



Northern Ireland  
Assembly

## Research and Library Service Bill Paper

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**30 November 2010**

# Autism Bill

**NIAR 591-10**

This Paper provides information to support consideration of the Autism Bill, which was introduced into the Assembly on 8<sup>th</sup> November 2010. The Autism Bill aims to enhance the provision of services to and support for people with conditions which are on the autistic spectrum. The Bill sets out to achieve this by:

- (1) amending the Disability Discrimination Act 1995 so as to resolve any ambiguity as to whether the term “disability” applies to autistic spectrum conditions; and
- (2) requiring the preparation and implementation of an autism strategy



## Executive Summary

The Autism Bill, which was introduced into the Assembly on 8th November 2010, aims to enhance the provision of services to and support for people with conditions which are on the autistic spectrum. The Bill sets out to achieve this by:

- (1) amending the Disability Discrimination Act 1995 so as to resolve any ambiguity as to whether the term “disability” applies to autistic spectrum conditions; and
- (2) requiring the preparation and implementation of an autism strategy.<sup>1</sup>

Section 2 of this paper provides information relating to the Bill’s amendments to the Disability Discrimination Act (DDA), which in Northern Ireland is the primary piece of legislation which protects those with a disability from discrimination. In spite of guidance and case law which indicate that, in a range of circumstances, the DDA can be relied upon by those with autistic spectrum conditions, there is continued ambiguity as to whether autistic spectrum conditions fall within the definition of disability contained within the DDA. The Bill provides for amendment of the DDA in two ways in an attempt to resolve this ambiguity.

The DDA currently refers to mental and physical impairments and the Bill adds a third category of impairment, namely, ‘social (including communication) in an attempt to broaden the scope of the definition of disabled person in a way which more clearly encompasses those with autistic spectrum conditions. This widening of the definition should mean the DDA would also more easily encompass other behavioural disorders, such as ‘Anxious [avoidant] personality disorder’.

In a further attempt to make access to the protections of the DDA more accessible to those with autistic spectrum conditions, the Bill provides for additions to the list of day-to-day activities set out in the DDA. A person’s impairment must have a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities for them to have a disability for the purposes of the DDA. The Bill adds the following two ‘day-to-day’ activities to those already contained in the DDA:

*taking part in normal interaction or  
forming social relationships.*

The DDA has been repealed in England, Scotland and Wales and the Equality Act 2010 is now the primary piece of legislation which protects those with a disability

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<sup>1</sup> Autism Bill – Explanatory and Financial Memorandum

from discrimination in a range of areas. The Equality Act defines disability in a similar way to the DDA but, whilst making reference to day-to-day activities, does not define those within the Act. The Equality Act makes reference only to physical and mental impairments. The Office for Disability Issues, the body set up to co-ordinate disability policies across the UK Government, however, has published a consultation document on guidance for defining disability within the context of the Equality Act. In the Republic of Ireland, the Disability Act 2005 uses a definition of disability<sup>2</sup> which refers not only to physical and mental health impairments but also to sensory and intellectual impairments. There is no reference, however, to social or behavioural impairments. Whilst the definition in the Disability Act 2005 refers to participation in social life, the legislation provides no further information as to what this refers.

Section 3 of this paper focuses on the provisions within Clause 2 of the Bill and how these compare with relevant provisions in the Autism Act 2009 and the Autism (Scotland) Bill, which both require the production of autism strategies. There is no legislative requirement on government to produce an autism strategy in Wales or the Republic of Ireland.

Clause 2(1) of the Bill places a duty on the Department of Health, Social Services and Public Safety (DHSSPS) to prepare and publish a strategy on autism within two years of the bill becoming an Act. DHSSPS must consult with the Northern Ireland departments before preparing the autism strategy and must request that every HSC trust provide data on the prevalence of autism in its area in order that the strategy can be published, implemented and updated (Clauses 2 (3)-(4)).

Clause 2(5) places a duty on the DHSSPS to review the strategy and publish a revised strategy at intervals of not more than seven years. The Department is required to monitor the implementation of the strategy by all the Departments (Clause 2(6) and all the Departments must co-operate with the DHSSPS as regards preparation, review and implementation of the strategy with regard to the parts that fall within their areas of responsibility (Clause 2(7), (8)). Clause 2(9) provides for the publication of an implementation report by the DHSSPS on the strategy every three years from publication.

