

Autism (Wales) Bill

Committee Stage 1 Report

December 2018



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Autism (Wales) Bill

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About the Committee

The Committee was established on 28 June 2016. Its remit can be found at:
www.assembly.wales/SeneddHealth

Committee Chair:



Dai Lloyd AM
Plaid Cymru
South Wales West

Current Committee membership:



Dawn Bowden AM
Welsh Labour
Merthyr Tydfil and Rhymney



Angela Burns AM
Welsh Conservatives
Carmarthen West and South
Pembrokeshire



Neil Hamilton AM
UKIP Wales
Mid and West Wales



Helen Mary Jones AM
Plaid Cymru
Mid and West Wales



Julie Morgan AM
Welsh Labour
Cardiff North



Lynne Neagle AM
Welsh Labour
Torfaen



Rhiannon Passmore AM
Welsh Labour
Islwyn

The following Members were also members of the Committee during this inquiry:



Rhun ap Iorwerth AM
Plaid Cymru
Ynys Môn



Jayne Bryant AM
Welsh Labour
Newport West

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Chair's foreword

Autism is a lifelong condition like no other. We have talked to people with Autism Spectrum Disorder (ASD) and their families who are struggling, and say they have waited 10 years for the autism strategies to deliver the support they need, and it has not happened.

The Committee understands the rationale of the Member in Charge in introducing this Bill and agree wholeheartedly with the need for improvements in provision of services for people with ASD. We have listened to people with ASD and their families and are convinced that further action is required in this area, particularly in terms of access to support services.

The current difficulties people with ASD and their families regularly face in attempting to access support is unacceptable and must be addressed. The message has clearly come through in evidence that more support services are urgently needed for people with ASD.

We have not, as a Committee, been able to reach consensus on whether this legislation, at this particular time, is the most appropriate way of achieving these much needed improvements.

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

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

We are, however, in agreement that there is a pressing need to improve support services for people with ASD and their families across Wales, and believe this must be addressed as a matter of priority.

Dr Dai Lloyd AM
Chair

Recommendations

Recommendation 1. We recommend that the Welsh Government directs the Integrated Autism Services to improve the consistency of the services across the regions, to ensure a national approach, and reports back to the Committee within six months. We also recommend that they produce clear public information to clarify what people can expect from the Integrated Autism Service..... Page 32

Recommendation 2. We recommend that the Welsh Government increases the provision of direct ASD support services across Wales (beyond the services currently offered by the Integrated Autism Service), and ensures vital third sector services receive sustainable funding to continue and expand their specialist support services, which are providing direct frontline support and plugging the gaps which the Integrated Autism Services cannot deliver..... Page 32

Recommendation 3. We recommend the Welsh Government takes urgent action to address the clear need for employment support for adults with ASD. There must be a clear pathway for adults to be able to access support to assist them into employment. Careers Wales should play a greater role but there is also a case for providing additional funding to third sector agencies to deliver specialised employment support services..... Page 32

Recommendation 4. We recommend that the Welsh Government amends the Codes of Practice for Parts 3 (assessing the needs of individuals) and 4 (meeting the needs) of the Social Services and Well-being (Wales) Act 2014 to include specific provisions on ASD..... Page 34

Recommendation 5. We recommend that the Welsh Government instructs Health Boards and local authorities to ensure there are multiple, appropriate, clear referral pathways available to all, including a specific primary care pathway, and that existing barriers between the health, care and education sectors are removed, for example to enable GPs to refer children for education support.
..... Page 36

Recommendation 6. We recommend that it should be mandatory for all school staff (particularly teachers and teaching assistants) to receive training in awareness and understanding of ASD, during their initial teacher training and as part of their continuing professional development. Page 39

Recommendation 7. We recommend that the implementation of the Additional Learning Needs and Education Tribunal (Wales) Act 2018 is closely monitored to assess whether it meets the needs of children and young people with ASD considered “high functioning” and who do not have a co-occurring learning disability..... Page 40

Recommendation 8. We recommend that, if the Bill proceeds to Stage 2, an amendment should be brought forward to ensure that Judicial Review is not the only route available for individuals to assert their rights. Page 41

Recommendation 9. We recommend that the Welsh Government’s Code of Practice makes provision to ensure that individuals can access appropriate information and support in their language of choice..... Page 43

1. Introduction

1. On 13 July 2018, Paul Davies AM (the Member in Charge) introduced the Autism (Wales) Bill (the Bill)¹ and accompanying Explanatory Memorandum² and made a statement on the Bill³ in Plenary on 18 July.
2. On 12 June 2018, the Business Committee agreed to refer the Bill to the Health, Social Care and Sport Committee to consider and report on the general principles. Business Committee agreed that we should report by 7 December 2018.⁴

Terms of reference

3. The Committee agreed the following framework within which to scrutinise the general principles of the Bill:

To consider—

- the general principles of the Autism (Wales) Bill and the extent to which it will make provision for meeting the needs of children and adults with Autism Spectrum Disorder (ASD) in Wales and achieve the aim of protecting and promoting their rights;
- any potential barriers to the implementation of the provisions and whether the Bill takes account of them;
- whether there are any unintended consequences arising from the Bill;
- the financial implications of the Bill (as set out in Part 2 of the Explanatory Memorandum);
- the appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation (as set out in Chapter 6 of Part 1 of the Explanatory Memorandum).

¹ [Autism \(Wales\) Bill as introduced](#)

² [Explanatory Memorandum](#)

³ [Record of Proceedings: 18 July 2018](#)

⁴ [Business Committee's report on the timetable for consideration of the Autism \(Wales\) Bill](#)

The Committee's approach

4. Between 20 July and 14 September 2018, the Committee conducted a public consultation to inform its work, based on the agreed terms of reference. The Committee received 34 responses, which are published on the Assembly's website. In addition, the Committee heard oral evidence from a number of witnesses. The schedule of oral evidence sessions is published on the Assembly's website.

5. The National Assembly's Outreach Team held a series of focus groups across Wales to capture the views and experiences of a cross-section of people.⁵ Sessions were arranged through organisations that support adults with Autism Spectrum Disorder (ASD) and their families, as well as through local support groups. Ten sessions were held across Wales, in Dyserth, Bronllys, Newtown, Bridgend, Ebbw Vale, Cardiff, Swansea and Wrexham and 95 people took part.

6. Members of the Committee also visited Autism Spectrum Connections Cymru (ASCC) One Stop Shop in Cardiff to talk to service users, and held roundtable discussions with family members of people with ASD.

7. The Committee would like to thank all those who have contributed to its work.

Other Committees' consideration of the Bill

8. The Assembly's Finance Committee took evidence from the Member in Charge on 11 October 2018 and the Cabinet Secretary for Health and Social Services (Cabinet Secretary) on 7 November 2018 on the financial implications of the Bill. It reported on its conclusions on 7 December 2018.

9. The Assembly's Constitutional and Legislative Affairs Committee took evidence from the Member in Charge on 24 September 2018 and the Cabinet Secretary on 15 October 2018 on the appropriateness of the provisions in the Bill that grant powers to make subordinate legislation. It reported on its conclusions on 7 December 2018.

⁵ [Inquiry into the Autism \(Wales\) Bill: Focus Group Summary](#)

2. Background

10. 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.

11. 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.

About the Bill

12. 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.

13. 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.

14. 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.

Welsh Government’s position

15. The Welsh Government published an Autism Spectrum Disorder Strategic Action Plan⁶ in 2008, a Refreshed Strategic Action Plan⁷ in December 2016, which

⁶ [Autism Spectrum Disorder Strategic Action Plan](#)

⁷ [Refreshed Autistic Spectrum Disorder Strategic Action Plan](#)

runs from 2016-20, and an Updated Delivery Plan⁸ in September 2018 which runs from 2018-21.

16. The 2008 action plan established an autism infrastructure in each local authority area, with local co-ordinators and strategies, and a Wales national co-ordinator. The 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.

17. The Welsh Government has stated⁹ that the Integrated Autism Service will:

- Bring together existing children’s autistic spectrum disorder neurodevelopmental teams within health boards to provide diagnostic, assessment and specialist interventions (therapies) for children with ASD;
- Develop new specialist adult teams, which will offer diagnostic provision;
- Develop new community support teams in health board areas, providing behavioural advice, low-level support, access to community services, support programmes and sign-posting. This service will also provide training for parents and carers across the age range;
- Build on existing services by developing professional capacity and enhancing skills, to improve diagnostic assessment and post-diagnostic support.

18. The Integrated Autism Service is currently operational in Cardiff and Vale, Cwm Taf, Gwent, Powys, and North Wales. The Cabinet Secretary for Health and Social Services told the Committee:

“the integrated autism service is up and running in most parts of the country. The two remaining areas will be dealt with before the end of this financial year with the start of the service in both western bay and in west Wales.”¹⁰

19. An independent evaluation of the ASD Strategic Action Plan published its interim report in March 2018, with a final report due for completion by January

⁸ [Updated Delivery Plan 2018-2021](#)

⁹ <https://gov.wales/newsroom/health-and-social-services/2016/autism/?lang=en>

¹⁰ <http://record.assembly.wales/Committee/5182>

2019. The Welsh Government has also committed to publishing an annual report on the Autism Spectrum Disorder Strategic Action Plan.

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

21. The Welsh Government has put in place a new 26 week waiting time standard for children, measuring waiting times from referral to first appointment, and said it is expected that 80% of first assessment appointments will be undertaken by 26 weeks. (NB: the relevant Quality Standard issued by the National Institute for Health and Care Excellence (NICE) (QS51) currently recommends that people with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within three months of their referral).

22. The Welsh Government has also committed to publish a Code of Practice on the delivery of autism services under the Social Services and Well-being Wales Act 2014 and the NHS Act 2006, which it states “can address all the issues identified in the Bill and can address additional concerns raised by stakeholders”.¹¹

23. The Cabinet Secretary for Health and Social Services has stated he will issue a public consultation in November to gather views on where to focus the autism Code. He stated that the consultation document will focus on five key areas and will “seek to capture many of the issues set out in the Autism Bill”:

- assessment and diagnosis;
- accessing care and support;
- staff training;
- planning; and
- stakeholder engagement in service planning and delivery.

24. The Welsh Government plans to maintain the 26 week assessment waiting time standard for children and expand this to adult services (whereas the Bill provides a new 13 week target). The Cabinet Secretary stated:

¹¹ Health, Social Care & Sport Committee, 25 October 2018, Paper 4

“We do not think it is wise to change these arrangements, as our tested approach will enable service providers to organise and deliver timely first assessment appointments, rather than just to signal assessment has commenced, as set out in the Autism Bill. Our approach will help to ensure there remains sufficient resources to provide a post diagnostic service. There is little to be gained by focusing hard pressed resources on funnelling individuals through assessment at the cost of providing care further down the line, when it is most needed.”¹²

25. The Welsh Government does not currently support the legislation:

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

We have closely scrutinised the Bill and considered the evidence presented by other contributors. It has become clear that the Bill raises unrealistic expectations of preferential services for autistic people which will be perceived as unfair, and will disadvantage others who have significant support needs but do not have an autism diagnosis.”¹³

26. It goes on to suggest that:

“the Bill is creating a perception that autistic people will receive preferential services, and this can only mean that resources will be diverted from other services, creating an inequity of support for other individuals who have other substantial support needs, such as people with learning disabilities or sensory impairments.”¹⁴

27. This was a concern expressed by a number of respondents and will be covered in more detail in Chapter 4.

¹² Plenary, 25 September 2018, paragraph 194

¹³ *ibid*

¹⁴ Health, Social Care & Sport Committee, 25 October 2018, Paper 4

Other UK nations

28. Autism Acts were passed in England in 2009 and Northern Ireland in 2011. An Autism Bill was introduced in Scotland in 2010 but did not progress past Stage 1 of the scrutiny process.

