National Assembly for Wales
Constitutional and Legislative Affairs Committee

Report on the Autism (Wales) Bill

December 2018

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About the Committee

The Committee was established on 15 June 2016. Its remit can be found at: www.assembly.wales/SeneddCLA

Committee Chair:

Mick Antoniw AM
Welsh Labour
Pontypridd

Current Committee membership:

Dawn Bowden AM
Welsh Labour
Merthyr Tydfil and Rhymney

Suzy Davies AM
Welsh Conservatives
South Wales West

Mandy Jones AM
Independent
North Wales

Dai Lloyd AM
Plaid Cymru
South Wales West

Lee Waters AM
Welsh Labour
Llanelli

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1. Introduction

The Committee's remit

1. The remit of the Constitutional and Legislative Affairs Committee (the Committee) is to carry out the functions of the responsible committee set out in Standing Order 21[1] (with the exception of Standing Order 21.8[2]) and to consider any other constitutional, legislative or governmental matter within or relating to the competence of the National Assembly or the Welsh Ministers, including the quality of legislation.

2. In our scrutiny of Bills introduced in the National Assembly, our approach is to consider:

- matters relating to the competence of the National Assembly, including compatibility with the European Convention on Human Rights (ECHR);
- the balance between the information that is included on the face of the Bill and that which is left to subordinate legislation;
- whether an appropriate legislative procedure has been chosen, in relation to the granting of powers to the Welsh Ministers, to make subordinate legislation; and
- any other matter we consider relevant to the quality of legislation.

Introduction of the Bill

3. On 13 July 2018, the Autism (Wales) Bill[3] (the Bill), and accompanying Explanatory Memorandum,[4] was introduced by Paul Davies AM (the Member in charge). On 18 September 2018, the Member in charge wrote to Dai Lloyd AM, Chair of the Health, Social Care and Sport Committee, copied to the Committee, enclosing a statement of policy for subordinate legislation to be made under the Bill.[5]

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[1] National Assembly for Wales, *Standing Orders of the National Assembly for Wales*, October 2018

[2] Functions under Standing Order 21.8 are the responsibility of the External Affairs and Additional Legislation Committee

[3] Available on the National Assembly's website.

[4] Paul Davies AM, *Autism (Wales) Bill: Explanatory Memorandum*, July 2018

[5] Paul Davies AM, *Autism (Wales) Bill, Statement of Policy Intent for Subordinate Legislation to be made under this Bill*, September 2018

4. The National Assembly's Business Committee referred the Bill to the Health. Social Care and Sport Committee on 12 June 2018 and set a deadline of 7 December 2018 for reporting on its general principles.[6]

5. We took evidence from the Member in charge at our meeting on 24 September 2018[7] and from Vaughan Gething AM, the Cabinet Secretary for Health and Social Services (the Cabinet Secretary) on 15 October 2018[8].

6. We received written evidence from the National Autistic Society Cymru on 23 October 2018.[9]

Background

7. The Explanatory Memorandum accompanying the Bill states that its overall purpose is to ensure the needs of children and adults with ASD (Autism Spectrum Disorder) in Wales are met, and to protect and promote their rights. Four ways are identified in which the Bill will deliver this purpose, namely by:

- introducing a strategy for meeting the needs of children and adults in Wales with ASD conditions;
- requiring the Welsh Ministers to issue guidance to the relevant bodies on implementing the strategy (local authorities and NHS bodies);
- requiring the Welsh Ministers to collect suitable data to facilitate the implementation of the Bill;
- requiring the Welsh Ministers to undertake a campaign to raise awareness and understanding of ASD.[10]

8. The Explanatory Memorandum recognises that:

> "A considerable amount of work has been undertaken in Wales in recent years to improve services for people with ASD, their families and carers. The Welsh Government's ground-breaking Autism Spectrum Disorder Strategic Action Plan, published in 2008, established an autism infrastructure in each local authority area, with local co-

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[6] Business Committee, Report on the timetable for consideration of the Autism (Wales) Bill, July 2018

[7] Constitutional and Legislative Affairs (CLA) Committee, 24 September 2018, RoP

[8] CLA Committee, 15 October 2018, RoP

[9] Letter from the National Autistic Society Cymru, 23 October 2018

[10] Explanatory Memorandum, paragraphs 4 and 113

> ordinators and strategies, and a Wales national co-ordinator. It expanded research capacity, raised the profile of ASD and made available a range of high quality information and resources for both service users and professionals."[11]

9. It adds that:

> "The Welsh Government published … a Refreshed Strategic Action Plan in December 2016, which runs from 2016-20. The Action Plan has led to improvements in services for people with ASD and to increased awareness of ASD.
>
> However, the improvements made by the non-binding voluntary strategy have been limited, and beyond the lifetime of the Action Plan there is an increased risk to the continued prioritisation of ASD. In order to secure comprehensive, consistent and high-quality services in the long term, a statutory requirement on the Welsh Ministers to publish an autism strategy is needed."[12]

10. The Explanatory Memorandum also says that although the Action Plan has "helped to improve services in many local areas and raise awareness of ASD, problems remain".[13]

11. The intention is for the Bill to supplement rather than replace measures undertaken by the Welsh Government,[14] with the Explanatory Memorandum drawing attention as to how it will complement the provisions in the *Additional Learning Needs and Education Tribunal (Wales) Act 2018*[15] and how it would go beyond the social services functions contained in the *Social Services and Well-being (Wales) Act 2014*[16].