Section 4 of the paper briefly outlines the existing strategies and action plans in Northern Ireland, England and Wales. It also outlines the content of the draft strategy that has recently been published in Scotland. In the Republic of Ireland, a National Review of Autism Services is currently being undertaken by the Health Service Executive and it is expected that a final report will be presented to the Health Service Executive Board later in 2010 or early in 2011.

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<sup>2</sup> Disability Act 2005 Section 2(1).

In Northern Ireland, the DHSSPS published an *Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09-2010/11* (June 2009). Whilst the Action Plan is primarily focused towards health and social care services, it notes the importance of partnership working to promote a person-centred approach to ASD service provision. With regard to the ASD Strategic Action Plan for Wales, published in 2008, the aim has been to take a holistic view encompassing the services offered by and across government and the voluntary sector and to include education, health, financial and social needs.<sup>3</sup> Wales has been heralded as the ‘*first European nation to commit to a ‘whole nation’ model for delivering high-quality services and research*’ into ASD.<sup>4</sup>

The Strategy for Adults with Autism in England (March 2010), draws on the findings of the National Audit Office report *Supporting people with autism through adulthood*<sup>5</sup> The strategy is designed to build on the progress already made in England in improving services for children with autism<sup>6</sup> but, in line with the requirement of the Autism Act 2010, focuses on adults only.

The Scottish Government recently published its draft autism strategy, *Towards an Autism Strategy for Scotland* (September 2010), which sets out what the Scottish Government in partnership with users, carers and professionals proposes to do to meet the needs of people with ASD. The Autism Spectrum Disorder Reference Group that led earlier work in Scotland from 2002 and 2008 has been reconvened and will be expanded to provide leadership for the strategy.

Clause 3 of the Bill sets out in further detail the proposed content of the autism strategy and Section 5 of this paper reviews this clause in the context of the existing strategies and action plans outlined above.

Clause 3(1) states that the strategy ‘*must set out how the needs of persons with autism are to be addressed throughout their lives*’. In a lifelong approach, the points of transition in an individual’s life are prioritised in all the strategies and action plans. It appears that it is in the area of transitions that the cross-cutting nature of services and co-operation between government departments, agencies, voluntary and community groups etc. becomes most important.

Clause 3(2) prescribes that the autism strategy shall include the health care, educational and social needs of persons with autism. The current DHSSPS Action

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<sup>3</sup> The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales, Welsh Assembly Government, April 2008, Page 47

<sup>4</sup> News from Autism Cymru and Autism Speaks, [www.autismspeaks.org.uk](http://www.autismspeaks.org.uk), 9<sup>th</sup> November 2007

<sup>5</sup> Supporting people with autism through adulthood, National Audit office, June 2009

<sup>6</sup> *Fulfilling and rewarding lives* The Strategy for adults with autism in England (2010), Department of Health, March 2010, Ministerial Foreward, page 4

Plan focuses primarily on health and social care services for those with ASD with five key themes linked to the central tenet of the Care Pathway for ASD.

The overall direction for health and social care service redesign in the Action Plan for Wales is based on its approach for developing all health and social services based on the concept of a four level/four tier strategic conception of their functions. Some of the main areas the Welsh strategy focuses on are: mapping prevalence; needs and services; supporting the establishment of a multi-agency ASD co-ordinating group in each local area; quality Standards in Education for Pupils with ASD; and clear arrangements for transitions including key transition workers to support to children and young people with SEN (including those with ASD) as they move through school to further education or the workplace.

Within the current English strategy for adults with ASD, two of the five core areas of focus are relevant to health and social care needs: the development of a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment; and improving access to the support needed to live independently. Of the remaining core areas, two focus on the wider spectrum of needs including helping adults with autism into work and enabling local partners to plan and develop services for adults with autism to meet identified needs.

The draft strategy for Scotland focuses on outlining what still needs to be done in Scotland to build on the work already achieved by the ASD Reference Group and lists twenty six specific recommendations for action, many of which cover the areas of health, education and social needs people with autism.