England

29. The Autism Act 2009¹⁵ places a duty on the UK Government to publish an adult autism strategy and associated statutory guidance for local authorities and local health bodies on supporting the needs of adults with autism.

30. The UK Government published a progress report in 2016¹⁶ and a “governance refresh” in 2017¹⁷, stating

“In 2017, it was agreed that the arrangements for overseeing implementation of the Strategy should be refreshed. In some areas, it was agreed with stakeholders that progress was not as quick as envisaged, and that there was scope to streamline the set of actions and commitments and to re-confirm ownership of specific actions to focus on those that would best realise the objectives of the Strategy. The Strategy itself has not changed, but the implementation activities required to deliver its intended outcomes, and who will do what, have been clarified. This has returned the focus to delivering what is required by the Autism Act and Statutory Guidance, in a realistic and measurable way. [...]

The aims and the objectives of the Think Autism Strategy stand but the revised governance model is expected to help drive progress this year before a formal review of the Strategy in 2019.”

Northern Ireland

31. The main objective of the Autism Act (Northern Ireland) 2011¹⁸ is to enhance the provision of services to, and support for, people with a condition on the autistic spectrum. The Act seeks to achieve this by means of:

¹⁵ [Autism Act 2009](#)

¹⁶ [Progress Report on *Think Autism*: the updated strategy for adults with autism in England](#)

¹⁷ [Think Autism strategy governance refresh](#)

¹⁸ [Autism Act \(Northern Ireland\) 2011](#)

- amending Schedule 1 to the Disability Discrimination Act 1995 to resolve any ambiguity as to whether the term “disability” applies to autistic spectrum conditions; and
- requiring the preparation and implementation of an autism strategy.

32. The Northern Ireland Government published a progress report in November 2015, with the relevant Minister stating:

“Many of the key themes of the Strategy are progressing well, with better support available to access services for people with autism, their families and carers. [...]

Although there has been significant progress in many areas, it is undoubtedly the case that the considerable increase in referrals has created a major challenge for the Health and Social Care Sector and particularly their ASD teams. Over the past six years, referrals of children and young people for assessment have increased from around 1,500 to 2,936 per annum. As there are a limited number of clinicians with the appropriate skills working in this area, this has inevitably resulted in longer waiting times for the first assessment and ultimate diagnosis.

I fully understand that an increase in waiting times is stressful and upsetting for families however, based on current service capacity autism services are unable to keep pace with demand. The Health and Social Care Board are reviewing the process of diagnosis with the aim of identifying more efficient methods of assessment and maximising clinical time, but still delivering a high quality diagnosis.

Given the scale of challenges I face in the current financial climate, it is simply not possible to guarantee the early intervention as outlined in the Autism Strategy, without additional funding to further develop autism specific assessment services. As I have reiterated before, such pressures are a fact of life. Therefore, to break out of this cycle we have to intensify our efforts to reform our thinking, processes and services, while at the same time, continuing to deliver the services people need.

It is with that aim the HSC Board is also working with all HSC Trusts to develop a new standard operating model which will focus on developing early intervention teams and seek to integrate and align autism services with other child development and young people’s mental health services. It is anticipated that, in the medium to longer term, this will help in the development of new ways of working with a

view to improving access to a timely assessment and diagnosis and provision of support services.”¹⁹

Scotland

33. The Autism (Scotland) Bill was introduced as a Members’ Bill in the Scottish Parliament on 26 May 2010 by Hugh O’Donnell MSP. The purpose of the Bill was to place a statutory duty on the Scottish Government to prepare and publish an autism strategy to meet the needs of young people and adults with autistic spectrum conditions, and to produce guidance for local authorities and NHS bodies to implement the autism strategy.

34. In December 2010 the Bill “failed to convince the Education, Lifelong Learning and Culture committee”, according to its Stage 1 report.²⁰

35. The committee praised the Bill’s good intentions and agreed that people with autism and their families faced significant barriers when trying to access services. However, it felt the Bill would be unable to deliver the improvements to services needed. In particular, the committee feared the proposed obligation on NHS bodies and councils to “have any regard to” any guidance, would not be robust enough.

36. Committee Convener Karen Whitefield MSP said:

“We recognise the good intentions and goodwill behind Hugh O’Donnell’s Members Bill, and that this bill has led to a number of significant steps being taken by the Scottish Government on autism.

However, the committee is not convinced the proposed Scottish Government strategy on autism would be improved by passing autism-specific legislation. We think that resources should be concentrated on improving services for adults, rather than creating new legislative burdens on NHS bodies and councils.

We are also concerned this bill could create a perception of two-tier disabilities with some strategies thought of as more worthy of legislation and therefore seen as having more weight.”²¹

¹⁹ [Department of Health, Social Services and Public Safety: Progress of the Cross-departmental Autism Strategy \(2013-2020\) and Action Plan \(2013-2016\) as at 30 September 2015](#)

²⁰ [Stage 1 of the Autism \(Scotland\) Bill](#)

²¹ [Autism Bill fails to make the case](#)

37. The Stage 1 debate took place on 12 January 2011, when the Parliament disagreed to the general principles of the Bill and the Bill therefore fell.

3. General principles and the need for legislation

General principles

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

39. 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.

40. It also includes arrangements for combining assessments, duties on the Welsh Ministers to collect suitable data and to undertake an autism awareness campaign, and duties on the Welsh Ministers and relevant bodies to have regard to United Nations Principles and Conventions.

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

- 1.** Introduce a strategy for meeting the needs of children and adults in Wales with ASD conditions which will:
 - Promote best practice in diagnosing ASD, and assessing and planning for meeting care needs;
 - Ensure a clear and consistent pathway to diagnosis of ASD in local areas;
 - Ensure that local authorities and NHS bodies take necessary action so that children and adults with ASD receive the timely diagnosis and support they need across a range of services;
 - Strengthen support for families and carers and ensure their wishes, and those of people with ASD, are taken into account;
 - Promote research, innovation and improvement in ASD Services;

- Establish practices to enable the collection of reliable and relevant data on the numbers and needs of children and adults with ASD, so that local bodies can plan accordingly;
 - Require key staff working with people with ASD to receive ASD training;
 - Ensure that local authorities and health boards publish information on the services they provide for people with ASD in their areas; and
 - 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.²²

Contents of the autism strategy

42. Section 2 of the Bill sets out what the contents of the autism strategy must cover including best practice models on assessment; a referral pathway; ensuring persons are not denied access to services on the grounds of IQ; access to employment; autism research; continuity of service with the transition from childhood to adult, and:

- “make provision so that an appropriate range of services to deliver the autism strategy is available consistently across Wales”;
- “make provision for the identification of key professionals and provision of appropriate training” in supporting people with ASD;
- “make provision to establish the necessary infrastructure and leadership to monitor and promote the implementation of the autism strategy”.

²² Explanatory Memorandum, paragraph 4

Diagnostic assessment and waiting times

43. According to the Explanatory Memorandum, “the length of time taken to receive a diagnosis continues to be a major problem for people with ASD, their families and carers”.²³

44. The Member in Charge told us:

“waiting times for diagnostic assessments are still unacceptably long, and in some parts of Wales they far exceed even the Welsh Government’s waiting times standard of half a year from referral to first diagnostic assessment. In one area, people have to wait two years, and in my own area people have had to wait up to seven years before their children have had a diagnostic assessment. Now, this Bill would actually introduce a three-month waiting time. This Bill also provides that needs assessments following diagnosis should be undertaken within 42 working days of a diagnosis or any post-diagnostic meeting.”²⁴

45. Evidence from Dr Duncan Holtom, Head of Research at People and Work, who carried out the evaluation of the Welsh Government’s original autism strategy and the interim evaluation of the Integrated Autism Service and refreshed autism strategy highlighted the importance of getting a diagnosis to adults with autism and to the parents and carers of children with autism:

“Diagnosis provides insight and understanding of the difficulties people with autism and their families face and, particularly for children, can improve access to services and provision.”²⁵

46. Dr Holtom’s evidence stated that while the evaluation of the original strategy had highlighted improvements in assessment and diagnosis for both children and adults in some areas, there was considerable inconsistency in practice across Wales, with long waiting lists in some areas; an excessive reliance upon individuals with an interest in and commitment to autism (which contributed to the fragility of services); and, in some areas, a lack of clarity about referral pathways.

47. It went on to say that the interim evaluation of the Integrated Autism Service and refreshed autism strategy confirms the need for action to strengthen assessment and diagnosis services as well as enhancing the sustainability of

²³ Explanatory Memorandum, paragraph 153

²⁴ RoP, 19 September 2018, paragraph 25

²⁵ Written evidence, A34

services; minimising inconsistencies in provision across Wales; and establishing clear referral pathways.

48. Evidence from the National Autistic Society Cymru stated that “getting a diagnosis can be the key that unlocks support and services for autistic people”.²⁶ It welcomes the proposal to link to the relevant Quality Standard issued by the National Institute for Health and Care Excellence (NICE) (QS51 currently recommends that people with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within three months of their referral).

49. The Association of Educational Psychologists also recognised that receiving a diagnosis of autism provides many individuals and their families with a measure of certainty, greater insight into the difficulties they experience, and access to services.²⁷

50. However, some respondents warned that “linking resource to a particular diagnosis is a risk that individuals or families will feel that their best opportunity to access the support they need is by securing that particular diagnosis”.²⁸

51. The Children’s Commissioner for Wales told us:

“Many families I speak to tell me about their need to fight to obtain a diagnosis for a child’s difficulties, as this is very often seen as the gateway to receiving services and support. This is not unique to autism; it relates to other matters as well such as mental health services and support for a child with learning difficulties. It should not be the case that a diagnosable condition is seen as a ‘golden ticket’ to receiving a suitable service.”²⁹

52. We heard some concerns about the new targets. The Welsh NHS Confederation and Royal Colleges believe that the changes in waiting time targets would have a significant impact on resources (both financial and workforce) as well as a team’s capacity to provide other services such as follow-up support, which is as important as the treatment itself.³⁰

²⁶ Written evidence, A13

²⁷ Written evidence, A28

²⁸ Written evidence, A18

²⁹ Written evidence, A16

³⁰ Written evidence, A07

53. The North Wales Integrated Autism Service told us:

“There are concerns across the IAS [Integrated Autism Service] nationally, that the pressure imposed on services to meet the 13 week waiting time from referral to first appointment will have a detrimental effect on the support element we are able to provide. We acknowledge that waiting times are an issue, but this is also linked to a wider workforce issue in that there is a relatively small pool of professionals who can undertake them.”³¹

54. The Integrated Autism Service Community of Practice state that a 13 week timescale for all diagnostic assessments does not reflect a person centred approach nor the length of time required to undertake often quite complex multi-disciplinary assessments. It also warns:

“[...] it must be clearly understood that the emphasis upon diagnostic waiting times will have an adverse effect upon the level and quality of support that the IASs [Integrated Autism Services] can deliver.”³²

55. Sian Lewis of the Gwent Integrated Autism Service told us:

“we’re very concerned that the legislation, which focuses on timescales rather than the quality of the service that’s going to be delivered, is going to cause us to take a backwards step. We would be struggling to provide a support service if we have to concentrate on starting diagnostic assessments within a 13-week time frame. I think we’d all be concerned about perhaps putting things in place that are not best practice, such as sending out forms in order to comply with that, or bringing people in for an initial meeting to discuss their possible diagnosis.”³³

56. The Integrated Autism Service Community of Practice also felt that it would be easy to superficially comply with the targets with an initial contact but this would not improve outcomes for individuals. Dr Rona Aldridge told us:

“[...] you will find that services will very easily fudge the numbers. We will make a phone contact, or you’ll send out a questionnaire, and you could say that the assessment started in 13 weeks. I don’t think that’s appropriate. I think the assessment should be started and finished in a

³¹ Written evidence, A17

³² Written evidence, A09

³³ RoP, 11 October 2018, paragraph 263

good time frame. We could easily report that assessment started in 13 weeks, but I don't think that's what anyone wants."³⁴

57. The Member in Charge responded to this point, telling the Committee:

"[...] the relevant NICE quality standard states, and I'll quote this:

'People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.'

