

SUBJECT:	DRAFT AUTISM (WALES) BILL
MEETING:	Joint Children and Young People and Adult Select Committee
DATE:	20th March 2018

1. PURPOSE:

To advise Members of the proposals contained in the Draft Autism (Wales) Bill and seek their views to inform the Council's response.

2. RECOMMENDATIONS:

That Members offer their views on the issues contained within the report to inform the Council's consultation response.

3. KEY ISSUES:

3.1 Background to the Bill: Paul Davies AM for Pembrokeshire has used Assembly protocol to bring forward a Private Member's Bill and run a consultation on a proposed Autism (Wales) Bill. In promoting the Bill he states that "many people with autism and their families still do not receive the services and support they need to enable them to cope with the challenges of autism and to fulfil their potential. Whilst good practice and responsive services are evident in some areas, the local focus of the Strategic Action Plan has meant that provision has remained inconsistent across Wales. Furthermore, the voluntary nature of the local autism infrastructure means it is more effective in some areas than others".

3.2 In broad terms the Autism (Wales) Bill seeks to:

- Require the Welsh Government to publish a strategy for meeting the needs of children and adults in Wales.
- Require the Welsh Government to issue statutory guidance to underpin the strategy.
- Ensure a clear and consistent pathway to diagnosis of autism spectrum conditions in every local area across Wales.
- Ensure that local authorities and health boards understand and take necessary action so that children and adults with autism spectrum conditions get the timely support they need (this might include, for example, putting duties on local authorities and health boards about the organisation of support for people with autism and their families, in their local areas).
- Establish practices, including the possible creation of a register, to enable the collection of reliable and relevant data on the numbers and needs of children and adults with autism spectrum conditions so that responsible local bodies can plan accordingly.
- Ensure that local authorities and health boards publish information on the services they provide for people with autism spectrum conditions in their areas.
- Regularly review the strategy and statutory guidance to ensure progress.
- Raise public awareness and understanding of the needs of children and adults with autism.

(A full copy of the draft Bill is attached as Appendix 1)

The Bill has a short consultation period with responses being sought by 17th April 2018.

3.3 Current ASD Infrastructure: In 2008 the Welsh Government launched the Autism Spectrum Disorder (ASD) Strategic Action Plan for Wales. The Strategic Action Plan set the direction for the development of services for those with ASD across Wales. During 2015 a public consultation was held by the National Development Team. Welsh Government accepted the findings of the consultation and the strategy was refreshed and updated.

Nationally, the ASD structure in Wales consists of a Welsh Government ASD Lead and a National Autism Development Team situated within the Welsh Local Government Association. Across Wales Integrated Autism Services based on a health footprint have been established, with Monmouthshire being an active partner in the Gwent Integrated Autism Service.

Since the inception of the Strategic Action Plan, Monmouthshire has adopted a positive approach to supporting children, families and adults with ASD and has an ASD Lead and ASD Coordinator. Monmouthshire hosts and facilitates an ASD Stakeholder Group; a multiagency group consisting of 25+ organisations, parents/carers and people with autism. The objective of this group is to help to implement the Welsh Government's ASD Strategic Action Plan within Monmouthshire, in particular supporting people of all ages to live as fulfilled and independent lives as possible. Monmouthshire has also played a leading role in promoting ASD awareness amongst its staff and communities.

3.4 The Consultation

The full consultation letter and questions is attached as Appendix 2 and Members' views on any aspect contained within the document are welcome.

There are specific aspects of the consultation on which Members' views would be appreciated:

Definitions: The Bill brings in the idea that its purview could be wider than autism and asks the following questions:

Do you agree that using the WHO ICD-11 definition in the draft Bill, together with the power for Welsh Ministers to include other neurodevelopmental disorders, is the right approach?

Neurodevelopmental disorders in children include attention-deficit/hyperactivity disorder (ADHD), autism, learning disabilities, intellectual disability, conduct disorders, cerebral palsy, and impairments in vision and hearing.

Some concerns might be that to include such a wide purview might dilute the focus on autism. There is also a concern that listing conditions might further medicalise an approach that seeks to enable children, families and adults to lead their lives. However,

for those experiencing other neurodevelopmental disorders, a greater focus and a more strategic approach is likely to be welcome.