Clause 3(3) of the Bill prescribes that the strategy for Northern Ireland must set out how the needs of families and carers for persons with autism are to be addressed. Within the current DHSSPS Action Plan, the principles of family support services for will be informed by the strategic context set out in *Families Matter: Supporting Families in Northern Ireland* (March 2009). A key action is the production of a communication plan to provide information to people with ASD, their families and carers

The Family and Carer support services section of the Welsh Strategy focuses specifically on the role that families and carers play in caring for (including a therapeutic input), advocating for and supporting people with ASD. Within the English Strategy for adults, providing relevant information to adults with autism and their families at the point of diagnosis has been identified as a key matter with statutory guidance to provide the detail of the type of information required. The current draft strategy for Scotland sees individuals, families and carers as co-

producers of planning and decision-making about the best use of funding for ASD services and highlights the success to date of its Local Area Coordination and ASD Co-ordinator/Lead Officer posts .

Clauses 3(4) and (5) prescribe that the autism strategy for Northern Ireland must set out proposals for promoting an autism awareness campaign and the steps the DHSSPS proposes to take to ensure that all Northern Ireland Civil Service staff who deal directly with the public are given autism awareness training. It is worth noting that Clause 3(5) as written does not appear to cover the public servants who deal directly with the public in relation to ASD who are not Civil Servants, for example, teachers and health and social care professionals. Training and raising awareness with both professionals, patients and their families and the wider community is one of the themes of all the current action plans and strategies with various options considered, including more specialist training for front-line posts to wider awareness training.

The Explanatory and Financial Memorandum which accompanies the Autism Bill states that the bill will not have significant financial implications. However, the implementation of any strategy is where the main financial implications lie. In a press statement made on 29<sup>th</sup> November 2010, Health Minister, Michael McGimpsey announced funding of £100k to improve autism services in Northern Ireland. At the same time, he announced that it was and remained his view that '...I have all the legislative authority I need to make the necessary improvements to services...Unlike other parts of the UK the structure here gives me control over social care as well as health care'.<sup>7</sup>

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<sup>7</sup> McGimpsey announces £100k funding to boost autism services DHSSPS – Press Release (29/11/10)  
<http://www.northernireland.gov.uk/index/media-centre/news-departments/news-dhssps/news-dhssps-291110-mcgimpsey-announces-100k.htm>





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## 1. Introduction

The Autism Bill, which was introduced into the Assembly on 8<sup>th</sup> November 2010, aims to enhance the provision of services to and support for people with conditions which are on the autistic spectrum. The Bill sets out to achieve this by:

- (1) amending the Disability Discrimination Act 1995 so as to resolve any ambiguity as to whether the term “disability” applies to autistic spectrum conditions; and
- (2) requiring the preparation and implementation of an autism strategy.<sup>8</sup>

The Bill was introduced as a Private Members’ Bill by Mr Dominic Bradley, who Chairs the All-Party Assembly Group on Autism.

At present, within the UK and Republic of Ireland, the Autism Act 2009 which applies to England only, is the only existing piece of legislation directed only at autism. In Scotland, a private members bill, the content of which mirrors the content of the Autism Act 2009, was introduced to the Scottish Parliament on 26 May 2010. A table comparing the content of the Bill, the Autism Act 2009 and the Autism (Scotland) Bill is contained in Appendix 1 to this paper.

## 2. Clause 1- Amendment to the Disability Discrimination Act 1995

In Northern Ireland, the Disability Discrimination Act 1995<sup>9</sup> (the DDA), as amended, is the primary piece of legislation which protects those with a disability from discrimination. The Bill provides for amendment of the DDA in an attempt to resolve the ambiguity as to whether autistic spectrum conditions fall within the definition of the term ‘disability’ contained within the DDA<sup>10</sup>. To appreciate the nature of the ambiguity, it is necessary to consider how the DDA defines disability and how autistic spectrum conditions are defined.