Now, I read this as meaning that the formal diagnostic process is to be started, rather than just being an administrative process, such as sending an appointment letter, for example, which, obviously, you've suggested. But, again, to avoid ambiguity, I'm happy to introduce an amendment at Stage 2 that makes this explicit, if you feel, as a committee, that should happen."³⁵

Focus of the Bill

58. A number of respondents raised concern that the Bill is too narrowly focused on diagnosis, and that a more holistic approach is needed.

59. The Welsh Government's evidence states:

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

60. It goes on to say:

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

³⁴ RoP, 11 October 2018, paragraph 326

³⁵ RoP, 7 November 2018, paragraph 204

creating an environment where an autism diagnosis could give preferential treatment to support and services.”³⁶

61. The Royal College of Nursing (RCN) suggested that “the legislation does not necessarily reflect the general trend in moving away from tight diagnoses of specific conditions, and taking a more needs-based approach to supporting people”.³⁷

62. Written evidence from the Royal College of Paediatrics and Child Health highlighted that the legislation is not child-centred:

“RCPCH members in Wales are concerned that in linking resource to a diagnosis – whether autism, ASD or a given definition of ND disorders - there is a risk that families will feel that their best opportunity to access the support they need is by securing that diagnosis. This is not child-centred, because children presenting with a range of issues or symptoms that may be similar to or overlap with ASD but where ASD is not an appropriate diagnosis, may then be excluded from a pathway to receiving the appropriate care and resources. RCPCH and our members believe that policy, legislation and services should meet the needs of all individuals with traits similar to ASD or ND, that impair their everyday social, psychological and intellectual functioning - whether or not they meet a diagnostic criteria. Otherwise we risk alienating vulnerable populations who have no diagnosis and a weaker voice to advocate for themselves.”³⁸

63. Written evidence from the parent of a young man with autism told us, “diagnosis is just one short moment in a person’s life and by no means the most important”. They went on to say:

“Getting a diagnosis is good but a piece of paper from a doctor saying you have autism doesn’t actually help you progress anywhere in life. My personal experience is that having a diagnosis has become less and less relevant to my son as the years have gone by. It’s the people he has met along the way, the support assistants, the teachers the employment coaches they are the ones who’ve made the difference. He hasn’t seen a clinician other than his GP in many years. Being able to access other things around employment or social opportunities these are actually

³⁶ Health, Social Care & Sport Committee, 25 October 2018, Paper 4

³⁷ Written evidence, A18

³⁸ Written evidence, A05

helpful but if everything goes into diagnosis those things simply won't be there."³⁹

64. Zoe Piper of ADHD Connections told the Committee that support shouldn't be conditional based on whether you have a certain label, and felt the Bill will drive us further down this route, whereas we should be focused on needs, so that individuals who don't quite reach the diagnosis threshold won't miss out:

"[...] some of the problem is that not all children will necessarily meet a full autism diagnosis. Like my son, you know. He's 14 now and he's finally got an autism diagnosis, but at three, I couldn't get any help and support for him, because he wasn't meeting that threshold. He had one or two boxes that he didn't quite tick. So, we struggled until he was six, to the point of family breakdown, because I couldn't get any help and support for him, just because he didn't tick two boxes. However, now he's 14, he has those ticked boxes. The support should have been there regardless."⁴⁰

65. Dr Catherine Norton, of the Royal College of Paediatrics and Child Health made a similar point, stating:

"So, children and families get referred because there's a problem or a concern. That may or may not be autism, and the risk of very diagnostic-specific legislation is you then hit on those children who don't quite meet that criteria..."⁴¹

66. We heard that the recently developed all-Wales shared neurodevelopmental pathway ("focused on need rather than diagnosis") had been helpful in supporting a move towards person and needs-led assessments and interventions, and the Bill would potentially undermine progress made with a focus on autism only (although Dr Dawn Wimpory gave an opposing view, stating that the shared pathway had not been helpful in her experience).

67. The Royal College of Speech and Language Therapists said that the shared pathway had been very helpful in supporting broader thinking around diagnosis to ensure that those who do not meet the threshold for diagnosis and their

³⁹ Written evidence, A03

⁴⁰ RoP, 25 October 2018, paragraph 76

⁴¹ RoP, 11 October 2018, paragraph 362

families have access to equitable and appropriate services, despite not necessarily meeting the criteria for autism that would be required under the proposed Bill.⁴²

68. Julie Mullis told us:

“I believe that if you have an autism diagnosis route and the question is, ‘Has this child got autism or not autism?’, it limits the ability to think holistically about a child. One of the reasons why the neurodevelopmental pathway is not called the ‘autism pathway’ is because we’re trying to move away from that narrow focus on one diagnosis and look more broadly, because we know about the myriad neurodevelopmental conditions that exist and the co-occurring conditions and the subtleties of how one affects another. So, I think when a child comes to you with concerns, with difficulties, with issues, you should be starting from a clean slate, not from thinking, ‘Well, is this autism?’”⁴³

69. Zoe Piper of ADHD Connections told us that the neurodevelopmental pathway was an improvement and a lot easier for families to navigate and understand, as previously:

“you’d either go to paediatrics or you’d go to CAMHS. It was very muddy. Whereas now, you go to one place, the new neurodevelopmental disorders service. So, it’s a lot easier for families to find out where they need to go and it’s also very clear for families, the way that the pathway is written.”⁴⁴

70. The Member in Charge did not accept the view that the Bill was too diagnosis focused, telling us:

“I don’t think my Bill is just about diagnosis. Yes, it does include the provision to ensure that there’s a clear pathway to diagnosis, but my Bill, I think, is much more holistic than that, because if you look at my Bill in the round it includes ensuring that there’s a comprehensive strategy delivered by the Government, and it ensures that we collect the right information so that local health authorities and local health

⁴² Written evidence, A14

⁴³ RoP, 25 October 2018, paragraph 110

⁴⁴ RoP, 25 October 2018, paragraph 61

boards and local authorities can actually plan their services ahead in the future.”⁴⁵

71. He further stated:

“And I understand that the social services and well-being Act, and the additional learning needs and education tribunal Act take a needs-based approach rather than a condition-based approach, but this Bill won’t change that in any way. The provision of services for people with autism, as for other conditions, will continue to be made on the basis of need. People with autism may have a range of needs, not all of them related to their diagnosis. Some may not require any additional help at all.”⁴⁶

Access to services

72. Parents who took part in our focus groups on 25 October told us that “services aren’t there” for people with ASD, and that statutory services tend to refer people to local third sector services which are often run by volunteers (and are struggling to meet demand in the face of funding cuts). We also heard from the Assembly Outreach team’s report that the majority of people who took part in the focus groups felt that they received no support at all other than from third sector support groups or organisations (again it was noted such organisations are losing funding). They were strongly in favour of the Bill, which some said was “a must” to deliver change and improvement.

73. The Assembly Outreach team heard from parents who said “everything was a fight”. They said they were at crisis point, exhausted and stressed, not because of the condition itself but because of the lack of support, communication and services available that are suitable for people with ASD.

74. We also heard in the focus groups that there are clear gaps in service provision for people with ASD with a high IQ and without a learning disability or mental health condition. Participants also said that they did not believe the Integrated Autism Service would provide the level of frontline support services which are urgently needed.

75. Adults with ASD who took part in the Committee’s visit to Autism Spectrum Connections Cymru (ASCC) felt the Bill was a positive step but there was a missing section relating to adults with ASD who are not “critical”. They

⁴⁵ RoP, 19 September 2018, paragraph 52

⁴⁶ RoP, 7 November 2018, paragraph 163

felt they were an invisible group in the Autism community as they did not fall into the category of children or adults who need day to day care and they are not affecting employability and disability statistics. We heard that these individuals are keen to work but unable to get a job and need support to help them into employment.

76. This was supported by research carried out by the British Psychological Society in 2017, which found that only 16 percent of adults with autism were in full time employment, compared with 80 per cent of the general population and 47 per cent of people with disabilities overall.⁴⁷

77. Evidence from NAS Cymru said:

“We welcome the fact that the Bill seeks to address the wider needs of autistic people including support around meeting employment and housing needs. More than half (55 per cent) of autistic people who responded to our 2016 survey said that they’d like more support around employment and only one in ten were in full time paid employment.”⁴⁸

78. Evidence from the Welsh Local Government Association said:

“The Welsh Government has also acknowledged that many people with ASD or similar conditions often find it difficult to find and maintain employment and have recently introduced an Employability Plan. The plan provides an individualised approach to employment support and gives advisers the autonomy and flexibility to address the needs, strengths and ambitions of the person preparing for work. The Welsh Government are also supporting the Getting Ahead 2 project, which is aimed at people between the ages of 16-25 with learning disabilities and/or ASD.”⁴⁹

79. The Member in Charge gave a commitment to look at strengthening the Bill in relation to employment support at Stage 2.⁵⁰

⁴⁷ Written evidence, A23

⁴⁸ Written evidence, A13

⁴⁹ Written evidence, A25

⁵⁰ RoP, 7 November 2018, paragraph 263

80. Dr Duncan Holtom told the Committee that his reviews have shown that there are clear gaps in services, particularly for adults who do not fit with either mental health or learning disability services.⁵¹

81. Evidence from the Gwent Integrated Autism Service states that:

“the Integrated Autism Service also ensures that no adult falls through the gap of service eligibility criteria i.e. based on IQ.”⁵²

82. However, people with ASD and their families who attended our focus groups held across Wales talked about the Integrated Autism Service being more of a signposting service and online support rather than offering the practical support people wanted.⁵³

83. Additionally, people who took part in the visit to Autism Spectrum Connections Cymru all expressed concern over the Integrated Autism Service and felt that the voices of those with ASD were missing from the way the policy had been developed.

84. One participant felt there was a gap in the support given by the Integrated Autism Service at the lower end of the spectrum following diagnosis. They felt that the Service had provided some help but in trying to get back into work, there was a gap in support. The Integrated Autism Service had signposted to the Citizen’s Advice and the Job Centre, but no appropriate support had been offered. They felt that they were not cognitively disadvantaged enough to benefit from the courses on offer, but could have used support with other things such as benefits they are entitled to.⁵⁴

85. Written evidence from an individual living with a diagnosis of Asperger’s Syndrome and ADHD also states:

“The IAS [Integrated Autism Service] has failed to provide an adequate level of support services for my needs as a person living with autism and they will never be as good as the One Stop Shop at 21 High Street in Cardiff.

