

# Consultation on the proposed Autism (Wales) Bill

## Introduction

01. This consultation document outlines some of the key issues that my Bill will seek to address. Throughout the document there are a number of consultation questions posed to all interested parties. For clarity, all of the questions are also listed at the end of this document.
02. You can answer all, or some of the questions.

## Background

03. Much work has been undertaken in recent years to improve the services and support for people with autism spectrum conditions, their families and carers. The Welsh Government's ground-breaking Autism Spectrum Disorder Strategic Action Plan, published in 2008, established an autism infrastructure in each local authority area, with local co-ordinators and strategies, and a Wales national co-ordinator. It expanded research capacity, raised awareness of autism spectrum conditions and made available a range of information and resources for both autistic people, their families and professionals. Additional funding was provided to all local authorities, although this was ring fenced only up to April 2015.
04. The Strategic Action Plan also recognised the need for better diagnostic services for children and adults with autism spectrum conditions. Awareness raising led to an increase in demand for diagnosis. However, in many areas there are lengthy waits for an assessment – in some cases of many years.
05. A Refreshed Strategic Action Plan 2016–20 is introducing further reforms, including improvements to diagnostic services which should lead to shorter waiting times, the development of a National integrated Autism Service, and measures to improve education and employment for people with autism spectrum conditions.
06. However, although the Strategic Action Plan has helped raise awareness of autism, implementation has been patchy and problems remain. Independent evaluation of the Strategic Action Plan, and the work of autism task and finish groups identified continuing gaps in services, particularly around diagnosis, transition to adulthood, employment support, and access to information on services.



07. Many people with autism spectrum conditions and their families still do not receive the services and support they need to fulfil their potential. Whilst good practice and responsive services are evident in some areas, the local focus of the Strategic Action Plan has meant that provision has remained inconsistent across Wales. Furthermore, the voluntary nature of the local autism infrastructure means it is more effective in some areas than others. There is a need to ensure that people with autism spectrum conditions receive quality support wherever they live.

## The need for an ongoing Autism strategy

08. The Welsh Government's Strategic Action Plan has made, and continues to make welcome improvements to autism services in Wales. Nevertheless, ongoing improvement is needed, and beyond the period of the revised autism Strategic Action Plan (2016–20) there is an increased risk to the continued prioritisation of autism.

09. In my experience ensuring that there are legal duties on public services and mandatory reporting on how well they are doing is essential to ensure:

- that services understand what actions they should be taking to support autistic children and adults effectively;
- that the momentum for improvement is not lost; and,
- that there is accountability on services to improve.

10. Both England and Northern Ireland have legislation requiring their governments to publish an autism strategy and guidance for adults, and for adults and children respectively. The Republic of Ireland is currently considering its own autism legislation.

11. I believe legislation should require the Welsh Government to develop, publish and review a national autism strategy on a periodic basis, in consultation not only with relevant public bodies, but also with people with autism spectrum conditions and others affected by it such as parents, other family members and carers. This would help secure a measure of permanence and sustainability in care and support services for people with autism spectrum conditions and ensure a continued, dedicated focus on their needs regardless of the financial or political climate of the time.



12. At this stage I do not believe that legislation should necessarily define the detail of such a strategy beyond the objectives I have set out for it, but that it should allow sufficient flexibility to accommodate future needs.
13. I believe legislation should also require Welsh Ministers to issue, and periodically review, statutory guidance to local authorities and NHS bodies on their duties around the implementation of the strategy and arrangements for local services. The Bill should include some key areas and issues that the guidance will cover, although this list should not be exhaustive. Local authorities and NHS bodies should be required to act under the statutory guidance.

## Questions

- a) What are your views on the effectiveness of the current arrangements for improving autism services in Wales?
- b) Do you believe Wales should have legislation requiring the Welsh Government to publish a national autism strategy for children and adults and issue guidance to local authorities and NHS bodies on implementing the strategy?
- c) To what degree of detail do you think the content of a national autism strategy should be defined in legislation?
- d) What (if any) consultation do you think the Welsh Government should be required in legislation to undertake, when developing, reviewing and updating a national autism strategy?
- e) Do you believe that legislation should define how often a national autism strategy should be reviewed and updated? If so, how often should it be reviewed and updated?
- f) Do you have any views on how Welsh Government should monitor what progress is being made and how public services should be held accountable for how they support autistic people and their families?

Please explain your answers if possible.



## Clarity on pathways to diagnosis

14. In many areas of Wales there is no clear pathway to diagnosis. Receiving a diagnosis of an autism spectrum condition provides many individuals and their families with a measure of certainty and greater insight into the difficulties they experience. It is also the key to accessing appropriate services.
15. I believe that establishing in legislation the necessity of a clear pathway to diagnosis, for each local health board area and local authority would make sure that regardless of where you live and what age you are, you could access a diagnostic assessment in a timely way. This would also enable health boards and local authorities to be accountable in law for the provision of a clear pathway.