12. According to the Explanatory Memorandum:

> "A key function of the Bill, therefore, is to secure consistent and continued provision of all ASD services across Wales in order to achieve

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[11] Explanatory Memorandum, paragraph 26

[12] Explanatory Memorandum, paragraphs 128-29

[13] Explanatory Memorandum, paragraph 30

[14] Explanatory Memorandum, paragraph 34

[15] Explanatory Memorandum, paragraph 34

[16] Explanatory Memorandum, paragraph 35

> the core purpose of ensuring the needs of people with ASD are met, and their rights protected and promoted."[17]

and

> "By creating a legal requirement to publish an autism strategy the Autism (Wales) Bill would help secure a measure of permanence and sustainability in care and support services for people with ASD. It would ensure a continued, dedicated focus on the needs of people with ASD, regardless of the prevailing financial or political climate. In this way, the Bill's core purpose would be realised: to ensure the needs of children and adults with ASD in Wales are met, and to protect and promote their rights."[18]

13. On 25 September 2018, the Cabinet Secretary made an oral statement saying that:

> "I have published an updated Autistic Spectrum Disorder Strategy Delivery Plan. The revised Plan reflects important new commitments which will improve services. These new commitments reflect feedback we and our partners have heard from autistic people, their families and carers, and wider stakeholders."[19]

14. The commitments included issuing a code of practice on the delivery of autism services under the *Social Services and Well-being (Wales Act) 2014* and the *National Health Service (Wales) Act 2006*. The code was subsequently published for consultation on 30 November 2018.[20]

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[17] Explanatory Memorandum, paragraph 36

[18] Explanatory Memorandum, paragraph 37

[19] Welsh Government, Statement by the Cabinet Secretary for Health and Social Services: The Autism Updated Delivery Plan and Autism Code of Practice, 25 September 2018

[20] Welsh Government, Cabinet Statement, Consultation on the Code of Practice on the Delivery of Autism Services, 30 November 2018

2. Legislative Competence

General

15. The Member in charge is satisfied that the Bill is within the legislative competence of the National Assembly. The Explanatory Memorandum states:

> "The Assembly's legislative competence is now framed by the reserved powers model. No provision in the Bill must relate to a reserved matter set out in Schedule 7A to GOWA. There are no reservations relating to health and social care that are relevant to the contents of this Bill and the Bill does not modify the law relating to a reserved matter. The Bill does not make prohibited provisions in relation to the private or criminal law."[21]

16. The Explanatory Memorandum also analyses the extent to which the Bill engages the following reservations:

- Reservation 140 – regulation of health professions;
- Reservation 170 – protection of personal data: and
- Reservation 187 – equal opportunities.[22]

17. The Explanatory Memorandum confirms that the Bill legislates in relation to Welsh public authorities permitted by the *Government of Wales Act 2006* (the 2006 Act).[23] It says that the Bill's legal standing does not extend beyond the jurisdiction of England and Wales, and that it does not apply otherwise than in relation to people in Wales.[24]

18. To be within the legislative competence of the National Assembly, section 108A(2)(e) of the 2006 Act requires all provisions of a Bill to comply with the European Convention on Human Rights (ECHR). The Explanatory Memorandum states that "the Bill is not incompatible with Convention Rights protected by the Human Rights Act, or with EU law".[25]

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[21] Explanatory Memorandum, paragraph 7

[22] Explanatory Memorandum, paragraphs 8-19

[23] Explanatory Memorandum, paragraphs 20-24

[24] Explanatory Memorandum, paragraph 25

[25] Explanatory Memorandum, paragraph 25

19. In her statement on legislative competence, the Llywydd, Elin Jones AM, stated that in her view the provisions of the Bill would be within the legislative competence of the National Assembly for Wales.[26]

Evidence from the Member in charge

20. When we asked the Member in charge about any human rights issues that emerge from the proposed Bill, he told us:

> "… I've explicitly included the consideration of human rights on the face of the Bill in section 8. This was included after a variety of informed responses to the consultations I ran requested specific reference to the United Nations conventions and the principles on the face of the Bill, and those relating to children, older persons and disability have therefore been included in section 8.
>
> … Therefore, the Bill seeks to fully reflect, I think, appropriate equality and human rights obligations and ensure that they are actually applied to the functions of relevant bodies under the Bill."[27]

21. An official accompanying the Member in charge added that consideration was also given to article 8 in relation to section 6 of the Bill (which seeks to gather certain data, including one element constituting personal data) and went on to say:

> "We were content that no article 8 rights were infringed, that the provisions contained in section 6 were the least interference with the citizens' rights and proportionate to the aim pursued."[28]

22. As regards section 6(6)(b) (which requires that NHS bodies capture the NHS number of persons with autism), the Member in charge told us: .

> "… expert advice strongly indicated that it's necessary to be able to analyse autism data of individual patients to generate valid statistics, as well as ensure that those patients are receiving the best possible services. And, paragraph 503 of the explanatory memorandum sets out the rationale for the inclusion of each data category in subsection 6(6), including for the collection of individual NHS numbers. The

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[26] National Assembly for Wales, *Presiding Officer's Statement on Legislative Competence, Autism (Wales) Bill*, 13 July 2018

[27] CLA Committee, 24 September 2018, RoP [147-149]

[28] CLA Committee, 24 September 2018, RoP [152-153]

> requirement to provide anonymised data to Welsh Ministers is to ensure compliance with data protection and human rights obligations, … and also, Welsh Ministers will only require macro-type data for the purposes of delivering the strategy. Based on the Supreme Court's judgment in the Christian Institute case, I felt it appropriate to consider in detail the effect of the data collecting provisions in section 6, and specifically, whether they interfere with the article 8 right to respect for private and family life, home and correspondence. And paragraphs 496 to 503 of the explanatory memorandum set out a detailed analysis of that."[29]

23. The Member in charge also told us that collecting individual NHS numbers does not breach anonymity.[30]

Evidence from the Cabinet Secretary

24. The Cabinet Secretary referred to concerns that had been expressed by people about the level of personal data being collected (whether published anonymously or not) and its purpose.[31]

Our view

25. We have noted the Member in charge's comments regarding legislative competence.

26. We welcome the way in which the Member in charge has explained the legislative basis for the Bill in the Explanatory Memorandum.

27. We have considered the Member in charge's responses to the questions we posed in relation to the Bill's compatibility with human rights and consider the approach adopted to be reasonable.

