Scheme. If the staff member is a member of the Universities Superannuation Scheme, this would give an annual FTE cost after on-costs of £50,056.[43] If the staff member works on the databases for an average of 2 days per week, this would give an annual FTE cost of £20,022.

284. For a grade 6 research project support officer, the midpoint annual salary is £28,936.[44] If the staff member is a member of the Universities Superannuation Scheme, this would give an annual FTE cost after on-costs of £37,012.[45] If the staff member works on this area for an average of 2.5 days per week, this would give an annual cost of £18,506.

285. Therefore, the costs associated with this approach are considered to be the costs associated with taking the Welsh Government's current approach forward. There will be ongoing annual costs past the five years set out in this Regulatory

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[38] Welsh Government, **Pay Circular: Agenda for Change Staff 2017-18**

[39] NHS England, **Workforce Mix Cost Calculator**

[40] Welsh Government, **Pay Circular: Agenda for Change Staff 2017-18**

[41] Again, based on the NHS England estimate of on-costs.

[42] Bangor University, **Scales and Rates**

[43] Ibid.

[44] Ibid.

[45] Ibid.

Impact Assessment. There are no additional costs for hardware, software maintenance and development included in Option 1 and 2 costings, these figures will be common to both options. Table 3 shows the current estimate of costs to maintain existing database, assuming no further development before Bill is enacted.

Table 3: Current staff costs for data collection on ASD

Staff member	Year 1	Year 2	Year 3	Year 4	Year 5	Total
LHB hosting database						
NHS Wales Band 8D consultant 0.2FTE	19,082	19,082	19,082	19,082	19,082	**95,410**
NHS Wales Band 5 assistant psychologist 0.5 FTE	15,969	15,969	15,969	15,969	15,969	**79,845**
University researcher Grade 7 0.4 FTE	20,022	20,022	20,022	20,022	20,022	**100,110**
University research project assistant Grade 6 0.5 FTE	18,506	18,506	18,506	18,506	18,506	**92,530**
Total costs	**73,579**	**73,579**	**73,579**	**73,579**	**73,579**	**367,895**

8. 6. General costs in relation to autism

286. There is no available information on the cost of providing direct services or of the indirect economic impacts of ASD in Wales. Therefore, the approach taken in this impact assessment is to take the latest data and research on the economic impacts of ASD from across the UK.

287. The economic effect of ASD on individuals, their families, and society as a whole has generally been poorly understood. There are a number of direct, indirect, and lifetime societal economic costs, such as individual and parental productivity costs, associated with ASD.

288. The latest and most robust information regarding autism prevalence and economic costs can be found in the report '*The Microsegmentation of the Autism Spectrum: Economic and research implications for Scotland (December 2017)*'[46].

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[46] http://www.gov.scot/Publications/2018/03/3640

This detailed study built on a national survey and the latest UK and international studies in this area to estimate the prevalence and cost of ASD in Scotland.

289. There is no evidence to suggest that figures for Wales would be significantly different, nor is there recent robust evidence specific to Wales. Therefore, for the purpose of this impact assessment, outputs from this recent study have been used to provide a basis for estimates of prevalence and costs in Wales.

290. Initial work as part of the Microsegmentation study highlighted that:

- while ASD is associated with many co-occurring conditions and other features, which will have an impact, the single most important moderator in terms of outcomes and how these translate into economic implications is the presence or absence of Intellectual Disability (ID); and
- There were many gaps in the evidence base, and insufficient evidence on intervention and outcomes to base economic evaluation.[47]

291. Estimates on the prevalence of ASD are based on the Microsegmentation report's recommendation that 103.5 per 10,000 population be used as the most accurate prevalence estimate available. This review also estimated that within this population the most accurate estimate of the prevalence with Intellectual Disability (ID) is 32.7%. These prevalence rates have been applied to 2016 mid-year population estimates for Wales (ONS, June 2017[48]) in table 4 below.

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[47] http://nationalautismproject.org.uk/wp-content/uploads/2017/01/autism-dividend-report.pdf

[48] https://cmd.onsdigital.co.uk/datasets/mid-year-pop-est/editions/time-series/versions/2

Table 4: Prevalence of autism in Wales by age and ID

Wales	ASD population			Total population
	with ID	without ID	Total	
Children (0-1)	227	468	695	67,188
Children pre-school (2-4)	359	739	1,098	106,073
Children primary school (5-11)	853	1,755	2,608	251,977
Children secondary school (12-15)	446	919	1,365	131,841
Adults (16-67)	6,887	14,174	21,061	2,034,839

Source: Calculations from ONS 2017 data based on The Microsegmentation of the Autism Spectrum 2017

292. The Microsegmentation report also conducted a detailed ASD survey in Scotland to obtain more accurate data relating to the economic costs of ASD and attempt to construct a meaningful segmentation of the spectrum. The sample covered early childhood to 86 years, and was weighted to ensure the results were representative. The outcome was that a model of segmentation was proposed in which intellectual ability and original symptom severity were stable moderators of outcomes, and co-occurring conditions were variable "additive risk factors".

293. The report looked in detail into the costs of ASD. This was achieved by looking at service utilisation and associated costs. The aim was for the incremental cost of ASD to be calculated: for example, standard educational provision was assigned a cost of £0.

294. Costs were reported at 2013-14 levels (with sources shown in brackets).

- Education. Intensity of use of educational services, and so unit costs for (ASD-relevant) educational services in mainstream schools, further education colleges and special day schools were estimated using cost figures from the PSSRU volume (Curtis, 2014) and intensity estimates (hours/week) from previous studies (Clifford & Thobald, 2012). This included estimated intensities for educational psychologists, psychotherapists, speech and language therapists, occupational therapists, and physiotherapist. Estimate for classroom or specialist assistants is half of the cost of a classroom assistant in special day schools (Clifford, 2011). School exclusions were not costed.

- Health and social care. Estimates were based on: PSSRU volume (Curtis, 2013, 2014), NHS reference costs (Department of Health, 2014), and previous research (Cognisant Research, 2012; Knapp et al., 2013).
- Cost of carer's employment were taken from ONS (2014) meant total weekly earnings, using the human capital method to estimate productivity loss as a result of disrupted employment.

295. Additional information on unit costs for the above is detailed in table 5, below.

Table 5, Extract from The Microsegmentation of the Autism Strategy, 2017, Unit costs (£, 2013/14) (Table 8.1 in the original report)

Table 8.1 Unit costs (£, 2013/14)

	Unit cost	Source
Accommodation		
Private household	£0	
Formal foster care	£100/day	Curtis, 2014
Supported living accommodation	£924/week	Curtis, 2014
Residential school	See below	-
Residential care	See below	-
Secure unit (adults)	£537/day	Curtis, 2014
Education		
Mainstream school	£0	-
Further education college	£0	-
University	£0	-
Special unit/resource in mainstream school	£140/week	Barron et al., 2013
Special day school	£527/week	Clifford & Thobald, 2012
Special residential school (38 weeks)	£2,087/week	Clifford & Thobald, 2012

	Unit cost	Source
Special residential school (52 weeks)	£3,308/week	Clifford & Thobald, 2012
Home education	£0	-
School family worker / education support worker	£0[a]	-
Educational psychologist	£138/week[b]	Curtis, 2014
Classroom assistant	£129/week[c]	Clifford, 2011
Specialist teacher	£129/week[c]	Clifford, 2011
Disability service advisor	£0[a]	-
School nurse	£0[a]	-
School doctor	£0[a]	-
After-school club	£0[a]	-
Home tuition	£26/hour	Tanner et al., 2009
Individual tuition	£26/hour	Tanner et al., 2009
Tuition in small groups	£10/hour	Education Endowment Foundation, 2015
Exclusion	£0[d]	
Health and Social Care (received at school)		
Individual counselling/therapy	£50/week[b]	Curtis, 2014
Occupational therapist	£70/week[b]	Curtis, 2014
Speech and language therapist	£70/week[b]	Curtis, 2014
Physiotherapist	£26/week[b]	Curtis, 2014
Health and Social Care		
Residential respite care		
Residential care-home (children)	£428/day	Curtis, 2014
Residential care-home (adults)	£205/day	Curtis, 2014
Foster care (children)	£100/day	Curtis 2014

	Unit cost	Source
Inpatient services		
Psychiatric hospital (children)	£614/day	Curtis, 2014
Psychiatric hospital (adults)	£351/day	Curtis, 2014
Psychiatric ward in a general hospital (children)	See Psychiatric hospital	-
Psychiatric ward in a general hospital (adults)	See Psychiatric hospital	-
General medical ward – short stay (e.g. =1 day) (children)	£837/episode	Department of Health, 2014
General medical ward – long stay (e.g. >1 day) (children)	£2,901/episode	Department of Health, 2014
General medical ward – short stay (adults)	£601/episode	Curtis, 2014
General medical ward – long stay (adults)	£2,593/episode	Curtis, 2014
Hospital care in prison/secure/semi-secure unit (children)	£968/day	Department of Health, 2014
Outpatient services		
Psychiatric outpatient visit (children)	£271/contact	Curtis, 2014
Psychiatric outpatient visit (adults)	£100/contact	Curtis, 2013
Accident & Emergency	£135/contact	Department of Health, 2014
Other hospital out-patient visits	Specified for each service	Department of Health, 2014

	Unit cost	Source
Community care services		
Psychiatrist	£262/hour	Curtis, 2013
Psychologist	£138/hour	Curtis, 2014
Individual counselling/therapy	£50/hour	Curtis, 2014
Group counselling/therapy	£50/hour	Curtis, 2014
General Practitioner	£175/hour	Curtis, 2014
Community learning disability nurse (children)	£95/hour	Curtis, 2014
Community learning disability nurse (adults)	£80/hour	Curtis, 2014
Community nurse (other services) (children)	£95/hour	Curtis, 2014
Community nurse (other services) (adults)	£57/hour	Curtis, 2014
Other community learning disability team member	£37/hour	Curtis, 2014
Community challenging behaviour team member	£37/hour	Curtis, 2014
Child development centre/community paediatrics	£310/contact	Curtis, 2014
Occupational therapist	£32/hour	Curtis, 2014
Speech therapist	£32/hour	Curtis, 2014
Physiotherapist	£32/hour	Curtis, 2014
Social worker	£55/hour	Curtis, 2014
Home help/home care worker	£24/hour	Curtis, 2014
Outreach worker/family support	£22/hour	Curtis, 2014
Befriender	£7/hour	Curtis, 2014
Day care centre (children)	£17/hour	Curtis, 2014

	Unit cost	Source
Day care centre (adults)	£16/hour	Curtis, 2014
Social club (<=4hours)	£7.5/half-day	Curtis, 2014
Social club (>4hours)	£15/day	Curtis, 2014
Play-schemes (<=4hours)	£7.5/half-day	Curtis, 2014
Play-schemes (>4hours)	£15/day	Curtis, 2014
Sheltered workshop	£54/week	Knapp et al, 2013
Individual placement and support	£72/day	Curtis, 2014
Holiday schemes (<=4hours)	£7.5/half-day	Internet searches
Holiday schemes (>4 & <24hours)	£15/day	Internet searches
Holiday schemes (>=24hours)	£305/day	Curtis, 2014
Child-minder	£19/hour	Curtis 2014
Other community care services	Specified for each service	Curtis, 2014; Cognisant Research, 2012; internet searches
Carers		
Health and social care services		
Psychiatrist	£262/hour	Curtis, 2013
Psychologist	£138/hour	Curtis, 2014
Individual counselling/therapy	£50/hour	Curtis, 2014
Group counselling/therapy	£50/hour	Curtis, 2014
General Practitioner	£175/hour	Curtis, 2014
Physiotherapist	£32/hour	Curtis, 2014
Social worker	£55/hour	Curtis, 2014
Outreach worker/family support	£22/hour	Curtis, 2014
Other health and social care services	Specified for each service	Curtis, 2014

	Unit cost	Source
Employment		
Employment (paid and unpaid)[e]	£15.17/hour	ONS, 2014

Notes:

a. Included in school costs.

b. Mainstream schools, special unit/resource in mainstream schools, further education colleges, and special day schools (hours/week): educational psychologist (1), psychotherapist (1), speech and language therapist (2.2), occupational therapist (2.2), and physiotherapist (0.8). Cost adjustment based on therapy intensity in Clifford & Thobald (2012) for all services but psychotherapist. Psychotherapist is estimated conservatively at the same intensity as educational psychologist.

c. Only for mainstream schools and further education colleges: classroom assistant/specialist assistant. Cost estimated conservatively as half of the cost of classroom assistant in a special day schools (Clifford, 2011).

d. It is assumed that in the event of exclusion there is no alternative provision for children with ASD, and parents are expected either to look after their children at home or to arrange alternative care.

e. The national mean total weekly paid hours for all employees is 33.1 (ONS, 2014).

296. In line with the Microsegmentation report, the age of diagnosis is assumed to be 3 years for children with ASD with ID and 7 years for those without ID. All children are assumed to be diagnosed at these ages, while only 10% of children with ASD with and without ID are assumed to receive a diagnosis before 3 and 7 years respectively.

Table 6: estimated lifetime costs

	People with ASD with ID						People with ASD without ID					
	0-1	2-4	5-11	12-15	16-67	Lifetime	0-1	2-4	5-11	12-15	16-67	Lifetime
No of years	2	3	7	4	52		2	3	7	4	52	
Accommodation	-	213	258	303	11,333	592,990	-	-	-	-	4,728	245,848
Education	-	9,898	18,520	18,115	1,954	333,430	-	10,023	9,226	6,130	806	161,101
Health and Social Care	293	5,218	6,972	5,954	1,847	184,627	293	5,275	4,085	1,684	1,161	111,819
Productivity loss												
- individuals	-	-	-	-	8,249	428,953	-	-	-	-	7,291	379,156
- parents	-	4,283	3,693	2,834	239	62,501	-	4,337	2,911	2,738	690	108,236
Benefits	-	4,040	3,629	2,999	2,001	153,573	-	510	431	356	-	5,969
Total costs	293	23,651	33,071	30,203	25,626	1,756,074	293	20,146	16,653	10,909	14,676	984,134
Total costs - incremental	293	22,011	29,317	26,693	25,181	1,687,757	293	18,496	14,862	9,388	14,329	942,470

Calculations based on The Microsegmentation of the Autism Spectrum 2018

297. Statistics of service use and cost for users were investigated and reported per annum by category and were also reported separately for children aged under 16 and adults. Within each group results were presented separately for the three diagnostic groups: 'Higher Functioning Autism,' 'ASD' and 'autism.'[49] Similarly costs are estimated for carers, including parents, family carers, or other non-professional unpaid carers for someone with ASD. In estimating average annual costs over a lifetime, life expectancy is assumed to be 67 years, in line with Shavell and Strauss research, 1998.

298. The numbers of people with ASD living in residential settings for different age bands is based on assumptions used in previous studies:

- children with ASD without ID (100% private household);
- children with ASD and ID (98.75% private household, 1.25% residential or foster care, 0% hospital),
- adults with ASD without ID (79% private household, 5% supported living accommodation, 16% residential care, 0% hospital), and
- adults with ASD and ID (48% private household, 27% supported living accommodation, 24% residential care, 1% hospital).

299. The resulting total costs were then discounted back to the present value (PV) using the 3.5% discount rate.

300. The incremental cost of ASD was estimated subtracting the cost of the "usual" provision (i.e. the cost of mainstream schools, and the cost of health care services in the general population. For more details see The Microsegmentation of the Autism Strategy, 2017 Table 8.2 page 173. Given the absence of evidence from previous research on per capita social care services cost in the general population, and the expected low use of social care services in the general population, the report authors assumed that the observed social care services use and cost in the ASD population were incremental.

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[49] Within this analysis for the Microsegmentation of the Autism Spectrum report, the following terminology was used: **autism**, Including 'Childhood Autism' or 'Autistic Disorder'; **Asperger's or Higher Functioning Autism**, Including 'Asperger's Disorder'; **Other ASD**, including general/nonspecific ASD diagnoses, 'Atypical Autism' or 'PDD-NOS' ('pervasive developmental disorder not otherwise specified'). This terminology is used in this Explanatory Memorandum only in relation to references to Microsegmentation of the Autism Spectrum report.

301. The Microsegmentation report also estimated the *national cost* for people with ASD and their carers by piecing together data on cost for different age groups.

302. Research in the Microsegmentation report shows that across diagnostic groups, over two-thirds of carers of children with ASD were in employment, averaging 26 working hours per week when in employment. Six per cent of carers of children with Higher Functioning Autism reported visiting a GP every two months on average, some visited other health and social care services more than once a month (individual or group therapist, outreach worker). Similarly, about two-thirds of carers of adults with ASD were in employment, averaging 30 working hours per week when in employment. Five per cent of carers of adults with Higher Functioning Autism saw a therapist, averaging more than one visit a month. A few carers saw their GP, averaging a visit every two months. Fewer than 5% of carers of adults with “autism”[50] used therapy, and a few saw a GP, both about every month.

303. The overall cost for carers of children with ASD was estimated as varying between £3,813 for carers of children with other ASD to £4,479 for carers of children with autism. For carers of adults the costs ranged from £1,612 for carers of adults with autism to £2,499 for carers of adults with Higher Functioning Autism. Nearly all of the costs related to productivity losses, which were attributed to needing to work part-time because of caring responsibilities. The largest health and social care costs for carers of children and adults with ASD are psychologist and individual or group therapists

304. The report estimated lifetime costs as £925,503 (£886k incremental cost) for individuals with ASD without intellectual disabilities, or £1,651,453 (£1.6m incremental cost) for individuals with ASD with intellectual disabilities, at 2013-14 prices. Of these costs, for ASD without intellectual disabilities, 40% related to productivity losses and 26% to accommodation. For people with ASD with intellectual disabilities, 35% related to accommodation and 25% productivity losses. The productivity loss of parents and carers of individuals with ASD with ID was almost double that of those without ID.

305. Applying this analysis to the Welsh population- with a prevalence rate of 1.035% and 32.7% of these people having an intellectual disability- provides the following annual costs. These are split between direct costs, with a total showing

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[50] As defined in footnote 45.

incremental costs, which excludes costs for people without ASD. Indirect costs are also shown separately, these are productivity loss costs. Also shown are UK Benefits, which are not included in the total costs as, while important, these are not devolved costs.

306. The original report was based on full employment, which was partly adjusted for by the use of average earnings and number of hours worked. To ensure that the indirect costs and benefits of productivity loss are not overestimated, the latest figures have been applied, at the time of drafting this assessment, for the proportion of people aged 16-65 who are economically active (January to March 2018).

307. Costs are estimated to be over £1.1 billion per year. 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. This does assume diagnoses have been provided and estimated current rates of provision are in place. Note, these figures have been included in the summary tables of overall costs for both option 1 and 2. Changes between years are calculated using the latest ONS population projections for years 2019 to 2024. So, costs for Year 2 are adjusted according to the change in overall population estimate from 2019 to 2020.

Table 7: National annual costs for individuals with ASD and their carers, Wales, by level of ID, disaggregated by sector (£, 2017/18)

Annual costs	People with ASD with ID					
	0-1	2-4	5-11	12-15	16-67	Total
Number of people	23	251	853	446	6,887	8,460
Direct costs						
Accommodation	-	58,985	289,167	214,972	255,590,344	256,153,468
Education	-	2,753,470	20,754,343	12,845,246	44,076,800	80,429,859
Health and Social Care	6,854	1,451,533	7,813,480	4,221,390	41,659,463	55,152,720
Total direct costs	6,854	4,263,988	28,856,990	17,281,608	341,326,607	391,736,047
Total incremental	6,854	3,807,670	24,649,141	14,792,482	331,326,683	374,582,830
Indirect costs						
Productivity loss						
- individuals	-	-	-	-	186,031,644	186,031,644
- parents	-	1,191,748	4,137,903	2,037,774	5,406,295	12,773,720
Total indirect costs	-	1,191,748	4,137,903	2,037,774	191,437,939	198,805,364
-Adjusted for 73.4% employed	-	874,743	3,037,221	1,495,726	140,515,447	145,923,137
Total costs - incremental	6,854	4,682,413	27,686,362	16,288,208	471,842,130	520,505,967

Annual costs	People with ASD with ID					
	0-1	2-4	5-11	12-15	16-67	Total
Benefits (UK not included)	-	1,123,978	4,066,251	2,126,082	45,123,624	52,439,935

Annual costs	People with ASD without ID						Combined
	0-1	2-4	5-11	12-15	16-67	Total	
Number of people	47	74	1,304	919	14,174	16,518	
Direct costs							
Accommodation	-	-	-	-	219,427,694	219,427,694	475,581,162
Education	-	822,066	15,804,480	8,956,574	37,419,360	63,002,480	143,432,339
Health and Social Care	14,006	432,678	6,999,872	2,462,001	53,875,374	63,783,931	118,936,651
Total direct costs	14,006	1,254,744	22,804,352	11,418,575	310,722,428	346,214,105	737,950,152
Total incremental	14,006	1,119,324	20,567,992	9,195,514	294,578,242	325,475,078	700,057,908
Indirect costs							
Productivity loss							
- individuals	-	-	-	-	338,418,424	338,418,424	524,450,068
- parents	-	355,718	4,987,800	4,001,326	32,047,414	41,392,258	54,165,978

Annual costs	People with ASD without ID						Combined
	0-1	2-4	5-11	12-15	16-67	Total	
Total indirect costs	-	355,718	4,987,800	4,001,326	370,465,838	379,810,682	578,616,046
-Adjusted for 73.4% employed	-	261,097	3,661,045	2,936,973	271,921,925	278,781,041	424,704,178
Total costs - incremental	14,006	1,380,421	24,229,037	12,132,487	566,500,167	604,256,119	1,124,762,086
Benefits (UK not included)	-	41,884	738,064	520,154	-	1,300,102	53,740,037

Source: Calculations based on The Microsegmentation of the Autism Spectrum 2018

308. The costs of physical and mental health conditions co-occurring with ASD have been included in the estimations above, as it is not possible for these to be disaggregated.