⁵¹ RoP, 3 October 2018, paragraph 142

⁵² Written evidence, A08

⁵³ [Autism \(Wales\) Bill Focus Group Summary – September 2018](#)

⁵⁴ Summary of focus group discussions – 25 October 2018

I am very concerned that the IAS [Integrated Autism Service] will not fulfil what is required for people living with autism and I have no confidence in the National ASD Strategic Action Plan.”⁵⁵

86. Dr Rona Aldridge of Cardiff and the Vale Integrated Autism Service denied that the Integrated Autism Service was merely a signposting service:

“The IAS [Integrated Autism Service] has a number of different roles and responsibilities. We have the direct work that we provide, which would be diagnostic assessments of adults, as well as individual and group intervention. Sometimes, that intervention is about signposting and supporting them to other services, because it doesn’t make sense for a specialist autism service to be supporting everybody with autism. It’s not sustainable, it’s not possible and it’s not about working alongside other services. Sometimes it’s about signposting, but it’s not only about signposting.”⁵⁶

87. We heard concerns about the funding for ASD services in Wales and the effectiveness of current spending and value for money. The Integrated Autism Service is funded by £13m for the seven health boards over five years (2016 - 2021) through the Integrated Care Fund (ICF). The service launched in Powys in July 2017, with Gwent and Cardiff and the Vale following in August and September 2017. Cwm Taf launched in March 2018 and North Wales in June 2018. The service is still not up and running in Hywel Dda or Western Bay areas.

88. NAS Cymru told us:

“We remain concerned about where funding for the IAS [Integrated Autism Service] has been directed, lengthy delays in developing the services across Wales and the services’ capacity to assess and meet the needs of those whose expectations have been raised by commitments that have not been followed through. The Cabinet Secretary painted a picture of calm, considered and timely roll-out of the service, however we are not aware of any evidence to support this description.”⁵⁷

89. We also heard concerns around accountability, with Gareth Morgan, Autism Spectrum Connections Cymru, saying:

⁵⁵ Written evidence, A01

⁵⁶ RoP, 11 October 2018, paragraph 273

⁵⁷ Health, Social Care & Sport Committee, 7 November 2018, Paper 15

“We are unaware of how the Welsh Local Government Association has been held to account over the way that that has been developed. We are aware that there are major disconnects between what Welsh Government says the integrated autism service will do, and what it does on the ground. We have very good relationships with the integrated autism services across south Wales. There are some very, very talented and skilled and dedicated members of staff who are working within those, but the job that they are being asked to do on the ground is different from what Welsh Government are saying they are doing. It is different from what they are capable of doing from the money that is provided to them.”⁵⁸

90. Written evidence from Dr Duncan Holtom noted that the interim review of the Integrated Autism Service identified encouraging signs of improvements from the services, along with fears that demand for assessment and diagnosis could exceed the capacity of the new Integrated Autism Service and/or side-line or undermine the other important aspects of its work, such as post-diagnostic support.

91. Dr Holtom’s evidence said that the interim evaluation of the Integrated Autism Service (2018) identifies consistent support from stakeholders for the Integrated Autism Service model as part of the means for filling this gap in services, but he warned, “The IAS [Integrated Autism Service] is not a panacea though, and cannot and should not seek to address all gaps or weakness in services”.⁵⁹

Our view

92. The message has clearly come through in evidence that more support services are urgently needed for people with ASD and their families.

93. There is confusion among people with ASD and their families about the depth and breadth of what the Integrated Autism Service will provide to the public; many see it as mainly a diagnostic and signposting service, noting that people are being signposted to third sector support services, which are often run by volunteers who struggle to cope with the demand.

94. We note that part of this confusion is due to the fact that the Integrated Autism Service is being delivered differently in every region. The Integrated

⁵⁸ RoP, 3 October 2018, paragraph 37

⁵⁹ Written evidence, A34

Autism Service is being billed as a *National* service and therefore we believe it needs to be more consistent in its approach and delivery across the regions.

95. The Welsh Government and public bodies need to provide more clarity about what the Integrated Autism Service will provide, so that members of the public know what they can expect from the service.

96. We share concerns raised that if funding and focus is being solely directed to the Integrated Autism Service, there is a danger that this could result in a greater reduction in frontline support services which are vital for people with ASD and their families.

97. We note this situation is part of a wider damaging pattern, of the third sector having to plug the gaps in public sector services, and struggling to cope with greater public demand, in the face of funding cuts to their own services.

Recommendation 1. We recommend that the Welsh Government directs the Integrated Autism Services to improve the consistency of the services across the regions, to ensure a national approach, and reports back to the Committee within six months. We also recommend that they produce clear public information to clarify what people can expect from the Integrated Autism Service.

98. We await the final Integrated Autism Service evaluation review report in January and will monitor developments in terms of the review's recommendations and the Welsh Government's subsequent response – we expect the Welsh Government's response to be shared with the Committee and to receive regular updates on progress.

Recommendation 2. We recommend that the Welsh Government increases the provision of direct ASD support services across Wales (beyond the services currently offered by the Integrated Autism Service), and ensures vital third sector services receive sustainable funding to continue and expand their specialist support services, which are providing direct frontline support and plugging the gaps which the Integrated Autism Services cannot deliver.

Recommendation 3. We recommend the Welsh Government takes urgent action to address the clear need for employment support for adults with ASD. There must be a clear pathway for adults to be able to access support to assist them into employment. Careers Wales should play a greater role but there is also a case for providing additional funding to third sector agencies to deliver specialised employment support services.

Social Services and Wellbeing (Wales) Act 2014

99. The Welsh Government has stated:

“The Welsh Government has all the powers we need to deliver improvement to autism services in current legislation in the Social Services and Well-being (Wales Act) 2014, the Additional Learning Needs and Education Tribunal (Wales) Act 2018 and the NHS (Wales) Act 2006.”⁶⁰

100. However, parents who took part in our focus groups told us that current legislation such as the Social Services and Wellbeing (Wales) Act 2014 had failed to deliver improved outcomes for their children because the assessments are not appropriate for people with ASD, and they are therefore often wrongly denied care and support. The parents told us that all “high functioning” people with ASD are not eligible for social services under the Act, and while they may have a high IQ they may have great difficulty undertaking daily tasks.

101. Gareth Morgan from Autism Spectrum Connections Cymru told us:

“from a coalface perspective, we are still seeing hundreds upon hundreds of people with autism who are unable to access assessment through social services. Anecdotally, I’m receiving feedback from people working within the integrated autism services that the assessment tools themselves actually are biased against people with autism and have a direct impact upon the ability of people to receive adequate care and support moving forward.”⁶¹

102. The Member in Charge told us that he believed his Bill would supplement the Social Services and Wellbeing (Wales) Act to ensure these gaps in service provision for adults are actually filled.⁶²

103. The Cabinet Secretary states in his letter to the Chair dated 19 November 2018:

“National eligibility criteria for care and support under the Social Services and Well-being (Wales) Act 2014 makes no reference to IQ. This should not therefore be a factor in the assessment process.

⁶⁰ Health, Social Care & Sport Committee, 25 October 2018, Paper 4

⁶¹ RoP, 3 October 2018, paragraph 18

⁶² RoP, 7 November 2018, paragraph 175

If there is concrete evidence about how the SSWBW [Social Services and Well-being (Wales)] Act is not working then this must be addressed for all citizens. This is also set out in Chapter 3 section 17 of the Autism Spectrum Disorder Strategic Action Plan. It states that ‘The Welsh Assembly Government has made clear to authorities that access to health and social care services for adults must not be based on IQ related criterion’.⁶³

Our view

104. Despite the Cabinet Secretary’s assertion that this should not be happening, we have been told by people with ASD and charities who support them that many people with ASD are not able to access the care and support they need under existing legislation and there are specific problems with the assessment process. We are in agreement that this must be addressed to ensure that people with ASD who need care and support are able to access it, and that further action is required to plug the gaps in existing legislation.

105. We recommend that specific statutory guidance is produced regarding assessing and meeting the care and support needs of people with ASD. If this legislation proceeds, such guidance could be issued under the Act, but if the Bill is not enacted, we recommend that the Welsh Government amends the Codes of Practice for Parts 3 (assessing the needs of individuals) and 4 (meeting the needs) of the Social Services and Well-being (Wales) Act 2014 to include specific provisions on ASD. We are not convinced that this issue will be addressed in the Welsh Government’s forthcoming Code of Practice on ASD, as there is a particular issue with social services assessments, and therefore amending the Act’s guidance would be the preferred approach.

Recommendation 4. We recommend that the Welsh Government amends the Codes of Practice for Parts 3 (assessing the needs of individuals) and 4 (meeting the needs) of the Social Services and Well-being (Wales) Act 2014 to include specific provisions on ASD.

Referral pathways

106. The Committee has heard that there should be a primary care pathway for referral, and that barriers between the health, care and education sectors should be removed, for example to enable GPs to refer children for education support.

⁶³ Letter from the Cabinet Secretary for Health and Social Services to the Chair of the Health, Social Care and Sport Committee – 19 November 2018

107. Parents in the focus groups also told us that in some areas, the only referral pathway for diagnosis was through the school, and this was not working as staff were not trained to identify ASD and there are only a limited number of referrals to educational psychologists available, so the less disruptive children tend not to be prioritised. They felt there should be clear referral pathways in both health and education, and said GPs need to be able to make referrals.

108. We note the parallels with evidence taken by the Children, Young People and Education Committee in its inquiry into the emotional and mental health for children and young people. Carol Shillabeer, chief executive of Powys Teaching Local Health Board and chair of the Together for Children and Young People programme, told the Committee:

“My own view is that there should be no wrong door to go through. So, if somebody is making a referral, they’re obviously worried about something. The child or young person may not have a mental illness, but they’re obviously in need of some support, so there is a responsibility, I think, to then try to make sure that that support is provided.”⁶⁴

109. Mair Hopkin of the Royal College of GPs told us:

“We need to improve services that GPs can make referrals to. There need to be clear pathways that GPs can make referrals to so that we don’t get referrals bounced back from different services, and there needs to be provision in health, social care and education for all our patients who have additional needs.”⁶⁵

110. The Welsh Government’s evidence states:

“We understand there is frustration amongst Primary Care practitioners that they cannot refer into local authority services, and we will look at how the Integrated Autism Service is bridging this perceived gap between health and social care. It must be emphasised again that an Autism Bill cannot require specific services to be available.”⁶⁶

⁶⁴ Children, Young People and Education Committee, RoP, 22 November 2018, paragraph 222

⁶⁵ RoP, 11 October 2018, paragraph 22

⁶⁶ Health, Social Care & Sport Committee, 25 October 2018, Paper 4

111. Matthew Jenkins, Deputy Director, Partnerships and Co-operation, Welsh Government, confirmed that this was being considered as part of the consultation on the Code of Practice:

“this was one thing that we were actively looking at with the discussions within Government as to whether the code could place requirements on local authorities and health boards to establish a primary care pathway in that regard. So, that’s actively under consideration as something we would want to put into the consultation work.”⁶⁷

112. The Member in Charge told us that the Bill will put the autism strategy on a statutory footing, and will require the 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 for persons with autism spectrum disorder:

“Therefore, I’d expect this to include referrals from all appropriate sources, including primary care.”⁶⁸

113. He also gave an undertaking to look further at these pathways at Stage 2.

Our view

114. It is clear that many people with ASD and their families are struggling to navigate their way through complex systems – this must improve. We endorse the view heard by the Children, Young People and Education Committee that “there should be no wrong door” for a person in need of help and support.