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[29] CLA Committee, 24 September 2018, RoP [159]

[30] CLA Committee, 24 September 2018, RoP [160-161]

[31] CLA Committee, 15 October 2018, RoP [52 and 71]

3. General observations

The need for legislation

Background

28. The Member in charge consulted on the principles of the Bill and subsequently on the text of a draft Bill.[32] In relation to the consultation on the Bill's principles and the view on whether a Bill is needed, the Explanatory Memorandum says that:

> "Most respondents to the consultation who expressed a view, agreed that there is a need for an Autism Bill. Support for the introduction of a Bill was particularly strong amongst users of ASD services and their families and carers. There was a clear view that services for people with ASD need improving, that services are variable across Wales, and that legislation would help to drive improvement.
>
> A minority of respondents (primarily statutory and professional bodies) were opposed to the introduction of legislation and to the principle of focusing on one condition (which they believed could be to the detriment of people with other conditions)."[33]

Evidence from the Member in charge

29. In explaining why the Bill was necessary the Member charge quoted from a 2017 report by the London School of Economics, *The Autism Dividend*, which said:

> "The Welsh government rejected calls for an Autism Act, believing that other current developments will support autistic people effectively. However, without such legislation, government initiatives lack statutory force resulting in an inability to require local authorities to implement the strategy to the full."[34]

30. He also said that "there are significant issues with autism services here in Wales", highlighting problems of long waiting times for diagnosis, access to health

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[32] Explanatory Memorandum, Chapter 4

[33] Explanatory Memorandum, paragraphs 45-46

[34] CLA Committee, 24 September 2018, RoP [163-164]

and social care services and the variability of services across Wales.[35] He explained how the Bill would address these issues, for example by:

- introducing a three-month waiting time for diagnostic assessments,[36] and providing that needs assessments following diagnosis should be undertaken within 42 working days of a diagnosis or any post-diagnostic meeting[37];
- addressing uneven provision by imposing a duty on health and social services across Wales to comply with the strategy to ensure consistency of provision (something, it is asserted, the existing strategic action plan has failed to achieve to date);[38]
- requiring the autism strategy to improve information provision and the Welsh Ministers to undertake an awareness-raising campaign, including amongst employers;[39]
- requiring an autism strategy to ensure continuity of service during transition from child to adult services;[40]
- addressing a need for better staff training, awareness raising, support for families and carers, and data collection on autism.[41]

31. The Member in charge added:

> "The Bill … requires … local authorities and local health boards, to comply with the autism strategy. This is, indeed, a stronger duty than under the current arrangements. It's also a stronger duty than under the Welsh Government's proposed code of practice on autism services, particularly on NHS bodies, for whom compliance with the code is not mandatory. A code, I'm sure you'd agree, can be revoked; an Act is arguably more enduring—a piece of legislation. There is clear evidence now that the overwhelming majority of people, I think, do actually support legislation on this. If you look at the two consultations I ran, it was quite clear that

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[35] CLA Committee, 24 September 2018, RoP [165]

[36] CLA Committee, 24 September 2018, RoP [165]

[37] CLA Committee, 24 September 2018, RoP [166]

[38] CLA Committee, 24 September 2018, RoP [166]

[39] CLA Committee, 24 September 2018, RoP [167]

[40] CLA Committee, 24 September 2018, RoP [168]

[41] CLA Committee, 24 September 2018, RoP [168]

> the overwhelming majority's responses to those two consultations supported legislation in this area."[42]

Evidence from the Cabinet Secretary

32. The Cabinet Secretary said he did not believe that the legislation is necessary and added that as a consequence the Welsh government is not supporting the Bill.[43] He said:

> "… we don't think the evidence exists to support the Bill in general terms—there are some general points to make, as well as the specifics in the scheme of the Bill, and, indeed, there's experience in other parts of the United Kingdom where they have either had autism-specific legislation or have considered it and rejected it. So, in Scotland, they considered it and decided not to proceed. In England, they have it, and you can't see a visible improvement in services and outcomes for autistic people."[44]

33. The Cabinet Secretary told us that the Welsh Government has already consulted on a strategy (non-statutory) and that he was:

> "… not at all persuaded that placing that strategy on a statutory footing is a good enough reason to pass this legislation. Even if you took everything else out and said, 'There must be a statutory strategy, and you can amend how that is laid and provided', I don't think that's a great use of our powers."[45]

34. When we asked the Cabinet Secretary about the Member in charge's comments that the Bill will improve problems relating to autism and is supported by the overwhelming majority of people, he told us:

> "… the code we're consulting on does everything that the Bill would want to do, and we actually think that it's a preferable scheme that we have as well … the point about the support is a different one, because lots of people have commented on the Bill and are supportive, but there are definitely autistic people who have not supported the Bill as well, and if I were the Member in charge, I would probably make a similar statement about the level of support about the Bill, but,

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[42] CLA Committee, 24 September 2018, RoP [168]

[43] CLA Committee, 15 October 2018, RoP [6]

[44] CLA Committee, 15 October 2018, RoP [6]

[45] CLA Committee, 15 October 2018, RoP [44]

> obviously, you'll know from the community of practice across a variety of disciplines that they're not supportive of the Bill. And we need to be clear that this isn't about saying that we don't want to improve the services, the life experience and outcomes for people. This is really about whether this legislation does what it sets out to achieve, and we don't think it will do. I think it will create an impression that services will improve by passing the legislation, and it's very difficult to see how that is. We're actually investing resources into the new integrated service that we're rolling out across the country."[46]

35. The Cabinet Secretary also expressed concerns about condition-specific legislation. While agreeing with the Member in charge about wanting to improve services and improve someone's lived experience, he said:

> "It's really about whether the Bill is the right vehicle to do that, and that's the point in dispute. That's where you get into whether condition-specific legislation is the right way to achieve that or not. Will driving something that relies on a diagnosis, and then having timescales that I don't think are really achievable, help to drive improvements or not? We part company there. So, I don't think the Bill is one that will achieve its objectives."[47]

36. Emphasising this point later he said:

> "… I think there's a challenge about condition-specific legislation, and what that does in terms of diagnosis and the demand for diagnosis to be able to get through a gate to access services. And that's the impression that's being given: if you have a diagnosis, you will access better and improved services. I think that will deliver adverse consequences in the way it will drive resources within the service."[48]

37. While noting that a code provided flexibility enabling it to be revisited more easily than primary legislation, the Cabinet Secretary said:

> "… once you have legislation like this, you will direct resources in a certain way, and I don't think that is a do-no-harm piece of legislation. You will direct resource at the specific areas chosen in this legislation. So, I think they will unbalance the system and it will not be an equitable way of meeting people's needs. People that don't have that

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[46] CLA Committee, 15 October 2018, RoP [8]

[47] CLA Committee, 15 October 2018, RoP [24]

[48] CLA Committee, 15 October 2018, RoP [87]

> diagnosis, but have other needs, will find that resources are being channelled in a different direction, and that's troubling, I think. Again, that isn't just my view—that is the view of a range of people who have submitted evidence on the Bill itself."[49]

