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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 -11¹). This means that if the World Health Organisation’s definition of autism spectrum

¹ <https://icd.who.int/dev11/l-m/en#/http%3a%2f%2fid.who.int%2ficd%2fentity%2f437815624>



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?
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 post–diagnostic 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 multi-disciplinary 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 level², communicative development, whether testing for phenylketonuria (PKU) was carried out.
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?

² 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.



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:
- the Assembly's official languages (Welsh and English);
 - equality, diversity and inclusion;
 - the justice system in England and Wales; or
 - 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.