Members' views to include in a response are welcome.

Relevant Bodies: The draft Bill refers to “relevant bodies” which have duties to implement the autism strategy. Relevant bodies are defined in section 7 as local authorities and NHS bodies but Welsh Ministers are provided with a power to include other bodies within the definition. The consultation letter asks the following question:

Are the “relevant bodies” in section 7 of the draft Bill the appropriate bodies to implement the autism strategy?

Noting that the key aspects of the Autism Strategy include:

- access to healthcare services;
- access to education;
- access to employment;
- access to housing;
- access to Welsh language services;
- access to other public services;
- social inclusion; and
- access to advocacy services

Whilst we would agree that Health and local government have key roles to play in implementing the Autism Strategy, partners such as the third sector must also play a part to ensure success. The importance of Welsh Ministers in being able to exercise the power to include other bodies could therefore be emphasised.

Members' views on this aspect of the consultation are sought, in particular whether there are other bodies who have key roles in implementing the Autism Strategy?

Power of Direction: Section 4 of the draft Bill states that relevant bodies must have regard to the Autism Strategy and guidance when exercising their functions. The consultation seeks views on whether this provision in the draft Bill should be reinforced by providing Welsh Ministers with a power of direction over relevant bodies. A power of direction means that the Minister is able to require a relevant body to do something. This power would only usually be exercised as a last resort if it were clear to the Minister that otherwise the required action would not be taken. This is a significant power to grant Welsh Ministers and is not included in legislation as a matter of course.

Should the duty on relevant bodies to have regard to the Autism Strategy and guidance be reinforced by providing Welsh Ministers with a power of direction over relevant bodies?

A key driver behind the draft Autism (Wales) Bill is consistent support for people with ASD across Wales so a power of direction could be useful in ensuring compliance. However, local experience would suggest that across public bodies and communities, people are motivated to provide support and we might be better served to build on that positivity rather than through the threat of intervention.

Members' views on this aspect of the consultation would be welcome.

Timescales for diagnosis and assessment of needs: The draft Bill states in section 2(1)(c) that the Autism Strategy must provide for diagnosis of persons to be completed as soon as is reasonably practicable and at least within timescales set out in relevant National Institute for Health and Care Excellence guidelines. This means that if there is a change to the recommended timescales set out in relevant National Institute for Health and Care Excellence guidelines, the maximum timescale for diagnosis as provided for in the Autism Strategy would also change.

The draft Bill also sets out in section 2(1)(e) the need to “ensure assessment of the care and support needs are completed as soon as reasonably practicable and at least within 2 months of a diagnosis of autism spectrum disorder or any post-diagnostic meeting, whichever is the later”. The consultation questions asked are as follows:

Do you agree that diagnosis should be completed within timescales in the relevant National Institute for Health and Care Excellence guidelines, as set out in in section 2(1)(c) of the draft Bill?

Do you agree that an assessment of care and support needs should be completed within 2 months of a diagnosis of autism spectrum disorder or any post-diagnostic meeting, as set out in section 2(1)(e)?

There would appear to be a logic in aligning timescales to National Institute for Health and Care Excellence guidelines. Our concern relates to the presumption that an assessment of care and support needs should be completed within two months of diagnosis. There is little detail at this stage, but this could imply that everyone diagnosed with ASD or a neurodevelopmental disorder must also receive an assessment of their care and support needs whether this is beneficial/necessary or not. This could potentially reinforce a negative, disability focused perception of ASD and is likely to create service demand rather than support the notion of wellbeing and independence.

We would ask Members to support further clarification of this point and suggest that an assessment of care and support needs only to take place where appropriate. Further views are welcome.

Raising Awareness: The draft Bill states (section 6(1)) that upon publication of the Autism Strategy, Welsh Ministers must initiate and maintain a campaign to awareness and understanding of the needs of persons with autism spectrum disorder. This would be intended to ensure a continuous campaign to promote understanding and awareness of the needs of persons with autism spectrum disorder. An alternative option would be for the draft Bill to state that Welsh Ministers must re-launch the campaign at least every three years. This would be intended to ensure a regular cycle of ‘new-impetus’ to awareness campaigning.