### **DDA Definition of Disability**

The DDA prohibits discrimination against ‘disabled persons’ in a range of circumstances, including in employment and occupation, transport, and the provision of goods, facilities and services. Only ‘disabled persons’, as defined

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<sup>8</sup> Autism Bill – Explanatory and Financial Memorandum

<sup>9</sup> Full text of the Disability Discrimination Act (the 1995 Act) can be accessed at [http://www.opsi.gov.uk/acts/acts1995/Ukpga\\_19950050\\_en\\_1.htm#end](http://www.opsi.gov.uk/acts/acts1995/Ukpga_19950050_en_1.htm#end)

<sup>10</sup> See Autism Bill: Explanatory and Financial Memorandum.

in Section 1 of the DDA and associated schedules and regulations, are entitled to the protection that the DDA provides. Section 1 of the DDA states the following:

Meaning of “disability” and “disabled person”.

(1) Subject to the provisions of Schedule 1, a person has a disability for the purposes of this Act if he has a physical 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.<sup>11</sup>

The DDA definition of who can be considered to have a disability, therefore, contains four key elements, each of which are considered in the table below.

<p><b>Impairment:</b> The definition covers physical and mental impairments. These include:</p> <ul style="list-style-type: none"> <li>• Physical Impairments affecting the senses such as sight and hearing, heart disease, diabetes, epilepsy.</li> <li>• Mental impairments including learning disabilities and mental ill health.</li> </ul> <p><b>Substantial:</b> For an effect to be substantial, it must be more than minor. The following are examples that are likely to be considered substantial:</p> <ul style="list-style-type: none"> <li>• Inability to see moving traffic clearly enough to cross a road safely</li> <li>• Inability to turn taps or knobs</li> <li>• Inability to remember and relay a simple message correctly</li> </ul> <p><b>Long-Term:</b> Schedule 1, para 2 provides that the effect of an impairment is only a long-term effect if-</p> <ul style="list-style-type: none"> <li>(a) it has lasted at least 12 months;</li> <li>(b) the period for which it lasts is likely to be at least 12 months; or</li> <li>(c) it is likely to last for the rest of the life of the person affected.</li> </ul> <p>Long-term effects include those, which are likely to recur. For example, an effect will be considered to be long-term if it is likely both to recur, and to do so at least once beyond the 12-month period following the first occurrence.</p> <p><b>Day to Day activities:</b> Schedule 1, para 4 provides that 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:</p> <ul style="list-style-type: none"> <li>• Mobility- moving place to place</li> <li>• Manual dexterity – for example, use of hands, wrists or fingers</li> </ul>
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<sup>11</sup> Section 1 (1) of the 1995 Act [http://www.opsi.gov.uk/acts/acts1995/ukpga\\_19950050\\_en\\_2#pt1-l1g1](http://www.opsi.gov.uk/acts/acts1995/ukpga_19950050_en_2#pt1-l1g1)

- Physical co-ordination
- Contenance
- The ability to lift, carry or move ordinary objects
- Speech, hearing or eyesight
- Memory, or ability to concentrate, learn or understand
- Being able to recognise physical danger

Under Section 3 of the DDA, the Office of the First Minister and deputy First Minister (OFMDFM) has the power to issue guidance on matters to be taken into account in determining whether a person is a disabled person for the purposes of that Act. The guidance does not impose any legal obligations in itself, nor is it an authoritative statement of the law. However, Section 3(3) of the DDA requires that an adjudicating body (such as a court or tribunal) which is determining whether a person is a disabled person for the purposes of the DDA, must take into account any aspect of the guidance which appears to it to be relevant. The guidance issued by OFMDFM includes examples of a child with autism (p.41) and a man with Asperger's Syndrome (p.60)<sup>12</sup>.

It has been argued that whilst Section 1, Schedule 1, and associated guidance to the DDA '*...all lend support to the argument that those with an Autistic Spectrum Disorder would ordinarily fall within the provisions of the Act*', the case of *Hewett v Motorola*<sup>13</sup> '*...put matters beyond doubt*'.<sup>14</sup> This case, taken in England, involved an individual whose Asperger's Syndrome was not considered by an employment tribunal to fall within the definition of disability in the DDA. The individual appealed, however, and the appeal tribunal concluded the following:

*We have not found this an easy case to determine as to whether this experienced Chairman and Tribunal fell into error in their approach, but after considerable consideration, we are unanimously of the view that their approach to the concept of "understanding" was at fault in failing to acknowledge that someone who has difficulty in understanding normal social interaction among people, and/or the subtleties of human non factual communication can be regarded as having their understanding affected and that concept is not limited simply to an ability to understand information knowledge or instructions.*