38. During his evidence, the Cabinet Secretary noted for example concerns expressed by the Children's Commissioner for Wales on this issue[50] and as regards the views of GPs, he said:

> "To be fair, the Royal College of General Practitioners are not supporters of the Bill that's before us either, and they share some of the concerns that I have about what it will actually do to the service in having condition-specific legislation."[51]

39. We asked whether there is anything in the Bill that cannot be achieved by the code and if not, whether the fact that it is a code, as opposed to legislation, makes any difference. The Cabinet Secretary replied:

> "If we set out a code, we expect public services to provide services in accordance with it. So, you'll still have the challenge if services aren't being provided in that way, whether it's in a Bill or in regulations, about what happens and potential remedies for individual citizens. The code, of course, itself is subject to scrutiny. There will be a consultation and it will be laid before the Assembly as well, so there will be scrutiny attached to it.
>
> Apart from putting the strategy that we already have on a statutory footing, I don't think there's anything the Bill does that we can't already do with our current set of powers, but it's really about the desirability of the scheme that the Bill sets out, and whether people would want to say it is worth putting a strategy itself on a statutory footing. But, of course, when we have a strategy and we spend money and we use our policy levers in that direction, the code supports that."[52]

Evidence from the National Autistic Society Cymru

40. Following the Cabinet Secretary's appearance, the National Autistic Society Cymru's letter to us highlighted the role that legislation has on behaviour change,

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[49] CLA Committee, 15 October 2018, RoP [89]

[50] CLA Committee, 15 October 2018, RoP [31]

[51] CLA Committee, 15 October 2018, RoP [16]

[52] CLA Committee, 15 October 2018, RoP [27-28]

noting that they view the Bill as a driver that will lead to improvements in service delivery and support.[53]

41. As regards the Cabinet Secretary's comments on condition-specific legislation and his view that autism legislation in England and Northern Ireland had not led to "visible improvements", the Society commented:

> "There are many examples of where clear and tangible duties included in those Acts have led to clear and tangible outcomes for autistic people. One clear example, to take the England Act, is that, prior to the 2009 Act, only 14 areas of England had an established adult Autism diagnostic pathway. As a result of the Act, only three areas do not have a diagnostic pathway.
>
> There is also no evidence to support the Cabinet Secretary's concern that the Bill will lead to more condition specific legislation. This simply hasn't been the case elsewhere."[54]

42. As regards the code, they said:

> "From our initial understanding we feel that the scope, permanence and enforcement of any such code would be limited in comparison to the Bill."[55]

Balance between what is on the face of the Bill and what is left to subordinate legislation

Evidence from the Member in charge

43. The Member in charge explained his approach to the Bill:

> "… we placed more detail on the face of the Bill in order to ensure that future Executives, future Welsh Governments, actually delivered on improving autism services. Of course, as I mentioned earlier, we did run two substantial consultations. We obviously considered the responses of those consultations as well, but I believe we've struck the right balance when it comes to this Bill. I think that it was important to put some of these things on the face of the Bill to make sure that any future

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[53] Letter from the National Autistic Society Cymru, 23 October 2018

[54] Letter from the National Autistic Society Cymru, 23 October 2018

[55] Letter from the National Autistic Society Cymru, 23 October 2018

> Governments are held to account to deliver services that people with autism are entitled to across Wales."[56]

Evidence from the Cabinet Secretary

44. We asked the Cabinet Secretary whether the Bill strikes the right balance between what is and what is not on the face of the Bill. He said "a simple answer is no" and went on to provide some examples, relating to section 6 (data on autism spectrum disorder) and section 8 (duty to have regard to the United Nations Principles and Conventions).[57]

45. In particular the Cabinet Secretary, drew attention to challenges in section 6 regarding "the time frames that it sets out, but also how much of that personal data you'd want to collect and be required".[58] He spoke about the need to consider the mechanics and resourcing of collecting data listed in section 6, before adding:

> "I actually think that our ability to collect data at present doesn't require the powers that the Bill sets out and the requirement to collect data in this way. I'm always interested, of course, in how we use data to help improve services but, as I said earlier, I'm not a fan of prescribing on the face of the Bill the number of areas to consider in how we discharge our functions in the Act. It says:
>
> 'NHS…must collect the following data'
>
> I'm not always sure that that's entirely appropriate…
>
> If there'd been a broader power that said the NHS must collect data to help improve the Act and they need to set out what that is, well, that would be something different."[59]

46. The Cabinet Secretary cited the example of the *Social Services and Well-being (Wales) Act 2014*, and indicated that in terms of running a real service, having a lot of material on the face of the Bill has caused more of a problem,[60] although he went on to say:

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[56] CLA Committee, 24 September 2018, RoP [197]

[57] CLA Committee, 15 October 2018, RoP [52-54]

[58] CLA Committee, 15 October 2018, RoP [52]

[59] CLA Committee, 15 October 2018, RoP [75-79]

[60] CLA Committee, 15 October 2018, RoP [54]

> "But, really, it's a matter for the Member in charge to try and set out his scheme as to how he thinks this will work."[61]

Our view

47. There is clearly a difference of opinion between the Member in charge and the Cabinet Secretary about whether the legislation is needed. This is an issue that will have been considered in greater detail by the Health, Social Care and Sport Committee.

48. We therefore draw attention to the evidence we have received to enable Assembly Members to come to a view during the Stage 1 debate.

49. We are content with the balance between what is on the face of the Bill and what is left to subordinate legislation, subject to our remarks on section 6 in Chapter 4.

50. Our predecessor Committee's report, *Making Laws in Wales,*[62] recommended that there should be a presumption in favour of publishing draft Bills. We echo these comments for the reasons highlighted in that report and consider it to be good legislative practice. We therefore commend the Member in charge for his consultation on a draft Autism (Wales) Bill.

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[61] CLA Committee, 15 October 2018, RoP [75-79]

[62] Constitutional and Legislative Affairs Committee, Making Laws in Wales, October 2015, paragraphs 66-78 and recommendation 3

4. Specific observations including powers to make subordinate legislation

51. The Bill contains three specific powers to make subordinate legislation in the form of regulations. Our scrutiny session focused on the sections of the Bill and powers to make subordinate legislation of most interest to us and our consideration below considers the specific matters that we wish to draw to the attention of the National Assembly.