Should a campaign to raise understanding and awareness of the needs of persons with autism spectrum disorder be rolled out on a continuous basis, or on a regular (three-year) cycle?

Monmouthshire has a great deal of experience in promoting autism awareness and would suggest that, in accordance with our own approach, to be effective it needs to be continuous. However, such activity, whilst of vital importance, is time and resource intensive. Members' views on the most effective means of promoting awareness and understanding would be welcome.

3 REASONS:

Paul Davies AM's Private Member's Bill offers us an opportunity to reflect upon the provision of support for people with ASD across Wales.

The Bill places a significant onus upon Health and local authorities to deliver the Autism Strategy envisaged within the Bill and whilst much of the detail will be developed and specified within guidance, we have the opportunity through this current consultation to offer a view on where we feel the focus should lie.

4 RESOURCE IMPLICATIONS:

At this early stage the resource implications of the proposed Autism Bill are difficult to assess. Since the inception of the Strategic Action Plan for Wales, the Welsh Government has made available significant resources to fund national, regional and local support for ASD.

Given that the current proposals, in particular those relating to care and assessment and training, could have significant resource implications, a key message to the Welsh Government might be that the introduction of the Autism Bill would need to be appropriately resourced?

9 CONSULTEES:

Social Care and Health DMT – 28th March 2018

10 BACKGROUND PAPERS:

None

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Autism (Wales) Bill

[DRAFT]

CONTENTS

1	Autism strategy
2	Contents of the autism strategy
3	Guidance by the Welsh Ministers
4	Relevant bodies: duty to have regard to the autism strategy and guidance
5	Data on autism spectrum disorder
6	Awareness campaign
7	Interpretation
8	Regulations
9	Coming into force
10	Short title

Autism (Wales) Bill

[DRAFT]

An Act of the National Assembly for Wales to make provision for meeting the needs of children and adults with autism spectrum disorder in Wales and protecting and promoting their rights.

Having been passed by the National Assembly for Wales and having received the assent of Her Majesty, it is enacted as follows:

5

Autism strategy

- (1) The Welsh Ministers must prepare and publish a document setting out 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.
- 10 (2) The document is referred to in this Act as “the autism strategy”.
 - (3) The autism strategy must, as a minimum, satisfy the requirement set out in section 2.
 - (4) The autism strategy must be laid before the National Assembly for Wales as soon as reasonably practicable after its preparation and published not later than 6 months after the day on which this Act comes into force.
- 15 (5) The Welsh Ministers –
 - (a) must keep the autism strategy under review; and (b) may revise it.
- (6) If the Welsh Ministers revise the autism strategy, they must lay the revised strategy before the National Assembly for Wales and publish it as soon as it is reasonably
20 practicable to do so.
 - (7) Not more than three years after the publication of the autism strategy, and at intervals of no more than three years thereafter, the Welsh Ministers must commission an independent report on its progress.
 - (8) The Welsh Ministers must lay the report prepared under subsection (7) before the ²⁵ National Assembly for Wales as soon as practicable after its preparation and publish it.
 - (9) The Welsh Ministers must consult with relevant bodies and such other persons as the Welsh Ministers may consider appropriate (including persons with autism spectrum disorder and organisations representing their interests or providing services to them) – (a) in preparing the autism strategy; or
30 (b) in revising it in a way which would, in the opinion of the Welsh Ministers, result in a substantial change to the autism strategy.
- (10) Steps taken by the Welsh Ministers before this section comes into force are as effective for the purposes of this section as if they had been taken after that time.