### Questions

- g) What are your views on how easy it is to access a diagnostic assessment where you live?
- h) What key challenges around how the diagnostic process works would you like legislation to address?
- i) Do you believe that Local Health Boards and Local Authorities in Wales should be required to publish information on the pathway to diagnosis for children and adults living in their areas?

Please explain your answers if possible.

## Delivery of services

16. Historically, because of the way local services are organised into teams, autistic people are likely to come into contact with either a learning disability team or a mental health team if they go to local health or care services to ask for support. However, while many autistic adults also have a learning disability or frequently experience mental ill health, autism itself is not a learning disability or mental health problem. Therefore frequently autistic adults, particularly those who don't also have a learning disability or mental health problem, are turned away from services or sent from one team to the other with no team taking responsibility for assessing and meeting needs. This can often mean that while their level of need



means that they are eligible for support, local service structures stop them from accessing help. As part of addressing this issue, I would want to make it absolutely clear to local services that screening people out of support on the basis of their IQ must not happen.

17. My intention is that the Autism (Wales) Bill would ensure that boards and local authorities understand the particular needs of children and adults with autism spectrum conditions and provide a holistic range of services to meet them.
18. In order to provide effective services, health boards and local authorities need to know the extent of need in their areas. Under the *Social Services and Wellbeing (Wales) Act 2014* they have a duty to assess the levels of need for care and support services in their areas and identify the range and level of services required to meet them. One of the core themes of these population assessments is learning disability/autism. Local authorities must draw up registers of children with disabilities in their areas and may do so for adults too.
19. However, anecdotal evidence suggests that there is currently significant variation in the scope and accuracy of information gathered. It is important that any population assessment identifies and recognises the distinctive needs of people with autism spectrum conditions. There is already a misconception among local authority social services that those autistic people who need help will also have a learning disability. Therefore without autism being recorded separately, there is a risk that the needs of those on the spectrum who don't have a learning disability will be overlooked. I want to ensure this doesn't happen and enable health boards and local authorities to address the gaps in local service provision.
20. I intend for this Bill to place a requirement on health boards and local authorities to establish data collection practices around the numbers and needs of children and adults with autism spectrum conditions so that local areas can plan services accordingly.

## Questions

- j) What are your views on the sufficiency of services currently provided to meet the needs of people with autism spectrum conditions in Wales?
- k) The legislation I am proposing would require the Welsh Government to issue statutory guidance that would put duties on local authorities and Local Health



Boards on how they should be delivering services for autistic children and adults and their families.

Do you agree that legislation should require statutory guidance?

If so, I would like to know your views on which requirements the guidance should place on local authorities and Local Health Boards.

The following is a list of the areas which I believe should be included in the statutory guidance for local authorities and Local Health Boards. Please indicate:

- whether you agree that these should be included, and,
- any other areas that should be included.
  - i. The provision of relevant services for the purpose of diagnosing autistic spectrum conditions in children and adults.
  - ii. The fact that assessment of the eligibility of children and adults for relevant services cannot be denied on the grounds of the person's IQ.
  - iii. Planning in relation to the provision of relevant services to people with autistic spectrum conditions, as they move from being children to adults.
  - iv. Other planning in relation to the provision of relevant services to children and adults with autistic spectrum conditions.
  - v. Local arrangements for leadership in relation to the provision of relevant services to children and adults with such conditions.
- l) Do you believe that Local Health Boards and Local Authorities in Wales should be required to establish and maintain new data collection practices around the numbers and needs of children and adults with autism spectrum conditions so that local areas can plan services accordingly?
- m) Do you have a view on how data can most effectively be gathered, on the numbers and needs of children and adults with autism spectrum conditions in different Local Health Board and Local Authority areas in Wales?

Please explain your answers if possible.

## Training

21. I intend that the Autism (Wales) Bill will ensure that key staff working with people with autism spectrum conditions, receive appropriate autism awareness training.
22. I recognise that a significant number of staff working with people with autism spectrum conditions have already received training through Welsh Government led initiatives.
23. I also recognise that there is a need for flexibility around the content of the training.
24. Nevertheless, I believe that legislation could promote consistency of training outcomes across all regions; provide a clear means by which implementation and maintenance of such standards can be monitored; and secure the delivery of such training on an ongoing and permanent basis.
25. I am minded to take an outcomes based approach in guidance on training requirements to allow flexibility on how training is provided while securing better awareness of autism amongst relevant staff.