This case, while highlighting significant difficulties in defining the effects of ASD in terms set out in the DDA , demonstrated that features such as

<sup>12</sup> <http://www.ofmdfmi.gov.uk/disabilitydiscriminationact1995.pdf>

<sup>13</sup> *Hewett v Motorola* 2004, UKEAT/ 0526/03: [http://www.bailii.org/uk/cases/UKEAT/2004/0526\\_03\\_1602.html](http://www.bailii.org/uk/cases/UKEAT/2004/0526_03_1602.html)

<sup>14</sup> Graham, *Autism, Discrimination and the Law* (2008), p.43

‘understanding’ and ‘social interaction’ could be considered under the existing provisions of the DDA.

## Definitions of Autistic Spectrum Conditions

In spite of the existing guidance and case law, meeting the definition of disability contained in the DDA is likely to continue to present challenges to those with autistic spectrum disorders. The Bill seeks to amend the DDA in a way which widens the scope of the existing definition in a way which would encompass autistic spectrum conditions.

In broad terms Autism has been described as follows:

*Autism is a lifelong developmental disorder which affects the way people interact with the world around them. The three main areas of difficulty which all people with autism share relate to ‘social communication’, ‘social interaction’ and ‘social imagination’.*<sup>15</sup>

Autism Northern Ireland defines the disorder in the following terms:

*Autism is a social and communication disability. It is not a learning disability, mental illness or health issue, although these conditions can co-exist alongside Autism.*

*Autism is referred to as a pervasive developmental disorder reflecting its impact across functioning levels.*<sup>16</sup>

In clinical terms, Autism is described as:

*...a neurodevelopmental disorder in the category of pervasive development disorders, and is characterised by severe and pervasive impairment in reciprocal socialisation, qualitative impairment in communication, and repetitive or unusual behaviour.*<sup>17</sup>

Clause 4 of the Bill itself defines autism in the following way:

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;

In the UK, Ireland and other European countries, ICD-10 is the International Classification of Diseases which is most widely used and describes the

<sup>15</sup> House of Commons Public Accounts Committee, *Supporting People with Autism through Adulthood*, Fiftieth Report of Session 2008-09, 15 July 2009: <http://www.publications.parliament.uk/pa/cm200809/cmselect/cmpubacc/697/697.pdf>.

<sup>16</sup> <http://www.autismni.org/understanding/index.asp>, accessed 6 September 2010.

<sup>17</sup> Susan Levy et al, ‘Autism’ in *The Lancet* (2009) 374, 1627-1638.

internationally accepted glossary of categories of mental disorders with key sets of clinical features. The definition of autism contained within the Bill closely reflects the ICD-10 definition of Pervasive Developmental Disorders (F84).<sup>18</sup>

**F84 Pervasive developmental disorders**

A group of disorders characterized by qualitative abnormalities in reciprocal social interactions and in patterns of communication, and by a restricted, stereotyped, repetitive repertoire of interests and activities. These qualitative abnormalities are a pervasive feature of the individual's functioning in all situations.

F84.0 Childhood autism

F84.1 Atypical autism

F84.2 Rett's syndrome

F84.3 Other childhood disintegrative disorder

(includes Heller's syndrome)

F84.4 Overactive disorder associated with mental retardation and stereotyped movements

F84.5 Asperger's syndrome

F84.8 Other pervasive developmental disorders

F84.9 Pervasive developmental disorder, unspecified

Definitions of each of the pervasive developmental disorders, as set out in ICD-10, are contained in Appendix 2 to this paper. It should be noted, however, that these definitions and the concept of autistic spectrum disorders itself are not unchallenged. Defining a 'social impairment' is problematic due to the difficulty in establishing diagnostic boundaries to the concept and some authors reject current classifications due to their poor evidence base and circularity.<sup>19</sup>

**Amendment to the Disability Discrimination Act 1995**

Clause 1 of the Bill amends the definition of disability contained in section 1 of the DDA. The amendment provides that the definition, which has been discussed above, will refer not only to 'physical, mental impairments' but to physical, mental or social (including communication) impairments'.