309. Costs have been shown under accommodation, education and health and social care, rather than attributed to local authority, NHS, voluntary sector and other. This is due to the interrelation of, in particular, health and social care services and costs, which makes splitting out NHS and other costs difficult, particularly in relation to health and social care costs.

310. While the focus of this section has highlighted economic impacts, the quality of life is also important to consider alongside these costs. Mental disorders, and more broadly the wide range of issues linked to low mood and a general sense of poor mental wellbeing, have major economic impacts. These are estimated at £70 - £100 billion per year for the UK (OECD 2014). The relationship between mental health and economic circumstances is recognised by the World Health Organisation (2001) in its definition of mental health as:

> ”a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.”

9. Option 2: Introduce a Bill

Table 8: Summary of costs of Option 2

Cost	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Welsh Government						
Developing an autism strategy	30,037	0	0	0	0	**30,037**
Developing guidance to implement the strategy	14,851	0	0	3,544	0	**18,394**
Making data publically available	265	265	265	265	265	**1,325**
Independent review of autism strategy	0	0	25,000	25,000	0	**50,000**
Training development / Awareness raising	100,000	20,000	20,000	100,000	20,000	**260,000**
Total costs to Welsh Government	**145,153**	**20,265**	**45,265**	**128,809**	**20,265**	**359,756**

Cost	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Local Health Boards						
Additional staff costs of operating databases	129,948	4,098	4,098	4,098	4,098	146,340
Delivery of 13 week waiting time target	1,454,188	1,454,188	1,454,188	0	0	4,362,563
Additional compliance / enforcement costs	0	0	0	0	0	0
Total costs to Local Health Boards	1,584,136	1,458,286	1,458,286	4,098	4,098	4,508,903
Total additional direct costs of Bill	1,729,288	1,478,550	1,503,550	132,907	24,363	4,868,658
Public sector organisations						
Indirect opportunity costs of staff undertaking training	0	2,013,763	168,315	168,315	168,315	2,518,708
Total indirect costs	0	2,013,763	168,315	168,315	168,315	2,518,708

Cost	Year 1	Year 2	Year 3	Year 4	Year 5	Total
of Bill						
Total admin costs	**1,729,288**	**3,492,313**	**1,671,865**	**301,222**	**192,678**	**7,387,366**
General costs of ASD: Public sector organisations						
Direct costs: accommodation	475,581,162	476,996,673	478,410,820	479,855,417	481,313,648	**2,392,157,720**
Direct costs: education	143,432,339	143,859,248	144,285,746	144,721,427	145,161,220	**721,459,980**
Direct costs: health and social care	118,936,651	119,290,652	119,644,312	120,005,587	120,370,271	**598,247,473**
Direct costs: Total	737,950,152	740,146,573	742,340,878	744,582,431	746,845,139	**3,711,865,173**
Direct costs: Total incremental	**700,057,908**	**702,141,547**	**704,223,179**	**706,349,633**	**708,496,156**	**3,521,268,423**
Total direct costs	**700,131,487**	**702,215,126**	**704,296,758**	**706,423,212**	**708,569,735**	**3,521,636,318**
Indirect costs individual productivity loss	524,450,068	526,011,031	527,570,491	529,163,529	530,771,602	2,637,966,721
Indirect costs	54,165,978	54,327,197	54,488,260	54,652,791	54,818,875	272,453,101

Cost	Year 1	Year 2	Year 3	Year 4	Year 5	Total
parents productivity loss						
Total indirect costs	578,616,046	580,338,228	582,058,751	583,816,320	585,590,477	2,910,419,822
Total indirect costs, adjusted for employment	424,704,178	425,968,260	427,231,124	428,521,180	429,823,411	2,136,248,153
Total Savings	Insufficient information to form robust savings estimates					

311. There are no specific provisions in the Bill which charge expenditure on the Welsh Consolidated Fund.

312. There are a range of direct and indirect costs that would result from the Bill. These are summarised below, and details of the data sources, assumptions and calculations that have been made to arrive at these costs are set out in the following sections of the RIA.

Table 9: Summary of the additional costs of the preferred option: to introduce the Autism (Wales) Bill

Cost	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Welsh Government						
Developing an autism strategy	30,037	0	0	0	0	30,037

Cost	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Developing guidance to implement the strategy	14,851	0	0	3,544	0	18,394
Making data publicly available	265	265	265	265	265	1,325
Independent review of autism strategy	0	0	25,000	25,000	0	50,000
Training development / Awareness raising	100,000	20,000	20,000	100,000	20,000	260,000
Total costs to Welsh Government	**145,153**	**20,265**	**45,265**	**128,809**	**20,265**	**359,756**
Local Health Boards						
Additional staff costs of operating databases	129,948	4,098	4,098	4,098	4,098	146,340
Delivery of 13 week waiting time target	1,454,188	1,454,188	1,454,188	0	0	4,362,563

Cost	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Additional compliance / enforcement costs	0	0	0	0	0	0
Total costs to Local Health Boards	**1,584,136**	**1,458,286**	**1,458,286**	**4,098**	**4,098**	**4,508,903**
Total additional direct costs of Bill	**1,729,288**	**1,478,550**	**1,503,550**	**132,907**	**24,363**	**4,868,658**
Public sector organisations						
Indirect opportunity costs of staff undertaking training	0	2,013,763	168,315	168,315	168,315	**2,518,708**
Total indirect costs of Bill	**0**	**2,013,763**	**168,315**	**168,315**	**168,315**	**2,518,708**
Total administrative costs	**1,729,288**	**3,492,313**	**1,671,865**	**301,222**	**192,678**	**7,387,366**

9. 1. Producing an autism strategy

313. Under the provisions of the Bill, the Welsh Government would need to publish an autism strategy and lay it before the Assembly within 6 months of the Bill coming into force.

314. The Welsh Government previously published its Autism Spectrum Disorder Strategic Action Plan[51] in March 2016. This is approximately 8,500 words, and it is envisaged that the updated strategy would be of a similar length. Updates to the strategy required by the Bill, would not necessitate the Welsh Government starting from scratch.

315. The Welsh Government will need to consult with stakeholders as part of this approach. It is envisaged that they would do this as part of the same process as consulting on the guidance they will be required to update following the Bill coming into force.

316. Salary and related costs are based on mid-point of the relevant salary range. Staff costs include Employer National Insurance contributions (at 13.8 per cent[52]) and contributions to the Principal Civil Service Pension Scheme (PCSPS); and the Cardiff and Vale of Glamorgan Pension Fund. The employer contribution rate for PCSPS member pensionable pay for salaries ranging from £22,001 and £74,500 is between 20.9 per cent and 22.1 per cent[53].

317. A single overall percentage for Employer National Insurance and pension contributions of 35 per cent has been included in calculating estimated costs for non-NHS staff.

318. This work is estimated to take one month of an Executive Band 2 member of Welsh Government staff's time, and six months of a Management Band 2 member of staff's time. This is based on the MB2 civil servant working on the strategy full time, with supervision and sign-off from the EB2 civil servant.

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[51] Welsh Government, **Autism Spectrum Disorder Strategic Action Plan**

[52] HMRC, Rates and allowances: National Insurance contributions Table 2.1. Available at: **https://www.gov.uk/government/publications/rates-and-allowances-national-insurance-contributions/rates-and-allowances-national-insurance-contributions** [accessed June 2017]

[53] Civil Service Pensions, EPN389 - Employer Contribution Rates from April 2015. Available at: **http://www.civilservicepensionscheme.org.uk/employers/employer-pension-notices/epn389/** [accessed June 2017]

319. The midpoint salary of a MB2 civil servant is £32,425, and including on-costs this is £43,774. Therefore, the costs to the Welsh Government of six months of a MB2 civil servant's time are £21,887.

320. The midpoint salary of an EB2 civil servant is £53,418, and including on-costs this is £72,114. Therefore, the costs to the Welsh Government of one month of an EB2 civil servant's time are £6,010.

321. This gives total staffing costs of £27,896 relating to updating the strategy in the first year after the Bill comes into force.

322. There will also be costs around design, typesetting, translation and proof-reading that will fall upon the Welsh Government.

323. The costs for design and typesetting are based on comparable costs to those in RIAs for the Public Health (Wales) Act[54] and the Public Health (Minimum Price for Alcohol) (Wales) Bill.[55] Based on these costings, it is estimated that this work would take two weeks of a Management Band 3 member of staff's time. The midpoint of the MB3 salary range is £25,513,[56] and including on-costs this is £34,443. Therefore, the cost to the Welsh Government will be £1,325.

324. The costs for translation and proofreading are based on those in the RIA for the Public Health (Minimum Price for Alcohol) (Wales) Bill, of £75 per 1,000 words for translation and £21 per 1,000 words for proof-reading.[57] If the strategy is around 8,500 words then this would mean that costs of £816 would be incurred (£638 for translation and £179 for proof-reading).

325. The strategy would be shared (for example with local authorities and NHS bodies) electronically, avoiding the need for printing and distribution costs.

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[54] National Assembly for Wales, **Public Health (Wales) Act 2017: Revised Explanatory Memorandum**

[55] National Assembly for Wales, **Public Health (Minimum Price for Alcohol) (Wales) Bill: Explanatory Memorandum**

[56] Welsh Government, **Welsh Government civil service pay and benefits**

[57] National Assembly for Wales, **Public Health (Minimum Price for Alcohol) (Wales) Bill: Explanatory Memorandum**, page 108

Table 10: Costs of developing the proposed autism strategy (£)

Cost	Year 1	Year 2	Year 3	Year 4	Year 5	Total
EB2 civil servant	6,010	0	0	0	0	**6,010**
MB2 civil servant	21,887	0	0	0	0	**21,887**
Total staff costs	**27,896**	**0**	**0**	**0**	**0**	**27,896**
Design and typesetting	1,325	0	0	0	0	**1,325**
Translation	638	0	0	0	0	**638**
Proof-reading	179	0	0	0	0	**179**
Total costs	**30,037**	**0**	**0**	**0**	**0**	**30,037**

9. 2. Producing updated guidance on implementation and delivery of the autism strategy

326. During the development of this Bill, the Welsh Government indicated that it intends to produce a Code of Practice on the delivery of ASD services.

327. The Autism (Wales) Bill is believed to be a more effective vehicle for delivering the intended policy objectives. For example, it will ensure that NHS bodies and local authorities understand the particular needs of children and adults with ASD and provide a holistic range of services to meet them.

328. Nevertheless, it is anticipated that there will be overlaps between the development of the Code of Practice, and many of the areas on which the Bill would require guidance to be produced.

329. As such, it is likely that the guidance published will- in practical terms- largely build on materials already prepared for this Code of Practice, rather than need to be written entirely afresh. As such, it will be able to be undertaken by one MB2 civil servant, within 3 months.

330. As stated above costs associated with consultation have been included in those for developing an autism strategy above, as it is foreseen that joined-up consultation on the strategy and guidance will take place as part of the same process.

331. Based on other Codes of Practice published by the Welsh Government, it is anticipated that the update required to produce the guidance required by this Bill will be in the region of 20,000 words.

332. The midpoint salary of a MB2 civil servant is £32,425, and including on-costs this is £43,774. Therefore the costs to the Welsh Government of three months of a MB2 civil servant's time are £10,943

333. There will also be costs around design, typesetting, translation and proof-reading that will fall upon the Welsh Government.

334. The costs for design and typesetting are based on comparable costs to those in RIAs for the Public Health (Wales) Act[58] and the Public Health (Minimum Price for Alcohol) (Wales) Bill.[59] Based on these costings, it is estimated that this work would take three weeks of a Management Band 3 member of staff's time. The midpoint of the MB3 salary range is £25,513[60], and including on-costs this is £34,443. Therefore, the cost to the Welsh Government will be £1,987.

335. The costs for translation and proofreading are based on those in the RIA for the Public Health (Minimum Price for Alcohol) (Wales) Bill, of £75 per 1,000 words for translation and £21 per 1,000 words for proofreading.[61] If the update required to produce the guidance is around 20,000 words then this would mean that costs of £1,920 would be incurred (£1,500 for translation and £420 for proof-reading).

336. This would give total costs to the Welsh Government of developing updated guidance that builds upon the existing Code of Practice of £14,851. These costs would be incurred in the first year after the Bill comes into force.

337. There would also be a periodic need to make further changes to this guidance. This would happen following the independent reviews of progress against the strategy that will be published every three years after the Bill comes into force.

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[58] National Assembly for Wales, **Public Health (Wales) Act 2017: Revised Explanatory Memorandum**

[59] National Assembly for Wales, **Public Health (Minimum Price for Alcohol) (Wales) Bill: Explanatory Memorandum**

[60] Welsh Government, **Welsh Government civil service pay and benefits**

[61] National Assembly for Wales, **Public Health (Minimum Price for Alcohol) (Wales) Bill: Explanatory Memorandum**, page 108

338. It is envisaged that these changes would be more minor than the initial changes made in the first year after the Bill comes into force. Therefore, it is estimated that this would require two weeks of a MB2 civil servant's time, at a cost of £1,684. There would also be design and translation costs of half of the original costs, at £1,860. The total cost for each review would be £3,544, every three years.

Table 11: Costs of producing and updating guidance on implementation and delivery of the autism strategy (£):

Cost	Year 1	Year 2	Year 3	Year 4	Year 5	**Total**
MB2 civil servant staff costs	10,943	0	0	1,684	0	**12,627**
Design and typesetting	1,987	0	0	900	0	**2,887**
Translation	1,500	0	0	750	0	**2,250**
Proof-reading	420	0	0	210	0	**630**
Total costs	**14,851**	**0**	**0**	**3,544**	**0**	**18,394**

9. 3. Independent review of effectiveness of the autism strategy

339. The Bill requires that the Welsh Government commission an independent review of its progress in achieving the aims of the autism strategy within three years of the publication of the strategy, and publish it. It will also be required to publish further independent reviews at intervals of no more than three years after this.

340. The Regulatory Impact Assessment for the Renting Homes (Wales) Act 2016[62] estimated that an independent review of that piece of legislation would cost £50,000. An argument could be made that these are different Bills, and that an independent review of the Welsh Government's progress in achieving the aims of the autism strategy would be more complex. However, it could also be argued that this would not be the first assessment of Welsh Government autism strategies and that the Autism (Wales) Bill's enabling of consistent collection of data sets would actually facilitate an independent evaluation. In the absence of other forecasts it has been estimated that independent reviews resulting from this Bill would cost £50, 000.

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[62] National Assembly for Wales, **Renting Homes (Wales) Act 2016: Revised Explanatory Memorandum**, paragraph 242, page 65

341. These costs would be split between years, with costs of £25,000 in year 3 and £25,000 in year 4. These costs would also be incurred at intervals of three years after this, when further independent reviews would be undertaken. These costs would fall on the Welsh Government and provide opportunity for post-legislative review.

9. 4. Designing training packages and awareness raising campaign on Autism Spectrum Disorder

342. The Welsh Government has already published a range of awareness raising materials and is running the 'Can You See Me?' campaign.[63] This includes a promotional video, posters, information packs and social media feeds. The awareness raising campaign for this Bill will build on these existing resources.

343. Previous awareness raising campaigns run by the Welsh Government as a result of the Renting Homes (Wales) Act 2016[64] have suggested that initial costs in the first year after the legislation comes in would be £100,000, with costs of £20,000 for other years. The complexity of the rental providers market, and the recent work of the Welsh Government in raising awareness and providing information and training in relation to ASD, means that awareness raising campaign for that Act is more complex and difficult to reach than for this Bill. Because of this, it is assumed that costs are around half of those estimated for the Renting Homes Act, with increased investment in year 4 following the independent review.

344. The National Autism Development team is currently designing and delivering generic and bespoke training in relation to ASD. This Bill will produce additional design and delivery costs on top of current costs. It is assumed that it will cost £10,000 to design, make available and deliver each training package. Costs of £50,000 are assumed in years 1 and 4 (to reflect potential changes following the independent report on the ongoing implementation and progress of the autism strategy) and £10,000 in other years.

345. Based on these estimates, the combined costs of awareness raising and design of training materials (in addition to those already being designed) are estimated at £100,000 in year 1 and year 4 (reflecting that the awareness raising

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[63] ASD Info Wales, **Can you see me?**

[64] National Assembly for Wales, **Renting Homes (Wales) Act 2016: Revised explanatory memorandum**, paragraph 240, page 65

campaign and training packages may need to be refreshed following independent review). For years 2, 3 and 5 costs would be £20,000.

346. A variety of methods would be used to raise awareness, with action tailored to the best means of reaching the target audiences of the public, professionals and businesses. It is anticipated that this would include online, social media and more traditional communications channels.

9. 5. Training on Autism Spectrum Disorder for professionals

347. As previously noted, there are a number of training resources available on www.ASDInfoWales.co.uk[65] for education, health and social care professionals. These include e-learning, toolkits, certification schemes, and training videos. Additionally, a number of organisations provide training on ASD to the public, private and third sectors.

348. The Bill makes provision for the identification of key professionals, and for appropriate training to enable them to support people with ASD. Attendance of such training is not a statutory requirement for individuals, but it is anticipated (and costs have been calculated on the basis) that periodic training will be undertaken by key professionals on ASD, and that much of this could be done through e-learning. It is also anticipated that individuals that require more intensive training than this will continue to undertake training courses.

349. The Welsh Government has indicated that it plans to explore professional training needs further in developing its Code of Practice. It considers that more information is required to determine key professionals who may require additional training, along with the level of additional training required.[66]

350. While the Bill does not specifically identify which occupations should be targeted for training, it is anticipated that these will include (amongst others) the education, health and social care professions. The Bill requires the autism strategy to make provision for the identification of key professionals and provision of appropriate training for them. Training would be undertaken as part of continuous professional development, but it would not be mandatory in respect of specific accreditation or professional qualifications.

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[65] www.ASDInfoWales.co.uk/Professionals

[66] Welsh Government, Autism (Wales) Bill Milestones Response

351. The Welsh Government has indicated that it is planning to include pathways relating to ASD in health and social care qualifications at levels 2, 3 and 5. In addition, a level 4 specialist practitioner qualification will be created.[67]

352. In addition, it has indicated that further work will be undertaken with professional bodies such as the Royal College of GPs to understand what training is currently available in the curriculum. This would need to include understanding how each organisation prioritises the many competing demands for specific areas to be included in training programmes.

353. To provide a basis for estimating the impact of training requirements within this Bill, we have made a number of assumptions in modelling. Numbers of people are based on 109,720 NHS staff and GPs, social care staff and teaching staff – while not all of these staff will require training, there will be other staff who do require training, so this is the best proxy figure to use. Training needs for individuals will differ, but it is estimated that an average of 1 hour of training across this group would be a fair average requirement. This estimate reflects that whilst some staff will need significantly more training, a majority of staff could undertake standardised learning packages.

354. It is assumed, in many cases, that e-learning provision could be used to deliver training. This would mean that people could undertake e-learning via the www.ASDInfoWales.co.uk website to achieve this, through completing one of the 'Autism Aware', 'Working with Autism', 'Teaching staff training', and the 'Learning support staff training' learning modules. People completing the modules are already required to register their personal details so that take up can be monitored by the National Autism Development team.

