

ACCOMPANYING DOCUMENTS
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Autism (Wales) Bill

[AS INTRODUCED]

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Autism (Wales) Bill

[AS INTRODUCED]

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, and for connected purposes.

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

1 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.
- (2) The document is referred to in this Act as “the autism strategy”.
- (3) The autism strategy must, as a minimum, satisfy the requirements 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.
- (5) The Welsh Ministers must keep the autism strategy under review and 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 practicable to do so.
- (7) Not more than 3 years after the publication of the autism strategy, and at intervals of not more than 3 years thereafter, the Welsh Ministers must commission an independent report on its ongoing implementation and progress.
- (8) The Welsh Ministers must lay the report prepared under subsection (7) before the National Assembly for Wales as soon as reasonably practicable after its preparation, and publish it.
- (9) The autism strategy must be revised to reflect any recommendations of the independent report prepared under subsection (7) within 3 months of publication of the report or of the conclusion of any consultation under subsection (10), whichever is the later.
- (10) The Welsh Ministers must consult with relevant bodies and such other bodies or 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
 - (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.

- (11) 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.

2 Contents of the autism strategy

- (1) The autism strategy must –

- 5 (a) establish a best practice model or models for the –
- (i) identification and diagnostic assessment of autism spectrum disorder;
 - (ii) assessment of the care and support needs of persons with autism spectrum disorder; and
 - 10 (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 defined points of referral, to map the services that are available and required for persons with autism spectrum disorder;
- 15 (c) provide for diagnostic assessments and any post-diagnostic meetings to be commenced as soon as reasonably practicable following a referral and at least within any timescales set out in the relevant Quality Standard issued by the National Institute for Health and Care Excellence (but this shall not prevent the provision of any other services prior to the commencement of a diagnostic assessment);
- 20 (d) make provision for individual diagnostic assessments to be conducted by a multi-disciplinary team of professionals;
- (e) provide for an assessment of care and support needs to be completed as soon as reasonably practicable and in any event within 42 working days of a diagnosis of autism spectrum disorder or any post-diagnostic meeting, whichever is the later;
- 25 (f) make provision to ensure that persons 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 are to be met by relevant bodies in respect of, but not limited to, –
- (i) access to healthcare services;
 - 30 (ii) access to education;
 - (iii) access to employment;
 - (iv) access to housing;
 - (v) access to Welsh language services;
 - (vi) access to services in other languages;
 - 35 (vii) access to other public services;
 - (viii) social inclusion; and
 - (ix) access to advocacy services;

- (h) make provision so that an appropriate range of services to deliver the autism strategy is available consistently across Wales;
- (i) make provision to ensure services that are provided are accessible to each person who needs those services;
- 5 (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 persons with autism spectrum disorder can be supported in meeting the needs of those persons;
- 10 (l) make provision for the wishes of persons with autism spectrum disorder and of their families and carers to be taken into account;
- (m) place an emphasis on achieving innovation and improvement in the commissioning and delivery of autism spectrum disorder services;
- (n) make provision for the commissioning and publication of research into any aspect of autism spectrum disorder;
- 15 (o) make provision for the collection, management and publication of data in accordance with section 6;
- (p) make provision for a campaign to raise awareness and understanding of the needs of persons with autism spectrum disorder in accordance with section 7;
- 20 (q) make provision for the identification of key professionals and provision of appropriate (but not mandatory) training for them in relation to supporting persons with autism spectrum disorder; and
- (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 –
- 25 (a) considered appropriate by the Welsh Ministers; and
- (b) within the legislative competence of the National Assembly for Wales if the provision were contained in an Act of the National Assembly.

3 Combining assessments

- 30 (1) A relevant body may carry out any assessment required under this Act of a person at the same time as the relevant body or another body carries out another assessment under any enactment in relation to that person.
- (2) For the purposes of subsection (1) –
- (a) The relevant body may carry out the other assessment on behalf of or jointly with the other body; or
- 35 (b) if the other body has already arranged for the other assessment to be carried out jointly with another body, the relevant body may carry out the other assessment jointly with the other body and that other body.

4 Guidance by the Welsh Ministers

- (1) The 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.
- 5 (2) The guidance must be issued under this section no later than 3 months after publication of the autism strategy.
- (3) The Welsh Ministers must keep the guidance under review and 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.
- 10 (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 current autism strategy; and
 - (b) whether revisions to the autism strategy make revisions to the guidance appropriate.
- 15 (6) Guidance issued under this section must in particular include guidance about –
 - (a) the identification of persons with autism spectrum disorder;
 - (b) persons who are to be classed as carers for the purposes of this Act;
 - (c) the provision of diagnostic and needs assessment services;
 - 20 (d) the inclusion of key professionals in multi-disciplinary diagnostic assessment teams, for example –
 - (i) a clinical psychologist;
 - (ii) a psychiatrist;
 - (iii) a speech and language therapist;
 - (iv) an occupational therapist;
 - 25 (v) a behavioural therapist; and
 - (vi) a social worker;
 - (e) the training of staff who provide services; and
 - (f) local arrangements for leadership in relation to the provision of services.
- 30 (7) The Welsh Ministers must consult with relevant bodies and such other bodies or 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
 - 35 (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.

5 Relevant bodies: compliance with the autism strategy and guidance

Relevant bodies must, in exercising their functions concerned with the planning and delivery of services to persons with autism spectrum disorder, comply with the autism strategy published under section 1 and guidance issued under section 4.