Sections 1 – 5 on the autism strategy

Background

52. Section 1 of the Bill requires the Welsh Ministers to prepare and publish a strategy "for meeting the needs throughout their lives of persons in Wales with autism spectrum disorder by improving the provision of services to such persons". Section 1(4) requires the strategy to be published not later than six months after the day on which the Act comes into force. In accordance with section 11, the coming into force date is three months after Royal Assent.

53. Section 1 also requires the Welsh Ministers to keep the strategy under review and to commission a report on its implementation and progress.

54. Section 2 sets out detailed requirements as to the contents of the strategy, while section 4 requires the Welsh Ministers to issue guidance following consultation and sets out specific matters to be addressed in the guidance. Section 5 requires relevant bodies to comply with the strategy and guidance when exercising their functions concerned with the planning and delivery of services to persons with ASD.

Evidence from the Member in charge

55. We asked the Member in charge why, when there is an obligation on Welsh Ministers to prepare and publish an autism strategy, it was merely to be laid before rather than approved by the National Assembly. In reply, he said he would be happy to consider that point further, noting in doing so that:

> "… we didn't want to limit the flexibility, if I'm absolutely honest, by getting any revised strategy approved every time, so that's why we've, obviously, gone for this course of action."[63]

56. An official accompanying the Member in charge added that:

> "We did give a lot of thought to the issue of strategy versus regulations, and also laying of the strategy versus approval via the Assembly. Whilst we shouldn't be led by other places, the regime that's been adopted across the UK has been the use of a strategy, as opposed to regulations. … The strategy offers flexibility and maybe strikes the right balance. It may, depending on the committee's views, be appropriate, for example—a middle ground might be that the first strategy might be laid for approval by the Assembly and subsequent strategies thereafter are simply laid."[64]

57. We asked why section 5 imposes a duty to comply with the strategy and guidance, rather than have regard to it. In response, the Member in charge said:

> "I accept that the normal duty in relation to strategies, guidance and codes is to have regard, but I felt it appropriate, I think, to strengthen the Bill following consultation feedback which supported a strong duty on relevant bodies to comply with the autism strategy and guidance. And in coming to this view, a power of direction was considered also as an option … but this would have amounted to a purely reactive power, in my view, reliant on Welsh Ministers identifying local failings and addressing them through direction in a timely manner. I didn't feel that a duty to have regard, or even a power of direction, would be sufficient to address the ongoing lack of consistent autism provision in Wales especially."[65]

58. He also noted that in response to the Bill, the Welsh Government has chosen to issue a code rather than regulations to support its existing autism strategy, before adding

> "Clearly, therefore, the Welsh Government considers a mandatory code to be appropriate as opposed to regulations, but my view is that the provisions under the Bill are a far more effective means of improving autism services, not least because they'll be mandatory on all relevant

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[63] CLA Committee, 24 September 2018, RoP [172]

[64] CLA Committee, 24 September 2018, RoP [179]

[65] CLA Committee, 24 September 2018, RoP [202]

> bodies. Clear obligations on relevant bodies imposed by a strategy and accompanying guidance, underpinned by the details set out on the face of the Bill … provide Welsh citizens with clarity as to their rights in relation to autism services. And I think such clarity and transparency also ensures that the citizen can actually seek to enforce those rights via a judicial review. This is a well-understood means of enforcement, and one that I consider to be appropriate and sufficient in the context of this Bill."[66]

59. In our exploration of the issue of enforcement, the Member in charge said "that if bodies do not comply with this legislation, if it's passed, then people will have the right to challenge that in a court of law via judicial review".[67] When questioned about why a power of direction was not pursued given the potential for delays and cost issues associated with judicial review, an official accompanying the Member in charge said:

> "It's inherent for Welsh Ministers, where a duty is mandatory, to direct that that duty is pursued or to seek means to ensure that it's properly delivered by the service in question … one of the concerns we had was that power of direction really does require a process, almost—that the Welsh Government is aware that there's a failing, or for the citizen to bring that to the attention of Welsh Government for Welsh Government to then resolve to take steps to address that issue. It might not always be the case that Welsh Government is aware of these failings or acts quickly. Our view was that a mandatory duty was more appropriate. It provides more certainty for the citizen … We were also mindful, if we applied other enforcement provisions within the legislation, whether that was proportionate in relation to the burden it would impose on Welsh Government and the court service as well. So, in the round, we thought this was an appropriate approach."[68]

60. The official added that the approach adopted gives citizens clarity about what their rights are in respect of these services.[69] He also noted that in similar legislation, the application of individual enforcement rights for citizens around this sort of duty does not appear.[70]

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[66] CLA Committee, 24 September 2018, RoP [204]

[67] CLA Committee, 24 September 2018, RoP [206]

[68] CLA Committee, 24 September 2018, RoP [209]

[69] CLA Committee, 24 September 2018, RoP [211]

[70] CLA Committee, 24 September 2018, RoP [207]

Evidence from the Cabinet Secretary

61. When asked whether the strategy required by the Bill should be subject to Assembly approval rather than laid before it, the Cabinet Secretary said:

> "I think it's one of the problems you probably could resolve in amending the Bill, but, as drafted, I think that's a problem. The code—there'll be a consultation, the code will be laid before the Assembly. The strategy, otherwise—you just say there has to be one. So, actually, I think that that in itself is problematic in the way that a statutory strategy would be set out. It's not my job, but you could, I think, amend that to have some scrutiny for it, but you still come back to whether that in itself is a good enough reason to pass the Bill."[71]

62. The Cabinet Secretary noted that the remedies for the legislation appear to be judicial review, commenting that this "is a very high bar to set".[72] He went on to say:

> "… some of this is about if the code isn't enacted, then Welsh Ministers can intervene, and Welsh Ministers can intervene both with the code about changing what's required under that and how that directs the way that services work. So, it is actually about balance and I think it's going to be easier to use than a straight judicial review remedy."[73]

63. In terms of whether the Bill provided an adequate period of time in which to prepare a strategy,[74] the Cabinet Secretary told us that it was not a realistic timetable.[75] In so doing he said:

> "If, within six months, you're going to have a statutory strategy, unless we just take what we have, that can't happen. Because for us to consult, and consult properly, then it just won't be ready. That's an honest point. If we wanted to have something like this, you'd normally offer the committee an opportunity to comment, you'd have a public

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[71] CLA Committee, 15 October 2018, RoP [40]

[72] CLA Committee, 15 October 2018, RoP [9]

[73] CLA Committee, 15 October 2018, RoP [23]

[74] Section 1(4) requires the strategy to be published not later than six months after the day on which the Act comes into force. By virtue of section 11, the coming into force date is three months after Royal Assent.