355. As an indication of potential coverage of this training, costings have been prepared to illustrate the indirect opportunity costs associated with the time commitment of this training. These costs are not monetised, and have therefore been deemed to be indirect costs.

356. Using the latest data for Wales from the Annual Survey of Hours and Earnings[68], median hourly pay for the following occupations has been used (including 25% for NHS staff on costs and 35% for other occupations):

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[67] Ibid.

[68] Office for National Statistics, **Annual Survey of Hours and Earnings 2017 Provisional Results and 2016 Revised Results – Table 15.5a**

- Doctors and medical staff: £40.48[69];
- Nurses, midwives and health visitors: £20.90[70];
- Social workers and allied health professionals: £23.38[71];
- Domiciliary care, residential care and day services staff: £12.29[72];
- Senior teaching staff: £48.02[73];
- Teachers: £30.78[74]; and
- Teaching assistants and special needs support staff: £12.26[75]

357. Under this modelling, it is assumed that staff will be undertake training in year 2 after the Bill comes into force.

358. There will also be staff turnover for these occupations. Therefore, there will also be an opportunity cost in years 3-5 as new starters undertake training. While costs have been included to cover staff turnover, it would be expected that these costs would be lower as ASD awareness training should become part of routine training for key professionals, including teachers, NHS and relevant local authority staff.

359. The percentage of existing staff who left during the year (the turnover rate) for medical and dental staff in NHS Wales was 7.28% in March 2017[76], and the turnover rate for nursing and midwifery staff was 6.91% over this period.[77] The turnover rate for GPs and dentists at March 2017 was 6.2%.[78]

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[69] Median hourly pay for medical practitioners has been used.

[70] Median hourly pay for nursing and midwifery professionals has been used.

[71] Median hourly pay for social workers has been used.

[72] Median hourly pay for caring personal services has been used.

[73] Median hourly pay for senior professionals of educational establishments has been used.

[74] Median hourly pay for teaching and educational professionals

[75] Median hourly pay for teaching assistants.

[76] Welsh Government, **Evidence to NHS Pay Review Body 2018-19**, page 9

[77] Ibid.

[78] Welsh Government, **Review Body on Doctors and Dentists Remuneration 2018-19**, page 10

360. The turnover rate for social workers was 7.9% in 2017[79], and for domiciliary care workers it was 32% in 2016[80]. In the absence of data for the residential care and day care sectors, a figure of 32% staff turnover has been assumed for these as well.

361. In 2015, the turnover rate for teachers employed in Wales was 2.8% for primary school teachers and 3.2% for secondary school teachers.[81] Therefore a turnover rate for all teachers is estimated to be 3%. In the absence of data for other school-based occupations, this figure has been used across all of these.

362. Three tables have been produced. One showing costs for all staff, one showing costs for all staff accounting for numbers taking recent National Autism Development team courses and then one taking a mid-point between these figures. The table showing the mid-point has been used in the summary table.

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[79] Social Care Wales, **Social Workers on the Register in Wales 2017**, page 22

[80] Social Care Wales, **Development of a strategic plan for care and support at home: Literature Review**, page 2

[81] NFER, **Retaining teachers in Wales – what do we know?**

Table 12: Indirect opportunity costs of undertaking training on ASD all staff

Occupation	Number of staff (headcount)	Hourly wage (£)	Staff turnover rate	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Medical staff	6,779	40.48	7.3%	0	274,380	19,975	19,975	19,975	334,305
Nurses, midwives and health visitors	34,238	20.90	6.9%	0	715,574	49,446	49,446	49,446	863,913
GPs	2,919	40.48	6.2%	0	118,147	7,325	7,325	7,325	140,122
Total NHS staff indirect costs	**43,936**			**0**	**1,108,101**	**76,746**	**76,746**	**76,746**	**1,338,339**
Social workers and allied health professional	6,461	23.38	7.9%	0	151,071	11,935	11,935	11,935	186,875
Domiciliary care workers	4,530	12.29	32.0%	0	55,651	17,808	17,808	17,808	109,076
Residential care staff	4,229	12.29	32.0%	0	51,953	16,625	16,625	16,625	101,828
Day services staff	2,855	12.29	32.0%	0	35,074	11,224	11,224	11,224	68,744
Total social care indirect costs	**18,075**			**0**	**293,749**	**57,592**	**57,592**	**57,592**	**466,524**
Senior teaching	3,641	48.02	3.0%	0	174,839	5,245	5,245	5,245	190,575

Occupation	Number of staff (headcount)	Hourly wage (£)	Staff turnover rate	Year 1	Year 2	Year 3	Year 4	Year 5	Total
staff									
Teachers	22,531	30.78	3.0%	0	693,504	20,805	20,805	20,805	755,920
Teaching Assistants	15,864	12.26	3.0%	0	194,461	5,834	5,834	5,834	211,962
Special needs support staff	5,693	12.26	3.0%	0	69,785	2,094	2,094	2,094	76,065
Total education indirect costs	**47,729**			**0**	**1,132,589**	**33,978**	**33,978**	**33,978**	**1,234,522**
Total indirect costs	**109,740**			**0**	**2,534,439**	**168,315**	**168,315**	**168,315**	**3,039,385**

Table 13: Indirect opportunity costs of undertaking training on ASD removing estimate for those who have completed National Autism Development Team training

Occupation	Number of staff (headcount)	Hourly wage (£)	Staff turnover rate	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Medical staff	4,937	40.48	7.3%	0	199,825	19,975	19,975	19,975	**259,750**
Nurses, midwives and health visitors	24,883	20.90	6.9%	0	520,055	49,446	49,446	49,446	**668,393**
GPs	2,113	40.48	6.2%	0	85,524	7,325	7,325	7,325	**107,499**

Occupation	Number of staff (headcount)	Hourly wage (£)	Staff turnover rate	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Total NHS staff indirect costs	**31,933**			**0**	**805,403**	**76,746**	**76,746**	**76,746**	**1,035,642**
Social workers and allied health professionals	3,112	23.38	7.9%	0	72,765	11,935	11,935	11,935	**108,569**
Domiciliary care workers	3,713	12.29	32.0%	0	45,614	17,808	17,808	17,808	**99,039**
Residential care staff	3,467	12.29	32.0%	0	42,592	16,625	16,625	16,625	**92,467**
Day services staff	2,341	12.29	32.0%	0	28,759	11,224	11,224	11,224	**62,430**
Total social care indirect costs	**12,633**			**0**	**189,730**	**57,592**	**57,592**	**57,592**	**362,505**
Senior teaching staff	2,584	48.02	3.0%	0	124,082	5,245	5,245	5,245	**139,818**
Teachers	8,771	30.78	3.0%	0	269,971	20,805	20,805	20,805	**332,387**
Teaching Assistants	4,434	12.26	3.0%	0	54,352	5,834	5,834	5,834	**71,853**
Special needs support staff	4,042	12.26	3.0%	0	49,547	2,094	2,094	2,094	**55,827**

Occupation	Number of staff (headcount)	Hourly wage (£)	Staff turnover rate	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Total education indirect costs	19,831			0	497,953	33,978	33,978	33,978	599,886
Total indirect costs	64,397			0	1,493,086	168,315	168,315	168,315	1,998,032

Table 14: Indirect opportunity costs of undertaking training using midpoint of two tables (these costs feed into the overall cost summary table)

Occupation	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Total NHS staff indirect costs	0	956,752	76,746	76,746	76,746	**1,186,990**
Total social care indirect costs	0	241,740	57,592	57,592	57,592	**414,514**
Total education indirect costs	0	815,271	33,978	33,978	33,978	**917,204**
Total indirect costs	0	2,013,763	168,315	168,315	168,315	**2,518,709**

9. 6. Costs of collecting and publishing data on Autism Spectrum Disorder

Data collection approach

363. Under this option, NHS bodies would be required to collect consistent data on the topics specified on the face of the Bill to assist in the planning and delivery of ASD services. Such data will also feed into the anonymised data to be provided to the Welsh Ministers to support their obligations to obtain, produce, publish and keep updated reliable data on ASD.

364. It is anticipated that NHS Bodies will be able to use existing systems to collect data for children. Data in relation to adults who receive an ASD diagnosis in childhood are also retained into adulthood.[82]

365. The Welsh Government has highlighted that the new Integrated Autism Service is accompanied by the development of a data collection approach, which will identify the individuals accessing the service and support they are receiving. This approach will be compatible with the Welsh Community Care Information System (WCCIS).[83]

366. The ONS estimate of people in Wales aged 0-1 is 33,345. Applying a prevalence rate of 1.035% to this figure gives an estimate of 343 people with ASD born each year. It is anticipated that the Welsh Government's funding and focus on reducing waiting times will have some impact by the time this Bill is enacted, therefore the number of diagnoses each year should not be significantly higher than the calculation above. As a basis for cost estimates in this impact assessment, it has been assumed that there will be approximately 400 newly diagnosed cases of ASD per year across Wales.

Staff costs associated with data collection

367. Based on the approach taken by Betsi Cadwaladr University Health Board and Bangor University to the ASD module for children, the LHB hosting the databases would require:

- 0.2 FTE of a NHS Wales Band 8D consultant;

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[82] Dr Dawn Wimpory, **Autism (Wales) Bill consultation response AWB72**

[83] Welsh Government, Autism (Wales) Bill Milestones Response

- 0.5 FTE of a NHS Wales Band 5 assistant psychologist;
- 0.4 FTE of a Grade 7 university Research Officer; and
- 0.5 FTE of a Grade 6 university Research Project Support Officer.

368. The Band 8D member of NHS Wales staff plays a strategic role in determining workload, communicates with senior management to ensure organisational provision of data and cross-organisation buy-in, and presents information about the work of the team and its findings externally.

369. The Band 5 member of NHS Wales staff liaises with clinicians to ensure that individual data records are provided, and prepares documents for sharing information on anonymised data.

370. The Band 7 research officer works on the database, has responsibility for the statistics the team produces, and undertakes analysis of anonymised data.

371. The Band 6 research project officer plays a role in administering the database, and contributes to the presentation of anonymised data.

372. In addition, for the first year after the Bill comes into force, it is estimated that the other 6 LHBs would require 0.5 FTE of a NHS Band 5 administrator, and 0.5 FTE of a university Grade 7 Research Officer. This amount of staff resource would be temporarily needed to get the database established. Including learning and training costs involved with showing others how to use the database for data input and extraction, populate children's database, record and analyse information within each health board. In subsequent years there would be a reduced staffing commitment and associated ongoing costs. There is no reason to believe the software maintenance and support costs will be higher than those either currently in place or being developed under Option 1.

Ongoing costs for the Local Health Board hosting the databases

373. The cost for the LHB hosting the databases are equivalent to the existing data collection costs outlined in Table 2: Summary of costs for Option 1. The potential cost is £73,579 annually and is based on the same elements as Option 1.

374. In 2017-18, the midpoint annual salary for a member of NHS Wales staff on pay scale Band 8D was £76,329.[84] Using the estimate of on-costs being 25% of

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[84] Welsh Government, **Pay Circular: Agenda for Change Staff 2017-18**

salary that is used by the NHS,[85] this would give an annual FTE cost of £95,411. If the staff member works on the databases for an average of 1 day per week, this would give an annual cost of £19,082.

375. In 2017-18, the midpoint annual salary for a member of NHS Wales staff on pay band 5 was £25,551.[86] Estimating that on-costs represent 25% of salary, this would give an annual FTE cost of £31,939. If the staff member works on this area for an average of 2.5 days per week, this would give an annual cost of £15,969.

376. For a grade 7 research officer at a university, the midpoint annual salary is £38,833.[87] If the staff member is a member of the Universities Superannuation Scheme, this would give an annual on-cost of £50,056.[88] If the staff member works on the databases for an average of 2 days per week, this would give an annual FTE cost of £20,022.

377. For a grade 6 research project support officer, the midpoint annual salary is £28,936.[89] If the staff member is a member of the Universities Superannuation Scheme, this would give an annual FTE on-cost of £37,012.[90] If the staff member works on this area for 2.5 days per week, this would give an annual cost of £18,506.

Transitional costs for the other Local Health Boards

378. For a grade 7 research officer at a university, the midpoint annual salary is £38,833.[91] If the staff member is a member of the Universities Superannuation Scheme, this would give an annual on-cost of £50,056.[92] If the staff member works on the databases for an average of 0.5 days per week, this would give an annual FTE cost of £5,006 per LHB. For 6 LHBs this would give an annual cost of £30,034 for the first year after the Bill comes into force.

379. In 2017-18, the midpoint annual salary for a member of NHS Wales staff on pay band 5 was £25,551.[93] Estimating that on-costs represent 25% of salary, this

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[85] NHS England, **Workforce Mix Cost Calculator**

[86] Welsh Government, **Pay Circular: Agenda for Change Staff 2017-18**

[87] Bangor University, **Scales and Rates**

[88] Ibid.

[89] Ibid.

[90] Ibid.

[91] Bangor University, **Scales and Rates**

[92] Ibid.

[93] Welsh Government, **Pay Circular: Agenda for Change Staff 2017-18**

would give an annual FTE cost of £31,939. If the staff member works on this area for 2.5 days per week, this would give an annual cost of £15,969. For 6 LHBs this would give an annual cost of £95,816.

Ongoing costs to Local Health Boards of medical staff inputting data

380. Based on the time commitment to input data at Betsi Cadwaladr University Health Board, it is estimated that inputting each new record would take 15 minutes of an NHS clinician's time. The most recent data from the Annual Survey of Hours and Earnings states that the hourly wage of an NHS practitioner in Wales is £32.38.[94] If 25% is added for on-costs this would be £40.48 per hour. As stated, it is estimated that there would be approximately 400 diagnoses per year of ASD. This would therefore require 100 hours of time commitment per year, as an ongoing cost. This would therefore mean that LHBs incur a cost of £4,048 per year, and total costs of £20,240 across the five years from 2019-20.

Table 15: Staff costs associated with data collection requirements of the Bill (£)

Staff member	Year 1	Year 2	Year 3	Year 4	Year 5	Total
LHB hosting database						
NHS Wales Band 8D consultant *0.2FTE*	19,082	19,082	19,082	19,082	19,082	95,410
NHS Wales Band 5 assistant psychologist *0.5 FTE*	15,969	15,969	15,969	15,969	15,969	79,845
University researcher Grade 7 *0.4 FTE*	20,022	20,022	20,022	20,022	20,022	100,110
University research project assistant Grade 6 *0.5 FTE*	18,506	18,506	18,506	18,506	18,506	92,530
Total costs	**73,579**	**73,579**	**73,579**	**73,579**	**73,579**	**367,895**
Other LHBs						

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[94] Office for National Statistics, **Annual Survey of Hours and Earnings 2017 Provisional and 2016 Revised Results: Table 15.5a Gross Hourly Pay**

Staff member	Year 1	Year 2	Year 3	Year 4	Year 5	Total
NHS Wales Band 5 administrator - *0.5 FTE*6*	95,816	0	0	0	0	95,816
University researcher Grade 7 - *0.1 FTE*6*	30,034	0	0	0	0	30,034
Inputting Records (NHS Clinician) - *100 hrs p.a.*	4,098	4,098	4,098	4,098	4,098	20,490
Total costs	**129,948**	**4,098**	**4,098**	**4,098**	**4,098**	**146,340**
Total costs of data collection	**203,527**	**77,677**	**77,677**	**77,677**	**77,677**	**514,235**
Existing costs for data collection	73,579	73,579	73,579	73,579	73,579	367,895
Additional costs of data collection	129,948	4,098	4,098	4,098	4,098	146,340

Publication of data

381. The Bill requires that the Welsh Government publishes and updates reliable data on ASD. The costs to relevant bodies of collecting this data are reflected in the costs outlined above. However, there would also be costs to the Welsh Government associated with publishing the data. Due to the relatively small number of cases involved per year, it could take a number of years for reliable data to become available for robust analysis at LHB level.

382. The Welsh Government is currently requiring LHBs to provide information on ASD referral to treatment times, which will be published. There would be minimal additional costs should the Welsh Government decide to publish data in its annual reports on the ASD Strategic Action Plan. It would be good practice for this information to be published on the NHS, Health in Wales or StatsWales websites, but not a prerequisite of this Bill. Therefore, requirements are not significantly different to current commitments to provide data to warrant additional cost. A generous addition of one day input of a Management Band 3 member of staff's time has been included to publish this limited data each year. Therefore, the costs to the Welsh Government will be £265 a year.

Table 16: Welsh Government costs: publishing data

Cost	Year 1	Year 2	Year 3	Year 4	Year 5	**Total**
EB 3 civil servant	265	265	265	265	265	**1,325**
Total costs	**265**	**265**	**265**	**265**	**265**	**1,325**

383. There are currently monthly meetings, where Health Boards are required to make presentations to the Welsh Government. Compliance with meeting the Bill and progress in terms of meeting waiting times targets could be included as part of such presentations with no additional cost.

384. The Bill entails no alterations or introductions of offences, sanctions or penalties. The Justice Impact Assessment accompanying this Bill sets out that the likelihood of individuals or businesses taking action against the public sector for non-compliance is very low. There is no expectation that courts or tribunals or Ministry of Justice services will be affected by this proposal, other than a minimal risk of Judicial Review in the event of the Welsh Ministers or relevant bodies not complying with the legislation. Therefore, there are no additional enforcement costs estimated for this Bill.

Waiting times

385. The Bill requires that the autism strategy provides for diagnostic assessments to be commenced as soon as reasonably practicable following a referral, and at least within any timescales set out in the relevant Quality Standard issued by NICE.

386. Currently, the Quality Standard for time from referral to first assessment is 3 months (13 weeks) for both adults and children. This differs to the current Welsh Government guidance, setting a 6 month (26 week) target.

387. The Welsh Government's 'Refreshed Autistic Spectrum Disorder strategic action plan'[95] and the associated Delivery Plan,[96] outline activity to improve the timeliness of access for children and young people through a 26 week waiting time target from referral to first assessment appointment. The Delivery Plan does not apply this target to adults.

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[95] Welsh Government, Refreshed Autistic Spectrum Disorder Strategic Action Plan

[96] Welsh Government, Refreshed Autistic Spectrum Disorder Strategic Action Plan, Delivery Plan 2016-2020

388. Identification, diagnosis and assessment are the most important routes into appropriate support and treatment for children and adults with ASD. Under-recognition of needs and missed diagnoses can lead to considerable, long-term difficulties for the individual and the family. Under-recognition and inadequate assessment will frequently lead to high and unnecessary costs for both the public purse and for families.

389. There have been relatively few studies of identification, diagnosis or assessment, especially in the UK. Some recent studies have explored ways to improve identification and diagnosis rates and processes, with some indications of success. Encouraging the use of standardised screening tools is clearly sensible – to help practice learn from and contribute to research, to support consistency in service responses and to facilitate data sharing between services and systems.

390. A US study of organisational changes in a private primary care practice calculated that the cost of screening was offset by revenue generated by identified cases.[97] Although not a comprehensive economic evaluation, the study at least suggested a financial incentive for private practitioners to be more alert to ASD.

391. The only other economic evidence available was simulation modelling carried out by the National Audit Office (NAO)[98], looking at the consequences of introducing specialist multidisciplinary teams to help identify and assess adults with high-functioning ASD, and then provide support in the areas of health and social care, housing and employment. Drawing on data from the best local models found by NAO, their analyses suggested that substantial savings to the public purse could be achieved even with modest increases in identification rates. More generally, the NAO argued that specialist multidisciplinary support and joint working across all areas – clinical, social and employment – could improve transition from childhood to adult services, and support high-functioning adults to achieve better quality of life in a way that offered value for money.

392. The Welsh Government has provided funding to build capacity for multi-disciplinary teams to meet this 26 week deadline. Therefore, we have estimated the impact of the Bill will be around reducing those waiting between 13 and under 26 weeks, providing funding to remove this element of the waiting list would free existing resource to move towards the Bill's 13 week target over time.

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[97] Gura, G. F., Champagne, M. T., & Blood-Siegfried, J. E. (2011). Autism spectrum disorder screening in primary care. Journal of Developmental & Behavioral Pediatrics, 32, 48-51.

[98] National Audit Office, Supporting people with autism through adulthood

Although data is not available in the public domain, responses to direct requests for information suggest that around 1,903 people are waiting between 13 and under 26 weeks (including an estimated 598 adults waiting over 13 weeks).