115. We are convinced that referral pathways must be improved as a matter of urgency and that a new primary care pathway must be developed to improve access to support. We note that this aligns with the Welsh Government’s vision in a Healthier Wales,⁶⁹ moving towards a greater focus on community and primary care.

Recommendation 5. We recommend that the Welsh Government instructs Health Boards and local authorities to ensure there are multiple, appropriate, clear referral pathways available to all, including a specific primary care pathway,

⁶⁷ RoP, 25 October 2018, paragraph 302

⁶⁸ RoP, 7 November 2018, paragraph 249

⁶⁹ [A Healthier Wales: Our plan for health and social care](#)

and that existing barriers between the health, care and education sectors are removed, for example to enable GPs to refer children for education support.

Access to education

116. We heard from families of people with ASD that the lack of support in schools is a big issue. Comments from parents who took part in our focus groups on 25 October included “support in mainstream education is not there” and “schools have always disappointed me”.⁷⁰

117. Frustration around mainstream schools and their lack of understanding, knowledge and provision for children with ASD dominated the conversation in the majority of the focus group sessions held over the summer. Parents discussed how their children were often sent home from school making it difficult for them to work and for their children to access a full education. It was said that teaching assistants hired to give 2:1 or 1:1 support lacked training on how to support children with ASD and were often supporting multiple children at a time which impacted on the flexibility of support they could offer.

118. Parents were largely positive about the support offered in ASD specific units or schools for children with learning needs. However, these were often difficult to access due to limited places or with no school provision for ASD in the county. Some parents described having to take the local authority to court in order to gain a place even when their child’s needs were severe. One parent’s child was only offered two hours a day in a SEN unit as an alternative to remaining in mainstream education.

119. It was also felt that there was a lack of ASD specific support available in mainstream schools. For instance, it was felt that children with a high IQ needed more emotional and social support within that setting without moving to a different school. Adults with ASD also described numerous instances of being bullied at school by other children who lacked awareness of autism.⁷¹

120. Evidence from NAS Cymru states that:

“while some good work has been done in the development of awareness resources and training, uptake in accessing these has in our view been too slow and is inconsistent across the country. For example, not all local authorities are taking up the ‘Learning with Autism’ programme for schools. And since the scheme was extended in

⁷⁰ Summary of focus group discussions – 25 October 2018

⁷¹ Autism (Wales) Bill Focus Group Summary – September 2018

September 2017, only three secondary schools have achieved the 'Learning with Autism Award'.⁷²

121. While the Association of Educational Psychologists highlighted concerns about the “sufficiency of provision in schools, as well as the provision of appropriate out-of-school activities that CYP with autism can join in”.⁷³

122. The Royal College of General Practitioners (RCGP) also talked about the lack of support in schools. Dr Jane Fenton-May told us:

“We have not enough educational psychologists supporting the schools; we don’t have the mechanisms for the school, sometimes, to refer to specialist child and adolescent mental health services to get the support they need already for the children that they have.”⁷⁴

123. She went on to say:

“I understand there is a limit on the number that the schools can refer to the educational psychologists, and they have huge waiting lists, so maybe your targets should be: how quickly can you see the educational psychologist? And it should be less than six months, because a lot can happen to that child, and it can be excluded from school in that six months, and things go even more pear-shaped as a result.”⁷⁵

124. A number of witnesses noted that the Additional Learning Needs Act has not been implemented yet, and when it is, support in schools should improve, with some suggesting the schools issue is one of the key reasons why people are calling for action. The Integrated Autism Service Community of Practice told us:

“I think a lot of the dissatisfaction quite often is from families and about accessing education? The Additional Learning Needs and Education Tribunal (Wales) Act 2018 is due to be implemented, and the ethos of that Bill is to address an awful lot of the issues that are coming through from families with autistic children, because that Bill is around being child-centred and person-centred around the needs of that child. All children will have an individual development plan and all the interventions will be based on the presenting issues that child has, whether they have a diagnosis or not. But that Act hasn’t actually been

⁷² Written evidence, A13

⁷³ Written evidence, A28

⁷⁴ RoP, 11 October 2018, paragraph 31

⁷⁵ RoP, 11 October 2018, paragraph 92

implemented yet, so I think to actually put some of this in place before that's implemented is almost putting things in place for things that we hope that Bill will address."⁷⁶

125. The Legal Adviser supporting the Member in Charge stated:

"I'll reiterate what Paul said about working in harmony with other legislation. We also need to be mindful that there are limitations to that other legislation, and the Bill will help to fill those gaps and also support them. For example, with ALN, one of the concerns that I had was the definition of additional learning needs. So, for example, the way it's drafted at the moment may not capture those people with ASD who are 'high functioning'. So, there's a lacuna there potentially. Now, that doesn't mean that ALN won't be effective in many ways, including in relation to autism, but the Bill would certainly address that lacuna amongst other things.

So, taken together, the legislation—our Bill and the other two Acts we discussed—will, hopefully, result in a fairly comprehensive system for addressing autism in our particular case, but then, more widely, the other legislation would address other needs-based issues as well."⁷⁷

Our view

126. We were concerned to hear about the lack of support currently available in some schools, and believe referral pathways need to be improved (see previous section), and that further staff training on awareness and understanding of ASD is required, both as matters of urgency.

127. We note that the Additional Learning Needs and Education Tribunal (Wales) Act 2018 has not yet been implemented, although we did hear that there may be issues with the legislation similar to that being reported about the Social Services and Well-being (Wales) Act 2014, where people considered to be "high functioning" may potentially be missed.

Recommendation 6. We recommend that it should be mandatory for all school staff (particularly teachers and teaching assistants) to receive training in awareness and understanding of ASD, during their initial teacher training and as part of their continuing professional development.

⁷⁶ RoP, 11 October 2018, paragraph 284

⁷⁷ RoP, 7 November 2018, paragraphs 256-257

Recommendation 7. We recommend that the implementation of the Additional Learning Needs and Education Tribunal (Wales) Act 2018 is closely monitored to assess whether it meets the needs of children and young people with ASD considered “high functioning” and who do not have a co-occurring learning disability.

Remedies

128. The Welsh Government has repeatedly stated that compliance with autism legislation can only be enforced by way of Judicial Review, whereas it says there are built in mechanisms within the Social Services and Well-being (Wales) Act 2014 and NHS (Wales) Act 2016 for enforcement, with intervention powers for Welsh Ministers.

129. The Member in Charge’s legal adviser told us:

“We heard in evidence from the Government criticism of the Bill in relation to so-called remedies. I touched on that earlier. I would suggest that’s misleading. The reason being that, yes, Welsh Government has some existing powers under the Social Services and Well-being (Wales) Act 2014, the National Health Service (Wales) Act 2006, in relation to powers of direction, intervention, warning, et cetera. But I would argue that those are not remedies available to the citizen. They’re enforcement powers, and that’s very different.”⁷⁸

130. He also noted that in their view, the Welsh Government’s forthcoming Code of Practice would be weaker in terms of duties on health bodies:

“whilst there’s been a lot of talk around the force of the code and the fact that it has a statutory basis, it’s not mandatory in relation to health bodies. The obligation there is to ‘have regard’. There’s also been some confusing evidence, or criticism, about the lack of so-called remedies under the Bill, but that’s slightly misleading, because actually what’s been referred to in evidence by the Government are actually powers that relate to enforcement, and that’s different, and we may well go on to that, but that’s not the same as a remedy. So, actually, the code does not trump the Bill. In fact, we consider it to be weaker than the Bill.”⁷⁹

⁷⁸ RoP, 7 November 2018, paragraph 267

⁷⁹ RoP, 7 November 2018, paragraph 231

131. He went on to say they would be willing to consider amendments to the Bill at Stage 2:

“if the committee considers that the Bill would benefit from the power of direction, which is something that we did consider earlier on in the Bill, then, at Stage 2, we’d be happy to introduce that, although one might argue that Welsh Government already has existing powers, say, for example, under the NHS Act, sections 12 and 26, which they could use to enforce the Bill anyway, but we’re very open to addressing those issues further if the committee recommends that.”⁸⁰

Our view

132. We are concerned about the rights of individuals to be able to seek appropriate remedies when necessary, and believe there needs to be clearer routes available to individuals. We agree with the point made that the intervention powers of enforcement under existing legislation gives powers to Welsh Ministers not an individual. We believe that the Welsh Government should take steps to address this as part of its forthcoming Code of Practice.

133. We also believe that should this legislation proceed, it should be amended so that Judicial Review is not the only route available for individuals to assert their rights.

Recommendation 8. We recommend that, if the Bill proceeds to Stage 2, an amendment should be brought forward to ensure that Judicial Review is not the only route available for individuals to assert their rights.

Information and services in Welsh and other languages

134. According to the EM:

“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.”⁸¹

⁸⁰ RoP, 7 November 2018, paragraph 268

⁸¹ Explanatory Memorandum, paragraph 181

135. NAS Cymru welcomed that the Bill included provision for autistic people to be able to access Welsh language services, saying:

“This combined with the Welsh Government’s Active Offer framework strengthens the rights of autistic people to access services in the language they choose.”⁸²

136. However, some respondents, including UCAC, expressed concern that there was no provision on the face of the Bill in relation to the Welsh language.

137. A letter from the Welsh Language Commissioner states:

“I believe that a specific clause should be included in the Bill which states that the Welsh language should be a consideration when making all of the provisions required in 2(1) of the draft Bill. In particular, a clause should be included which requires the autism strategy to make provision to ensure that an appropriate range of services and personnel are provided to meet the care needs of persons with autism spectrum disorder along with their families and carers.”⁸³

138. The letter also asks that consideration be given to including provisions regarding data collection on people who wish to receive Welsh language services; the degree to which that demand is met; and data on practitioners in the field.

139. Evidence from Dr Elin Walker-Jones highlights some of the difficulties she has experienced with Welsh language provision, including a limited number of fluent, Welsh speaking staff, difficulties in recruiting Welsh speaking staff and the lack of linguistically appropriate testing resources.⁸⁴

140. In the focus groups on 25 October we also heard from the Chinese in Wales Association about the difficulties faced by Chinese people with autism in getting appropriate information, advice and support in an appropriate format. It was noted that interpreters need to be autism trained and diversity aware to ensure they convey information accurately and appropriately.

Our view

141. It is extremely important for individuals to be able to access appropriate information and support in their language of choice, and we believe further work

⁸² Written evidence, A13

⁸³ Health, Social Care & Sport Committee, 7 November 2018, Paper 14

⁸⁴ Written evidence, A29

is needed by the Welsh Government and all public bodies to ensure that this is delivered consistently across Wales.

Recommendation 9. We recommend that the Welsh Government’s Code of Practice makes provision to ensure that individuals can access appropriate information and support in their language of choice.

Data on autism spectrum disorder

142. Section 6 of the Bill states that the Welsh Ministers must obtain, produce and keep updated reliable data on ASD and publish it annually. According to the EM:

“Evidence shows that better information is needed on the number of people in Wales with a diagnosis of ASD and their needs. 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.”⁸⁵

143. Evidence from Dr Dawn Wimpory states:

“Under my own direction, BCUHB has successfully collected and collated such diagnostic information for children over the last 6yrs and is therefore unique in Wales in being able to identify accurately whether or not research-supported internationally-recognised prevalence rates are being adhered to, or exceeded or failing to be reached. BCUHB’s Autism Module enables examination of such figures within each of the 3 constituent areas of BCUHB and over the HB as a whole. Such figures are absolutely essential in Wales being able to identify whether diagnoses are being made at appropriate levels.