[75] CLA Committee, 15 October 2018, RoP [45-46]

> consultation, you'd then want to consult on the final draft of a strategy."[76]

Evidence from the National Autistic Society Cymru

64. In its response, the National Autistic Society Cymru told us:

> "It was noted by the Cabinet Secretary that the only remedy option, where it appears duties within the Bill aren't adhered to, is Judicial Review. Similar is ultimately true of a whole range of legislation.
>
> Suzy Davies AM pointed out that this could be said of the Social Services and Well Being Act, under which the proposed code of practice will be published. As you will know public services have their own complaint resolution mechanisms that aim to resolve concerns at an early stage.
>
> In this context we would urge the Committee to consider the role that legislation has on behaviour change. We very much view the Bill as a driver that will lead to improvements in service delivery and support.
>
> Autistic people and their families will have their rights strengthened and made clearer through this legislation. In our view, this could lead to less cause for remedial action, or remedy at an early stage."[77]

Our view

65. We recognise that the Welsh Government published a Refreshed ASD Strategic Action Plan in December 2016.

66. If the Bill becomes law, section 1 would require the preparation of a new autism strategy. Should that prove to be the case, we believe that the strategy should be laid before the National Assembly and subject to the negative procedure.

Recommendation 1. The Member in charge should table an amendment to the Bill to require that the autism strategy under section 1 of the Bill is subject to the negative procedure.

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[76] CLA Committee, 15 October 2018, RoP [46]

[77] Letter from the National Autistic Society Cymru, 23 October 2018

67. We share the concern of the Cabinet Secretary that the preparation of a new strategy could not be completed within the current timeframe set by the Bill.

> **Recommendation 2.** The Member in charge should discuss with the Cabinet Secretary a suitable timeframe for completion of the autism strategy and table an amendment to section 1(4) of the Bill to increase the 6 month deadline in line with those discussions.

68. We are concerned that, in the absence of enforcement provisions within the Bill, the only potential remedy available would appear to be an action to seek judicial review, which is unsatisfactory because of its complexity, high costs and potential for delays.

> **Recommendation 3.** The Member in charge should re-consider whether the remedies available to citizens under the Bill are appropriate, and if necessary, table amendments at Stage 2 to provide a more effective way of enforcing the Bill's provisions.

Section 6 – Data on autism spectrum disorder

Background

69. Section 6 of the Bill places a duty on the Welsh Ministers to obtain, produce and keep updated the data that they require to exercise their functions under the legislation and to publish that data annually. Section 6(2) says that the Welsh Ministers may request data from relevant bodies in order to carry out their functions under the legislation. Relevant bodies are defined in section 9(1) as meaning a local authority, an NHS body and such other bodies as may be prescribed in regulations.

70. Section 6(6) sets out categories of data to be collected by NHS bodies to assist them in the diagnosis and provision of services to persons with autism spectrum disorder and to enable NHS bodies to provide reliable data on autism spectrum disorder to the Welsh Ministers under section 6(2).

71. Section 6(6)(j) permits the Welsh Ministers to make regulations prescribing additional categories of data to be captured by NHS bodies. They are subject to the affirmative procedure "given that any additional categories of data prescribed may include personal data".[78]

72. The statement of policy intent states:

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[78] Explanatory Memorandum, Chapter 6, page 55

> "Section 6(6) sets out categories of data to be collected by NHS bodies to assist them in the diagnosis and provision of services to persons with ASD, and to enable NHS bodies to provide reliable data on ASD to the Welsh Ministers.
>
> In the interest of transparency and clarity, key data categories that NHS bodies must collect are set out on the face of the Bill. This data categories list has been compiled following advice from experts in data collection and clinical practice in ASD services and is judged to meet the minimum requirements for satisfying the functions of diagnosis, service planning and development of ASD services in Wales. However, should it become apparent/necessary to expand this list in future, this power gives the Welsh Ministers flexibility to do so."[79]

Evidence from the Member in charge

73. Given that relevant bodies have to provide anonymised data to the Welsh Minister if they are requested to do so, we asked why section 6(6) only sets out specific data collection requirements for NHS bodies. In response, the Member in charge said:

> "… expert advice strongly indicated that it's necessary to be able to analyse autism data of individual patients to generate valid statistics, as well as ensure that those patients are receiving the best possible services. And, paragraph 503 of the explanatory memorandum sets out the rationale for the inclusion of each data category in subsection 6(6), including for the collection of individual NHS numbers. The requirement to provide anonymised data to Welsh Ministers is to ensure compliance with data protection and human rights obligations, … and also, Welsh Ministers will only require macro-type data for the purposes of delivering the strategy."[80]

Evidence from the Cabinet Secretary

74. We asked the Cabinet Secretary whether there was value in having an obligation to collect data as set out in sections 6(1) and 6(2) of the Bill. He said:

> "It's always useful to have the data, but it's a very broad power to say that I, or a Welsh Minister, could request that data from any body that I determine. So, I determine who the relevant bodies are and I

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[79] Statement of policy intent, page 4

[80] CLA Committee, 24 September 2018, RoP [159]

> determine what data they must provide to me. You'd have people saying, 'Well, what's the relevance of the data and what are the safeguards, if you're a relevant body, for what that data would be and what it would require of your organisation?' Actually, we tend not to find a problem in acquiring data from people who deliver services where it's useful, because, actually, those people are normally in a relationship with the public sector to deliver those services, if they're in the third sector, and, if they're in the public sector, we can get the data anyway—so far as it's useful."[81]

75. When asked about the regulation-making powers under section 6 of the Bill, and whether the affirmative or a superaffirmative procedure should apply in each case, the Cabinet Secretary told us he didn't have a particular view on that issue.[82]

Our view

76. We consider it a weakness in the Bill that it only sets out data collection requirements for NHS bodies. We believe data collection requirements should be included on the face of the Bill for local authorities, which are also defined as relevant bodies under section 9(1) of the Bill.