Contents of the autism strategy

- (1) The autism strategy must –
- (a) define a best practice model or models for the:
 - (i) identification and diagnostic assessment of autism spectrum disorder;
 - 5 (ii) assessment of the care and support needs of persons with autism spectrum disorder; and
 - (iii) planning for and meeting the care and support needs of persons with autism spectrum disorder;
 - (b) make provision for the development of a pathway, that includes access through
10 defined points of referral, to map the services that are available and required for persons with autism spectrum disorder;
 - (c) provide for diagnostic assessments and any post-diagnostic meetings to be completed as soon as reasonably practicable following a referral and at least within any timescales set out in relevant guidelines issued by the National
15 Institute for Health and Care Excellence¹;
 - (d) make provision for individual diagnostic assessments to be conducted by a multidisciplinary team of professionals;
 - (e) provide for an assessment of care and support needs to be completed as soon as reasonably practicable and at least within 2 months of a diagnosis of autism 20 spectrum disorder or any post-diagnostic meeting, whichever is the later;
 - (f) make provision to ensure that people are not denied access to services on the grounds of IQ or receipt of services for other medical conditions;
 - (g) outline how the needs of persons with autism spectrum disorder should be met by relevant bodies in respect of, but not limited to, –
 - 25 (i) access to healthcare services;
 - (ii) access to education;
 - (iii) access to employment;
 - (iv) access to housing;
 - (v) access to Welsh language services;
 - 30 (vi) access to other public services;
 - (vii) social inclusion; and
 - (viii) access to advocacy services;
 - (h) make provision so that an appropriate range of services to deliver the autism strategy are available consistently across Wales;

¹ NICE Autism guidance: <https://www.nice.org.uk/guidance/conditions-and-diseases/mentalhealth-and-behavioural-conditions/autism>

- 35 (i) make provision to ensure services that are provided are accessible to each person who needs those services;
- (j) make provision to ensure a continuity of service that reflects and facilitates the transition from childhood to adulthood;
 - (k) place an emphasis on how families and carers of a person with autism spectrum disorder can be supported in meeting the needs of that person;
 - (l) make provision for the wishes of people with autism spectrum disorder and of their family and carers to be taken into account;
- 5 (m) place emphasis on achieving innovation and improvement in the commissioning and delivery of autism spectrum disorder services;
- (n) make provision for the commissioning of research into any aspect of autism spectrum disorder;
 - (o) make provision for the collecting of data in accordance with section 5;
- 10 (p) make provision for a campaign to raise awareness and understanding of the needs of persons with autism spectrum disorder in accordance with section 6;
- (q) make provision about the identification of key professionals and provision of appropriate training to them in relation to supporting people with autism spectrum disorder; and
- 15 (r) make provision to establish the necessary infrastructure and leadership to monitor and promote the implementation of the autism strategy.
- (2) The autism strategy may address any other matter considered appropriate by the Welsh Ministers.

Guidance by the Welsh Ministers

- 20 (1) Welsh Ministers must issue guidance to relevant bodies about the exercise of their functions for the purpose of securing the implementation and delivery of the autism strategy and publish that guidance.
- (2) The guidance must be issued under this section no later than 3 months after publication of the autism strategy.
- 25 (3) The Welsh Ministers –
- (a) must keep the guidance under review; and
 - (b) may revise it.
- (4) If the Welsh Ministers revise the guidance they must publish the revised guidance as soon as it is reasonably practicable to do so.
- 30 (5) In keeping the guidance under review the Welsh Ministers must in particular consider:
- (a) the extent to which the guidance has been effective in securing the implementation of the autism strategy; and
 - (b) whether revisions to the autism strategy make revisions to the guidance appropriate.
- 35 (6) Guidance issued under this section must in particular include guidance about –

- (a) the identification of persons with autism spectrum disorder;
- (b) the provision of diagnostic and needs assessment services;
- (c) the inclusion of key professionals in multi-disciplinary diagnostic assessment teams, in particular –
 - (i) a psychologist;
 - (ii) a psychiatrist;
 - (iii) a speech and language therapist;
 - (iv) an occupational therapist;
- 5 (v) a behavioural therapist; and
- (vi) a social worker;
- (d) what data should be collected and how it should be published;
- (e) the training of staff who provide services; and
- (f) local arrangements for leadership in relation to the provision of services.

10 (7) The Welsh Ministers must consult with relevant bodies and such other persons as the Welsh Ministers may consider appropriate (including persons with autism spectrum disorder and organisations representing the interests of or providing services to them) before –

(a) issuing guidance under this section; or

15 (b) revising it in a way which would, in the opinion of the Welsh Ministers, result in substantial change to the guidance.

(8) Steps taken by the Welsh Ministers before this section comes into force are as effective for the purposes of this section as if they had been taken after that time.