393. To obtain a simplistic and generous estimate of the costs to deliver the Bill's 13 week target, we have applied a typical cost of up to £2,500 for a **private diagnosis**[99] for children and £1,500 for adults to this number of people. In this simplistic modelling, it has been assumed that all costs will be met by local health boards. This forms an estimate of £3,148,500 when considering a scenario that includes children waiting 13-26 weeks, £5,576,625 when considering a scenario where all children waiting over 13 weeks are accounted for, and gives a mid-point between those two scenarios of £4,362,563. The mid-point has been taken as, by the time the Bill enacted, it would be expected that current additional investment provided by the Welsh Government in multi-disciplinary teams to reduce waiting times has significantly reduced the number of people on waiting lists.

394. These transitional costs have been spread over 3 years. This overestimate will be balanced against the need for services currently funded to provide first assessment meeting within 26 weeks to move towards 13 weeks. Following this transition period, it is assumed that Welsh Government investment in multi-disciplinary teams would maintain waiting list performance, with the Welsh Government maintaining necessary funding once this backlog has been addressed. It could be argued that as these assessments would take place under the existing system, they do not necessarily need to be estimated as part of this Impact Assessment. However, without the Bill this increase in performance is unlikely to take place, and this quantity of people would still be on the waiting list at the end of the RIA review period. As such, these costs have been included, to reflect that under the Bill these costs will fall approximately 3 months earlier.

395. An estimate of the number of children waiting for a first assessment appointment has been made using information obtained from local health boards. Where possible, information on waiting times for autism referrals has been obtained directly from local health boards, however, not all local health boards have been able to provide waiting time information. Where a local health board has not provided waiting time information an average has been calculated across Wales, based on the relevant age population (under 18 for Children, 18 and over for

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[99] Figure obtained from http://www.thefamilypsychologist.co.uk/content/frequently-asked-questions

adults[100]), which has then been used to estimate the number of children and adults on the waiting list.

396. Information obtained from local health boards has been provided as either those waiting at the end of March 2018 or on the basis of those waiting throughout 2017-18. This will provide a generous overestimate of those individuals waiting. Some local health boards have included information for children up to the age under 18 (e.g. 17 or 17.5 years), rather than 18. As it is not possible to break down mid-year population estimates by half year, and it is unknown how many individuals fall in each age group, calculations consider children as aged up to 18. As the cost per diagnoses of child is higher than an adult, this will provide an overestimate.

397. Of those local health boards that have provided data, the majority have provided referral and waiting times information based on neurodevelopmental services. This data therefore includes patients waiting for conditions other than ASD (such as ADHD), an assumption has been made that 75% of those children on the waiting list have a referral based on ASD. No similar assumption has been made for adults as there is limited information available in this area.

398. The following paragraphs include information on the estimated costs of waiting times, including a low point that is calculated based on those waiting 13-25 weeks and a high point that is calculated based on all those waiting over 13 weeks. A mid-point is then taken between those two options as the best estimate. Scenarios do not adjust for the number of adults waiting over 26 weeks as the Welsh Government's target currently applies to children only, therefore in each scenario all adults waiting 13+ weeks are included.

399. Abertawe Bro Morgannwg University Health Board Adult service is managed by Cwm Taf University Health Board. Therefore no information or calculation is included.

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[100] Mid-year population estimates (2017), by local health board and age: https://statswales.gov.wales/Catalogue/Population-and-Migration/Population/Estimates/Local-Health-Boards/populationestimates-by-lhb-age

400. Information on the reduction of waiting times is broken down by LHB and includes the estimated number of children and adults. Table 17 contains information on the cost to reduce waiting times shows that for years one to three, based on those waiting 13-25 weeks. The total number waiting in this scenario is 1,417 (including 598 adults). The overall cost of this scenario is £3,148,500, this comprises an annual cost over the first three years of £1,049,500.

Table 17: Cost of reducing waiting times (13-25 weeks)

	Estimated children on waiting list and waiting 13-25 weeks	Estimated adults on waiting list and waiting 13+ weeks	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Betsi Cadwaladr University Health Board	137	164	£196,375	£196,375	£196,375	£0	£0	**£589,125**
Powys Teaching Health Board	10	62	£39,125	£39,125	£39,125	£0	£0	**£117,375**
Hywel Dda University Health Board	42	179	£124,500	£124,500	£124,500	£0	£0	**£373,500**
Abertawe Bro Morgannwg University Health Board	68	*	£56,250	£56,250	£56,250	£0	£0	**£168,750**

	Estimated children on waiting list and waiting 13-25 weeks	Estimated adults on waiting list and waiting 13+ weeks	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Cwm Taf University Health Board	270	77	£263,500	£263,500	£263,500	£0	£0	**£790,500**
Aneurin Bevan University Health Board	161	137	£202,250	£202,250	£202,250	£0	£0	**£606,750**
Cardiff and Vale University Health Board	132	115	£167,500	£167,500	£167,500	£0	£0	**£502,500**
Total	**819**	**598**	**£1,049,500**	**£1,049,500**	**£1,049,500**	**£0**	**£0**	**£3,148,500**

401. If all children on the waiting list with an ASD referral and waiting over 13 weeks are included in the figures, the total number waiting is 2,388 (including 598 adults). The overall cost to meet the waiting time target in this scenario is £5,576,625 or £1,858,875 per year for the first three years.

Table 18: Cost of reducing waiting times (over 13 weeks)

	Estimated children on waiting list and waiting 13+ weeks	Estimated adults on waiting list and waiting 13+ weeks	Year 1	Year 2	Year 3	Year 4	Year 5	**Total**
Betsi Cadwaladr University Health Board	626	164	£603,875	£603,875	£603,875	£0	£0	**£1,811,625**
Powys Teaching Health Board	39	62	£63,500	£63,500	£63,500	£0	£0	**£190,500**
Hywel Dda University Health Board	114	179	£184,500	£184,500	£184,500	£0	£0	**£553,500**
Abertawe Bro Morgannwg University Health Board	72	*	£60,000	£60,000	£60,000	£0	£0	**£180,000**
Cwm Taf University Health Board	299	77	£287,875	£287,875	£287,875	£0	£0	**£863,625**

	Estimated children on waiting list and waiting 13+ weeks	Estimated adults on waiting list and waiting 13+ weeks	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Aneurin Bevan University Health Board	351	137	£361,000	£361,000	£361,000	£0	£0	**£1,083,000**
Cardiff and Vale University Health Board	289	115	£298,125	£298,125	£298,125	£0	£0	**£894,375**
Total	**1790**	**598**	**£1,858,875**	**£1,858,875**	**£1,858,875**	**£0**	**£0**	**£5,576,625**

402. In order to obtain a best estimate of the cost of reducing waiting times, a mid-point has been taken between the two scenarios. This provides a reasonable estimate of the likely number of people waiting assessments at the time this Bill would be implemented, following the impact of the Welsh Government's policy to reduce the number of children waiting over 26 weeks for a first assessment. The mid-point value is £4,362,563, or £1,454,188 for the first three years, this accounts for 1,903 individuals (including 598 adults waiting over 13 weeks).

Table 19: Cost of reducing waiting times (mid-point)

	Estimated children on waiting list mid-point	Estimated adults on waiting list and waiting 13+ weeks	Year 1	Year 2	Year 3	Year 4	Year 5	**Total**
Betsi Cadwaladr University Health Board	382	164	£400,125	£400,125	£400,125	£0	£0	**£1,200,375**
Powys Teaching Health Board	24	62	£51,313	£51,313	£51,313	£0	£0	**£153,938**
Hywel Dda University Health Board	78	179	£154,500	£154,500	£154,500	£0	£0	**£463,500**
Abertawe Bro Morgannwg University Health Board	70	*	£58,125	£58,125	£58,125	£0	£0	**£174,375**
Cwm Taf University Health Board	285	77	£275,688	£275,688	£275,688	£0	£0	**£827,063**

	Estimated children on waiting list mid-point	Estimated adults on waiting list and waiting 13+ weeks	Year 1	Year 2	Year 3	Year 4	Year 5	**Total**
Aneurin Bevan University Health Board	256	137	£281,625	£281,625	£281,625	£0	£0	**£844,875**
Cardiff and Vale University Health Board	210	115	£232,813	£232,813	£232,813	£0	£0	**£698,438**
Total	**1305**	**598**	**£1,454,188**	**£1,454,188**	**£1,454,188**	**£0**	**£0**	**£4,362,563**

Increase in service demand

403. Information on the cost of services provided to people with ASD that do not yet have a diagnosis is lacking. While the diagnosis will enable easier access to more appropriate services (which have a cost), the person in question- and their families and carers- may already be incurring considerable direct, indirect and well-being costs.

404. Implementing the guidance as part of this Bill is intended to improve the quality of diagnoses and reduce variability across Wales.

405. As previously noted, across Wales there are differences in the availability of services which are not necessarily based on an assessment of need. This Bill is seeking to provide information and an environment where gaps in existing services for people with ASD can be identified and addressed. While this will necessarily result in increased unavoidable costs in providing these services, it will also enable other costs and economic impacts to be avoided.

406. The high and wide-ranging costs of ASD represent a mix of what could be called “good” and ”bad” costs. ‘’Good’ costs are include the appropriate ways that health, education and other systems identify, assess and respond to the needs of individuals with ASD, and their carers and families.

407. ’Bad’ costs result from avoidable crises, or from interventions being delivered which are inappropriate to the needs of a person with ASD. Reducing the ‘bad costs’ whilst increasing ‘good costs’ represents a better and more equitable way to use society’s scarce human, capital and other resources. Bringing down the overall costs in the long run - by preventing unnecessary needs from emerging, or tackling those that do emerge early enough to avoid distressing difficulties later on - would obviously be more efficient in the grander scheme of things..

408. Interventions that are funded from public resources must be effective in the sense that they meet needs, improve health, personal functioning or quality of life. For interventions also to make economic sense, they need to be feasible in that they only employ resources that are available. They also need to be affordable within current budget constraints. They need to be cost-effective, which means that their outcomes are sufficient to justify the resources that must be spent to generate them. This does not mean that an intervention needs to be cost saving, but rather that if the intervention costs more than its best alternative (or more than what is currently provided), then the higher costs are considered by decision makers to be “worth” incurring because of the scale and nature of the gains.

409. Consequently this Bill aims to focus resources towards earlier identification and diagnosis to enable more investment to be preventative, rather than reactive.

410. What the latest studies suggest is that available public and private resources could be better used than they are currently, if more funds were directed towards interventions that have been shown to be effective and cost-effective. The National Autism Project study- *the Autism Dividend, 2017*- explored the business case for interventions for people with autism in more detail.

411. *Factors Affecting Age at ASD Diagnosis in UK: No Evidence that Diagnosis Age has Decreased Between 2004 and 2014*[101], concludes that there is a growing body of evidence to suggest that early intervention programmes can improve overall functioning, social communication, language, cognition and adaptive behaviour in children with ASD. As children get older, treatments may be less effective (Harris and Handleman 2000), highlighting the importance of early ASD diagnosis leading to timely intervention. Whilst ASD can reliably be diagnosed as early as 24 months (Steiner et al. 2012; Johnson et al. 2007), population based studies have found that the median age of diagnosis tends to be at around school entry age (Shattuck et al. 2009). This further suggests that the earlier diagnoses following implementation of this Bill will lead to earlier and potentially more effective provision.

412. The impact in terms of demand for services is very complex and difficult to estimate with the lack of information on numbers of adults and children with ASD diagnosis or information on services they, or people with undiagnosed ASD, receive. In this regard, this Bill will not result in new costs per se, but the identification of people with needs to be serviced by the Social Services and Well-being (Wales) Act 2014 and Additional Learning Needs and Education Tribunal (Wales) Act 2018 may increase, or be identified earlier. The costs in terms of funding these services for local government, health and other sectors need to be sufficiently funded.

413. 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

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[101] *Factors Affecting Age at ASD Diagnosis in UK: No Evidence that Diagnosis Age has Decreased Between 2004 and 2014*, (2016), Denise Brett, Frances Warnell, Helen McConachie, Jeremy R. Parr.

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. Note, it has been assumed that prevalence rates of ID are as national averages for children, but 5% ID for adults, as it has been assumed that these people are less likely to be identified at such a late stage. In the absence of a diagnosis many costs may already be being incurred as children (with or without ID) may be in receipt of levels of additional support (even if this is not appropriate to their needs). Likewise, carers will already be incurring similar levels of productivity loss (potentially even higher, in the absence of support that takes account of a diagnosis). Without an accurate diagnosis services are less likely to be as well tailored and effective as they could be and many reactive (or “bad”) costs will be incurred. These costs are already estimated as part of the status quo position, in the section detailing general costs in relation autism, as a calculation has been made of the number of people with ASD in Wales and the cost of average level of service provision.

Table 20: Annual costs of people with ASD, with and without ID, identified earlier due to this Bill

Annual costs	People with ASD with ID					
	0-1	2-4	5-11	12-15	16-67	Total
Number of people	*8*	*84*	*284*	*149*	*30*	*555*
Direct costs						
Accommodation	-	4,935	24,069	17,955	278,340	325,299
Education	-	230,370	1,727,501	1,072,837	48,000	3,078,708
Health and Social Care	596	121,443	650,360	352,571	45,368	1,170,338
Total direct costs	596	356,748	2,401,930	1,443,363	371,708	4,574,345
Total incremental	**596**	**318,570**	**2,051,687**	**1,235,471**	**360,818**	**3,967,142**
Indirect costs						
Productivity loss						
- individuals	-	-	-	-	202,590	202,590
- parents	-	99,708	344,421	170,195	5,888	620,212
Total indirect costs	-	99,708	344,421	170,195	208,478	822,802
-Adjusted for 73.4% employed	**-**	**73,186**	**252,805**	**124,923**	**153,023**	**603,937**

Annual costs	People with ASD with ID					
	0-1	2-4	5-11	12-15	16-67	Total
Total costs - incremental	**596**	**391,756**	**2,304,492**	**1,360,394**	**513,841**	**4,571,079**
Benefits (UK not included)	-	**94,038**	**338,457**	**177,571**	**49,140**	**659,206**

Annual costs	People with ASD without ID						Combined
	0-1	2-4	5-11	12-15	16-67	Total	
Number of people	*16*	*25*	*434*	*305*	*568*	*1,348*	1,903
Direct costs							
Accommodation	-	-	-	-	2,198,302	2,198,302	2,523,601
Education	-	69,431	1,315,020	741,914	374,880	2,501,245	5,579,953
Health and Social Care	1,192	36,544	582,428	203,939	539,742	1,363,845	2,534,183
Total direct costs	1,192	105,975	1,897,448	945,853	3,112,924	6,063,392	10,637,737
Total incremental	**1,192**	**94,538**	**1,711,371**	**761,707**	**2,951,186**	**5,519,994**	**9,487,136**

Annual costs	People with ASD without ID						Combined
	0-1	2-4	5-11	12-15	16-67	Total	
Indirect costs							
Productivity loss							
- individuals	-	-	-	-	3,390,392	3,390,392	3,592,982
- parents	-	30,044	415,013	331,448	321,062	1,097,567	1,717,779
Total indirect costs	-	30,044	415,013	331,448	3,711,454	4,487,959	5,310,761
-Adjusted for 73.4% employed	**-**	**22,052**	**304,620**	**243,283**	**2,724,207**	**3,294,162**	**3,898,099**
Total costs - incremental	**1,192**	**116,590**	**2,015,991**	**1,004,990**	**5,675,393**	**8,814,156**	**13,385,235**
Benefits (UK not included)	-	3,538	61,411	43,087	-	108,036	767,242

414. An earlier diagnosis should lead to a better balance of “good” rather than “bad” costs as services can be more targeted and emergency action less likely.

9. 7. Benefits

415. The direct benefits of this Bill will be through improving diagnoses of ASD and also information to plan and deliver services. There will be clear benefits in terms of receiving more accurate and timely diagnoses, for the individual, carers and those delivering services. These will mainly be due to improving the focus of services and the additional benefit of receiving more targeted services earlier.

416. This impact assessment considers both the "good and bad costs of ASD". Costs that may be viewed as 'good' relate to matters which are of a fixed or static nature that cannot be modified by any intervention framework currently available. For example, prevalence, occurrence of an intellectual disability and co-occurring conditions can be viewed as "fixed factors" in terms of budgetary and service planning. However, some costs can be viewed as "bad" costs are those for which evidence based interventions can reduce such costs.

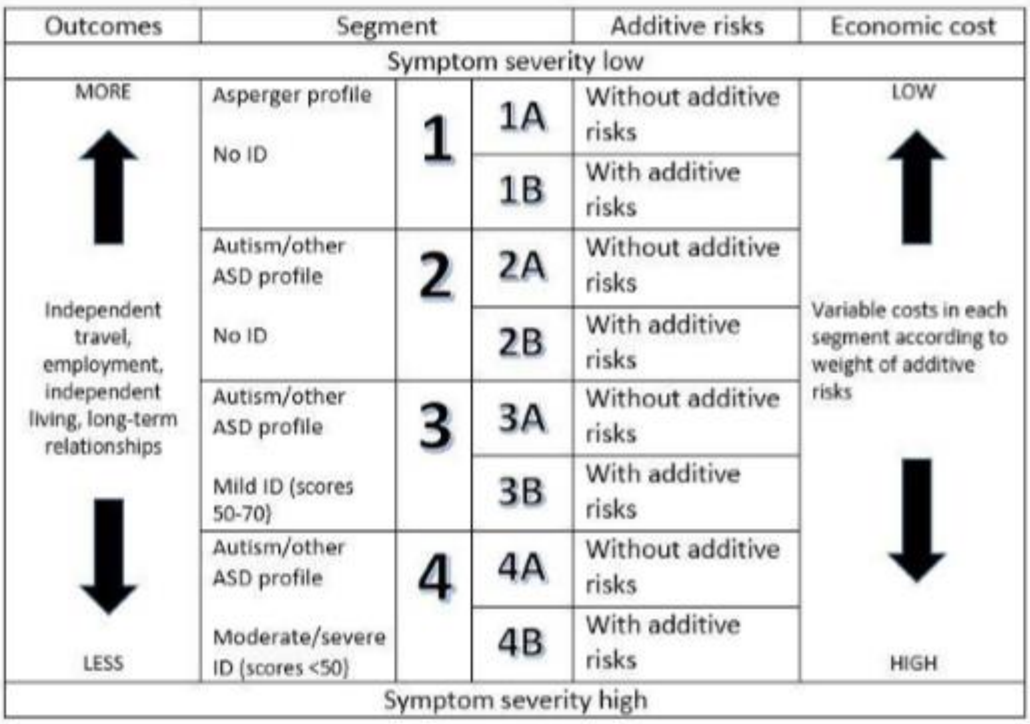
417. As such, any expenditure to support and address the need of people with ASD under this Bill can be viewed as preventative investment. Looking at the estimated annual current costs of ASD in **Table 7 every reduction of 1% in the current annual direct and indirect costs of ASD, would represent a saving of approximately £1 million**.

418. The costs of physical and mental health conditions comorbid to ASD have been included in the estimations above, as it is not possible for these to be disaggregated.

419. The Scotland based Microsegmentation report acknowledged the spectrum of ASD but also sought to group the ASD population in different segments to help plan research, services or interventions. This allowed the construction of a microsegmentation matrix, containing four segments which reflect the gradation from higher intellectual ability and lower symptom severity, commonly represented currently in the Asperger/Higher Functioning Autism profile, through to those, currently with a diagnosis of autism or other ASD, with moderate or severe intellectual disability and higher symptom severity. These four segments reflect the stable moderators of intellectual status and symptom severity, and each is then subdivided to reflect the variable additive risk factors associated with co-occurring conditions. Thus, the matrix comprises eight segments.

420. Figure 1.1 shows the microsegmentation matrix in terms of these eight segments, together with indications of the gradation of outcomes from more to less independent travel, employment, independent living and long-term relationships, and economic costs ranging from low to high. As noted in the matrix, there are variable costs within each segment according to the impact of additive risks. So, an individual in segment 1, where outcomes would generally be more favourable and economic costs lower, may in fact prove to have a disproportionately high level of need and cost depending on the extent of impact of additive risk factors.

Figure 1.1 The autism spectrum: microsegmentation matrix



Outcomes	Segment			Additive risks	Economic cost
Symptom severity low					
MORE ↑	Asperger profile No ID	1	1A	Without additive risks	LOW ↑
			1B	With additive risks	
	Autism/other ASD profile No ID	2	2A	Without additive risks	
Independent travel, employment, independent living, long-term relationships			2B	With additive risks	Variable costs in each segment according to weight of additive risks
	Autism/other ASD profile Mild ID (scores 50-70)	3	3A	Without additive risks	
			3B	With additive risks	
↓	Autism/other ASD profile Moderate/severe ID (scores <50)	4	4A	Without additive risks	↓
LESS			4B	With additive risks	HIGH
Symptom severity high					

421. As previously noted, the National Audit Office in England (2009) carried out simulation modelling to explore the potential economic benefits of multi-disciplinary teams identifying and assessing adults with ASD. It concluded that substantial economic gains might be achievable even with modest increases in identification rate (National Audit Office, 2009).