It is both inappropriate for ASD diagnoses to be missed and for people without ASD to be erroneously diagnosed as having ASD. These are real dangers and can only be addressed through accurate data recording and analysis in a constant manner. BCUHB’s database, conceived originally by WG, as a pilot for the whole of Wales, has demonstrated that such data can be efficiently and routinely recorded/analysed. I understand concerns from other services that this may be an

⁸⁵ Explanatory memorandum, paragraph 221

impossible task but 6yr's experience with our ASD database proves otherwise."⁸⁶

144. NAS Cymru also supported the new data collection provisions.

145. However, some respondents were uncomfortable about the level of personal information to be collected. Cardiff Council Social Services and the Disability Futures Programme Board at Cardiff Council both highlighted the need for any personal data collected to comply with data protection legislation (GDPR). Cardiff Council Social Services further states:

“Any other data for ‘interest’ purposes should be done via research units only. Collecting and processing data should not be to an extent that is significantly beyond that collected for other similar conditions. To do so risks marginalising this population for study purposes. Were this being done for in a research setting it would be accompanied by extensive work around consent and ethics and involve a clear understanding by the individuals as to exactly how the data will be used and processed.”⁸⁷

146. We also heard from the parent of a young man who has autism, who was very concerned about the volume of personal data the Bill would allow to be collected:

“It is outrageous to think that this level of intrusion is appropriate. My son is an active contributing member of our society. Yes, he has a condition but he makes the best of his life as we all do. He volunteers for a charity and has recently begun actual work 3 mornings a week. It is ridiculous to think that it is OK just because he has a disability to gather data on him as if he is some kind of a lab specimen.”⁸⁸

147. The Welsh Government also raised concerns about the proposed level of data to be collected, stating:

“The detailed person specific data requirement in this Bill does not tell us about the impact of services, only the individual characteristics of those with a diagnosis. As the Community of Practice for Adult Diagnosis and IAS [Integrated Autism Service] Clinicians points out in their evidence, the level of data required in the Bill is onerous and adds little additional relevant information to both planning and

⁸⁶ Written evidence, A26

⁸⁷ Written evidence, A21

⁸⁸ Written evidence, A03

commissioning. It does appear to be collecting for data's sake and there is a need to ensure it will be GDPR compliant."

148. It went on to say:

"To give a clearer picture of the numbers of autistic people and to raise awareness of their needs, we are introducing a GP autism register of the numbers of patients diagnosed."⁸⁹

149. However, the RCGP and Dr Dawn Wimpory both raised concerns regarding the Welsh Government's proposal of a GP register. Dr Mair Hopkin, RCGP, told us:

"I think we'd want to see what the benefits of a register would be. We can already identify our patients who have a diagnosis of autism within the practice. The list of the items that were put in this proposed Bill—it's difficult to know how that particular information is going to improve services. We already know that we don't have enough services to help with the diagnosis. We already know that there's often a delay. We already know that there's no linked up care between health, social services and education, which is what these patients need. And we'd like to know how a register would improve that and what the benefits of a register would be, because I don't think there's any evidence that having a register, particularly, for any disorder, improves care."⁹⁰

150. While Dr Wimpory states:

"We certainly need an obligation on clinicians to record their diagnoses, and it was a major obligation on our clinicians, and that's how we got them to do it. We didn't ask them for goodwill—it became a responsibility of the diagnosing clinicians to record each diagnosis that they made, and that's worked successfully.

So, I see that as recognised within the Bill. I also see that we have, for example, in the code that's recently been outlined—there's a suggestion that the GP database system could be used to record diagnoses. But the research using GP database records of autism—very thorough research—gives diagnostic levels lower than we've had in Betsi over the last six years. So, I've got evidence that, really, GPs are not picking up, not recording the autism in the way that, if the autism clinicians record it, then it gets done directly. I think they're more invested in it. I think

⁸⁹ Health, Social Care & Sport Committee, 25 October 2018, Paper 4

⁹⁰ RoP, 11 October 2018, paragraph 30

there are loads of responsibilities and burdens on GPs already, and autism is not their priority.”⁹¹

151. The Member in Charge told us:

“I think the data collection provisions are actually a key element of the Bill and I believe they actually reflect the importance of good data to enable service planning and to ensure the best possible use of limited resources. Improvements to data collection on autism under the Bill will help to improve service planning, resource allocation and financial planning. The benefits, of course, have already been highlighted by Dr Dawn Wimpory in her evidence to you as a committee. I think there’s great value in taking a consistent approach to data collection across Wales in the way that is actually set out in the Bill. It would enable comparison of rates of diagnosis, co-occurring impairments or developmental delay, diagnostic tools, waiting times for diagnosis and professionals undertaking diagnostic assessments. I think such data will enable identification of trends, for example in terms of gender, co-morbidity, professional practice, and will allow improvements to be made where necessary. This will permit more efficient and effective allocation of scarce resources.”⁹²

152. He did not accept that data collection was improving anyway through the Welsh Community Care Information System, as had been suggested by the Integrated Autism Service Community of Practice:

“I think the Welsh Government itself at the moment can’t actually accurately collect data. In its refreshed autism strategy, it said that it would collect data on the 26-week waiting time in March 2017. We’re still actually waiting for those figures. So, I haven’t seen any evidence that there has been an improvement in the collection of data, and that’s why it’s so crucial that this is actually included in the Bill—so that we do actually collect the appropriate data in the future.”⁹³

The need for legislation

153. Opinion was divided over whether or not this legislation is necessary.

⁹¹ RoP, 3 October 2018, paragraphs 244-245

⁹² RoP, 7 November 2018, paragraph 272

⁹³ RoP, 7 November 2018, paragraph 278

154. The Committee has heard about individuals with ASD and their families struggling to access support, long waits for diagnosis, and clear gaps in service provision. We've received evidence that the autism strategy and current legislation such as the Social Services and Wellbeing (Wales) Act 2014 have failed to deliver improved outcomes for people with ASD, and views that the Integrated Autism Service will not provide the level of frontline support services which are urgently needed.

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

156. People with ASD and their families told us that the Bill was needed, with some suggesting it did not actually go far enough. They said that they had lost faith in the Welsh Government to deliver the improvements needed through policy and the only way to drive the changes needed in services was statutory compulsion. They also said that their right to services would be enforceable under the Bill, giving them a mechanism to legally challenge lack of provision (via judicial review), stating that parents can say "I know my child has these rights under the Autism Act".

157. NAS Cymru told the Committee:

"[...] we're at a situation in Wales where autistic people and family members are having such distressing experiences on a daily basis—and that's from diagnosis rates to trying to get post-diagnosis support, to trying to get employment, to professionals just not understanding them within health and social care, education, employment.

We're now at a point where, actually, unfortunately, according to our evidence, some areas are getting worse. So, diagnosis—more people are saying that they're waiting too long for diagnosis. More people are saying that they're not getting the support that they need after diagnosis. And we really need to see a push from Government."⁹⁴

158. The Welsh Government, as previously stated, does not support the legislation. It believes that it already has all the legal powers required to deliver the improvements set out in the Bill and more, and we should be building on existing

⁹⁴ RoP. 3 October 2018, paragraphs 5-6

powers in recent legislation to support the improvements that are being put in place.

159. The timeliness and appropriateness of introducing this legislation has also been questioned by others, including the Royal Colleges of health professionals and NHS and local authority bodies, who stress that the impact of current initiatives, which are still in the early stages of development, should be assessed prior to the introduction of new legislation. We've heard views that time should be allowed to enable new policies and legislation to "bed-in" including the Additional Learning Needs and Educational Tribunal (Wales) Act 2018, the Integrated Autism Service which has not yet been rolled out in all areas, and the Welsh Government's forthcoming Code of Practice on the delivery of autism services.

160. Concerns were also raised about the Bill's focus on an ASD diagnosis and what that would mean for people who do not meet the diagnostic thresholds or who have other neurological conditions (more detail is provided in chapter 4).

161. Some Members questioned the consistency of the Welsh Government's approach, asking if the Welsh Government is against what it sees as "condition specific" legislation, why then does it plan to produce a specific statutory code of practice on ASD.

162. The Cabinet Secretary responded to this point in a letter to the Chair dated 19 November 2018. He said the purpose of the Code is to reinforce existing duties to provide services and support, and:

"This will help to create the level playing field which supporters of the Bill are seeking. However, it will not exclude individuals with similar needs but without an autism diagnosis from accessing certain services which will be a negative consequence of the Bill should it pass into legislation."⁹⁵

Our view

163. Autism is a lifelong condition like no other. There is no magic pill or cure. As parents told us, autism is with the person forever, and short term measures are not going to work.

⁹⁵ Letter from the Cabinet Secretary for Health and Social Services to the Chair of the Health, Social Care and Sport Committee - 19 November 2018

164. We have talked to people with ASD and their families who are struggling, and say they have waited 10 years for the autism strategies to deliver for them, and it has not happened.

165. The Committee understands the rationale of the Member in Charge in introducing this Bill and agree wholeheartedly with the need for improvements in provision of services for people with ASD. We have listened to people with ASD and their families and are convinced that further action is required in this area, particularly in terms of access to support services.

166. The current difficulties people with ASD and their families regularly face in attempting to access support is unacceptable and must be addressed. The message has clearly come through in evidence that more support services are urgently needed for people with ASD.

167. We have not, as a Committee, been able to reach consensus on whether this legislation, at this particular time, is the most appropriate way of achieving these much needed improvements.

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

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

170. One specific area of agreement, however, was the urgent need to improve the provision of support services across Wales, and there are clear gaps in current provision, including services such as employment support for adults with a high IQ and without a learning disability or mental health condition. It is clear there is a gap in provision of support for this cohort, preventing them from reaching their full potential.

4. Unintended consequences

Impact on other neurodevelopmental conditions

171. According to the Welsh Government, the Bill is creating a perception that autistic people will receive preferential services, which can only mean that resources will be diverted from other services, creating an inequity of support for other individuals who have other substantial support needs, such as people with learning disabilities or sensory impairments.