Relevant bodies: duty to have regard to the autism strategy and guidance

20 Relevant bodies must, in exercising their functions concerned with the planning and delivery of services have regard to the autism strategy issued under section 1 and guidance issued under section 3.

Data on autism spectrum disorder

(1) The Welsh Ministers must obtain, produce, publish and keep updated reliable data in 25 order to carry out their functions under this Act.

(2) In order to comply with the duty under subsection (1), the Welsh Ministers may request anonymised data from relevant bodies.

(3) Relevant bodies must provide the Welsh Ministers with the data that may be requested under subsection (2) unless they are prohibited from doing so by virtue of an enactment
30 or any other rule of law.

Awareness campaign

- (1) Upon publication of the autism strategy the Welsh Ministers must initiate and maintain a campaign to raise awareness and understanding of the needs of persons with autism spectrum disorder
- 35 (2) The campaign must include elements that enhance the understanding of the needs of such persons by members of the public, employers and those providing services.
- (3) Welsh Ministers must report on the progress and effectiveness of the campaign in any report prepared under section 1(7).

Interpretation

- (1) In this Act—
 - “adult” (“oedolyn”) means a person who is aged 18 or over;
 - 5 “autism spectrum disorder” (“anhwylder sbectrwm awtistiaeth”) means—
 - (a) autism spectrum disorder as defined by the World Health Organization International Classification of Diseases from time to time²; or
 - (b) any other neurodevelopmental disorder prescribed by the Welsh Ministers;
 - 10 “carer” (“gofalwr”), in relation to a person with autism spectrum disorder, means those persons specified as carers in the guidance issued under section 3(1);
 - “child” (“plentyn”) means a person who is aged under 18;
 - 15 “local authority” (“awdurdod lleol”) means a county council or county borough council in Wales;
 - “National Institute for Health and Care Excellence” (“y Sefydliad Cenedlaethol dros Ragoriaeth mewn Iechyd a Gofal”) means the Non Departmental Public Body established 20 under section 232 of the Health and Social Care Act 2012;
 - “NHS body” (“corff GIG”) means—
 - (a) a Local Health Board established under section 11 of the National Health Service (Wales) Act 2006;
 - 25 (b) a Special Health Authority established under section 22 of the National Health Service (Wales) Act 2006;

² This reflects the forthcoming WHO ICD-11 due to be published in May 2018:
<https://icd.who.int/dev11/l1-m/en#/http%3a%2f%2fid.who.int%2fid%2fentity%2f437815624>

30 (c) a National Health Service trust all or most of whose hospitals, establishments and facilities are situated in Wales or any trustees appointed in pursuance of paragraph 10 of Schedule 3 to the National Health Service (Wales) Act 2006 for such a trust; or

(d) a body of trustees appointed in pursuance of section 29(1) of the National Health Service Reorganisation Act 1973 (c. 32) and section 95(1) of the National Health Service Act 1977 (c. 49) and section 160(1) of the National Health Service (Wales) Act 2006 for a trust all or most of whose hospitals, establishments and facilities are situated in Wales.

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“parent” (“rhiant”) means any person who has parental responsibility (within the meaning of section 3 of the Children Act 1989 (c.41)) for a child;

“persons” (“personau”) means children and adults and “person” shall be construed accordingly;

5 “prescribed” (“rhagnodi”) means prescribed in regulations made by the Welsh Ministers;

“relevant body” (“corff perthnasol”) means a local authority, an NHS body and such other bodies as may be prescribed.

(2) In this Act references to the provision of services include references to arranging for the 10 provision of services (and reference to services provided are to be construed accordingly).

Regulations

(1) A power of the Welsh Ministers to make regulations under this Act is exercisable by statutory instrument.

(2) A statutory instrument may not be made unless a draft of the instrument has been laid 15 before, and approved by resolution of, the National Assembly for Wales.

Coming into force

This Act comes into force at the end of the period of 3 months beginning with the day on which it is passed.

Short title

20 The short title of this Act is the Autism (Wales) Act 2018.



Address Line 1

Address Line 2

Address Line 3

Address Line 4

Address Line 5

Dyddiad | Date: 22 February 2018

Pwnc | Subject: Autism (Wales) Bill

Dear Colleague,

Following a ballot conducted by the Presiding Officer, the National Assembly for Wales agreed that I can introduce proposals for a new law in Wales, to make provision for meeting the needs of children and adults with autism spectrum disorder, and protecting and promoting their rights.