422. Some examples of the benefits of timely diagnostic assessment of children and adults are as follows:

- Supported employment schemes can provide individualised training and workplace support through job coaches, and often involve a range of stakeholders whilst aiming to take account of the individual strengths and preferences. UK research shows that supported employment can be both effective and (strongly) cost-effective from a societal perspective, and has important economic benefits for people with ASD.
- Early intervention – there are many approaches to early intervention, however few have been evaluated from an economic point of view. Early

interventions are a great example of preventative investment and could benefit children with ASD, both with and without ID.

- Cognitive behavioural therapy (CBT) to treat anxiety problems experienced by adults with ASD has been found to be effective, and – when delivered on a group basis – also cost-effective. NICE calculated group-based CBT for ASD children without ID to be cost-effective from a health and social care perspective and also from a societal perspective. Parent training and support programmes: evidence suggest that inexpensive group interventions for parents of children with ASD (such as Cygnet, ASCEND and Riding the Rapids) can be effective, at least for the short time periods over which they were evaluated, and probably cost effective.

423. In summary, there is evidence that the Bill will result in considerable benefits, both direct and indirect, but these are not possible to quantify and hence unknown. As stated earlier, **every reduction of 1% in the current annual direct and indirect costs of ASD, would represent a saving of approximately £1 million**.

9. 8. Unintended consequences

424. The consultations undertaken as part of developing this Draft Bill highlighted diverse views around potential unintended consequences. Where risks and potential consequences were raised, the perceived impact was not quantified or monetised. Consequently the likelihood or combined costs (or benefits) of these potential consequences are unknown.

425. A minority of respondents (primarily statutory and professional bodies) were opposed to the introduction of legislation and to the principle of focusing on one condition (which they believed could be to the detriment of people with other conditions).

426. Issues which were believed could arise include:

- generating additional demand for a diagnosis of ASD as a gateway to services, even where it is not appropriate;
- the resource implications of the above, including diverting resources into diagnosis and away from service provision;
- an increase in appeals from people who do not receive a diagnosis;
- creating a culture of ‘entitlement’ with legal challenges;

- undermining the needs, rather than diagnosis, based approach to care and support promoted in other recent legislation (e.g. the Additional Learning Needs (Wales) Act and the Social Services and Well-being (Wales) Act);
- the risk of creating inequality and resentment from other groups and a push for further impairment-specific legislation;
- the focus of duties on statutory services which may inhibit innovation and marginalise third sector services;
- an increase in costs, both in terms of implementation and for additional services which will be required.

427. Some respondents believed the Bill risks disadvantaging people whose condition does not fall within its scope, and some commented on the absence of references in the Bill to people from black and minority ethnic communities, and to languages other than English and Welsh.

428. Conversely, others commented that the Bill would have a positive impact in terms of fairness and that it would help to raise awareness of, and help to change attitudes towards, ASD.

429. The final Bill has been drafted with the intention of mitigating these concerns, as far as it is possible. For example, it requires the autism strategy to place an emphasis on achieving innovation and improvement in the commissioning and delivery of autism spectrum disorder services. Likewise, it includes a safeguard against inadvertently diminishing relevant bodies' focus on addressing the needs of people with other neurodevelopment disorders. It includes that the definition of 'Autism Spectrum Disorder' may include any other neurodevelopmental disorder prescribed by regulations by Welsh Ministers. This means that if future Welsh Ministers believe the provisions of this Bill should be applied to people with other neurodevelopmental disorders, they would have the power to do so (subject to a future Assembly passing such regulations). It would be for Welsh Ministers to justify, in bringing forward such regulations, whether the provisions of the Bill would be appropriate in relation to the needs of people with other neurodevelopmental disorders.

A

10. Equality Impact Assessment

10. 1. Introduction

Name of Legislation

430. The Autism (Wales) Bill

Date of Impact Assessment

431. Initiated January 2018 and maintained on an ongoing basis until introduction of Bill in July 2018.

Purpose of the Legislation

432. To make provision for meeting the needs of children and adults with ASD in Wales.

Who has been involved/or consulted with as part of developing this impact assessment?

433. External consultation responses received from a range of stakeholders in two consultations (on the concept of a Bill, and on the text of a draft Bill) are accessible via **http://www.assembly.wales/en/bus-home/bus-legislation/proposed_members_bills/Pages/paul-davies.aspx**

10. 2. Equality and human rights impacts

434. As an overarching comment, the Bill seeks to fully reflect appropriate equality and humans rights obligations. A variety of informed responses to the consultations[102] requested specific reference to the key United Nations Conventions and Principles on the face of the Bill, and those relating to children, older persons, and disability have been so included in section 8. The Bill requires that the autism strategy places an emphasis on innovation and improvement in the commissioning and delivery of ASD services, and to make provision for the commissioning of research into ASD. It is anticipated that services will therefore respond to improved knowledge and innovative practice, in terms of delivering services in relation to protected characteristics.

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[102] See the responses from: the Children's Commissioner in consultation 1 (57); Barnardo's 2 (29), and the Equality and Human Rights Commission 2 (47)

Age

435. The Bill is intended to positively address the needs of both children and adults with ASD in Wales.

436. In relation to children and young people, the Bill includes a provision at section 8(4) and 8(5) that:

> (4) Any relevant body exercising functions under this Act in relation to a child must have due regard to Part 1 of the United Nations Convention on the Rights of the Child adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989 ("the Convention").
>
> (5) For the purposes of subsection (4), Part 1 of the Convention is to be treated as having effect—
>
> - (a) as set out for the time being in Part 1 of the Schedule to the Rights of Children and Young Persons (Wales) Measure 2011, but
> - (b) subject to any declaration or reservation as set out for the time being in Part 3 of that Schedule.

437. In relation to older people, the Bill includes a provision at section 8(1) that:

> "The Welsh Ministers and any relevant body exercising functions under this Act in relation to an adult must have due regard to the United Nations Principles for Older Persons adopted by the General Assembly resolution 46/91 on 16 December 1991 ("the Principles")."

438. The Bill also requires (at section 2(1)(j)) that an Autism Strategy makes provision to address the needs of persons with ASD when transitioning from childhood to adulthood, and make provision for the continuity of services to support such transition.

439. As such, the Bill is not considered to have an age-related differential impact, but instead will improve the provision of autism services to all age groups.

Disability

440. The Bill is intended to positively address the needs of people with ASD in Wales, thereby making a significantly positive contribution in relation to people with a disability.

441. Consultations on the development of this Bill highlighted that many people with ASD- and their families and carers- still do not receive the services and support they need to fulfil their potential. During the Bill's development, consultees repeatedly described the difficulties they had experienced in getting a diagnosis.

442. The Bill addresses this issue by requiring that the autism strategy must in future define a best practice model or models for the identification and diagnostic assessment of ASD; assessment of the care and support needs of persons with ASD; and planning for and meeting the care and support needs of persons with ASD.

443. The Bill also includes a provision at section 8(2) that:

> "The Welsh Ministers and any relevant body exercising functions under this Act in relation to a disabled child or adult must have due regard to the United Nations Convention on the Rights of Persons with Disabilities."[103]

444. During the Bill's development, concerns were expressed that while good practice and responsive services are evident in some areas, the local focus of the Welsh Government's Strategic Action Plan has meant that provision has remained inconsistent across Wales. To address this issue, the Bill requires that the austism strategy makes provision:

- so that an appropriate range of services to deliver the autism strategy are available consistently across Wales; and
- to establish the necessary infrastructure and leadership to monitor and promote the implementation of the autism strategy.

445. There appears widespread recognition that the Welsh Government's Strategic Action Plan has made, and continues to make, welcome improvements to autism services in Wales. Nevertheless, ongoing improvement is needed, and beyond the period of the revised Autism Strategic Action Plan (2016-20) there is an increased risk to the continued prioritisation of autism. The Bill addresses this by:

- requiring the Welsh Ministers to prepare and publish an autism strategy;

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[103] Autism (Wales) Bill, Section 8(2).

- requiring the Welsh Ministers to keep such a strategy under review; and
- enabling the Welsh Ministers to revise the strategy.

446. Concerns arose during the development of the Bill that in addressing the needs of people with ASD, an unintended consequence could be to diminish relevant bodies' focus on addressing the needs of people with other neurodevelopment disorders. For example, one consultee expressed concerns that:

> "By giving a particular condition special legal status there is a risk that other conditions are somehow demeaned. This could create inequality, imbalance in provision and clamour for specialist services over inclusion."[104]

447. In considering this possibility, it was noted that the Welsh Government had previously published an Autism Strategic Action Plan, and that no substantive evidence was raised that this had diminished focus on addressing the needs of people with other neurodevelopment disorders.

448. It was also noted that the UK Parliament had previously passed the **Autism Act 2009** (though this applies only to England), and that the Northern Ireland Assembly had previously passed the Autism Act (Northern Ireland) 2011. Similarly, no substantive evidence was raised that such legislation has had a detrimental effect on provision for people with other neurodevelopment disorders.

449. It was also noted that a range of equality legislation has historically been passed in the UK that individually addressed the rights of different groups.

450. Moreover, the Bill includes a safeguard against inadvertently diminishing relevant bodies' focus on addressing the needs of people with other neurodevelopment disorders. It includes that the definition of 'Autism Spectrum Disorder' may include any other neurodevelopmental disorder prescribed by regulations by the Welsh Ministers. This means that if in the future the Welsh Ministers believe the provisions of this Bill should be applied to people with other neurodevelopmental disorders, they would have the power to do so (subject to a future Assembly passing such regulations). It would be for Welsh Ministers to justify, in bringing forward such regulations, whether the provisions of the Bill

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[104] Consultation on the Proposed Autism (Wales) Bill: Response of the Torfaen Autism Spectrum Disorder Stakeholder Group

would be appropriate in relation to the needs of people with other neurodevelopmental disorders.

451. As such, the Bill is not considered to have an adverse impact in relation to disability, but instead will improve the provision of autism services.

Gender Reassignment / Gender identity

452. There is limited research available on the prevalence of ASD in relation to gender variance, and indeed whether gender identity develops differently in people with ASD. An article in 2016 on Spectrum, a website dedicated to ASD research, notes that:

> "A handful of studies over the past five years – and a series of case reports going back to 1996 – show a linkage between autism and gender variance." [105]

453. In one of these studies, researchers examined 231 children and adolescents who identified as gender-dysphoric and found a 7.8 percent prevalence of ASD.[106]

454. The provisions of the Bill include a requirement on the Welsh Ministers to obtain, produce, publish and keep updated reliable data in order to carry out their functions under this Act. Analysis of such data may enable future studies to more conclusively determine prevalence of ASD amongst people who are transgender, and ensure that services take appropriate account of such persons' needs.

455. As such, in the short-term, the provisions of the Bill are not considered to have a differential impact on those who are transgender. In the long-term, the Bill may ultimately have a beneficial impact in enabling further research and understanding.

Marriage and civil partnership

456. Following the two consultation exercises and research, the provisions of the Bill are not considered to have a differential impact in relation to marriage or civil partnership.

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[105] Living between Genders, Deborah Rudacille, 13 April 2016, Spectrum.

[106] Autism spectrum disorders in gender dysphoric children and adolescents, de Vries AL, Noens IL, Cohen-Kettenis PT, van Berckelaer-Onnes IA, Doreleijers TA, August 2010.

Pregnancy, Maternity and Parental Leave.

457. Following the two consultation exercises and research, the provisions of the Bill are not considered to have a differential impact on those who are pregnant or on periods of maternity or parental leave.

Race

458. A number of studies have examined racial and ethnic disparities in the prevalence of ASD.

459. For example, in November 2017, a study into *ASD Among US Children (2002-2010): Socioeconomic, Racial, and Ethnic Disparities*, found that between 2002 and 2010, prevalence rose:

- from 6.7 per 1,000 children to 13.2 among white children;
- from 5.9 to 11.1 among black children; and
- from 3.9 to 8 among Hispanic children.[107]

460. Prevalence studies into ASD in different parts of the world have also found different rates. A study in Brazil found 27.2 cases of autism per 10,000 people,[108] whereas a study in Japan calculated prevalence at 181 cases per 10,000 people.[109]

461. It is generally believed that methodological and cultural factors explain the majority of differences in ASD prevalence around the world. However, the possibility of genetic differences amongst populations also having influence has not been comprehensively ruled out.

462. In developing the Bill, an assumption has not been made as to the underlying cause of racial and ethnic disparities in the prevalence of ASD. However, in the event that such disparities are due to under-diagnosis of ASD amongst particular racial, ethnic and cultural groups, it is anticipated that

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[107] Autism Spectrum Disorder Among US Children (2002-2010): Socioeconomic, Racial, and Ethnic Disparities, November 2017, Durkin MS, Maenner MJ, Baio J, Christensen D, Daniels J, Fitzgerald R, Imm P, Lee LC, Schieve LA, Van Naarden Braun K, Wingate MS, Yeargin-Allsopp M.

[108] Brief report: prevalence of pervasive developmental disorder in Brazil: a pilot study, December 2011, Paula CS, Ribeiro SH, Fombonne E, Mercadante MT.

[109] Kamamura Y, Takahashi O, Ishii T, Re-evaluating the incidence of developmental disorders: impact of elevated rates of detection through implementation of an integrated autism system of screening in Toyota, Japan. Psychiat Clin Neuros 2008; 62:152-9.

increased understanding of ASD would address this issue. As previously detailed, the Bill facilitates such understanding, both through training for key professionals, and a wider campaign to raise awareness and understanding of the needs of persons with ASD.

463. Moreover, the Bill includes a requirement on the Welsh Ministers to obtain, produce, publish and keep updated reliable data in order to carry out their functions under this Act. Analysis of such data may enable future studies to more conclusively determine the underlying causes of racial and ethnic disparities in the prevalence of ASD.

464. In summary, the provisions of the Bill are not considered to have a negative impact in relation to race, and may have a positive impact if disparities in prevalence are attributable to under-diagnosis (rather than differences in prevalence).

Religion and belief or non-belief

465. Following the two consultation exercises and extensive research, the provisions of the Bill are not considered to have a differential impact in relation to religion and belief or non-belief.

Sex

466. A range of studies have previously ascertained that a higher number of males than females are diagnosed with ASD, but it is not known to what extent this:

- reflects actual differences in prevalence; or
- represents under-diagnosis of women and girls with ASD.

467. Baron-Cohen and others have argued for higher prevalence of ASD in males from a neuropsychological standpoint.[110]

468. Others have suggested that females have superior ability to cope with ASD deficits,[111] that they are more likely to be quiet and compliant in school,[112] or that

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[110] Baron-Cohen, S. (2002). The extreme male brain theory of autism. Trends in Cognitive Sciences, 6(6), 248–254.

Baron-Cohen, S. (2009). Autism: The empathizing-systemizing (E-S) theory. The Year in Cognitive Neuroscience, 1156, 68–80. Baron-Cohen, S., Scott, F. J., Allison, C., Williams, J., & Bolton, P. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. The British Journal of Psychiatry, 194(6), 500-509.

they are more able to imitate appropriate social behaviour.[113] Such behaviours may make it more difficult for females with ASD to get a diagnosis, because symptoms may be masked, missed or misunderstood. A number of responses to the consultation on a draft Bill similarly advocated that ASD may result in different characteristics for females, and as such may not be identified/acknowledged.

469. The development of the Bill has not presumed whether the higher number of males than females diagnosed with ASD reflects actual differences in prevalence; or under-diagnosis of women and girls with ASD.

470. However, the Bill states that the autism strategy must make provision about the identification of key professionals and provision of appropriate training to them in relation to supporting people with ASD, and that guidance covers the training of staff who provide services. It is anticipated that such training will facilitate greater understanding of how ASD may affect both males and females.

471. The Bill will also facilitate understanding of ASD through its requirement that, upon publication of the autism strategy, the Welsh Ministers must initiate and maintain a campaign to raise awareness and understanding of the needs of persons with ASD. Again, it is anticipated that such a campaign will facilitate greater understanding of how ASD may affect both males and females.

472. In the event that there is under-diagnosis of women and girls with ASD, it is believed that increased understanding of ASD may address this issue. Moreover, the Bill includes a requirement on the Welsh Ministers to obtain, produce, publish and keep updated reliable data in order to carry out their functions under this Act. Analysis of such data may enable future studies to more conclusively determine whether the higher number of males being diagnosed:

- reflects actual differences in prevalence; or
- represents under-diagnosis.

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[111] Kreiser N, White S (2014). ASD in females: are we overstating the gender difference in diagnosis?; Dworzynski K, Ronald A, Bolton P, Happé F (2012), How different are girls and boys above and below the diagnostic threshold for autism spectrum disorders?

[112] Lai, M.C., Lombardo, M.V., Pasco, G., Ruigrok, A.N., Wheelwright, S.J., Sadek, S.A., & Baron-Cohen, S. (2011). A behavioral comparison of male and female adults with high functioning autism spectrum conditions. Plos One, 6(6), 1–10.

[113] Gould J, Ashton-Smith J (2011) Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum.

473. In summary, the provisions of the Bill are not considered to have a negative impact in relation to sex, and would have a positive impact if the lower number of females diagnosed reflects under-diagnosis (rather than differences in prevalence).

Sexual orientation

474. Following the two consultation exercises and extensive research, the provisions of the Bill are not considered to have a differential impact in relation to sexual orientation.

Monitoring

475. The Bill would require the Welsh Ministers - not more than three years after the publication of the autism strategy, and at intervals of no more than three years thereafter - to commission an independent report on its progress against the requirements of the Bill.

People with caring responsibilities and people from differing socio-economic backgrounds

476. Although not covered under protected characteristics, consideration has been given as to whether the Bill could have an impact on people with caring responsibilities or people from differing socio-economic backgrounds.

477. One of the concerns raised in the development of the Bill is that it can be hard for people currently caring for a person with ASD to simultaneously find information about ASD, or identify how a diagnosis takes place. For example, one person commented that she had:

> "to fight for everything… [but its] so exhausting, when you have to spend all day looking after child who spends all day pinching, head-butting and biting you."[114]

478. To address this issue, the Bill will require the Autism Strategy to:

- define a best practice model or models for the:
    - identification and diagnostic assessment of ASD;
    - assessment of the care and support needs of persons with ASD; and

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[114] Note of informal meeting between Paul Davies AM and interested members of public at National Autistic Society Merthyr Tydfil Branch.

    - planning for and meeting the care and support needs of persons with ASD;

- make provision for the development of a pathway accessed through clearly defined points of referral and that clearly maps the services that are available and required for persons with ASD;

- place an emphasis on how families and carers of a person with ASD can be supported in meeting the needs of that person; and

- make provision for the wishes of the person with ASD and of that person's family and carers to be taken into account in so far as is possible in respect of the services to be provided to that person.

479. As such, the provisions of the Bill are considered to have a beneficial impact for carers. The provisions of the Bill are not considered to have an adverse impact for people from differing socio-economic backgrounds.

Human rights

480. Acts of the National Assembly for Wales must be compatible with the Convention for the Protection of Human Rights and Fundamental Freedoms (the European Convention on Human Rights).[115]

481. The Bill is concerned with the promotion and safeguarding of the rights of people with ASD. No Convention rights are interfered with by the provisions of the Bill. Article 8: right to respect for private and family life, insofar as it relates personal information about individuals, is not interfered with by section 6 of the Bill for the following reasons.

482. Consultation feedback on data collection (detailed in paragraphs 221 and following of this Explanatory Memorandum), clearly identified inconsistent and inadequate ASD data collection practices across Wales. This assessment was echoed by such bodies as National Autistic Society Cymru and a medical data expert, Dr Dawn Wimpory[116]. Comprehensive and reliable data is essential to the proper planning of ASD services and, of equal importance, to improving diagnosis and treatment. Considerable variation in waiting times and outcomes has been identified across Wales and, again, the consultation responses confirm this.

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[115] Government of Wales Act 2006, subsection 108A(2)(e).