## Questions

- n) Do you have a view on the current scope and effectiveness of training in Wales for key staff working with people with autism spectrum conditions?
- o) Do you believe that legislation should specify outcomes that training should achieve, thereby providing greater flexibility around the delivery of such training?

An alternative approach would be for legislation to specify that key staff working with people with autism spectrum conditions should undertake autism training

Please explain your answers if possible.

## Employment

26. The Welsh Government's Strategic Action Plan recognised that work was needed to promote employment of people with autism spectrum conditions and to provide employment support to individuals. An Autism Employment Ambassador provided



training and awareness on autism to employers and employment support providers up to April 2016.

27. Nevertheless, rates of employment amongst young people and adults with autism spectrum conditions remain much lower than for the general population and further work is needed to address this.

28. The Welsh Government's Refreshed Strategic Action Plan 2016–20 is introducing further reforms around improving education and employment for people with autism spectrum conditions. These include work on the Getting Ahead employment support programme for young people, action to make the Welsh Government an autism friendly employer, and work with employers and support staff to raise awareness of autism.

## Questions

- p) Do you have any suggestions for additional action that could be taken through legislation to improve the rates of employment of people with autism spectrum conditions (bearing in mind that the National Assembly for Wales does not have the power to make changes to employment law)?

Please explain your answer if possible.

## Definition of autism

29. I intend that this Bill would address a wide spectrum of needs of people with autism spectrum conditions in Wales. Existing legislation in other parts of the UK has taken varying approaches to providing a definition of autism: in some cases it is set out on the face of the Act, in others it is in a strategy, or guidance. My approach would be to require a definition of autism to be included in the autism strategy, as it is at present, and for this to be updated from time to time as necessary.

## Questions

- q) Do you believe that a definition of autistic spectrum disorder should:
- be included on the face of legislation (which makes it more difficult to change in the future);
  - be included in an autism strategy;





- be included in guidance; or,
- not be stated at all?

Please explain your answer if possible.

## Unintended consequences

30. I will carry out a range of impact assessments on my proposals as I develop the Bill to make sure that it does not adversely affect people with autism spectrum conditions, people who aren't on the autism spectrum, staff involved in the delivery of autism services, organisations or other areas disproportionately.

### Questions

r) Can you identify any possible unintended consequences which could arise as a result of this legislation? If so, what steps could be taken to deal with them?

Please explain your answer if possible.

## Costs

31. Most legislation will bring with it costs of some kind. I believe the main potential areas of costs for this Bill are likely to be around:

- gathering relevant information and developing a national autism strategy;
- periodically reviewing the strategy and issuing guidance and communicating changes to legislation;
- additional duties for local authorities and NHS bodies to act under guidance;
- creating and maintaining practices to enable the collection of data on the numbers and needs of adults and children with autism spectrum conditions; and,
- training for key staff.

32. The Social Services and Well-being (Wales) Act 2014 already places a statutory duty on local authorities to establish information, advice and assistance services, including to people with autism spectrum conditions, their families and carers. I believe that this could be extended to publishing information on services



specifically for people with autism spectrum conditions in local authority areas at little or no additional cost. The Refreshed Autistic Spectrum Disorder Strategic Delivery Plan 2016–2020 also says that Local Health Boards provide advice and support for all people with autism including family and carers as part of the new Integrated Autism Service.<sup>1</sup> Again, I believe that this could be extended by the Bill to include awareness-raising by local health boards at little or no additional cost.

## Questions

- s) Do you believe that the proposals in this consultation would give rise to any substantial costs, in addition to the cost-areas already noted in this consultation? How can such costs best be mitigated?
- t) What would the impact or costs be in terms of:
  - i. producing a national autism strategy;
  - ii. placing duties on local authorities and NHS bodies to act under guidance;
  - iii. creating and maintaining data collection practices on the numbers and needs of adults and children with autism spectrum conditions; and,
  - iv. providing training for key staff?
- u) Do you envisage any other additional administrative and regulatory costs as a result of this legislation and if so, how can any such impacts be mitigated?
- v) What factors should be measured to determine the cost-benefit analysis of this legislation should it become law?

Please explain your answers if possible.

## Savings

33. Legislation can also give rise to financial savings.

34. The National Audit Office in its publication “Supporting people with autism through adulthood”, emphasised that if services identified and supported four per cent of adults with what it describes as “high functioning” autism spectrum conditions in

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<sup>1</sup> Refreshed Autistic Spectrum Disorder Strategic Delivery Plan 2016–2020, Welsh Government, <http://www.asdinfo.wales.co.uk/resource/161130ASD-deliveryplanen.pdf>

the local area, then the outlay would be cost neutral over time in England.<sup>2</sup> Identification of six per cent and eight per cent could lead to potential savings in England of £38 million and £67 million per year respectively. This provides evidence that savings could be made based on effective identification and support of individuals with high functioning autism.