172. It also believes the Bill will undermine the significant progress achieved in the development of neurodevelopmental assessment and diagnostic services. It says that separating autism from other neurodevelopmental conditions will create barriers to access services for many, and prevent needs-based services, particularly where individuals have co-existing conditions or not easily diagnosable conditions.⁹⁶

173. The NHS Confederation and Royal Colleges also support the view that autism-specific legislation could lead to people with other neurodevelopmental conditions receiving inequitable services:

“Through introducing Autism-specific legislation there is a risk of excluding and disadvantaging other groups with neurodevelopmental conditions such as hyperkinetic disorder, learning disabilities, tic disorders, sensory impairments etc. It could also lead to other interested parties, patient groups and third sector organisations to call for the introduction of specific legislation for other illnesses and conditions to ensure they also given equal status and provision.”⁹⁷

174. Evidence from the Royal College of Occupational Therapists notes that around 5% of the population are affected by developmental coordination disorder, and around 5% of the population have ADHD (referencing 2018 NICE information); whereas only 1% of the population has autism. RCOT warns:

“If services for people with autism (which represent 1% of the population) are prioritised by legislation, occupational therapists will be diverted from other areas of practice (particularly CAMHS) to the

⁹⁶ Health, Social Care and Sport Committee, 25 October 2018, Paper 4

⁹⁷ Written evidence, A07

detriment of other populations who would benefit from occupational therapy.”⁹⁸

175. In its evidence paper, ADHD Connections says:

“In most counties within Wales ADHD is not a recognised disability and gaining access to any support and services is almost impossible. If you have a diagnosis of Autism as well as ADHD however, you are entitled to a multitude of support services, such as a disability social worker, respite, 1-2-1 support and access to specialised holiday clubs to name just a few. As a result, I am finding more and more families are becoming aware that by having an Autism diagnosis, they gain access to this additional help, support and money, therefore they are now trying to get a dual diagnosis on the proviso that the Autism diagnosis carries significantly more weight than just ADHD alone. My concern is that if the bill is passed, it will encourage more families to go down the Autism route in the bid to gain access to the much-needed help and support they fail to receive if they solely receive a ADHD diagnosis.”⁹⁹

176. This was supported by Dr Elin Walker-Jones, who told us:

“There are children and families out there with learning disability who will never get a diagnosis of autism or a genetic disorder or something because learning disability can be non-specific. That means that they don’t access any specialist service. There’s this perception that autism is the diagnosis *du jour*, and that really does worry me. That’s not to say that we don’t need legislation, but it does mean that we need to consider—sorry, you need to consider very carefully—the impact of that legislation and how you make sure that other children and families, adults—sorry, the whole population of people with learning disabilities—don’t miss out.”¹⁰⁰

177. And we heard concerns that autism-specific legislation could lead other interested parties, patient groups and third sector organisations to call for the introduction of specific legislation for other illnesses and conditions.¹⁰¹

178. However, NAS Cymru told us that autism had fallen behind other conditions, particularly in terms of waiting times for diagnosis and support, noting they were

⁹⁸ Written evidence, A31

⁹⁹ Health, Social Care and Sport Committee, 25 October 2018, Paper 3

¹⁰⁰ RoP, 3 October 2018, paragraph 330

¹⁰¹ Written evidence, A07 and A14

not aware of other conditions where some people are waiting seven years for a diagnosis as in Pembrokeshire for ASD. It says that autism as a condition is currently at a disadvantage, and this legislation would “level the playing field”. It believes the legislation would actually deliver parity with existing support provided to those with learning disabilities and mental health, for people with ASD.¹⁰²

179. Asked if he thought the Bill would disadvantage other conditions, the Member in Charge told us:

“No, I don’t accept that it will disadvantage other conditions. Obviously, Wales has an autism strategy at the moment. As far as I’m aware, it hasn’t disadvantaged people with other conditions; no-one has suggested that the planned statutory code of practice on the delivery of autism services will actually disadvantage other groups either. Now, this Bill doesn’t seek to prioritise people with autism over other groups, but to ensure that services to which they are actually entitled are in place in all areas of Wales. And I’m not aware of any concrete evidence that other groups are also clamouring in other parts of the United Kingdom, even though they’ve actually passed specific autism legislation in England. So, I’ve yet to see any evidence that people with other conditions are actually disadvantaged in those places where there is already autism legislation.

I believe that this Bill has the potential to actually benefit people with other conditions, by, for example, raising skill levels of clinical staff, which would benefit other service areas. I think it could also raise awareness of autism generally, and of its distinct features, generating a better understanding of what is and is not autism. In order to identify autism, I think practitioners need a good understanding of related and co-occurring conditions, as well as of autism itself. National Institute for Health and Care Excellence guidelines take account of comorbidity issues in the diagnosis of autism, so services should actually be addressing this issue. And I think the Bill has the potential to benefit people with other conditions, by helping to ensure that people with other conditions—whether they co-occur with autism or not—have these conditions identified earlier.”¹⁰³

¹⁰² RoP, 3 October 2018, paragraph 111

¹⁰³ RoP, 7 November 2018, paragraphs 171 and 172

Increased demand

180. We heard concerns that the Bill could lead to increased demand for diagnosis and increased risk of inappropriate diagnosis.

181. Dr Duncan Holtom told us that this had been identified in the interim review:

“There was a concern about the level of demand. There was an uncertainty about how much unmet demand there was out there, and services were understandably concerned about whether they would be able to meet that demand in a timely fashion or not, and, if demand was much greater than expected, the knock-on impact that would have on their capacity to provide post-diagnostic support. So, essentially, I’d say that’s a resourcing question.”¹⁰⁴

182. Evidence from Hywel Dda University Health Board says that:

“The Bill could result in pressures to under diagnose to act as a mechanism for rationing services and financial responsibilities. Over diagnosis could arise as a result of trying to obtain service especially in the current climate of constraints. There are real risks of services and resources being allocated disproportionately according to diagnosis rather than need. Additionally there are risks of sequential appeals and reassessments with associated distressing consequences for individuals and diversion of precious resources.”¹⁰⁵

183. The Royal College of Psychiatrists suggested that autism legislation would not necessarily drive good practice and could lead to a push for higher diagnosis rates rather than focus on meeting the needs of the individual. It went on to say that the need for diagnosis to push for resource would only artificially increase diagnosis rates for the wrong reasons.¹⁰⁶

184. Evidence from the Association of Educational Psychologists states that it is concerned that an increased demand for diagnosis, if met with a failure to increase resources, will result in poor assessments and more false positives. Dr Kate Swindon told us:

“I can give an example of that whereby where waiting times for diagnosis have gone up so far within a certain service that there has

¹⁰⁴ RoP, 3 October 2018, paragraph 191

¹⁰⁵ Written evidence, A06

¹⁰⁶ Written evidence, A20

been some outsourcing of diagnosis to a private company, and the private company, in my opinion, are not adhering to NICE guidelines to the same level. So you've got a sort of hierarchy of diagnosis, even, where you either get a health board, CAMHS-based diagnosis or it goes to the private company, and you will get a totally different process, and a totally different gathering of information to lead to that diagnosis, to the point that, perhaps, schools won't be contacted for their input, there won't be any input from education at all, which, for children and young people, is obviously really important, and an approach of, 'We will take what we see on the day and parent report to lead to a diagnosis.' So, that sort of inequality is a result of financial pressures, of workload stresses."¹⁰⁷

185. Dr Dawn Wimpory also stressed the importance of the Bill being applied to private services:

"It would seem essential that the bill is applied to private services as well as to statutory services so that the former adhere to standards required of the latter; this is particularly important to help address any over-diagnosis of ASD in private provision, possibly through less thorough assessment strategies."¹⁰⁸

Resource implications

186. A number of witnesses suggested that the need to meet statutory targets could divert resources away from other areas, such as post-diagnostic support services.

187. The Welsh Government's evidence states:

"Feedback from practitioners and evidence from the independent evaluators of the ASD Strategy around the proposed 13-week waiting time targets is that this duty is likely force services to focus limited resources on meeting the duties in the Bill. That is funnelling more people through diagnostic assessment at the expense of providing much needed pre- and post diagnostic support. The evaluation has found that service providers are already concerned about future

¹⁰⁷ RoP, 11 October 2018, paragraph 483

¹⁰⁸ Written evidence, A26

capacity to meet demand for diagnosis, this will be exacerbated by legislation focussing services on a single diagnosis.”¹⁰⁹

188. Dr Duncan Holtom told us:

“I would also have some concerns about the potential unintended impacts of the Bill if it, for example, distorts priorities. So, a greater focus is placed upon assessment and diagnosis, which is clearly very important, but if that then sucks resources away from post-diagnostic support—. I think that was one of the problems the first evaluation identified—that where, for example, assessment and diagnosis were up and running, there was often a lack of post-diagnostic support, and some people therefore questioned the value of getting a diagnosis without post-diagnostic support.”¹¹⁰

189. The Royal College of Occupational Therapists were concerned that “clinicians may be required to prioritise assessments rather than intervention, meaning that individuals do not receive the post-diagnostic support they need to live healthy and productive lives”.¹¹¹

190. The Royal College of Speech and Language Therapists said:

“Our primary concern in the Royal College of Speech and Language Therapists is for those individuals who don’t meet the criteria for autism who still have significant needs. [...] With the autism legislation, the resources will be put more into that, because they’ll have targets to meet in order not to breach, and other areas of the service will be detrimentally affected.”¹¹²

191. NAS Cymru, however, told us:

“[...] this isn’t about taking up resources to focus only on diagnosis at the risk of not being able to provide other pre and post diagnostic support. The Bill is clear that a diagnosis shouldn’t prevent support from being made available either for the autistic person themselves or their

¹⁰⁹ Health, Social Care and Sport Committee, 25 October 2018, Paper 4

¹¹⁰ RoP, 3 October 2018, paragraph 147

¹¹¹ Written evidence, A31

¹¹² RoP, 25 October 2018, paragraph 9

families and carers, from the point at which their needs first become apparent. Support should be available regardless of a diagnosis.”¹¹³

192. The Member in Charge told us that, in his opinion, the majority of the Bill was concerned with the provision of support needed by people with autism:

“[...] if you look at section 2(1)(c), it requires that diagnostic assessments and any post-diagnostic meetings are commenced within the National Institute for Health and Care Excellence timescales, which is, of course, 13 weeks currently. In addition, section 2 requires the autism strategy to actually outline how the needs of people with autism are to be met by a range of services, including healthcare, education, employment and housing. So, I don’t think that my Bill would change that in terms of post-diagnosis support.”¹¹⁴

193. He did, however, give an undertaking to reconsider this issue at Stage 2.

Our view

194. While we heard some concerns that the Bill could lead to calls for more condition-specific legislation, we do not believe that we have received sufficient evidence to support this suggestion.

195. Some members are concerned about the potential impact on other neuro-developmental conditions, given the current pressures on workload and capacity.

196. Some members believe that there is a risk of resources being channelled into ASD diagnosis at the expense of other services, such as post-diagnostic support, to meet the requirements of the legislation.

197. However, we maintain that it is not acceptable for resource constraints to prevent action to improve access to services for people with ASD, and do not believe that a lack of resources is a valid reason to oppose the legislation.

¹¹³ Written evidence, A13

¹¹⁴ RoP, 7 November 2018, paragraph 200

5. Barriers to implementation

198. The lack of existing workforce capacity has been cited as a major barrier to the Bill's implementation.

199. The Royal College of Speech and Language Therapists state that a major challenge to the implementation of the Bill would be workforce capacity, and that Speech and Language Therapists have highlighted that neurodevelopmental services are already under significant pressure to provide assessment and support under referral to treatment time targets. It goes on to say:

“It is our view that learning from other nations suggests that legislation without significant extra funding and detailed consideration of the impact on the workforce will not deliver the ambitions outlined in the general principles of the bill.”¹¹⁵

200. The Royal College of Paediatrics and Child Health say the biggest barrier to implementation would be a possible increase in demand on Community Paediatric services, along with Psychiatry and a range of other services including Speech and Language Therapy and Occupational Therapy. It states that many services are already operating at capacity, or have waiting lists, or have workforce shortages placing additional pressure on existing staff who have to cover gaps.¹¹⁶

201. A further concern highlighted by a number of witnesses was the ability to recruit enough suitably trained professionals. The Royal College of Nursing “remain unconvinced that there are sufficient appropriately trained professionals available to fill such posts if they were to be created”.¹¹⁷

202. Julie Mullis, Royal College of Speech and Language Therapists, voiced similar concerns:

“I think in terms of the workforce issues, we are already having difficulties with recruitment. A difficulty with that is that our speech and language therapists are currently feeling that they're spending too much time on diagnostic assessments and not enough time on interventions. And I don't think creating more posts is going to necessarily help that, because they've got to come from somewhere. At the moment, I think we're already employing all the specialist speech