[116] Consultant Clinical Psychologist – Lead for ASD (BCUHB) & Lecturer (Bangor University)

483. For example, the first consultation on the Bill received a detailed response from The Wales Autism Research Centre ('WARC')[117], which identified the long term benefits of appropriate data collection:

> "Other countries have shown significant success from recording autism at a population level. For example, the National Patient Register in Sweden has been used to document rates of and reasons for mortality in autism (Hirvikoski et al., 2016) as well as stability of rates of diagnosis over time (Lundström et al., 2015). The Danish Psychiatric Central Register was used to demonstrate that there is no evidence linking the measles, mumps and rubella (MMR) vaccine to autism (Madsen et al., 2002)."[118]

484. NHS bodies already capture, process and share a large amount of health data. The current Community Child Health 2000 database ('CCH2000') is the central repository for child immunisation and other child health data in Wales. CCH2000 is in the process of transitioning to the Children and Young Persons Integrated System database ('CYPrIS'), currently being piloted in Aneurin Bevan health board[119]. In 2012, the ASD database module was established within the CCH2000 database. Although the software is already in place throughout NHS Wales, via CCH2000/CypRIS, a trial has been confined to the 6 counties served by the Betsi Cadwaladr University Health Board ('BCUHB'), where ASD data collection has taken place since 2012. Currently only child diagnoses have been entered, but those children who become adults are retained within this ASD database. The data categories set out in section 6(6) of the Bill reflect those currently being captured by the ASD database. Further data sharing via a cross agency system to promote integrated services, including ASD services, may be achieved via the planned Welsh Community Care Information System ('WCCIS')[120].

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[117] The Wales Autism Research Centre (WARC) is a research centre at Cardiff University's School of Psychology within the Centre for Human Developmental Science. It was set up in 2010 to create research capacity in response to the WG's 2008 Autism Spectrum Disorder Strategic Action Plan and supported by a collaboration between the two charities Autism Cymru and Autistica with Cardiff University and the Welsh Government.

[118] Wales Autism Research Centre, Autism (Wales) Bill- Bill Development, Consultation Response, no. 66.

[119] http://www.wales.nhs.uk/nwis/page/52630

[120] http://www.wales.nhs.uk/nwis/page/66175

485. The Bill promotes the interests of both children and adults with ASD, and WARC, the body leading on ASD database development, responded to the Bill consultation about an adult ASD database as follows:

> "A comparable system could be drawn up for those receiving a diagnosis in adulthood and thereby benefit from the WG-funded pilot of the ASD module database in BCUHB which was established and has served appropriately as a pilot in anticipation of its extension as an all-Wales ASD database, for which the software is already in place. This ASD module, within the CCH2000/CYPRIS database, enables recording of co-morbidities, including PKU status."[121]

486. ASD data collection is both appropriate and necessary to promote the interests of persons with ASD and their families and carers. Not only will benefits accrue in respect of planning and delivery of services, but also via improvements to the quality of diagnosis, treatment and support services. This conclusion is supported by consultation feedback from, amongst others, the National Autistic Society Cymru, who commented that::

> "A key challenge for public services when trying to plan and commission services that autistic children and adults might need is that there is a lack of data on numbers of autistic people and their needs. We believe that data collection is vital to help the NHS, local authorities and other public services in the planning and provision of support and services. As a result of this Bill, this is an issue that we believe should be urgently addressed."[122]

487. WARC responded to the Bill consultation in a similar manner (response number 66):

> "We strongly support the need for systematic data collection that captures the number and needs of autistic people in Wales. Not only does this enable local areas to plan services but it gives scope for capturing the effectiveness of initiatives (e.g. take up, outcomes) and changes to individuals over time. Analysis of data can be fed back to improve services and to better understand the profile of the autistic

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[121] Wales Autism Research Centre, Draft Autism (Wales) Bill- Consultation, Consultation Response no. 28.

[122] National Autistic Society Cymru, Draft Autism (Wales) Bill- Consultation, Consultation Response no. 26

> community in Wales. Such a database could be a valuable resource for policymakers, health professionals and researchers and bring these" professional groups together."[123]

488. Whereas ASD prevalence figures are far from complete, other health conditions are better served by good data collection, particularly around prevalence. For example, the national diabetes audit, which is part of the clinical audit programme for the NHS in Wales, indicated there were approximately 178,000 people registered with type 2 diabetes in Wales in the 2016-17 reporting year. The National Institute for Health and Care Excellence recommended in 2017 that all GP practices create local autism registers to tackle the current poor data practices around ASD.

489. The Bill imposes a duty on NHS bodies (section (6(6)) to capture specified categories for ASD data. Consideration was given to whether this duty should be imposed on other bodies such as Local Authorities, but in order to minimise processing of personal data and intrusion of privacy, it was considered appropriate to confine this data collection activities to the NHS, where the data is captured directly and already processed within the relevant databases. Again this approach is supported by WARC:

> "Our view is that data can most effectively be gathered through the NHS. Given the evidence on data collection to date, the Bangor team's experience shows that whilst LEA data can contribute to such database records, there is greater diagnostic accuracy about which cases should be included, where diagnoses are logged by the agency primarily responsible for those diagnoses, in this case, the NHS."[124]

490. Notwithstanding the fact that a large amount of health data is already being captured, processed and shared within the NHS in Wales, it is necessary still to consider data protection and Human Rights issues that may arise from the data collection and sharing provisions in section 6 of the Bill.

491. The protection of personal data is governed by the regime established under the Data Protection Act 2018 ('DPA18'), which operates in tandem with the General Data Protection Regulation ('GDPR').

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[123] Wales Autism Research Centre, Autism (Wales) Bill- Bill Development, Consultation Response, no. 66.

[124] Wales Autism Research Centre, Autism (Wales) Bill- Bill Development, Consultation Response, no. 66.

492. Currently the processing of personal data within the CCH200 database, amongst others, is based on consent by the patient or their parent/guardian. Where appropriate and informed consent is obtained from persons with ASD or being diagnosed, this will be sufficient to share their data within the NHS in accordance with the consent. Where consent is not available or sufficient, particularly in relation to data that has already been captured, the DPA18 and GDPR permit processing of health data on a number of bases:

- Sub-paragraph 5(2) of Schedule 2 to the DPA18: "The listed GDPR provisions do not apply to personal data where disclosure of the data is required by an enactment, a rule of law or an order of a court or tribunal, to the extent that the application of those provisions would prevent the controller from making the disclosure." Section 6 of the Bill constitutes such an enactment, and requires 'disclosure' of data within NHS bodies by way of capturing and sharing data by NHS staff for the purposes of planning, provision of services and research.

- Article 9(2)(h) of the GDPR which provides that processing is lawful where: "necessary for the purposes of preventative or occupational medicine…medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems and services on the basis of Union or Member State law or pursuant to contract with a health professional and subject to the conditions and safeguards referred to in paragraph 3." Paragraph 3 of Article 9 creates an obligation that, where data is processed in line with this legal basis, it must be, "by or under the responsibility of a professional subject to the obligation of professional secrecy…or rules established by national competent bodies or by another person also subject to the obligation of secrecy…". This requirement will be met as the data will be processed by staff within the NHS. The legal basis under Article 9(2)(h) is fleshed out by paragraph 2 of Sch. 1 to the DPA18, which states that the condition of health or social care purposes, "is met if the processing is necessary for health or social care purposes." Health or social care purposes can mean, amongst other things, medical diagnosis, the provision of health care or treatment, the provision of social care, or the management of health care systems or services or social care systems or services. All these potentially fall under the purposes of the Bill.

- Article 9(2)(g) which provides that processing is lawful where, "necessary for reasons of substantial public interest, on the basis of Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject." Article 9(2)(g) is read in conjunction with Part 2 of Schedule 1 to the DPA18, which expands on the "substantial public interest" basis. Para. 6 of Schedule 1, which deals with statutory and governmental purposes, states that the condition of "substantial public interest" is met if, amongst other things, the "processing is necessary for the purpose…[of]…the exercise of a function conferred on a person by an enactment…". Section 6 of the Bill imposes such a function on NHS bodies to capture the specified data.

- Paragraph 27 of Schedule 2 to the DPA18: "The listed GDPR provisions do not apply to personal data processed for (a) scientific or historical research purposes, or (b) statistical purposes, to the extent that the application of those provisions would prevent or seriously impair the achievement of the purposes in question." The safeguards and restrictions set out in sub-paragraph (3) of paragraph 27, and Article 89 of the GDPR (in relation to technical safeguards and minimisation, and medical decision making and the avoidance of substantial damage/distress) will be met by the regime set out in the Bill by confining data collection to NHS bodies only and permitting only anonymised data to be provided to the Welsh Ministers.

493. Safeguards exist within the NHS for the processing of personal data. Data sharing within the NHS and with external bodies is managed in accordance with the requirements of the DPA18 and GDPR, relying on appropriate consent or applicable bases for processing. All processing is assessed on a case by case basis to ensure the processing is lawful and proportionate, with relevant information provided to data subject including, where required, notification that processing has occurred without consent.

494. NHS Wales Informatics Service (NWIS'), provides digital solutions to the NHS in Wales, including the collection and processing of "…facts and figures that help NHS Wales run effectively. The data we collect is stored in the NHS Wales data warehouse, in accordance with national standards and Information Governance policies. Collected data is analysed and converted to useful information that helps staff across NHS Wales and the Welsh Government in their work"[125]. Proposals for data analysis within the NHS go through stringent checks before being approved,

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[125] http://www.wales.nhs.uk/nwis/page/52709

including an ethical assessment. If approved a projects is then assessed against data protection and confidentiality considerations generally, and for each stage of data sharing within the NHS or with external bodies.

495. As such, the sharing of NHS data is appropriately regulated. For example, where a research proposal requires the sharing of personal data between one NHS department and another, a valid justification has to be provided as to why that data cannot be shared in an anonymised or pseudonymised form. Taken together, these safeguards inherently address concerns around proportionality and lawfulness. It is expected that NWIS will carry out the anonymisation function to provide anonymised data to the WMs.

496. Whilst the data processing required under the Bill is permitted by the DPA18 and GDPR, consideration has also been given as to whether the Bill's data collection requirements interfere with the rights of individuals as set out in Article 8 of the European Convention on Human Rights ('ECHR'). Article 8 provides for the right to respect for private and family life, home and correspondence. It is a qualified right which may only be interfered with by state authorities if actions can be justified in terms of the general framework of principles set out in Article 8(2). These require that, in order to be legitimate, any interference must be:

- in accordance with the law;
- in pursuit of one of the legitimate aims listed in Article 8(2): national security, public safety, economic well-being, the prevention of disorder or crime, the protection of health or morals, or the protection of the rights and freedoms of others; and
- necessary in a democratic society.

497. The processing of personal data within NHS bodies for the purposes of the Bill is in accordance with the law to be established by the Bill and subject to the overarching legal regime established by the DPA18 and GDPR. A necessary element of this Article 8 requirement is that the law is sufficiently accessible and foreseeable. Section 6 of the Bill sets out clearly defined categories of data to be collected by NHS bodies and the basis upon which this data is captured is set out in the DPA18 and GDPR as considered in paragraph 491 above and following. The interaction of data protection law with the requirements of section 6 is both accessible and foreseeable due to the defined and limited nature of the data capture, and the fact that the DPA regime is a universal one that applies to all data processing whether connected to this Bill or otherwise. Additional safeguards are provided in section 6 of the Bill:

- The data categories have been confined to those which we have been advised are the minimum necessary to ensure a valid data set. The bulk of them are not in the nature of personal data. The reasons for and benefits of the chosen data categories are set out in paragraph 503 below.
- Data will only be processed within the NHS, either under the basis of consent, or one of the other bases permitted under the DPA, for example as set out above in paragraph 492.
- Only anonymised data can be provided or the Welsh Ministers by NHS and other relevant bodies.
- Section 6(6) sets out only defined categories of data to be captured, and additional categories of data can only be added by regulation under paragraph 6(6)(j).

498. The purpose pursued by the Bill in general, and section 6 in particular, is the wellbeing of children and adults with ASD. Appropriate diagnosis and support not only benefits those persons and their families, but also the state in respect of providing appropriate and effective treatment and support, thus enabling those persons to reach their potential and lead as productive a life as they are able. The importance of the data categories and the benefits the capturing of such data will provide, are set out in paragraph 503 below. The pilot study in Betsi Cadwaladr University Health Board, which uses the same data set, has generated a number of benefits to date (e.g. identifying under (and over) diagnosis of ASD in certain regions).

499. The evidence set out in the preceding paragraphs of this section demonstrate the necessity for improvement in ASD data collection practices, namely an identified and pressing social need to improve ASD services and the wellbeing of those persons diagnosed. The proposed improvement will result in tangible benefits to the wellbeing of persons with ASD, both for the reasons set out above and in the wider context of the aims of the Bill. Benefits will also accrue to the State through better targeted services, less demand on resources and persons with ASD achieving their maximum potential[126]. Valid and reliable data will also help or inform the development and ongoing implementation of the autism strategy and all the benefits it seeks or deliver.

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[126] 'Paragraph 415 (and following) set out projections of benefits and saving that may accrue to the State."

500. For the reasons set out, section 6 of the Bill pursues a legitimate aim. However, any interference with Article 8 rights by the aims of section 6 must be propionate. It is necessary to consider proportionality with respect to:

1. whether the objective is sufficiently important to justify the limitation of a protected right,
2. whether the measure is rationally connected to the objective,
3. whether a less intrusive measure could have been used without unacceptably compromising the achievement of the objective, and
4. whether the impact of the rights infringement is disproportionate to the likely benefit of the proposed measure.

501. The measures in section 6 pursue a legitimate aim, to promote and safeguard the wellbeing of children and adults with ASD, and are clearly and rationally connected to those aims for the reasons stated above. Section 6 is also a reasonable measure to impose in order to achieve these legitimate aims. This is because it has been established in this Explanatory Memorandum that current data collection practices are inadequate. Further, the current trial in Betsi Cadwaladr University Health Board has demonstrated tangible benefits using the data set included in section 6(6) of the Bill. The measures in section 6(6), based on expert advice, have been reduced to the minimum necessary to achieve the aim and, allowing for the appropriate margin of appreciation, are as minimally intrusive as possible to achieve that aim. The general data protection regime under the DPA18 and GDPR also provides safeguards in that it includes requirements of necessity and proportionality within the bases for the processing of personal data. Balancing the benefits for persons with ASD that will result from better data collection against any possible interference with the Article 8 rights of those persons, and taking into account the safeguards that will be implemented by the Bill (as set out in paragraph 497 above) and the overarching data protection regime, the measures in section 6 are proportionate to the aim they pursue.

502. It is helpful to distinguish the Christian Institute case[127]. This case did not find that the data sharing being considered could not be undertaken under the Data Protection Act 1998 or Article 8, but that the regime was insufficiently clear to the

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[127] The Christian Institute and others (Appellants) v The Lord Advocate (Respondent) (Scotland) 2016] UKSC 51

citizen and the guidance produced was inadequate. The situation dealt with by section 6 of the Bill is very different to that in the case and considerably more safeguards have been included. No discretion exists under section 6 allowing the information holder to make a judgement about what data to share, when to share it, or whether or not to share it. Such decisions under the Scottish regime dealt with in the case required a consideration of proportionality in each case. Further, section 6 makes it clear on the face of the Bill what categories of data will be collected, whereas in the case, a wide variety of data could potentially be captured and shared with a wide group of bodies. Section 6 purposefully restricts sharing to within the NHS by requiring that any data provided to the Welsh Ministers is to be anonymised. Due to the clearly stated categories to be captured and the lack of any discretion on the part of the data holder, the law relevant to the sharing can be reasonably ascertained, thus avoiding the “logical puzzle” found specifically in the case[128].

503. The rationale and benefits of the individual data categories set out under subsection 6(6) are as follows:

(a) the numbers of persons diagnosed with autism spectrum disorder in each Local Health Board:

This data is key to identifying anomalies in ASD prevalence patterns in Wales. By capturing this data nationally, it can be compared to existing prevalence research data to identify, for example, under or over diagnosis of ASD (both in Wales generally, and in particular areas in Wales). If anomalies are identified, these can be investigated to address the cause. Under diagnosis means that some people with ASD do not get the services and treatment they should, and are entitled to, to enable them to reach their full potential and lead fulfilling lives. Equally, if persons are incorrectly diagnosed with ASD, then they may receive inappropriate treatment and services, and their true underlying condition may well not be addressed, resulting in potentially poor outcomes for those people and their families. This data therefore helps ensure accurate targeting of resources.

(b) the NHS numbers of those persons:

Comprehensive and accurate data is essential to ensure valid statistical analysis, which can be undermined by double counting. A person’s NHS

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[128] See para. 83 of the judgement

number is the method by which services, treatment and medical records are managed within the NHS. Use of the NHS number will enable those analysing ASD data to remove or limit double counting. Further, there are facilities within NHS information systems (e.g. NWIS) whereby anonymised datasets may be constructed. The collection of NHS numbers is essential to both the proper treatment of persons with ASD and the development of reliable data to support the provision of autism services. NHS numbers are allocated to all patients as a matter of course when they enter the NHS system (for ASD or otherwise) and follow them around thereafter. As such this data is already being collected. But, it is not automatically linked with corresponding ASD data, or indeed other medical data, depending on what database is used, and this is why it important that it is explicitly collected with the other ASD data. In addition to avoiding double counting when producing ASD data, the NHS number is also essential to be able to look at individual cases to identify particular trends, including incorrect diagnoses. For example, if it is not possible to identify what children have been diagnosed and in what manner, it would not then be possible to show that a particular diagnostic tool being used in a particular area is producing disproportionately high or low numbers of diagnoses or, at a micro level, whether the diagnosis is correct in a particular case. It might be the case that the data shows that a particular area is diagnosing a large number of persons with severe ASD symptoms, but failing to identify others who have a relatively high IQ and other coping skills, which require more subtle diagnostic techniques. Equally, there is concern that persons with ASD who also have severe learning difficulties are not being properly diagnosed in respect of ASD - resulting in a failure to gain access to appropriate services that may better enable those persons to reach their potential - and again access to the NHS number would permit appropriate data analysis to address such anomalies.

(c) the age at diagnosis (in years and months) of those persons:

Research evidence confirms that early diagnosis of ASD provides the greatest opportunity to support the persons diagnosed to reach their full potential[129]. Age difference in terms of months can have an impact on

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[129] For example, para. 5.1, *Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Final Report*, Welsh Government Rhif/Number: 09/2016 -

outcomes in very young children. By analysing data on the age of diagnosis, regional anomalies can be identified. For example, as an inadvertent consequence of organisation of services, it might be identified, by comparison with cross-Wales and published international ASD prevalence data, that a region was diagnosing a disproportionate number of older (e.g. more high functioning) children compared to younger children who may have more severe symptoms. By identifying such an anomaly, intervention can occur to address the issue, thus improving both the age at which ASD is diagnosed, and capturing people with the full spectrum of ASD. Wider benefits can also accrue to the State through early diagnosis[130].

(d) the gender of those persons:

This data will enable analysis of the relative proportion of males to females being diagnosed with ASD in Wales. This is particularly important as there is a recognised gender prevalence split, with 3.3 males to every female. A particular concern has been the possible underdiagnoses of females with indications of significant variation in this, and other areas of diagnostic practice across different areas of Wales. Analysis of the data will identify whether different regions are under or over diagnosing each gender, based on the current research-identified prevalence figures regarding gender ratios.

(e) the diagnostic tools employed for diagnostic assessment, if any, and any scores generated by use of those tools:

There are a number of recognised tools for diagnosis of ASD, but some carry greater research-based and clinical validity than others, and not all clinicians use diagnostic tools. By analysing data on the diagnostic tools used, it would be possible to identify, for example, whether one tool is associated with a disproportionately high or low number of diagnoses. Such data would allow for refinement of clinical accuracy through use of more appropriate diagnostic tools, thus improving the quality of the diagnostic practice across Wales. Scores from these tools would give an indication of the degree of ASD that is being diagnosed; ASD is a continuum ranging from severe to milder social impairment. (ASD also

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https://gov.wales/docs/caecd/research/2016/160218-evaluation-autistic-spectrum-disorder-strategic-action-plan-en.pdf

[130] See for example para. 415 and following.

spans an intellectual continuum that must also be considered in making an accurate diagnosis - see (g) below.)

(f) the time taken from referral for diagnostic assessment to presentation of the autism spectrum disorder diagnosis:

A key issue for people with ASD and their families is excessively long waiting times for ASD diagnosis. Capturing this data will provide an accurate picture of waiting times across Wales and also assist with identifying whether national diagnostic targets are being met. It will also show regional variations, which will enable better targeting of resources. Early diagnosis is key to achieving the best possible outcomes for people with ASD, and this data will assist in this regard.