<sup>18</sup> World Health Organisation, *ICD-10 Classification of Mental and Behavioural Disorders: Diagnostic criteria for research* (1993), pp.179-187.

<sup>19</sup> See, for example, Sami Timini et al, *The Myth of Autism* (2010), pp.170-1.

Whilst the categorisation of impairments as either physical or mental could be considered to encompass all impairments, it could also be argued that they do not encompass impairments which are behavioural in nature, such as impairments of social functioning. In this context it is worth noting that pervasive developmental disorders are included in Chapter V of ICD-10, which covers 'Mental and behavioural disorders'. In addition to pervasive developmental disorders, the broadening of the definition has the potential to facilitate access to the protections provided by the DDA to those with behavioural disorders, such as Anxious [avoidant] personality disorder (FP60.4).

Clause 1 of the Bill also extends the definition of 'normal day-to-day activities' in Schedule 1 of the DDA. Currently, Schedule 1 of the DDA defines 'normal day-to-day activities' in the following terms<sup>20</sup>:

*Normal day-to-day activities*

- 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

The Bill amends this to add

*taking part in normal interaction or  
forming social relationships*

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<sup>20</sup> Disability Discrimination Act 1995 Schedule 1 Paragraph 4.



## The Equality Act 2010

The Equality Act 2010<sup>21</sup> which provided for the repeal of the DDA in England, Scotland and Wales, is the key piece of legislation which provides protection against discrimination on nine specific grounds. Section 6 of the Equality Act defines 'disability' in the following way<sup>22</sup>:

### 6 Disability

(1) A person (P) has disability if –

- (a) P has a physical or mental impairment, and
- (b) The impairment has a substantial and long-term effect on P's ability to carry out normal day to day activities.

The Equality Act definition of disability does not make reference to social impairments.

In spite of the reference to normal day to day activities in the definition above, the Equality Act, unlike the DDA, does not itself define what these are. The UK Parliament's Joint Human Rights Committee, when scrutinising the then Equality Bill, noted that these impeded access to taking cases on the grounds of disability,<sup>23</sup> stating:

*These provisions of the Bill substantially re-enact the definition of disability contained in the DDA. However, the Bill clarifies the definition and extends protection against discrimination by removing the restrictive list of "capacities" currently set out in Schedule 1 of the DDA, which serves as an aid in defining what are "normal day-to-day activities". The Government has taken the view that this list constituted an "unnecessary extra barrier to disabled people taking cases in courts and tribunals". We welcome the deletion of the list of "capacities" from the definition of disability, which will clarify the law and make it easier for claimants to demonstrate that they are "disabled" for the purposes of the legislation.*

The Office for Disability Issues, the body set up to co-ordinate disability policies across the UK Government, however, has published a consultation document on guidance for defining disability within the context of the Equality Act. The

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<sup>21</sup> The Equality Act, with some minor exceptions, does not cover Northern Ireland, but a future Single Equality Act for Northern Ireland may well include much of the detail of the Westminster Act.

<sup>22</sup> Equality Act 2010, Section 6(1).

<sup>23</sup> House of Commons House of Lords Joint Committee on Human Rights, *Legislative Scrutiny: Equality Bill* (2009), p.49.

consultation opened on 9 August 2010 and closed on 31 October 2010<sup>24</sup>. Section D of the consultation document presented guidance on defining ‘normal day-to-day activities’. The document also refers specifically to ASD in several areas:

- ASD as a developmental impairment (p.8)
- A child diagnosed with autism used as an example of a ‘substantial adverse effect on his ability to carry out normal day to day activities’ (p.36)<sup>25</sup>
- A man with Asperger’s Syndrome used as an example of someone who, because of the difficulties with communication the disorder causes, is considered to be a person with an impairment that has a substantial adverse effect on normal day to day activities (p.45)<sup>26</sup>

An appendix to the Guidance gives a list of factors which it would be reasonable to regard as having an adverse effect on normal day to day activities, which includes the following (pp.48-9):

- Difficulty giving clear basic instructions to colleagues or providers of a service
- Difficulty asking specific questions to clarify instructions
- Taking longer than someone who does not have an impairment to say things
- Significant difficulty taking part in normal social interaction or forming social relationships

### **Disability Act 2005**

In the Republic of Ireland, section 2 of the Disability Act 2005 uses the following definition of disability<sup>27</sup>:

“disability”, in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment

This definition refers not only to physical and mental health impairments but also to sensory and intellectual impairments. There is no reference, however, to social or behavioural impairments. Whilst the definition in section 2 of the Disability Act 2005 refers to participation in social life, the legislation provides no further information as to what this refers.