Recommendation 4. The Member in charge should table an amendment to the Bill setting out the data that must be collected by local authorities, with the addition of a power for the Welsh Ministers to prescribe in regulations, subject to the affirmative procedure, other categories of data (in effect replicating the provision in section 6(6)(j)).

77. It follows from recommendation 4 that we are content with regulation-making power in section 6(6)(j) and the application of the affirmative procedure.

Section 9 – Interpretation

Background

78. Section 9(1) of the Bill contains a number of defined terms and states in particular that:

> "'autism spectrum disorder' (*anhwylder sbectrwm awtistiaeth*) means—

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[81] CLA Committee, 15 October 2018, RoP [81]

[82] CLA Committee, 15 October 2018, RoP [68]

> (a) autism spectrum disorder as defined by the World Health Organization International Classification of Diseases from time to time; and
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> (b) for the purpose of this Act, any other neurodevelopmental disorder prescribed by the Welsh Ministers;

and

> 'relevant body' (*corff perthnasol*) means a local authority, an NHS body and such other bodies as may be prescribed;"

79. Prescribed is defined in the same section as meaning "prescribed in regulations made by the Welsh Ministers".

80. As regards the definition of "autism spectrum disorder", the Explanatory Memorandum says that the regulation-making powers allow the Welsh Ministers to make regulations, for the purposes of this Bill only, for other neurodevelopmental disorders in addition to the WHO International Classification of Diseases definition of "autism spectrum disorder". The regulations are subject to the affirmative procedure "given that these regulations may significantly extend the scope of the disorders to which the Bill will apply".[83]

81. The statement of policy intent states that:

> "There may be changes to policy, or evidence may come to light, that further neurodevelopmental disorders should be captured by this legislation.
>
> This power would give the Welsh Ministers the flexibility to respond to address the needs of persons with other neurodevelopmental disorders, should they consider such disorders ought to be captured by this legislation at a future date. For example, the ongoing review of the strategy as required by section 1(5) and the periodic independent report on its progress under section 1(7), may provide evidence that the legislation can be properly applied to, and improve the diagnosis and treatment of, other neurodevelopmental disorders."[84]

82. As regards the definition "relevant body", the Explanatory Memorandum says that the regulation-making powers allow the Welsh Ministers to make regulations,

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[83] Explanatory Memorandum, Chapter 6, page 4

[84] Statement of policy intent, page 5

for the purposes of the Bill, beyond the local authorities and NHS bodies already included as relevant bodies. The regulations are subject to the affirmative procedure "given that these regulations will extend the range of bodies that will be required to comply with the autism strategy and accompanying guidance".[85]

83. The statement of policy intent states that:

> "This regulation making power will enable the Welsh Ministers to prescribe further 'relevant bodies' to whom the provisions of this Bill would apply, should this be deemed appropriate and there is evidence to support the requirement to capture other bodies under this legislation.
>
> 'Relevant bodies', which includes Local Authorities (across all functions) and NHS bodies (as defined in section 9(1)), are currently the principal providers or commissioners of services for people with ASD in Wales. This power would give the Welsh Ministers flexibility to prescribe additional bodies to reflect changing circumstances in the future so as to ensure the continued provision of appropriate ASD services."[86]

Evidence from the Member in charge

84. We asked the Member in charge why the definition of autism spectrum disorder includes a provision to extend the definition for the purposes of this Bill by regulations beyond that of the WHO definition and to cover other neurodevelopment disorders. The Member in charge told us:

> "Of course, the primary focus of this Bill is on the improvement of autism services in Wales. However, you're quite right, section 9(1) permits Welsh Ministers to prescribe other neurodevelopmental disorders by regulations, and this means that, if future Welsh Ministers believe the provisions of this Bill should be applied to people with other neurodevelopmental disorders, they would have the power to do so. Now, for example, advances in understanding autism and other neurodevelopmental disorders, and developments in clinical practice, could potentially make this appropriate, I think, in the future. Also, if the Bill is shown to make a significant improvement in autism services, Welsh Ministers may wish to extend the regime to deliver like

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[85] Explanatory Memorandum, Chapter 6, page 4

[86] Statement of policy intent, page 6

> improvements in the treatment and care of other neurodevelopmental disorders."[87]

85. He also told us that:

> "… the power to extend the definition can also be utilised as a safeguard, I think, against inadvertently diminishing relevant bodies' focus on addressing the needs of people with other neurodevelopmental disorders as well. However, I've made it quite clear that the Bill is first and foremost about the improvement of autism services in Wales, and this is its primary focus, but I do consider it appropriate to make provision for future developments that cannot be currently identified, and, for this reason, this safeguard has actually been included."[88]

86. The Member in charge noted that 62 per cent of the responses received to the second consultation supported the inclusion of a power to specify other neurodevelopmental disorders.[89] However, when asked about separate Bills for other conditions, he went on to say that "as far as I'm aware, other organisations or people with other conditions aren't clamouring for legislation for other conditions".[90]

87. The Member in charge felt that, although it had been considered, it would be excessive to use a superaffirmative procedure to make regulations extending the definition of autism spectrum disorder to cover other neurodevelopmental disorders as opposed to the affirmative procedure currently proposed in the Bill.[91]

88. When we asked about what was meant by "neurodevelopmental" in the context of the Bill, the official accompanying the Member in charge told us:

> "… autism spectrum disorder, under the World Health Organization international classification of diseases, is … No. 11 … within the current ICD 11, you have a top-line category of neurodevelopmental disorders and, beneath that, one of those disorders is autism spectrum disorder … the definition of neurodevelopmental disorder …
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> … is a recognised definition within the WHO catalogue there, or classification. Again, it may be appropriate to include that simple

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[87] CLA Committee, 24 September 2018, RoP [226]

[88] CLA Committee, 24 September 2018, RoP [227]

[89] CLA Committee, 24 September 2018, RoP [227]

[90] CLA Committee, 24 September 2018, RoP [230]

[91] CLA Committee, 24 September 2018, RoP [239]

> definition. We didn't because, equally, we didn't want to limit any changes that may occur around future classification of neurodevelopmental disorders, but, that said, again, if the committee feels strongly, and subject to any further expert advice, there's no reason why, at Stage 2, we can't introduce a definition of neurodevelopmental disorder."[92]