(g) the diagnostician's estimation or diagnosis of whether those persons diagnosed with autism spectrum disorder have an additional learning disability or developmental delay:

The range of abilities of people with ASD varies dramatically from high functioning (with normal to high intellect) to low functioning (with very limited intellect and functionality). This data would assist in assessing the general quality of diagnoses against existing research data to identify whether correct diagnoses are being delivered, and whether different areas of Wales are correctly identifying, in addition to the diagnosis of ASD, additional learning disabilities or developmental delay. Analysis will also identify whether those people with additional conditions are receiving the correct treatment and services, both for their ASD and the additional conditions.

(h) whether those persons at diagnosis are verbal and nonverbal, and for those who are verbal, whether or not they have language delay:

This data will identify whether children, in particular, in this category are being underdiagnosed compared to current research data. It will also enable better planning of services for such children and adults.

(i) which professional groups are involved in the diagnostic assessment (for example paediatrician, psychiatrist, clinical psychologist, etc):

NICE guidelines, for example, say a multi-disciplinary approach should be taken to ASD diagnosis. This data will help to identify possible issues with the composition of such multi-disciplinary teams where diagnostic levels are identified as too low or high compared to published standard prevalence levels. It will also help appropriate allocation of resources to better refine the composition of such groups over time[131].

Summary – Human Rights Assessment and Equality Impact Assessment

504. The policy underpinning the Bill is intended to have a positive impact on people with ASD. Its aim is to enable those people to better realise their full potential and place them on a more equal footing with fellow citizens in Wales.

505. The Bill's provisions are considered compatible with the European Convention on Human Rights, and there will be no adverse impact on human rights for the reasons stated. Instead the Bill will improve the provision of autism services to all persons with ASD in Wales.

10. 3. Does this legislation provide an opportunity to advance equality of opportunity and foster good relations between different groups of people?

506. Yes. The Bill, in section 8, explicitly applies the United Nations Conventions on the Rights of the Child and Rights of Person with Disabilities, and the Principles for Older Persons.

507. And, by positively addressing the needs of children and adults with ASD in Wales, the Bill advances the potential of equality of opportunity between people with and without ASD. For example, section 2(1)(g) of the Bill requires that the autism strategy must outline how the needs of persons with ASD should be met by relevant bodies in respect of, but not limited to:

- access to healthcare services;
- access to education;
- access to employment;
- access to housing;
- access to Welsh language services;

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[131] See for example para. 415 and following.

- access to services in other languages;
- access to other public services;
- social inclusion; and
- access to advocacy services.

10. 4. Conclusion

508. Following the impact assessment, the intention remained to introduce this legislation in its current form.

11. Children's Rights Impact Assessment (CRIA)

11. 1. Introduction

509. This Children's Rights Impact Assessment (CRIA) considers the effect of the Autism (Wales) Bill on children in Wales and their rights under the United Nations Convention on the Rights of the Child (UNCRC).

510. In preparing the Bill, consideration has been given to whether children and particular groups of children may be affected. This has informed the analysis of how the Bill impacts on the Articles of the Convention.

511. Two consultations have been undertaken on this proposed legislation. No concerns were raised specifically in relation to children and young people, although some wider concerns were raised which could have a potential impact on children's rights. These are discussed in the section '*Unintended consequences and risks*'.

11. 2. The purpose of the Bill and its effect on children

512. The Bill aims to positively address the needs of both children and adults with ASD in Wales.

513. The need for the Bill is covered in detail elsewhere within the Explanatory Memorandum and not all of the arguments put forward are replicated within this CRIA.

514. However, one of the main groups of people which the Bill seeks to benefit are children and young people themselves. The preparation of the Bill has been informed by a need to address the risk of children and young people with ASD not having a clear pathway to diagnosis. Receiving a diagnosis of an ASD 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 appropriate services.

11. 3. Analysing the Bill's impact on children and their rights under the UNCRC

515. The Bill includes a provision at Section 8(4) and 8(5) that:

> (4) Any relevant body exercising functions under this Act in relation to a child must have due regard to Part 1 of the United Nations Convention on the Rights of the Child adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989 ("the Convention").
>
> (5)For the purposes of subsection (4), Part 1 of the Convention is to be treated as having effect—
>
> (a) as set out for the time being in Part 1 of the Schedule to the Rights of Children and Young Persons (Wales) Measure 2011, but
>
> (b) subject to any declaration or reservation as set out for the time being in Part 3 of that Schedule.

516. The Bill is also relevant to a number of specific articles within the UNCRC.

517. **Articles 1 to 5** contain general principles of the Convention in relation to who is protected, an affirmation that all relevant organisations should work towards the best interests of children, and parental freedom.

518. Article 3(2) is particularly relevant, "States Parties undertake to ensure the child such protection and care as is necessary for his or her wellbeing, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures." This reflects one of the legitimate aims of the Bill in respect of any impact on the European Convention on Human Rights Article 8 right to privacy.

Articles 1 to 5 are respected by the Bill.

519. **Article 6** states that Governments must do all they can to ensure that children "develop to their full potential". The Bill provides that the Autism Strategy must define a best practice model or models for the identification and diagnostic assessment of ASD, and any associated care and support needs. The Bill also provides that diagnosis must take place within timescales set out in relevant guidelines issued by the National Institute for Health and Care Excellence.

520. This is intended to address concerns raised in consultation on the Bill that diagnosis can sometimes take far too long (with geographic variance around waiting times), which means that children and young people do not get the care and support that their individual circumstances require, which compromises their opportunity to reach their full potential.

Article 6 is given effect under the Bill.

521. **Article 12** states that every child has the right to express their views, and to have their views considered and taken seriously.

522. To inform the development of the Bill, both consultations (on the general concept of the Bill, and the text of a draft Bill) were produced in Easy Read to facilitate a wide range of people (including children and young people) in giving their opinions on the proposed Bill.

523. The Bill itself provides that the Autism Strategy must make provision for the wishes of the person with ASD to be taken into account in so far as is possible in respect of the services to be provided to that person.

Article 12 is given effect under the Bill.

524. **Article 16** states that every child has the right to privacy.

525. The Bill provides that the Welsh Government would undertake data collection to carry out their functions under the Act, including:

- the development, delivery and review of an Autism Strategy, and
- the defining of a best practice model (through the Autism Strategy) to enable effective planning for the care and support needs of persons with ASD.

526. Any form of data collection creates the potential for a breach of privacy. However, a number of safeguards have been built into the Bill to protect against any unjustified interference with this right.

527. The Welsh Government's power to request data from relevant bodies is limited to requesting anonymous data. Anonymous in this context will not purely mean a person's name, but other distinguishing characteristics that might be used to identify a person. Any data that will be collected and processed by NHS bodies under section 6 of the Bill is subject to clear limitations, and the relevant privacy issues are considered in detail in paragraph 480 (and following) above.

528. The Bill also provides that the Welsh Government will set out through guidance what data should be collected and how it should be published. This is intended to ensure a consistency of approach and provide clear safeguards to prevent individuals' personal privacy being compromised.

Article 16 is respected under the Bill

529. Article 23 provides that a child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence, and to play an active part in the community.

530. The Bill is intended to positively address the needs of people of all ages with ASD in Wales. As such, it will make a significantly positive contribution in relation to children and young people with a particular disability.

531. A detailed consideration of the Bill's impact on people with disabilities (including children and young people) is set out in paragraph 440 and following of the Bill's Equality Impact Assessment.

532. In summary, the Bill is not considered to have an adverse impact in relation to children and young people with disabilities in general, and will have a beneficial impact in relation to children and young people with a particular disability (i.e. ASD).

Article 23 is respected under the Bill.

533. Article 24 states that every child has the right to the best possible health.

534. The Bill will establish the necessity of a clear pathway to diagnosis, so that regardless of where a person lives or what age they are, they can access a diagnostic assessment in a timely way.

535. This would also enable health boards and local authorities to be accountable in law for the provision of a clear pathway.

536. The Bill also provides that assessment of the care and support needs of a person with ASD are to be completed as soon as reasonably practicable and at least within 42 working days of a diagnosis of ASD or any post-diagnostic meeting (whichever is the later).

Article 24 is given effect under the Bill.

537. **Article 27** states that every child has the right to a standard of living that is good enough to meet their physical and social needs and support their development. The Bill does not directly relate to standards of living; its overall impact is to facilitate access to, and improve, the provision of services to persons with ASD. In turn, such services will facilitate persons with ASD to better realise their potential and thus achieve a standard of living that is more equivalent to those without ASD.

538. For example, section 2(1)(g) of the Bill requires that the Autism Strategy must outline how the needs of persons with ASD should be met by relevant bodies in respect of, but not limited to:

- access to healthcare services;
- access to education;
- access to employment;
- access to housing;
- access to Welsh language services;
- access to services in other languages;
- access to other public services;
- social inclusion; and
- access to advocacy services;

As such, article 27 is given effect under the Bill.

539. **Article 28** states that every child has the right to an education, while **article 29** sets out the goals of such education.

540. The Bill will affect the education of children and young people through the training of teachers and other staff in education settings to support children and young people with ASD. In particular, the Bill states that the Autism Strategy must make provision about the identification of key professionals and provision of appropriate training to them in relation to supporting people with ASD, and that guidance covers the training of staff who provide services. This reflects concerns arising in the consultation that “more teachers need training in autism”.[132]

541. ASD is a common condition affecting one in one hundred people. This means that every teacher is likely to teach many pupils with ASD throughout their career. Understanding the reasons why children may respond in particular ways to particular situations, and knowing what to do to help, results in better outcomes for those children.

542. In addition to teacher training, the Bill will facilitate understanding of ASD through its requirement that upon publication of the autism strategy the Welsh Ministers must initiate and maintain a campaign to raise awareness and understanding of the needs of persons with ASD.

Articles 28-29 are given effect under the Bill.

543. Article 31 states that every child has the right to relax, play and take part in a wide range of cultural and artistic activities. However, the extent to which a child with ASD can relax, play and take part in cultural/artistic activities can be impeded by other people’s understanding of ASD.

544. The Bill addresses this impediment by stating that the Autism Strategy must make provision about the identification of key professionals and provision of appropriate training to them in relation to supporting people with ASD. The Bill also states that guidance must cover the training of staff who provide services.

545. In addition, it provides for the Welsh Government to initiate and maintain a campaign to raise awareness and understanding of the needs of persons with ASD.

11. 4. Summary of the Bill’s impact on children’s rights

546. In summary, the Bill is considered complementary to the United Nations Convention on the Rights of the Child. Due regard of children’s rights has been taken during the development of the Bill.

547. An Easy Read version of both consultations was produced (including an Easy Read version of the draft Bill), to enable a wider range of people with a potential

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[132] Referenced re 39

interest in the Bill (including children and young people) to engage with the consultations.

548. The impact on particular groups has been considered and, where necessary, proposals have been adapted to ensure that the Bill has as positive an impact as possible without causing detriment to any particular groups. Potential risks and unintended consequences have also been considered, which have influenced the content of the Bill.

12. Impact on the Welsh Language

549. Concerns arose during the development of the Bill about the need for Welsh language provision for people with ASD, particularly in assessment processes.

550. For example, the Welsh Language Commissioner cited examples of barriers to diagnosis in Welsh. The Welsh Language Commissioner also emphasised the importance of referring to the Welsh language on the face of the Bill so that guidance and subordinate legislation could elaborate on it. She pointed out that ASD services need to make an "active offer" of Welsh language services.

551. To address this concern, section 2(1)(g) of the Bill will require that the Autism Strategy outlines how the needs of persons with ASD should be met by relevant bodies in respect of access to Welsh language services. It is anticipated that guidance about the implementation of the strategy issued under the Bill would be used to supplement the provisions in the Bill around Welsh language services.

552. As such, it is believed that the provisions of the Bill will not have a positive impact in relation to Welsh language speakers, particularly in terms of facilitating services and diagnosis provided through the Welsh language.

13. Sustainable development

553. Sustainable development is about improving the way that we can achieve our economic, social, environmental and cultural well-being. The Well-Being of Future Generations (Wales) Act 2015 sets out the following definition:

> "'sustainable development' means the process of improving the economic, social, environmental and cultural well-being of Wales by taking action, in accordance with the sustainable development principle, aimed at achieving the well-being goals."[133]

554. "A more equal Wales" is one of the seven well-being goals set out in the Well-being of Future Generations (Wales) Act 2015. The Bill is expected to have a positive impact on equality of opportunity between people with and without ASD.

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[133] Well-being of Future Generations (Wales) Act 2015, Part 2 'improving well-being' section 2 'sustainable development'

555. The Bill also includes two provisions which are aimed at improving the commissioning and sustainability of services. Section 2(1)(m) states that the autism strategy must "place an emphasis on achieving innovation and improvement in the commissioning and delivery of ASD services". Similarly, section 4(6)(f) details that guidance must be issued to relevant bodies about "local arrangements for leadership in relation to the provision of services."

556. As such, it is believed that the provisions of the Bill will not have a negative impact on sustainable development.

14. Health and well-being

14. 1. Direct impacts on health, mental health and well-being

557. The Bill would have a range of positive impacts for health, mental health and well-being. In particular, it would:

- define a best practice model or models for the identification and diagnostic assessment of ASD;
- require the autism strategy to outline how the needs of persons with ASD should be met by relevant bodies in respect of access to healthcare services; and
- require the issuing of guidance about the composition of multi-disciplinary diagnostic assessment teams.

14. 2. Impacts on social, economic and environmental living conditions that could indirectly affect health

558. The Bill would require the Autism Strategy to outline how the needs of persons with ASD should be met by relevant bodies in respect of:

- access to education;
- access to employment;
- access to housing;
- social inclusion; and
- access to advocacy services.

14. 3. Impact on an individual's ability to improve their own health and well-being

559. The Bill would not adversely affect the ability of individuals to be physically active, choose healthy food, and reduce drinking and smoking.

560. The Bill makes provision for a campaign to raise awareness and understanding of the needs of persons with ASD. This could indirectly assist individuals in improving their own health and well-being, because sometimes other people's lack of awareness and understanding creates barriers to improving health and well-being.

561. For example, during the development of the Bill, one parent described how their child had been excluded from sports activities, because their PE teacher considered their behaviour to be deliberately disruptive, rather than understanding it was symptomatic of a person with ASD.[134]

562. Similarly, gyms and leisure centres typically utilise louder volumes of music, which may be challenging for some people with ASD. Increased levels of understanding might result in such centres choosing to reduce noise levels at certain times of the day, thereby attracting a new sector of customers, and making for a better experience for children and adults with ASD. Consequently, this could improve the health and well-being of such persons.

563. Likewise, if staff involved in public transport had a better understanding of ASD, this could make it easier for people with ASD to use public transport. In turn, this would facilitate people to more easily move around the community, thereby helping to reduce social isolation and improve health and well-being.

14. 4. Demand for or access to health and social care services

564. As previously noted, in responding to consultations on the development of this Bill, some consultees described difficulties obtaining a diagnosis (such as long waiting times) while others reported positive experiences. Overall, the picture set out in the responses was one of inconsistency across Wales.

565. The Bill builds on the ambitions of the Welsh Government's Autism Spectrum Disorder Strategic Action Plan, which originally established an autism

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[134] Note of informal meeting between Paul Davies AM and interested members of public at National Autistic Society Merthyr Tydfil Branch.

infrastructure in each local authority area, with local co-ordinators and strategies and a Wales national co-ordinator. However, the voluntary nature of the local autism infrastructure means it has been more effective in some areas than others.

566. The Bill aims to deliver a more consistent level of service provision across Wales. As such, it could potentially increase demand for, or access to, health and social care services in some parts of Wales, in the course of bringing about such consistency. In particular it would require the strategy to make provision for the development of a pathway, accessed through clearly defined points of referral, and which clearly maps the services that are available for persons with ASD. The strategy would also define a best practice model (or models) for planning for and meeting the care and support needs of persons with ASD.

14. 5. Impact on global health

567. The provisions of the Bill are not expected to have a detrimental impact on global health.

15. Rural impact

568. The provisions of the Bill are not expected to have a detrimental impact on the rural community.

16. Impact on small businesses and the third sector

569. It is anticipated that although the Bill will have impacts for private businesses and organisations in the third sector, such impacts will be positive rather than negative in nature.

570. For example, the Bill requires that the Autism Strategy makes provision that an appropriate range of services deliver the autism strategy, and these services are to be available consistently across Wales.

571. In practice, this is likely to increase commercial opportunities for small businesses and third sector organisations. These will involve contractual relationships between Local Authorities and NHS Bodies, and those they contract with to deliver relevant services.[135]

572. The Bill recognises this by requiring that the Autism Strategy places emphasis on achieving innovation and improvement in the commissioning and delivery of ASD services. As such, the Bill may have an indirect impact on private sector and third sector bodies through the terms and conditions set by Local Authorities and NHS bodies, when commissioning ASD Services. However it is not believed that such impacts will be negative.

573. In addition, the Bill would require the Welsh Ministers to consult and seek participation of relevant bodies and such other persons as the Welsh Ministers may consider appropriate (including persons with ASD and organisations representing their interests or providing services to them) in preparing and revising the autism strategy and guidance. In practice, third sector bodies are likely to form the majority of organisations representing the interests of persons with ASD.

574. As such, although the Bill will have indirect impacts for private businesses and organisations in the third sector, it is believed that such impacts will be positive rather than negative in nature.

17. Impact on privacy

575. The Equality Impact Assessment of this Bill stated that Article 8 of the European Convention on Human Rights (the right to respect for private and family life, insofar as it relates personal information about individuals), is not interfered with by section 6 of the Bill for the reasons set out in paragraph 480 and following.

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[135] During the initial consultation on the concept of an Autism (Wales) Bill, one consultee expressed concern that a possible focus of duties on statutory services could inhibit innovation and marginalise Third Sector services. The Bill has been developed to recognise the value of innovation and services that may be commissioned, in addition to those directly delivered by relevant bodies.

18. Environmental and social benefits and dis-benefits that cannot be quantified financially

576. No environmental benefits or disbenefits have been identified in relation to the Bill.[136] There are numerous social benefits which cannot be quantified financially; these are set out in Part 1, chapter 5 of this Explanatory Memorandum.[137]

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[136] An analysis of the Bill's impact on sustainability is set out in Chapter 12: Sustainable development.

[137] See also Chapter 8.13: Benefits.

19. Justice System Impact Assessment: Autism (Wales) Bill

19. 1. Purpose of the Bill

577. Paul Davies AM is introducing a Bill into the National Assembly for Wales to make provision for meeting the needs of children and adults with ASD in Wales and protecting and promoting their rights.

578. The Bill includes a requirement on the Welsh Ministers to prepare and publish a document setting out a strategy for meeting the needs throughout their lives of persons in Wales with ASD by improving the provision of services to such persons.

579. The Bill also requires the Welsh Ministers to obtain, produce, publish and keep updated reliable data in order to carry out their functions under this Act.

19. 2. How do you expect the relevant provisions of this (new) legislation to be enacted?

580. The Bill comes into force at the end of the period of 3 months beginning with the day on which it receives Royal Assent.

581. Following Royal Assent, regulations made under the Bill will be made by the affirmative procedure.

Please indicate the anticipated date when a) the legislative changes are expected to come into force and b) the date when the first anticipated impact on the justice system will arise.

582. The legislative changes are expected to come into force during 2019 or 2020.

583. It is not anticipated that there will be any substantive impacts on the justice system.

If altering or introducing an offence, sanction or penalty, which groups will the proposal affect and in what circumstances?

584. The Bill entails no alterations or introductions of offences, sanctions or penalties.

Does the legislation only have impact in Wales or are you working jointly with other administrations?

585. It is believed that the legislation will only have direct impact in Wales.

If your legislation could directly impact visitors to Wales or other people not normally resident in Wales, or if your legislation is significantly different from elsewhere in England, Scotland or Northern Ireland;-
a) what arrangements have you made to ensure ongoing awareness raising of the different legislative approach on this issue in Wales?
b) what will be the implications on the enforcement agencies of taking forward action against individuals not usually resident in Wales?

586. Due to the nature of the legislation and its purposes, the legislation will not directly impact visitors to Wales or other people not normally resident in Wales. For this reason, it is not considered necessary to undertake additional awareness raising beyond that resulting from the passage of the legislation and the awareness raising provisions contained in the Bill. It may also be noted that England and Northern Ireland already have similar legislation in place.

What are the options under consideration and how does this change the existing situation?

587. As set out in the Regulatory Impact Assessment to the Bill, the two options considered were to continue with the Welsh Government's future plans and to introduce a Bill.

If you are creating a new civil sanction or penalty which court or tribunal, in your opinion, should deal with it?

