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TO

Make provision for the identification of persons in Northern Ireland with severe learning disability; to make provision for the assessment of their health, social care and other needs; to make provision for appropriate services for such persons and for independent advocates to act on their behalf; and for connected purposes.

BE IT ENACTED by the Queen’s most Excellent Majesty, by and with the advice and consent of the Lords Spiritual and Temporal, and Commons, in this present Parliament assembled, and by the authority of the same, as follows:—

1 Purpose of the Act

- (1) The purpose of the Act is to clarify and strengthen the entitlement of persons with severe learning disability to support and services.
- (2) The provisions of this Act shall not in any way abrogate or diminish the rights of severely disabled persons under other legislation. 5

2 Interpretation

In this Act—

- (a) “person with severe learning disability” means any person aged 16 years or over who has been recognised by a competent professional as having severe impairment of intellectual ability with associated impairment of social and economic competence originating before birth, at birth or before the age of 10 years; 10
- (b) “competent professional” means a qualified psychiatrist, psychologist, nurse specialising in learning disability or teacher specialising in special education; 15
- (c) “severe impairment of intellectual ability” means a measured intelligence quotient of 35 or less, or a comparable degree of intellectual impairment; and
- (d) “impairment of social and economic competence” means substantial disadvantage in the normal activities of everyday life and in earning a living. 20

3 Identification of persons with a severe learning disability

The Department of Health, Social Services and Public Safety shall by regulations make provision for –

- (a) the identification of persons with severe learning disability, 5
- (b) drawing the attention of those who may be in touch with such persons, through their family, voluntary or professional responsibilities, to the provisions of this Act, and
- (c) the establishment and maintenance of a database of such persons, incorporating such identifying particulars as are agreed with the person, or, where the person is unable to consent, with the nearest relative, or independent advocate or a person with the duty of care. 10

4 Assessment of persons with severe learning disability

- (1) The Health and Social Services Board, in the area in which a person who is identified as having or as likely to have a severe learning disability lives, shall make arrangements for the assessment of the needs of that person (“the assessee”). 15
- (2) The process of assessment under subsection (1) shall begin within three weeks of identification of the assessee, or immediately in cases of urgency, and shall be completed within four weeks of the commencement of the process or such longer period as may in exceptional circumstances be agreed with the assessee, or, where he is unable to consent, with the nearest relative, or independent advocate or a person with the duty of care. 20
- (3) The Board shall appoint a competent professional to co-ordinate any assessment under subsection (2).
- (4) The assessment shall identify as far as possible the needs and wishes of the assessee in relation to the provision of care, support, and access to education, social networks and work. 25
- (5) The assessment shall take account, where these can be ascertained, of the wishes of –
 - (a) the immediate family of the assessee and such other family members as are in regular contact with them; 30
 - (b) any person with a duty of care in respect of the assessee;
 - (c) any unrelated person in whose house the assessee may live;
 - (d) any independent advocate appointed to act on behalf of the assessee;
 - (e) any other persons without formal responsibilities who are in close and regular contact with the assessee; and 35
 - (f) all professionals and other paid staff and voluntary workers who are in close and regular contact with the assessee.
- (6) A draft of the assessment shall be prepared by the competent professional.
- (7) The competent professional shall consult, and seek the approval to the draft of, parties to the assessment listed in subsection (5), subject to the restriction of personal information about the assessee to those who provided it or need to know it. 40
- (8) Once the competent professional has consulted, and sought the approval of, the parties to the assessment, he shall produce a final assessment. 45

- (9) Each draft assessment under subsection (6) and final assessment under subsection (8) shall be prepared in formats appropriate to the assessee and of the parties listed in subsection (5).