<sup>24</sup> Office for Disability Issues, *Equality Act 2010: Guidance – Guidance on matters to be taken into account in determining questions relating to the definition of disability*.

<sup>25</sup> This same example is used in the current OFMDFM guidance p.41.

<sup>26</sup> This same example is used in the current OFMDFM guidance p.60.

<sup>27</sup> Disability Act 2005 Section 2(1).

### 3. Clause 2 - Autism Strategy

Clause 2(1) of the Bill places a duty on the Department of Health, Social Services and Public Safety (DHSSPS) to prepare and publish a strategy on autism within two years of the bill becoming an Act.

Section 1 (1) of the Autism Act is similar but the strategy is restricted to meeting the needs of adults by local authorities and the responsibility for preparation and publication of the strategy rests with the Secretary of State.

The relevant provision of the Autism (Scotland) Bill mirrors that of the Autism Act but responsibility for preparation and publication lies with the Scottish Ministers and the strategy covers all persons, not only children, and extends beyond local authorities to include NHS bodies.

Clause 2 (2) of the Bill requires the DHSSPS to consult with the Northern Ireland departments before preparing the autism strategy. The Autism Act requires the Secretary of State to consult with such persons as he or she considers appropriate. Whereas, the Autism (Scotland) Bill requires the Scottish Ministers to 'consult and seek participation of appropriate stakeholders and other persons' as they consider appropriate.

Clause 2(3) requires the DHSSPS to request that every HSC trust must provide data on the prevalence of autism in its area in order that the strategy can be published, implemented and updated. Clause 2 (4) requires the HSC trusts to provide the information requested. There are no similar legislative provisions in the other jurisdictions.

It is known that the prevalence of autism is increasing, however it is unclear whether this is due to rising awareness and improved diagnosis or a genuine increase in prevalence. It is believed that improved diagnosis, increased awareness and more specialist provision resulting from a specific diagnosis could account for some of the increase<sup>28</sup>.

The Medical Research Council's review of autism research suggests that "*there is fairly good agreement between epidemiological studies that ASD, if broadly defined, currently affects around 60 per 10,000 children under 8 and if narrowly defined, 10-30 per 10,000*"<sup>29</sup>. A study of diagnostic trends in ASD in the South Wales Valleys has been undertaken over a 15 year period and supports a prevalence rate of 60 per 10,000 population<sup>30</sup>.

The National Autism Plan for Children noted that in a typical local population unit of 55,000 children under 16 with 4,000 new births per year, an annual incidence of 24 new cases is implied with presentation at varying ages. This in

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<sup>28</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 1, page 8

<sup>29</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 1, page 7

<sup>30</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 1, page 7

turn suggested that there would be more than 250 children (under 16 years) with ASD at any one time in every such local health area<sup>31</sup>.

Current estimates suggest that approximately 200 new ASD cases can be expected per year in Northern Ireland and that for every three suspected cases referred for diagnosis and assessment, one case will be confirmed. ASD “occurs more commonly in boys than girls at a ratio of 4:1, although this varies across the ASD spectrum”<sup>32</sup>. The DHSSPS notes however, that in addition to these cases there are an unknown number of older people still to be identified.<sup>33</sup>

In the absence of suitable ‘benchmarking’ information for Northern Ireland, the Independent Review of Autism Services, assumed that every child with either a suspected or likely diagnosis of ASD is referred from general childcare services to the proposed ASD specific specialist Trust teams and from this estimated the likely number of new cases requesting ASD specialist services per year (taking into account several factors<sup>34</sup>), to be as follows<sup>35</sup>:

- Northern Trust - 50 new cases;
- Belfast Trust - 37 new cases;
- South Eastern Trust - 37 new cases;
- Southern Trust - 44 new cases; and
- Western Trust - 35 new cases.