6 Data on autism spectrum disorder

- (1) The Welsh Ministers must obtain, produce, and keep updated reliable data on autism spectrum disorder in Wales and publish annually such data as they consider appropriate to discharge their functions under this Act.
- (2) The Welsh Ministers may request data from relevant bodies in order to carry out their functions under this Act.
- (3) Relevant bodies must provide the Welsh Ministers with anonymised data if data is requested under subsection (2).
- (4) All data published by the Welsh Ministers must be in an anonymised form.
- (5) The Welsh Ministers must provide such anonymised data as may be requested by the authors of the independent report prepared under section 1(7).
- (6) NHS bodies must collect the following data 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 under subsection (2) to assist the Welsh Ministers to discharge their functions under this Act—
- (a) the numbers of persons diagnosed with autism spectrum disorder in each Local Health Board (including diagnoses not carried out but accepted by NHS bodies);
 - (b) the NHS numbers of those persons;
 - (c) the age at diagnosis in years and months of those persons;
 - (d) the gender of those persons;
 - (e) the diagnostic tools employed for diagnostic assessment, if any, and any scores generated by use of those tools;
 - (f) the time taken from referral for diagnostic assessment to presentation of the autism spectrum disorder diagnosis;
 - (g) the diagnostician's estimation or diagnosis of whether those persons diagnosed with autism spectrum disorder have an additional learning disability or developmental delay;
 - (h) whether those persons at diagnosis are verbal or nonverbal, and for those who are verbal, whether or not they have language delay;
 - (i) which professional groups were involved in the diagnostic assessment (for example, paediatrician, psychiatrist, clinical psychologist, etc); and

- (j) such other categories of data as the Welsh Ministers may prescribe.

7 Awareness campaign

- 5 (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.
- (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) The Welsh Ministers must ensure that information on the progress and effectiveness of the campaign is included in any report prepared under section 1(7).

10 8 Duty to have regard to the United Nations Principles and Conventions

- 15 (1) The Welsh Ministers and any relevant body exercising functions under this Act in relation to an adult must have due regard to the United Nations Principles for Older Persons adopted by General Assembly resolution 46/91 on 16 December 1991 (“the Principles”).
- (2) The Welsh Ministers and any relevant body exercising functions under this Act in relation to a disabled child or adult must have due regard to the United Nations Convention on the Rights of Persons with Disabilities and its optional protocol adopted on 13 December 2006 by General Assembly resolution A/RES/61/106 and opened for signature on 30 March 2007 (“the Disabilities Convention”).
- 20 (3) For the purposes of subsection (2) the Disabilities Convention is to be treated as having effect subject to any declaration or reservation made by the United Kingdom Government upon ratification, save where the declaration or reservation has subsequently been withdrawn.
- (4) Any relevant body exercising functions under this Act in relation to a child must have due regard to Part 1 of the United Nations Convention on the Rights of the Child adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989 (“the Convention”).
- 25 (5) For the purposes of subsection (4), Part 1 of the Convention is to be treated as having effect –
- 30 (a) as set out for the time being in Part 1 of the Schedule to the Rights of Children and Young Persons (Wales) Measure 2011, but
- (b) subject to any declaration or reservation as set out for the time being in Part 3 of that Schedule.
- (6) Guidance issued under section 6 may make provision setting out what is required to discharge the duties in subsections (1) to (5) of this section, and these subsections are to be interpreted in accordance with any such provision.
- 35

9 Interpretation

- (1) In this Act –
- “adult” (“*oedolyn*”) means a person who is aged 18 or over;

“autism spectrum disorder” (*“anhwylder sbectrum awtistiaeth”*) means –

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

“autism strategy” (*“strategaeth awtistiaeth”*) means the strategy required to be published under section 1(1);

“carer” (*“gofalwr”*), in relation to a person with autism spectrum disorder, means those persons specified as carers in the guidance issued under section 4(1);

“child” (*“plentyn”*) means a person who is aged under 18;

“guidance” (*“canllawiau”*) means the guidance required to be issued under section 4(1);

“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 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;
- (b) a Special Health Authority established under section 22 of the National Health Service (Wales) Act 2006 (except the National Health Service Litigation Authority) solely in connection with its functions in relation to Wales; or
- (c) a National Health Service trust established under section 18 of the National Health Service (Wales) Act 2006.

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

“persons” (*“personau”*) means, except in section 8, children and adults in Wales and “person” shall be construed accordingly;

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

“Quality Standard” (*“Safon Ansawdd”*) means publications by the National Institute for Health and Care Excellence which set out care or service standards and priority areas for quality improvement in health and social care;

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

“working day” (“*diwrnod gwaith*”) means any day which is not Saturday, Sunday, Christmas Day, Good Friday or a day which is a bank holiday in England and Wales under the Banking and Financial Dealings Act 1971 (c.80).

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

10 Regulations

- (1) A power of the Welsh Ministers to make regulations under this Act is exercisable by statutory instrument.
- 10 (2) A statutory instrument may not be made unless a draft of the instrument has been laid before, and approved by resolution of, the National Assembly for Wales.

11 Coming into force

This Act comes into force at the end of the period of 3 months beginning with the day on which it receives Royal Assent.

12 Short title

15 The short title of this Act is the Autism (Wales) Act 2019.