

# Regional Autistic Spectrum Disorder Reference Group

## *Amendment to the Disability Discrimination Act 1995*

### **Amendment to the Disability Discrimination Act 1995 (c. 50)**

1.—(1) The Disability Discrimination Act 1995 is amended in its application to Northern Ireland as follows.

(2) In section 1(1), after the words “a physical” insert “, social (including communication)”;

(1) Subject to the provisions of Schedule 1, a person has a disability for the purposes of this Act if he has a physical, **social (including communication)** or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities.

(2) In this Act “disabled person” means a person who has a disability. (DDA 1995

(3) At the end of paragraph 4(1) of Schedule 1 insert—

“(i) taking part in normal social interaction; or

(j) forming social relationships.”

4(1) An impairment is to be taken to affect the ability of the person concerned to carry out normal day-to-day activities only if it affects one of the following—

(a) mobility;

(b) manual dexterity;

(c) physical co-ordination;

(d) continence;

(e) ability to lift, carry or otherwise move everyday objects;

(f) speech, hearing or eyesight;

(g) memory or ability to concentrate, learn or understand; or

(h) perception of the risk of physical danger.

**(i) taking part in normal social interaction; or**

**(j) forming social relationships.**

(DDA 1995

Insofar as the (inserted in purple above) relevant extract from the Disability Discrimination Act 1995 in concerned one can see what is being attempted BUT the argument is flawed – not least in that only OFMDFM has competence in relation to the DDA 1995.

While one can define medically physical and mental – how does one define ‘social’ – what is ‘social’ ... indeed what is normal? Is it refusal to take part in the church choir; to play rough sport; to participate in hare-coursing or to go down to the pub with the lads? To use this term is to create a ‘silo’ where individuality, personal prejudices and choices must be subjected to scrutiny. ‘Social’ identifies society, but society varies according to so many things e.g. the guy who makes frequent use of the ‘f’ word is normal in some circles and could be a virtual outcast in others.

To seek to define Autism Spectrum Disorder exclusively in terms of it being a ‘social disorder’, as this Bill does, would actually eliminate many on the spectrum who need interventions and support.

Whatever this Bill is intended to do - and at no point is that clear – it is drafted to be exclusive, not inclusive, in relation to those on the spectrum.

(Purely for compatible drafting and grammatical consistency (i) should read ‘social interaction’ and (h) ‘social relationships’.)

For much of the Bill the word ‘Department’ appears undefined – in fact it is eventually found in 4(1) to be the DHSSPSNI. What are the implications of this?

## *The Autism Strategy*

### **Autism strategy**

2.—(1) **The Department** must prepare a strategy on autism to be known as the autism strategy and must publish the autism strategy not less than two years after the passing of this Act. **The Department has already carried out an Independent Review of Autism Services and is a year into implementing the Review's recommendations. It is, literally, involving parents, carers and users at Trust level in all aspects of service provision including 'commissioning'. Should this work be suspended for 2/3 years to facilitate the Bill.**

(2) Before preparing the autism strategy, the Department must consult the Northern Ireland departments on it. **This means the disempowerment of Parents, Carers and Users – it would be retrograde – a bureaucratic exercise involving groups of Civil Servants (who would initially have to be brought up to a standard of specialisation) taking literally years – anyway other Departments will not be willing to be subservient to Health.**

(3) The Department must request every HSC trust to provide data on the prevalence of autism in its area in order—

(a) that it can publish and update the strategy; and

(b) that the Northern Ireland departments can effectively implement the strategy. **This is inherent in the current implementation of the Independent Review's Recommendations and is already happening.**

(4) The HSC trusts must provide the Department with all information it requests under subsection (3). **Already in place among professionals.**

(5) The Department must keep the autism strategy under review and must publish a revised strategy at intervals of not more than seven years. **Why 7 years – effective reviewing is professionally in-built – it should be seamless development and not some sort of staging post.**

(6) The Department must monitor the implementation of the autism strategy by the Northern Ireland departments. **Again, Departments co-operate but one cannot be 'bossed' by another.**

(7) The Northern Ireland departments must co-operate with the Department in relation to the preparation, review and implementation of the autism strategy. **This is currently being done by consultation, with Parents, Carers & Users who form the N.I. Regional ASD Reference Group being consulted and directly involved at both Trusts and Departmental level.** (see note on Autism N.I. below).

(8) The Northern Ireland departments must implement that part of the autism strategy which falls within their responsibilities and the Department must implement that part of the autism strategy which falls within its responsibilities. **Don't need an act to state the obvious – but it's done by co-operation – not by diktat.**

(9) Not more than three years after the publication of the autism strategy, and at intervals of no more than three years thereafter, the Department must prepare a report on implementation of the autism strategy by the Northern Ireland departments and the Department. **Once again Health simply do not and cannot speak for or have the dominance over other Departments that this would require.**

(10) The Minister shall lay a report prepared by the Department under subsection (9) before the Assembly as soon as possible after its preparation.