89. We also considered the power that permits Welsh Ministers to extend the range of relevant bodies beyond local authorities and NHS bodies. The Member in charge told us:

> "… future bodies and the bodies that haven't yet been identified could be captured under this legislation … I think that was considered necessary to ensure flexibility, because should Welsh Ministers need to extend the Bill's functions to further bodies as circumstances require, then I think it's only right and appropriate that this piece of legislation will allow them to do that. The other bodies that you could look at may not exist at the moment. However, what this will do is it will allow gaps in provision to be addressed, perhaps, in the future, due to future changes arising from restructuring, perhaps, reallocation of services, new initiatives et cetera, and it may therefore be necessary to capture the bodies that will be delivering autism services in the future. The provision in this section provides the necessary flexibility to achieve this, and thus ensure the Bill remains fit for purpose, and that's why we've included this section in the Bill."[93]

Evidence from the Cabinet Secretary

90. As regards whether the power was needed for the Welsh Ministers to extend the range of relevant bodies beyond local authorities and NHS bodies, the Cabinet Secretary told us:

> "I think this is part of the problematic part of the Bill, because if, say, it was me—or whatever role I may hold in the future—and I said, 'I will now make sure that there are other relevant bodies', well, if they're smaller bodies, then their ability to comply with all of the requirements in the Bill could be difficult. So, actually, I think that's troubling. Sometimes, backbench legislators are reticent about trusting the good judgment of a Minister and their civil servants to always do the right thing, and this is

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[92] CLA Committee, 24 September 2018, RoP [245-247]

[93] CLA Committee, 24 September 2018, RoP [213]

> quite a broad power to use. It might be sensible to have some parameters about what you would need to go through and do before you decide that a particular body will be subject to all of the requirements in the Bill. If you just think about the United Nations convention, well, actually, the health service and local government, you'd say it's fair to expect them to comply with that. You might want to look at other delivery organisations and say, 'Well, is that really a fair imposition to make on them, with all of the detail within it?' So, it's worth thinking about that, but it's a pretty broad-brush power to give to a Minister and then require them to undertake."[94]

91. With regard to the definition of an autism spectrum disorder, we asked whether the Cabinet Secretary agreed with the power to extend it to other neurodevelopmental disorders. He told us (in respect of the long title):

> "If you look at the start, it says:
>
> > 'to make provision for meeting the needs of children and adults with autism spectrum disorder in Wales'.
>
> We then have a broad-brush section at the end that says that Welsh Ministers can decide that actually it isn't just people with autism at all, and that's part of the problem about having condition-specific legislation. This says you can decide other conditions that can get through the same gate, but we're still going back to conditions, not the needs of the person. I think that is not the right way for us to deal with legislation, because otherwise you can potentially see a way we end up trying to legislate on all sorts of different conditions to try and say these people matter enough to have a piece of legislation. That isn't the point."[95]

92. When asked about the regulation-making powers under section 9 of the Bill, and whether the affirmative or a superaffirmative procedure should apply in each case, the Cabinet Secretary told us he didn't have a particular view on that issue.[96]

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[94] CLA Committee, 15 October 2018, RoP [56]

[95] CLA Committee, 15 October 2018, RoP [58-60]

[96] CLA Committee, 15 October 2018, RoP [68]

Our view

93. The regulation-making powers under section 9(1) of the Bill are Henry VIII powers, both subject to the affirmative procedure.

94. The power to amend the definition of autism spectrum disorder to include other neurodevelopmental orders is exceptionally broad. In effect, this power could enable the Welsh Ministers to potentially apply unspecified neurodevelopment disorders to the legislation. We are concerned at this approach for a number of reasons.

95. It is clear from the Member in charge's Explanatory Memorandum that a considerable amount of thought and research has gone into preparing a Bill that relates solely to autism.

96. However, the Bill permits subordinate legislation to be used to extend the Bill's provisions to other unspecified neurodevelopmental disorders (a term that itself is not defined in the Bill), without the guarantee of that legislation being accompanied by the same level of supporting evidence and analysis. In addition, it arguably makes the assumption that the provisions as drafted for autism would apply equally to those for other neurodevelopmental disorders.

97. Not only that, but if the Bill was enacted, it could, if the powers in section 9(1) were used, become an "Autism Act" that applies to a range of neurodevelopmental orders and not just autism. Similarly the autism strategy could apply to more than just autism. This has the potential to cause confusion to stakeholders.

98. Furthermore, it would mean that subordinate legislation related to other neurodevelopmental disorders would not be subject to the same level of scrutiny as the Autism Bill at Stage 1, and should its general principles be agreed to, nor would it be subject to amending stages at which Assembly Members can table amendments to test and potentially improve the Bill's provisions. Rather, as a piece of subordinate legislation, the widening of the enacted Bill's application would be subject to a "take it or leave it" vote, with no opportunity to amend that legislation.

99. We do not believe that given the breadth of the power, the application of a superaffirmative procedure would overcome our concerns.

100. In our view the approach in the Bill does not amount to good legislative practice and would not lead to good law.

101. For that reason we believe that the Bill should not permit the provisions of the Bill to be applied to other neurodevelopmental orders by means of subordinate legislation.

102. In reaching this view, we acknowledge that the provisions were included on the basis of consultation responses received by the Member in charge. In our view, the appropriate way to do this would, in theory, have been to introduce a Bill related to neurodevelopmental orders generally. However, we recognise that this would have been outside the terms of the Member in charge's original ballot proposal and his ability to do this was restricted.

> **Recommendation 5.** The Member in charge should table an amendment to section 9(1) of the Bill to remove paragraph (b) of the definition of autism spectrum disorder.

103. We are satisfied, however, that the provision in section 9(1) permitting the Welsh Ministers to use regulations to prescribe other bodies as relevant bodies for the purpose of the Bill is appropriate.

104. However, in view of our comments in recommendation 4, we believe that a power should be included in the Bill to enable the date collection requirements for new relevant bodies prescribed under section 9(1) to be set out in regulations.

> **Recommendation 6.** The Member in charge should table an amendment to the Bill to enable the data collection requirements for new relevant bodies prescribed under section 9(1) to be set out in regulations subject to the affirmative procedure.