Last year I undertook an extensive public consultation and engagement exercise to assist me in developing my proposals. I also outlined that I intended to undertake further consultation once a draft Bill had been prepared. This work has now been completed and I am pleased to attach a copy of the draft Bill for your information.

I am grateful to all those who responded to the initial consultation and I am pleased that the majority of responses are supportive of the principles of this legislation. In drafting the Bill I have given careful consideration to the points raised within these responses.

One concern that arose in my first consultation was that by legislating to meet the needs of children and adults with autism spectrum disorder, I might inadvertently reduce the Welsh Government's focus on addressing the needs of children and adults with neurodevelopmental conditions other than autism spectrum disorder.

To minimise this risk, the draft Bill defines 'autism spectrum disorder' in the following way:

- autism spectrum disorder as defined by the World Health Organization**

International Classification of Diseases from time to time; and also

- any other neurodevelopmental disorder prescribed by the Welsh Ministers.**

This means that if 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.

Depending on the outcome of this additional consultation, the Bill may be subject to further drafting and technical changes before I formally introduce it to the National Assembly. Upon formal introduction I will also publish an Explanatory Memorandum and Regulatory Impact Assessment to support the detailed scrutiny process which is required before a final decision is made on whether it should become law.

I would, therefore, be very grateful if you could find the time to contribute to this consultation and let me have your or your organisation's views on the draft Bill and what it is seeking to achieve. The draft Bill has also been published on the Assembly's website to allow as many people as possible to send in their comments.

I would welcome comments on all aspects of the draft Bill. However, there are a number of specific matters which I would particularly welcome views on. For full details about how the information you provide will be used please see the National Assembly for Wales' Member Bill privacy policy.

Definition of Autism Spectrum Disorder

As mentioned above, I have included on the face of the draft Bill in section 7(1) a reference to the definition of 'autism spectrum disorder' in the forthcoming World Health Organization International Classification of Diseases (WHO ICD - 11³). This means that if the World Health Organisation's definition of autism spectrum disorder changed in the future, the Bill's definition would automatically change with it.

This definition would apply throughout the Bill but Welsh Ministers would also have the power to include other neurodevelopmental disorders (i.e. neurodevelopmental disorders other than autism spectrum disorder).

Questions

- 01. Do you agree that a definition of 'autism spectrum disorder' should appear on the face of the Bill?**

3 <https://icd.who.int/dev11/l-m/en#/http%3a%2f%2fid.who.int%2fid%2fentity%2f437815624>

02. Do you agree that using the WHO ICD-11 definition in the draft Bill, together with the power for Welsh Ministers to include other neurodevelopmental disorders, is the right approach?

Range of bodies with functions under the Bill

I would welcome views on whether the range of bodies which would have functions affected by the draft Bill is appropriate. The draft Bill refers to “relevant bodies” which have duties to implement the autism strategy. Relevant bodies are defined in section 7 as local authorities and NHS bodies but Welsh Ministers are provided with a power to include other bodies within the definition. It should be noted that the definition of ‘NHS body’ in section 7 captures a number of different bodies providing health services.

Questions

03. Are the “relevant bodies” in section 7 of the draft Bill the appropriate bodies to implement the autism strategy?

Duty to have regard to the autism strategy and guidance

Section 4 of the draft Bill states that relevant bodies must have regard to the autism strategy and guidance when exercising their functions.

I would welcome views on whether this provision in the draft Bill should be reinforced by providing Welsh Ministers with a power of direction over relevant bodies. A power of direction means that the Minister is able to require a relevant body to do something. This power would only usually be exercised as a last resort if it were clear to the Minister that otherwise the required action would not be taken. This is a significant power to grant Welsh Ministers and is not included in legislation as a matter of course. Welsh Ministers already have a number of existing powers of direction, under, for example, the Social Services and Wellbeing (Wales) Act, so a further power of direction would only be required if there appeared to be a deficiency within current powers.