### **Content of the autism strategy**

3.—(1) The autism strategy must set out how the needs of persons with autism are to be addressed throughout their lives.

(2) Without prejudice to the generality of subsection (1) the needs to be set out in the autism strategy shall include the health care, educational and social needs of persons with autism. **This Bill is flawed insofar as it fails to address individual Departments' responsibilities – this Bill would impose on Health responsibilities outside its bailiwick.**

(3) The autism strategy must set out how the needs of families and carers of persons with autism are to be addressed. **Now what does this mean –**

**again it appears that e.g. benefits somehow all fall within the scope of Health – it becomes more ridiculous insofar as it suggests a one size fits all policy – currently the Reference Group in looking at how one provides individual pathways.**

(4) The autism strategy must set out the Department's proposals for promoting an autism awareness campaign.

(5) The autism strategy must set out the steps the Department proposes to take to ensure that public servants who deal directly with the public in the course of their duties are given autism awareness training. **Everyone including bus drivers, taximen and shop assistants? Seems like this is DELNI's Area of Responsibility – the Reference Group is already engaged in this exercise.**

(6) The Department may make regulations as regards the content of the autism strategy.

**3 above has already a multiplicity of sources of information; ongoing research and practical aspects to be implemented.** *“Within a year we have had every Health Visitor 'uptrained' so that every child of 2 years old can have a home visit to assess developmental progress (early identification); for those identified the waiting time for Assessment and Diagnosis will soon be down to 13 weeks in all Boards (4 Boards by Dec 'this year and the last by May '11); and interventions will be in place by 13 weeks after that. When I began the Independent Review there was an official waiting list of "387 waiting up to 35 months",*

**The difference in the current strategy is that it is being shaped by the Parents, Carers and Users themselves in direct consultation with the professionals – not dictated from Knockbracken by a Charity that is little more than a business selling services and with a CEO who believes she has a 'Right' to dictate from a detached 'ivory tower'– i.e. who claims virtual 'ownership' of all the 20,000 who are on the spectrum but has no tangible 'on the ground' role. Remember the sponsors (or is it sponsor) of this Bill originally wanted to create a £100,000 per annum “Autism Advocate” post for someone .**

## Supplementary

### Interpretation

4.—(1) In this Act, unless the context otherwise requires—

“autism” means autism, Asperger’s syndrome, Rett’s syndrome, Heller’s syndrome or **any pervasive developmental disorder not otherwise specified**; **Well! Very scientific – Autism is a ‘catch-all!!**

“autism strategy” means the strategy required to be published under section 2; **So ‘strategy’ means ‘strategy’ – very enlightening !!!**

“carer”, in relation to a person with autism, means an individual who provides a substantial amount of care on a regular basis for that person;

“Department” means the Department of Health, Social Services and Public Safety; **So now we know – ridiculous - but, implicitly, the DHSSPS will have superiority over all other Depts including OFMDFM?**

“HSC trust” refers to a body established under Article 10 of the Health and Personal Social Services (Northern Ireland) Order 1991 (NI 1);

“Minister” means the Minister of Health, Social Services and Public Safety;

“Northern Ireland department” means the Department of Culture, Arts and Leisure, the Department of Education, the Department for Employment and Learning, the Department of Agriculture and Rural Development, the Department of Enterprise, Trade and Investment, the Department of the Environment, the Department of Finance and Personnel, the Department of Justice, the Department for Regional Development, the Department for Social Development and the Office of the First Minister and deputy First Minister; **Pure nonsense – devoid of rationality and logic – ‘department’ now officially means ‘Departments’.**

“public authority” means a body established or constituted by or under a statutory provision;

“public servant” means an officer or servant of the Crown or of any public authority.

## **Regulations and orders made under this Act**

5.—(1) No order or regulation may be made under this Act unless a draft of the order or regulation has been laid before, and approved by resolution of, the Assembly. **Obviously this is the weakest element – basically no-one can actually show initiative unless the Assembly so permits – makes it more convenient for someone handily ensconced in Knockbracken to dictate the way forward – AND WHERE THE MONEY GOES!!!**

(2) Before making a regulation or an order under this Act the Department must consult the Northern Ireland departments and such other persons as the Department thinks appropriate. **Advocates a consultation procedure simply for the sake of adding the word “Social” - Sounds like ‘manyana’ to me – politicians to be led by Arlene Cassidy and to blazes with the professionals and consumers!!! Is Eileen Bell a paid lobbyist?**

## **Commencement**

6. This Act comes into operation after the end of the period of three months beginning with the day on which it is passed.

## **Short title**

7. This Act may be cited as the Autism Act (Northern Ireland) 2010.

**This Bill would be a hindrance to initiative, professionalism and progress. Already any Department finding itself ‘short’ of a legislative provision is quickly and easily able to amend an appropriate current Act – Health has made huge strides without needing to do so. This Draft Bill is an aberration.**