¹¹⁵ Written evidence, A13

¹¹⁶ Written evidence, A05

¹¹⁷ Written evidence A18

and language therapists who are interested in autism, with the creation of the new services—the neurodevelopmental service, the integrated autism service service. I've got vacancies at the moment that have been difficult to fill. So, I think that that is a very real issue.”¹¹⁸

203. The Welsh Government made a similar point in its evidence:

“[...] there is an absence of suitably qualified staff that can be recruited to deliver support, and therefore, ‘if autism is mandated then that is where services will have to be focused’.”¹¹⁹

204. Sally Payne, Royal College of Speech and Language Therapists told us:

“I think our concern is that as therapists we're a limited resource. If all of our focus is on assessments and diagnosis, then we don't then have the capacity to deliver the intervention before and after diagnosis.”¹²⁰

205. Dr Katherine Norton, Royal College of Paediatrics and Child Health said:

“But there's another problem here: what about my other day job? So, I'm doing autism every other week, but in the other week I'm doing actually all our special schools in Cardiff and I'm working with Amani around children with learning disability, our children with trisomy 21, with other genetic syndromes. So, actually, there are only so many ways you can cut individuals up, and does anybody have any knowledge about the evidence and the size of that workforce before we put through specific legislation that cuts into that workforce?”¹²¹

206. While Julie Mullis, RCSLT, raised the issue of the potential impact on staff morale:

“We have a half a speech and language therapist in our Cardiff and Vale multidisciplinary team, so, you know, she doesn't have a lot of time to actually do much speech and language therapy, because she's focused on just assessing children to see whether they have autism or not. I don't think that's the best use of her time, because she's very skilled and very expert. She came into the job thinking she was going to be

¹¹⁸ RoP, 25 October 2018, paragraph 8

¹¹⁹ Health, Social Care and Sport Committee, 25 October 2018, Paper 4

¹²⁰ RoP, 25 October 2018, paragraph 126

¹²¹ RoP, 11 October 2018, paragraph 369

doing intervention, and that was what she wanted to do. I'm surprised she's still with us."¹²²

207. The Member in Charge told us:

"Well of course there are continuous workforce issues, even under the current system, and I accept that there are continuous pressures—of course there are—but at the end of the day, it will be up to local health boards and local authorities to actually plan. If my Bill is passed, of course, the Government will have up to nine months to actually publish a strategy. So, I'd like to think that, in those nine months, there will be sufficient time to cover some of these issues and to plan the workforce accordingly."¹²³

208. The legal adviser supporting the Member in Charge noted:

"Also, the Bill recognises that additional resource will be required to deliver it, and that's fully costed within the impact assessment. So, it recognises that additional resource may be required to deliver its purposes, including diagnosis."¹²⁴

209. Paul Davies AM went on to say that, although it would be difficult to include workforce planning in the Bill, it would be something he would be happy to look at it at Stage 2.¹²⁵

Our view

210. We are concerned about the sustainability of the workforce and therefore the ability of professionals to meet the requirements of the Bill in the context of current staffing and workforce pressures. We agree that statutory requirements do tend to direct attention and therefore resources, thus it follows that it is reasonable to consider that the legislation will have an impact upon how time and resources are directed.

211. There is a clear need for a sustainable workforce plan, and we urge the Welsh Government to address this as a priority.

¹²² RoP, 25 October 2018, paragraph 127

¹²³ RoP, 19 September 2018, paragraph 72

¹²⁴ RoP, 7 November 2018, paragraph 183

¹²⁵ RoP, 19 September 2018, paragraph 74

212. We would stress again that while resource constraints (both financial and workforce capacity) are an important consideration, this is not necessarily an acceptable reason to oppose such legislation.

6. Financial implications

213. The Regulatory Impact Assessment (RIA) included in the EM estimates the total administrative costs of the Bill as £7,387,366. This includes:

- £359,756 costs to Welsh Government (to develop the strategy and guidance, publish data, review the strategy, and for training/awareness raising);
- £4,508,903 costs to Local Health Boards (additional staff costs of operating databases, and delivery of 13 week waiting time target);
- £2,518,708 indirect “opportunity costs” of staff undertaking training.¹²⁶

214. The EM also states that “there is little information in the public domain to estimate the current provision and future plans with regard to both the administrative costs of providing services to people with ASD... The Welsh Government was unable to provide specific information regarding the cost of the status quo”.¹²⁷ It is therefore difficult to estimate the current costs of provision in its entirety due to a lack of reliable data, which is something the Bill seeks to address.

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

216. It goes on to say:

“It is difficult to determine what the additional costs and benefits of the Bill will be. The evidence around the potential benefits of the Bill is relatively weak. It is suggested that a 1% reduction in the direct and indirect costs associated with ASD will save £1m per annum but there is little evidence to indicate how the Bill might achieve this saving. Given the estimated direct and indirect cost of ASD in Wales each year is

¹²⁶ Explanatory Memorandum, pages 92-94

¹²⁷ Explanatory Memorandum, paragraph 254

estimated to be £1.1bn, a 1% reduction in this cost would represent an £11m saving and not £1m as reported in the RIA.”¹²⁸

217. The Welsh Government has not published any financial information about delivery of its forthcoming Code of Practice. The Member in Charge told the Finance Committee:

“I did ask the Cabinet Secretary what the cost of his code of practice would be during Plenary, and he responded, and I quote:

‘The code is already planned in to the work that we have, so we have budgeted for it and expect not only to go through the process of consultation but to deliver services.’

However, it is worth noting that many of the issues that the Welsh Government is planning to address in this particular code are, of course, the same as those in my Bill. For example, assessment and diagnosis, accessing care and support, staff training, planning and stakeholder engagement and service planning and delivery. So, surely introducing the code would also use resources and cost money, because obviously the Welsh Government at the moment is saying that they don’t want to see legislation being passed because they feel that resources will be diverted in order to introduce this legislation.”¹²⁹

218. The Cabinet Secretary stated in a letter to the Finance Committee Chair dated 20 November 2018:

“The code will reinforce existing duties placed on Local Authorities and Local Health Boards under the Social Services and Well-being (Wales) Act and the NHS (Act). I do not envisage there being any additional funding required for services to be shaped in a way that is consistent with the code.”¹³⁰

219. Gwent Integrated Autism Service told us “it is evident that to meet the needs of the Autism Bill and the NICE Quality standards a significantly greater level of

¹²⁸ Health, Social Care and Sport Committee, 25 October 2018, Paper 4

¹²⁹ Finance Committee, 11 October 2018, paragraphs 34-36

¹³⁰ Letter from the Cabinet Secretary for Health and Social Services to the Chair of the Finance Committee – 20 November 2018

funding is required to meet identified time scales and to ensure the ongoing provision of support”.¹³¹

220. The Royal College of Speech and Language Therapists (RCSLT) were also of the view that in order for the legislation to address issues around inconsistencies in services, significant additional funding would be required to support local authorities and local health boards to fulfil their duties.¹³²

221. However, the Cabinet Secretary has already confirmed there will be no additional funding for the Bill. He told us:

“[...] the Bill isn’t going to deliver any more resources. The challenge for the Bill and the Member in charge is how and where that money comes from, or does he just say, ‘I will pass the Bill, then it’s for the Government to make sure it’s funded’, as opposed to questions about where do you expect the money come from. We have less money overall, and, within that context, the extra resource we’ve already put into funding to deliver the roll-out and improving the integrated autism service is a significant additional commitment that this Government has been proud to make.”¹³³

222. The potential for long-term cost benefits was identified by a number of witnesses, including the RCSLT, who said it believed that improved autism services would bring a number of savings in terms of wellbeing, such as reductions in hospital admittance and early discharge,¹³⁴ and ColegauCymru who suggested that the introduction of the Bill could provide benefits in terms of earlier identification of needs and interventions that could make a difference and lead to a possible reduction of costs over a lifetime.¹³⁵

223. NAS Cymru told us:

“The Explanatory Memorandum is clear in where costs would occur. A net initial cost of around £7million is estimated. However, this needs to be measured against the cost effectiveness of current provision, resource and policy. It is also anticipated that there will be longer term

¹³¹ Written evidence, A08

¹³² Written evidence, A14

¹³³ RoP, 25 October 2018, paragraph 364

¹³⁴ Written evidence, A14

¹³⁵ Written evidence, A24

savings due to the effective identification and support of individuals with autism.

While we recognise that there will be some cost involved in introducing and implementing legislation, we believe that introducing autism legislation will not result in significant burdens. This must also be balanced against the cost of not intervening and the economic impact of having to access acute services.”¹³⁶

224. The Member in Charge told us:

“I’ve made it absolutely clear in the explanatory memorandum and in the regulatory impact assessments that there will be a cost of just over £7 million over a period of five years, but I believe that my Bill will have huge long-term savings because, by identifying people with autism early, it will ensure that we reduce costs on reactive services.”¹³⁷

225. However, the Cabinet Secretary said he did not have the same level of faith in the evidence about the potential benefits of the Bill:

“He [the Member in Charge] suggested that there’d be a 1 per cent reduction in direct and indirect costs, which would save £1 million a year. I don’t quite understand how you get to that point.

I have some experience of this from being—not the Member in charge, but I worked alongside Mick Antoniw when the asbestos recovery Bill was introduced, and we went through and had a healthcare economist produce a level of analysis to look at a recognised tool for collecting resources in on the back of successful legal cases being run. So, we were able to demonstrate a mechanism that already existed that people had confidence in about what that would then mean. I don’t see that same evidence in the regulatory impact assessment on the financial consequences, but that’s really a question for the Member in charge, rather than the Government.”¹³⁸

226. The WLGA also pointed out that “whilst the Memorandum argues that there is evidence that the Bill will result in considerable benefits, both direct and

¹³⁶ Written evidence, A13

¹³⁷ RoP, 19 September 2018, paragraph 25

¹³⁸ RoP, 25 October 2018, paragraph 359-360

indirect, it fails to identify what these are, stating that, ‘these are not possible to quantify and hence unknown’.¹³⁹

227. In response to this point, the Member in Charge said:

“Whilst no savings are quantified in my regulatory impact assessment, there is reference to National Audit Office work that actually suggests that substantial savings could be achieved with modest increases in the identification rates, for example. However, without accurate information on the costs of autism in Wales, it’s not appropriate to actually make an estimate of those costs. The reason we don’t have that information is because, obviously, we have asked the Welsh Government for information, but they have been minded not to give us that information, unfortunately. So, it’s very difficult, therefore, for me and for my team to actually predict the costs.”¹⁴⁰

228. He went on to say:

“Of course, it would be up to the Government to locate this money. They have found additional money for autism services over the last 12 to 18 months as well, as we know. However, the point I’m making is: this £7.5 million, in the big scheme of things, is a drop in the ocean compared to the huge difference that it could actually make to people’s lives.”¹⁴¹

Our view

229. The Welsh Government has stated that there is no additional funding available for the Bill, and also that it does not envisage that additional funding will be required to deliver its forthcoming code of practice. We are concerned with these assertions, as we are in agreement that additional funding is required in either case. We would question whether the required change can be delivered and access to support services significantly improved, without further investment in support services (beyond that committed to the Integrated Autism Service.

230. Nevertheless, for us the main consideration about this Bill is not financial; rather it is whether legislation is the most appropriate route forward, to deliver the much needed improvements in access to services for people with ASD and their

¹³⁹ Written evidence, A25

¹⁴⁰ RoP, 19 September 2018, paragraph 91

¹⁴¹ RoP, 19 September 2018, paragraph 95

families. We have been unable to reach agreement on this, and it will be for the Assembly to decide whether the Bill should proceed to Stage 2.