Question

04. Should the duty on relevant bodies to have regard to the autism strategy and guidance be reinforced by providing Welsh Ministers with a power of direction over relevant bodies?

Timescales in the draft Bill

I would also welcome views on whether the timings set out in the draft Bill are appropriate, including the following:

- **section 1(4) of the draft Bill states that “the autism strategy must be published not later than six months after the day on which this Act comes into force.”**
- **Section 3(2) states that “the guidance must be issued under this section no later than 3 months after publication of the autism strategy.”**
- **Section 9 states “this Act comes into force at the end of the period of 3 months beginning with the day on which it is passed.”**

Questions

05. **Do you have any views about the timing set out in section 1(4) of the draft Bill for the publication of the Autism Strategy?**
06. **Do you have any views about the timing set out in section 3(2) for issuing guidance under the Bill?**
07. **Do you have any views about the timing set out in section 9 for when the Act comes into force?**

Timescales for diagnosis and assessment of needs

The draft Bill states in section 2(1)(c) that the Autism Strategy must provide for diagnosis of persons to be completed as soon as is reasonably practicable and at least within timescales set out in relevant National Institute for Health and Care Excellence guidelines. This means that if there is a change to the recommended timescales set out in relevant National Institute for Health and Care Excellence guidelines, the maximum timescale for diagnosis as provided for in the Autism Strategy would also change. I would be grateful for views on whether this is appropriate.

The draft Bill also sets out in section 2(1)(e) the need to “ensure assessment of the care and support needs are completed as soon as reasonably practicable and at least within 2 months of a diagnosis of autism spectrum disorder or any postdiagnostic meeting, whichever is the later”. I would be grateful for views on this.

Questions

08. **Do you agree that diagnosis should be completed within timescales in the relevant National Institute for Health and Care Excellence guidelines, as set out in in section 2(1)(c) of the draft Bill?**
09. **Do you agree that an assessment of care and support needs should be completed within 2 months of a diagnosis of autism spectrum disorder or any post-diagnostic meeting, as set out in section 2(1)(e)?**

Multi-disciplinary team

The draft Bill currently states in section 3(6) that the Autism Strategy must make provision for individual diagnostic assessment of persons with autism spectrum disorder to be conducted by a multi-disciplinary team of professionals. The draft Bill states in section 3(6)(c) that guidance on the strategy must include guidance about this multi-disciplinary diagnostic assessment team and in particular about the inclusion of —

- i. a psychologist;
- ii. a psychiatrist;
- iii. a speech and language therapist;
- iv. an occupational therapist;
- v. a behavioural therapist; and vi. a social worker.

I would welcome views on this list generally, and on whether there are any other disciplines that you think should be listed as possible members of such a multidisciplinary team.

The list in the Bill is intended as an illustration and would not require the inclusion of the professionals in the list on each occasion a diagnostic assessment is undertaken. It would require guidance on the Autism Strategy to include guidance whether, and when, the listed professionals should be included. I would welcome views on whether it is useful to include a list of multi-disciplinary team members on the face of the Bill, or whether there would be a preference for no such list.

Questions

10. Do you agree that it is useful to include in the draft Bill a list of professionals who may form the multi-disciplinary team for diagnostic assessment?
11. If so, are there any other disciplines that you think should be listed as possible members of such a multi-disciplinary team?

Ensuring equity of access to services

The draft Bill seeks, in section 2(1)(f), to ensure that individuals with autism spectrum disorder are not denied access to services on the grounds of IQ or receipt of services for other medical conditions. I would welcome views on whether the Bill should refer to other factors or circumstances which may inappropriately prevent individuals with autism spectrum disorder accessing services.

Question

12. Are there any other factors or individual circumstances which may inappropriately prevent access to services and which should be set out in the Bill?

Data on autism spectrum disorder

The draft Bill makes provision in sections 5 and 3(6)(d) for data collection by Welsh Ministers to enable them to carry out functions under the Bill. This is likely to include information on people with autism spectrum disorder in Wales, their use of services, etc.

I would welcome views on whether the types of data to be collected should be specified, either on the face of the Bill or in guidance. Specifying the type of data to be collected might help to ensure consistency of data reporting across Wales, which in turn will better enable Welsh Ministers to identify any regional differences.