588. N/A, the Bill does not create any new civil sanction or penalty.

Which of the following are you creating / amending: Civil Sanctions; Fixed Penalties; Civil Orders; Criminal Sanctions; Criminal Offences; Other.

589. None of the above.

If you are creating a criminal offence, is it: summary only (heard before a bench of lay magistrates / judge only); triable either way; indictable only (heard before a judge and jury)?

590. N/A, no criminal offence is created.

Who will be responsible for the enforcement of your legislative proposal and how will they take this role forward? Will there be a reduced need for enforcement action?

591. N/A, no specific enforcement provisions are provided for in the Bill or required generally to implement its provisions.

What is the anticipated number of cases per year? Please provide details of any evidence of assumptions on which estimates are based.

592. The anticipated number of cases per year is zero.

What proportion of offenders will be tried in the Crown Court and what proportion will be tried in the Magistrates' Court?

593. Zero.

Please state the maximum associated fine and/or custodial penalties. In the case of offences involving penalties of a fine or custody, please indicate and explain the circumstances which would result in a custodial sentence upon conviction and the proportion of custodial penalties which will be at the maximum level.

594. N/A

Please provide details of any proxy or current offences and / or penalties on which the proposed penalties are based.

595. N/A

Please provide details of the relevant legislation (where appropriate) and confirm whether the creation or amendment of criminal offences and penalties has been agreed in line with the guidance available at https://www.gov.uk/government/publications/making-new-criminal-offences.

596. No creation or amendment of criminal penalties.

What will be the short, medium and lifelong implications for an individual found guilty of this offence, and how is this proportionate to the offence created?

597. N/A

Does this legislation impose any duty on the public sector? If so, please provide your assessment of the likelihood of individuals or businesses taking action against the public sector for noncompliance with this legislation.

598. Yes. In addition to placing duties upon the Welsh Ministers, the Bill states that relevant bodies (Local Authorities, NHS bodies and such other bodies as may be prescribed by the Welsh Ministers) must:

- in exercising their functions concerned with the planning and delivery of services to persons with ASD, comply with the autism strategy published under section 1 and guidance issued under section 4 of the Bill;
- provide the Welsh Ministers with the anonymised data that may be requested under section 6 of the Bill.

599. It is anticipated that public sector bodies would comply with this legislation, and as such that the likelihood of individuals or businesses taking action against the public sector for non-compliance is very low. However, if they considered that the Welsh Ministers or a relevant body took an action or decision that represented non-compliance with the legislation, they would have the right to make a claim for Judicial Review.

Do you expect there to be a change in Court or Tribunals process or an increase / decrease in applications / cases to HM Courts and Tribunals Service and / or the Welsh Tribunals through the creation or amendment of this law? Please provide an estimate of the change to volumes of cases going through the court system as a whole, explain any changes in process and outline the evidence and sources that support these estimates.

600. No change anticipated, on the basis that non-compliance with the legislation is expected to be very low, and as such the likelihood of Judicial Review is considered minimal.

Please confirm if the courts / tribunals would be under any duty to inform any regulatory authorities of any convictions made under this offence.

601. N/A

Does your proposal create a new right of appeal or expand an existing jurisdiction in the Unified Tribunals System or route to judicial review? If so, how do you expect these to be handled (i.e. administered by HM Courts & Tribunals Service or Welsh Tribunals)?

602. N/A

Do you expect to establish a new tribunal jurisdiction? If so, has this been discussed with the Welsh Tribunals Unit / Ministry of Justice?

603. N/A

To what extent could the use of alternative dispute resolution (ADR) procedures (including mediation) be appropriate? How will success in ADR be measured?

604. N/A

If the proposal is to add a new offence, will the Crown Prosecution Service act to prosecute defendants? If not, please identify who will prosecute.

605. N/A

Will the proposal require enforcement mechanisms for civil debts, civil sanctions or criminal penalties? If yes, who do you expect to enforce these?

606. N/A

Do you anticipate that Court and/or Tribunal procedural rules will have to be amended? If so, when is the likely date for the changes?

607. No.

Will the proposals require sentencing and / or penalty guidelines to be amended?

608. No.

What evidence is there that individuals affected by your proposal will be able to afford legal representation and legal advice in order to secure a fair hearing of their case; and associated court fees? What legal costs for a typical case could each party bear and what provisions exist for a party found innocent to recover all or any of their legal costs? Appeals to the First Tier Tribunal are not currently in scope for civil legal aid and could only be funded via Exceptional Case Funding.

609. N/A

Once implemented, is your proposal likely to require individuals to seek legal advice and to apply for legal aid? In each case please provide supporting evidence.

610. No.

If legal aid may be affected, would legal aid costs increase or be reduced (and by what margin)?

611. N/A

Will the proposals result in a change in the number of offenders being committed to custody (including on remand) or probation (including community sentences)? If so, please provide an estimate and reasoning behind it, an estimated timeframe to reach this number of sentences, what evidence this is based on, and the source for your information.

612. No.

Does the proposal create, remove or change an existing offence with a custodial or probationary sentence, or change the way offenders go through the prison / probation service? If so, please provide details, including the expected impact on probationary services.

613. No.

Volumes and Costs or Savings for courts or tribunals or Ministry of Justice services that will be affected by this proposal.

614. N/A – no expectation that courts or tribunals or Ministry of Justice services will be affected by this proposal, other than a minimal risk of Judicial Review in the event of the Welsh Ministers or relevant bodies not complying with the legislation.

Part 3: EXPLANATORY NOTES

INTRODUCTION

1. These Explanatory Notes are for the Autism (Wales) Act, which Paul Davies AM was given leave to introduce on 14 June 2017, introduced on 13 July 2018 and which received Royal Assent on [XXXX]. They have been prepared by Paul Davies AM to assist the reader of the Act.

2. The Explanatory Notes should be read in conjunction with the Act but are not part of it. They are not meant to be a comprehensive description of the Act.

OVERVIEW OF THE ACT

3. The Act makes provision for meeting the needs of children and adults with autism spectrum disorder in Wales and promoting their rights, and for connected purposes. The Act does this by requiring the Welsh Minsters to prepare an autism strategy for Wales and accompanying guidance. Relevant bodies must comply with the strategy and guidance when they exercise functions concerned with the planning and delivery of services to persons with autism spectrum disorder. The Welsh Ministers are also required to gather and publish relevant data on ASD and undertake an awareness-raising campaign. They and relevant bodies are required to comply with certain United Nations conventions and principles when exercising functions under this Act.

POLICY BACKGROUND

4. A considerable amount of work has been undertaken in Wales in recent years to improve services for people with autism spectrum disorder, their families and carers. The Welsh Government's 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 spectrum disorder and made available a range of high quality information and resources for both service users and professionals.

5. The Action Plan recognised the need for better diagnostic services for children and adults with autism spectrum disorder. However, evidence suggested 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. There was also recognition in the

Strategic Action Plan that work was needed to promote employment of people with autism spectrum disorder and to provide employment support to individuals.

6. Evaluation of the Strategic Action Plan, and the work of autism task and finish groups identified continuing gaps in services, particularly around diagnosis, transition to adulthood, employment support, and access to information on services. Many people with autism spectrum disorder, and their families, did not receive the services and support they needed to enable them to cope with the challenges of autism spectrum disorder and to fulfil their potential. Whilst good practice and responsive services were evident in some areas, the local focus of the Strategic Action Plan meant that provision remained inconsistent across Wales. The voluntary nature of the local autism infrastructure meant that it was more effective in some areas than others. There was a need to ensure that people with autism spectrum disorder receive high quality support wherever they live. 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 spectrum disorder.

7. Developments in education support include the Additional Learning Needs and Education Tribunal (Wales) Act 2018 ('the ALN Act') which gained Royal Assent in January 2018. The Autism (Wales) Act will support the implementation of the ALN Act by, for example, ensuring that key staff working with people with autism spectrum disorder, including teachers, receive appropriate training. A significant number of staff working with people with autism spectrum disorder have already received training through Welsh Government led initiatives. This Act promotes consistency of training across all regions, provides a clear means by which implementation and maintenance of training can be monitored, and secures the delivery of such training on an ongoing and permanent basis.

8. The Social Services and Well-being (Wales) Act 2014 promotes person centred assessment and services, and includes a power for Welsh Ministers to issue codes (which could include a code in relation to the needs of people with autism spectrum disorder), on the exercise of social services functions. During the development of this Bill, the Welsh Government indicated that it intends to issue a Code of Practice[138] on the delivery of

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[138] Letter from Cabinet Secretary for Health and Social Services to Paul Davies AM, 29 March 2018, and Statement by the Cabinet Secretary for Health and Social Services: The Autistic Spectrum Disorder Strategic Action Plan, National Assembly for Wales Record of Proceedings, 19 June 2018.

autism services under sections 145 and 169 of the Social Services and Well-being (Wales) Act 2014 and sections 1 and 2 of the National Health Service (Wales) Act 2006.

9. However, to date, such a code has not been formally issued. Moreover, the needs of people with autism spectrum disorder extend beyond such social services functions. By contrast, the Autism (Wales) Act will ensure that health boards and local authorities understand the particular needs of children and adults with autism spectrum disorder and provide a holistic range of services to meet them.

10. A key function of the Act, therefore, is 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. By creating a legal requirement to publish an autism strategy the Autism (Wales) Act helps secure a measure of permanence and sustainability in care and support services for people with autism spectrum disorder. It will also ensure a continued, dedicated focus on the needs of people with autism spectrum disorder, regardless of the prevailing financial or political climate.

TERRITORIAL EXTENT AND APPLICATION

11. The provisions in the Act extend to England and Wales (as one legal jurisdiction). The Act applies to the provision of services to persons in Wales with autism spectrum disorder.

COMMENTARY ON SECTIONS

Section 1 –Autism strategy

12. This section requires the Welsh Ministers to prepare and publish a strategy for meeting the needs of persons in Wales with autism spectrum disorder. It includes a requirement to lay the strategy before the National Assembly for Wales and to publish it. The Welsh Ministers must also keep the strategy under review and they may revise it. A revised strategy must also be laid and published.

13. The Welsh Ministers must also commission an independent review of the implementation of the Act and the progress being made, three years after the publication of the autism stagey, and at no more than three yearly intervals thereafter. Subsection (9) requires the strategy to be reviewed following the publication of that report and subsection (10) contains a requirement to consult. To avoid unnecessary duplication of effort and delay, subsection (11) enables steps taken before the section comes into force to satisfy the requirements of the section.

Section 2 – Contents of the autism strategy

14. Section 2(1) contains a non-exhaustive list of matters that must be addressed in the strategy. These include:

- establishing best practice models;
- developing a pathway for services;
- providing for diagnostic assessments and meetings;
- providing for assessments of care and support needs;
- ensuring that people are not denied access to services because of their IQ or the receipt of other services;
- outlining how the needs of persons with autism spectrum disorder are to be met by relevant bodies in relation to access to various services;
- ensuring that services are accessible to each person, and consistently across Wales;
- ensuring continuity of services, especially during the transition from childhood to adulthood;
- placing an emphasis on supporting families and carers;
- taking into account the wishes of individuals and their families and carers;
- emphasising innovation and improvement in the commissioning and delivery of services;
- commissioning research and collecting data, and their publication;
- raising awareness and understanding;
- identifying key professionals and the provision of appropriate training for them; and

- establishing the infrastructure and leadership needed to monitor and promote the implementation of the strategy.

15. Section 2(2) permits the Welsh Ministers to include in the strategy any other matter they consider appropriate and within the Assembly's legislative competence if it had been included in an Act of the Assembly.

Section 3 – Combining assessments

16. This section permits relevant bodies to combine assessments of an individual for the purposes of this Act with other assessments being undertaken in relation to that individual.

Section 4 – Guidance by the Welsh Ministers

17. Section 4 of the Act requires the Welsh Ministers to issue guidance to relevant bodies about how they should exercise their functions to implement the autism strategy. It requires the guidance to be published no later than three months after publication of the strategy. The Welsh Ministers are also required to keep the guidance under review, and may revise it. Subsection (5) contains the considerations for such a review, whilst subsection (6) sets out matters to be included in the guidance:

- how persons with autism spectrum disorder are identified;
- how carers are to be identified for the purposes of the Act;
- the provisions of diagnostic and needs assessment services;
- the key professionals to be included in diagnostic assessment teams;
- staff training; and
- local leadership arrangements.

18. Subsection (7) contains consultation requirements and subsection (8) enables steps taken before the section comes into force to satisfy the requirements of the section.

Section 5 – Relevant bodies: compliance with the autism strategy and guidance

19. Section 5 requires relevant bodies (see section 9) to comply with the autism strategy and guidance when they exercise their functions relating to the planning and delivery of services to persons with autism spectrum disorder.

Section 6 – Data on autism spectrum disorder

20. Section 6 places a duty on the Welsh Ministers to obtain, produce and keep updated the data that they require to exercise their functions under this Act, and to publish that data annually.

21. The Welsh Ministers may request data under subsection (2), and subsection (3) imposes a duty on relevant bodies to provide that data, and in an anonymised form. Subsection (4) requires the Welsh Ministers to publish only anonymised data and subsection (5) imposes a duty on the Welsh Ministers to provide anonymised data required for the purposes of the independent report to be prepared under section 1(7). The requirement that data be anonymised is to limit the processing of personal data and interference with privacy rights.

22. Subsection (6) sets out categories of data to be collected by NHS bodies (see section 9) to assist them in the diagnosis and provision of services to persons with autism spectrum disorder and to enable NHS bodies to provide reliable data on autism spectrum disorder to the Welsh Ministers under subsection (2).

23. Subsection (6)(j) permits the Welsh Ministers to prescribe additional data categories by regulations.

Section 7 – Awareness campaign

24. Subsections (1) and (2) require the Welsh Ministers to undertake an ongoing campaign to raise awareness and understanding of the needs of persons with autism spectrum disorder amongst the public, employers and service providers. Subsection (3) imposes a duty on the Welsh Ministers to ensure that information on the progress and effectiveness of the campaign is included in any report prepared under section 1(7).

Section 8 – Duty to have regard to the United Nations Principles and Conventions

25. Section 8(1) of the Act requires the Welsh Ministers and relevant bodies exercising functions under the Act to have regard to the United Nations Principles for Older Persons. Subsection (2) and (3) contain a similar duty in relation to the United Nations Convention on the Rights of persons with Disabilities and its optional protocol.

26. Subsections (4) and (5) imposes a similar duty on relevant bodies in relation to the United Nations' Convention on the Rights of the Child. The Welsh Ministers are already under such a duty by virtue of the Rights of Children and Young Persons (Wales) Measure 2011.

27. Subsection (6) provides for guidance to be issued under section 4 setting out what is required to discharge the duties under subsections (1) to (5), and these subsections are to be interpreted accordingly.

Section 9 – Interpretation

28. This section contains a number of defined terms, some of them by reference to other provisions of the Act.

29. 'Autism spectrum disorder' is defined by reference to the World Health Organization International Classification of Diseases. However, the Welsh Ministers may extend by regulations that classification for the purposes of the Act to include other neurodevelopmental disorders.

30. 'Relevant body' means a local authority, an NHS body and any other bodies prescribed by the Welsh Ministers in regulations. Local authorities are county and county borough councils in Wales.

31. NHS bodies are Local Health Boards, NHS Trusts and Special Health Authorities. The relevant NHS Trusts are the Public Health Wales NHS Trust, Velindre NHS Trust and the Welsh Ambulance Services NHS Trust. Relevant Special Health Authorities are the NHS Business Services Authority, NHS Blood and Transplant, and Health Education and Improvement Wales.

Section 10 - Regulations

32. This section explains that powers to make regulations under the Act are to be exercised by statutory instrument (which means that certain procedural and other requirements contained in the Statutory Instruments Act 1946 apply in relation to regulations made under the Act) and specifies that the affirmative procedure will apply to each use of the regulation-making powers. This means that any regulations made under the Act are subject to the express approval of the National Assembly for Wales.

33. The relevant regulation-making powers are:

- the power to prescribe additional categories of data to be collected by NHS bodies (section 6(6)(j));

- the power to prescribe additional neurodevelopmental disorders as 'autism spectrum disorders' for the purposes of this Act (section 9(1)); and
- the power to prescribe additional relevant bodies (also section 9(1)).

Section 11 – Coming into force

34. Section 11 specifies that the provisions of the Act will come into force three months after the Act receives Royal Assent.

Section 12 – Short title

35. This section states that the short title of this Act will be the Autism (Wales) Act 2019

Annex: Index of Standing Order requirements

Standing Order 26.6 requires certain documentation to accompany a Bill. The following index sets out where these can be found in the Explanatory Memorandum.

Table 21: Index of Standing Order requirements.

Standing order		Section	Pages
26.6(i)	Statement that the provisions of the Bill would be within the legislative competence of the Assembly	Member's declaration	Page 1
26.6(ii)	Set out the policy objectives of the Bill	Chapter 5 – What the Bill does and why	Page 31 and following
26.6(iii)	Set out whether alternative ways of achieving the policy objectives were considered and, if so, why the approach taken in the Bill was adopted	Part 2 – Regulatory Impact Assessment	Page 56 and following
26.6(iv)	Set out the consultation, if any, which was undertaken on: (a) the policy objectives of the Bill and the ways of meeting them; (b) the detail of the Bill, and (c) a draft Bill, either in full or in part (and if in part, which parts)	Chapter 4 – Support for the Bill and public consultation	Page 18 and following

26.6(v)	Set out a summary of the outcome of that consultation, including how and why any draft Bill has been amended	Chapter 4 – Consultation	Page 18 and following (particularly pages 25-26 and 29-30)
26.6(vi)	If the bill, or part of the Bill, was not previously published as a draft, state the reasons for that decision	N/A – although changes to the Bill arose from consultation.	N/A
26.6(vii)	Summarise objectively what each of the provisions of the Bill is intended to do (to the extent that it requires explanation or comment) and give other information necessary to explain the effect of the Bill	Part 3 – Explanatory Notes	Page 177 and following
26.6(viii)	Set out the best estimates of: (a) the gross administrative, compliance and other costs to which the provisions of the Bill would give rise; (b) the administrative savings arising from the Bill; (c) net administrative costs of the Bill's provisions; (d) the timescales over which such costs and savings would be expected to arise; and (e) on whom the costs would fall	Part 2 – Regulatory Impact assessment (Chapter 9: Option 2)	Page 89 and following
26.6(ix)	Any environmental and social benefits and dis-benefits arising from the Bill that cannot be quantified financially	Chapter 18. Environmental and social benefits and dis-benefits that cannot be quantified financially	Page 170

26.6(x)	Where the Bill contains any provision conferring power to make subordinate legislation, set out, in relation to each such provision: (a) the person upon whom, or the body upon which, the power is conferred and the form in which the power is to be exercised; (b) why it is considered appropriate to delegate the power; and (c) the Assembly procedure (if any) to which the subordinate legislation made or to be made in the exercise of the power is to be subject, and why it was considered appropriate to make it subject to that procedure (and not to make it subject to any other procedure);	Chapter 6 - Power to make subordinate legislation	Page 54 and following.
26.6(xi)	Where the Bill contains any provision charging expenditure on the Welsh Consolidated Fund, incorporate a report of the Auditor General setting out his or her views on whether the charge is appropriate	The requirement of Standing Order 26.6(xi) does not apply to this Bill	Page 92 (clarifies that no expenditure is charged on the Welsh Consolidated Fund)
26.6(xii)	Set out the potential impact (if any) on the justice system in England and Wales of the provisions of the Bill (a “justice impact assessment”), in accordance with section	Chapter 19- Justice System Impact Identification	Page 171 and following

	110A of the Government of Wales Act 2006.		
26.6A	The Explanatory Memorandum to the Bill must state precisely where each of the requirements of Standing Order 26.6 can be found within it, by means of an index or otherwise	Annex: Index of Standing Order Requirements	Page 185 and following
26.6B	Where provisions of the Bill are derived from existing primary legislation, whether for the purposes of amendment or consolidation, the Explanatory Memorandum must be accompanied by a table of derivations that explain clearly how the Bill relates to the existing legal framework	The requirement in Standing Order 26.6B for a Table of Derivations is not applicable to this Bill as the Bill is a standalone piece of legislation and does not derive from existing primary legislation for the purposes of amendment or consolidation.	N/A
26.6C	Where the Bill proposes to significantly amend existing legislation, the Explanatory Memorandum must be accompanied by a schedule setting out the wording of existing legislation amended by the Bill, and setting out clearly how that wording is amended by the Bill.	The requirement in Standing Order 26.6C for a Schedule of Amendments is not applicable to this Bill as the Bill does not propose to significantly amend existing primary legislation.	N/A