5 Person-centred care plan

- (1) Following a final assessment of severe learning disability under section 4, the Board shall make provision, in consultation with the assessee and competent professionals, for drafting a person-centred care plan (“a plan”). 5
- (2) A plan shall be completed within four weeks of the production of a final assessment, unless in exceptional circumstances a longer period is agreed with the assessee or, where he is unable to consent, with the nearest relative, or independent advocate or a person with the duty of care. 10
- (3) A plan shall consider the assessee’s requirements in relation to –
- (a) the maintenance and improvement, where possible, of his general health and the avoidance of additional disability, or the reduction in disability; 15
 - (b) personal care in all aspects of daily living;
 - (c) relationships and social networks;
 - (d) accommodation;
 - (e) personal development, education and training, and occupational and leisure activities; and 20
 - (f) empowerment through the establishment of agreed and effective means of communication, involvement in peer-group advocacy, recognition of an independent personal advocate, or by other means.
- (4) A plan shall include an estimate of the costs likely to be incurred in providing the assessee with full-time accommodation and support and day-time occupation in line with his social, health and educational needs, but shall not determine the actual costs which may be incurred. 25
- (5) A plan shall specify –
- (a) the outcomes to be achieved for the assessee;
 - (b) the means by which those outcomes are to be achieved; and 30
 - (c) who is responsible for helping to achieve those outcome.
- (6) Where it is unnecessary, or not possible, to make arrangements for implementing any aspect of a plan, the plan should include –
- (a) an explanation of why it is unnecessary or not possible; and
 - (b) a timetable, where appropriate, for implementing that aspect of the plan or reviewing its implementation. 35
- (7) A plan shall, as far as possible, be agreed with those who contribute to it and shall be provided in appropriate formats to those listed in section 4(5) above.

6 Review and revision of assessment and plans

- (1) The final assessment and the plan shall be reviewed, and where necessary revised, at intervals of not less than 12 months, starting with a review 12 months from the completion of the original plan. 40
- (2) The same process shall be followed in drawing up subsequent assessments and plans as are required under sections 4 and 5.

- (3) The assessment and the plan shall also be reviewed, and where necessary revised, whenever the relevant Health and Social Services Board is notified by a competent professional of a substantial change in the health, disability or social circumstances of a person with severe learning disability.

7 Personal entitlements and independent advocacy 5

- (1) The assessee shall be entitled to receive the support specified in the plan to achieve the outcomes specified in the plan.
- (2) Such support may, as agreed from time to time with the person or his nearest relative or independent advocate or person with a duty of care, take the form of—
- (a) direct provision by the Health and Social Services Trust (“the Trust”);
 - (b) provision commissioned by the Trust from an independent provider or providers; or
 - (c) provision arranged by the person himself or a third party approved by the person and the Trust, using monies allocated for that purpose by the Trust. 15
- (3) The assessee shall be entitled, in particular and without prejudice to any other provisions, to the services of—
- (a) an independent advocate approved by the Trust; or
 - (b) a volunteer nominated by the assessee and recognised by the Trust or its agents. 20
- (4) An independent advocate under subsection (3) will be funded, trained, accredited and supported through a prescribed independent advocacy scheme.
- (5) The independent advocate or volunteer shall have access to meetings and records relating to the assessee where the assessee would himself have such access except where good cause can be shown to the contrary. 25
- (6) In the event of any dispute about the provisions of the plan and the rights of the independent advocate or volunteer, the assessee, the independent advocate or volunteer or the Trust may refer the dispute to a prescribed independent complaints procedure. 30
- (7) In this section, “prescribed” means prescribed in regulations made by the Department of Health, Social Services and Public Safety.

8 Financial provision

- There shall be paid out of money provided by Parliament—* 35
- (a) *any expenditure of the Secretary of State in consequence of this Act; and*
 - (b) *any increase attributable to this Act in the sums payable out of money so provided by virtue of any other Act.*

9 Short title

- (1) This Act may be cited as the Northern Ireland (Severe Learning Disability) Act 2004. 40
- (2) This Act extends to Northern Ireland only.

Northern Ireland (Severe Learning Disability) Bill

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To make provision for the identification of persons in Northern Ireland with severe learning disability; to make provision for the assessment of their health, social care and other needs; to make provision for appropriate services for such persons and for independent advocates to act on their behalf; and for connected purposes.

*Ordered to be brought in by
The Reverend Martin Smyth, Mr David Amess,
Mr Roy Beggs, David Burnside,
Mr Jeffrey M. Donaldson, Mr Tom Clarke,
Lady Hermon, Mr Eddie McGrady, Lembit Öpik
and Mr David Trimble.*

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