I would also welcome views on whether the provision in section 5(2), to allow Welsh Ministers to request anonymised data from relevant bodies, is appropriate given existing data protection legislation which provides safeguards around the use of data.

Questions

- 13. Should the draft Bill specify the types of data to be collected by Welsh Ministers to enable them to carry out functions under the Bill?**
- 14. If so, do you have any views about the types of data which should be collected? Examples of types of data which should be collected might include: age, age at diagnosis, gender, health board/local authority area, time from assessment to diagnosis, profession(s) of diagnosing staff and service in which based, diagnostic assessment tool(s) used, use of a scored assessment, the diagnosing clinician's estimate of intelligence level⁴, communicative development, whether testing for phenylketonuria (PKU) was carried out.**

⁴ For clarity, IQ or other existing medical conditions should not be used in assessing eligibility for services. For instance, a person can have both autism spectrum disorder and a very high intelligence level, and this must not make them ineligible to receive services. However, in practical terms a very low intelligence level can make it more difficult for a clinician to accurately assess whether a person has autism spectrum disorder. As such, I believe there to be value in capturing data on the diagnosing clinician's assessment of intelligence level.

15. Should the types of data be specified on the face of the Bill or in guidance?

16. Do you agree that:

- a. the provision in section 5(2) to allow Welsh Ministers to request anonymised data from relevant bodies is appropriate, and**
- b. it should be included on the face of the Bill?**

Campaign to raise awareness and understanding

Finally, the draft Bill currently states (section 6(1)) that upon publication of the Autism Strategy, the Welsh Ministers must initiate and maintain a campaign to raise awareness and understanding of the needs of persons with autism spectrum disorder. This would be intended to ensure a continuous campaign to promote understanding and awareness of the needs of persons with autism spectrum disorder.

An alternative option would be for the draft Bill to state that the Welsh Ministers must re-launch the campaign at least every three years. This would be intended to ensure a regular cycle of ‘new-impetus’ to awareness campaigning. I would welcome views on whether a campaign to raise understanding and awareness of the needs of persons with autism spectrum disorder should be rolled out on a continuous basis, or on a regular (three-year) cycle.

Question

17. Should a campaign to raise understanding and awareness of the needs of persons with autism spectrum disorder be rolled out on a continuous basis, or on a regular (three-year) cycle?

Impact of this legislation

It would be very helpful if you could comment on whether there are any issues, benefits or risks which could result from the draft Bill in relation to the issues listed below.

Questions

- 18. Giving reasons for your answer, could any of the proposals in the draft Bill be reformulated so as to increase its positive effects or reduce its possible adverse effects, in relation to:**
- a. the Assembly’s official languages (Welsh and English);**
 - b. equality, diversity and inclusion;**

- c. the justice system in England and Wales; or
- d. costs and benefits to you or your organisation

19. Do you have any other comments to make on the draft Bill?

Deadline

The Bill must be introduced to the National Assembly by 13 July 2018 and in order to meet this deadline the closing date for this consultation is 17 April 2018.

How your information will be used

Information you provide may be used by me and other Assembly Members, support staff and Assembly Commission staff, for the purposes of the development of the Member Bill, promotion of the intended effect of the Bill, and subsequent scrutiny of the Bill.

Your name, contact details (if you are responding in your professional capacity) and full response may be published on the National Assembly for Wales' website, and potentially in subsequent publications or publicity material. You must make clear in your response if you would like it to be anonymised.

Your contact details may be used in order to provide further opportunities to engage in the development and/or scrutiny of the Bill. If you would like to ask a

question about how your information will be used please contact Consultation.AutismBill@assembly.wales

For full details about how your information will be used please see the National Assembly for Wales' [Member Bill privacy policy](#). If you would like your response to be anonymised, please make this clear.

I welcome responses in English and Welsh. I ask organisations with Welsh Language policies / schemes to provide bilingual submissions, in line with their public information policies. I am also publishing this consultation bilingually in Easy Read.

Further information about the Member Bill process can be found at [Member Bills](#).

I look forward to receiving your views and thank you for your time.

Croesewir gohebiaeth yn Gymraeg neu Saesneg.

We welcome correspondence in Welsh or English.