## Questions

- w) Do you have any views on how savings that might arise from this legislation can most effectively be identified and calculated?

## Other issues

35. This consultation is the beginning of a process of engagement with stakeholders as I develop my Bill. I welcome comments on any issues that I have not raised here that may be relevant.

## Questions

- x) Do you wish to make any other comments on my proposals?

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<sup>2</sup> Supporting people with Autism through adulthood, National Audit Office, 5 June 2009, <https://www.nao.org.uk/wp-content/uploads/2009/06/0809556.pdf>

# Consultation Questions

- a) What are your views on the effectiveness of the current arrangements for improving autism services in Wales?
- b) Do you believe Wales should have legislation requiring the Welsh Government to publish a national autism strategy for children and adults and issue guidance to local authorities and NHS bodies on implementing the strategy?
- c) To what degree of detail do you think the content of a national autism strategy should be defined in legislation?
- d) What (if any) consultation do you think the Welsh Government should be required in legislation to undertake, when developing, reviewing and updating a national autism strategy?
- e) Do you believe that legislation should define how often a national autism strategy should be reviewed and updated? If so, how often should it be reviewed and updated?
- f) Do you have any views on how Welsh Government should monitor what progress is being made and how public services should be held accountable for how they support autistic people and their families?
- g) What are your views on how easy it is to access a diagnostic assessment where you live?
- h) What key challenges around how the diagnostic process works would you like legislation to address?
- i) Do you believe that Local Health Boards and Local Authorities in Wales should be required to publish information on the pathway to diagnosis for children and adults living in their areas?
- j) What are your views on the sufficiency of services currently provided to meet the needs of people with autism spectrum conditions in Wales?
- k) The legislation I am proposing would require the Welsh Government to issue statutory guidance that would put duties on local authorities and Local Health



Boards on how they should be delivering services for autistic children and adults and their families.

Do you agree that legislation should require statutory guidance? If so, does the following list cover the right areas to be included under the duties on local authorities and Local Health Boards?

- i. The provision of relevant services for the purpose of diagnosing autistic spectrum conditions in children and adults.
  - ii. The fact that assessment of the eligibility of children and adults for relevant services cannot be denied on the grounds of the person's IQ.
  - iii. Planning in relation to the provision of relevant services to people with autistic spectrum conditions, as they move from being children to adults.
  - iv. Other planning in relation to the provision of relevant services to children and adults with autistic spectrum conditions.
  - v. Local arrangements for leadership in relation to the provision of relevant services to children and adults with such conditions.
- l) Do you believe that Local Health Boards and Local Authorities in Wales should be required to establish and maintain new data collection practices around the numbers and needs of children and adults with autism spectrum conditions so that local areas can plan services accordingly?
- m) Do you have a view on how data can most effectively be gathered, on the numbers and needs of children and adults with autism spectrum conditions in different Local Health Board and Local Authority areas in Wales?
- n) Do you have a view on the current scope and effectiveness of training in Wales for key staff working with people with autism spectrum conditions?
- o) Do you believe that legislation should specify outcomes that training should achieve, thereby providing greater flexibility around the delivery of such training?
- p) An alternative approach would be for legislation to specify that key staff working with people with autism spectrum conditions should undertake autism training.
- q) Do you have any suggestions for additional action that could be taken through legislation to improve the rates of employment of people with autism spectrum

conditions (bearing in mind that the National Assembly for Wales does not have the power to make changes to employment law)?

- r) Do you believe that a definition of autistic spectrum disorder should:
  - be included on the face of legislation (which makes it more difficult to change in the future);
  - be included in an autism strategy;
  - be included in guidance; or,
  - not be stated at all?
- s) Can you identify any possible unintended consequences which could arise as a result of this legislation? If so, what steps could be taken to deal with them?
- t) Do you believe that the proposals in this consultation would give rise to any substantial costs, in addition to the cost-areas already noted in this consultation? How can such costs best be mitigated?
- u) What would the impact or costs be in terms of:
  - i. producing a national autism strategy;
  - ii. placing duties on local authorities and NHS bodies to act under guidance;
  - iii. creating and maintaining data collection practices on the numbers and needs of adults and children with autism spectrum conditions; and,
  - iv. providing training for key staff?
- v) Do you envisage any other additional administrative and regulatory costs as a result of this legislation and if so, how can any such impacts be mitigated?
- w) What factors should be measured to determine the cost-benefit analysis of this legislation should it become law?
- x) Do you have any views on how savings that might arise from this legislation can most effectively be identified and calculated?
- y) Do you wish to make any other comments on my proposals?



# Responses

I look forward to receiving any comments you wish to make by 20 November 2017.

Please send your responses by e-mail to:

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