Clause 2(5) places a duty on the DHSSPS to review the strategy and publish a revised strategy at intervals of not more than seven years. The Autism Act requires the Secretary of State to review the autism strategy but does not contain a period within which a new strategy must be published. The same is true for the Scottish Ministers under the provisions contained with the Autism (Scotland) Bill.

The Department is required to monitor the implementation of the strategy by all the Departments (Clause 2(6)). All the Departments must co-operate with the DHSSPS as regards preparation, review and implementation of the strategy with regard to the parts that fall within their areas of responsibility (Clause 2(7), (8)). Clause 2(9) provides for the publication of an implementation report by the DHSSPS on the strategy every three years from publication.

<sup>31</sup> National Autism Plan for Children, March 2003, National Initiative for Autism: Screening and Assessment, Executive Summary

<sup>32</sup> Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09-2010/11, DHSSPS, June 2009, page 7

<sup>33</sup> Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09-2010/11, DHSSPS, June 2009, page 7

<sup>34</sup> Factors included numbers living in each Trust area, birth rate patterns 2004-2007 and current ASD prevalence rates

<sup>35</sup> The Independent Review of Autism Services, Chaired by Lord Maginnis of Drumglass, May 2008, page 45

#### 4. Existing Strategies and Action Plans

Northern Ireland, England and Wales have either current autism strategies or action plans with a draft strategy recently published for Scotland. In the Republic of Ireland, a National Review of Autism Services is currently being undertaken by the Health Service Executive following a recognised need to review and clarify at national level the direction of health service provision for individuals with Autism. Consultation has been undertaken and a range of issues for consideration identified and it is expected that a final report will be presented to the Health Service Executive Board later in 2010 or early in 2011.

In Northern Ireland, the DHSSPS published an *Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09-2010/11* (June 2009). The Action Plan follows the publication of a series of documents including the *Independent Review of Autism Services*, the recommendations of the Bamford Review relating to ASD and its *Equal Lives Report*, and “*other local, national and international work*”<sup>36</sup>.

The Action Plan is primarily focused towards health and social care services, however, notes the importance of partnership working to promote a person-centred approach to ASD service provision recognising that ASD is a life-long condition.<sup>37</sup> The Action Plan for Northern Ireland is to be taken forward by the Regional ASD Network Group under the chairmanship of Dr Stephen Bergin from the Public Health Agency, which commenced its work in April 2009. The Group is accountable to the HSC Board.<sup>38</sup>

With regard to the ASD Strategic Action Plan for Wales published in 2008, the approach taken has been to drive improvement across services for children, young people and adults in the areas of health, social services, and education, and expanding into the areas of housing, leisure and society in general<sup>39</sup>. In Wales the aim has been to take a holistic view encompassing the services offered by and across government and the voluntary sector and to include education, health, financial and social needs.<sup>40</sup> Wales has been heralded as the “*first European nation to commit to a ‘whole nation’ model for delivering high-quality services and research*” into ASD<sup>41</sup> which commenced with a new Chair in Autism Spectrum Disorders based in Cardiff University’s School of Psychology.

The Strategy for Adults with Autism in England, published in March 2010, draws on the findings of the National Audit Office report *Supporting people with autism*

<sup>36</sup> Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09-2010/11, DHSSPS, June 2009, page 10

<sup>37</sup> Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09-2010/11, DHSSPS, June 2009, page 6

<sup>38</sup> Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09-2010/11, DHSSPS, June 2009, page 4

<sup>39</sup> The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales, Welsh Assembly Government, April 2008, Page 1

<sup>40</sup> The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales, Welsh Assembly Government, April 2008, Page 47

<sup>41</sup> News from Autism Cymru and Autism Speaks, [www.autismspeaks.org.uk](http://www.autismspeaks.org.uk), 9<sup>th</sup> November 2007

*through adulthood*<sup>42</sup> and builds on the Autism Act 2009. It focuses on adults only and is designed to build on the progress already made in England in improving services for children with autism<sup>43</sup>. It is currently the only strategy in the UK to be linked to legislation, the Autism Act 2009, described in the Ministerial foreword as signalling “*a new commitment across government to transforming the way public services support adults with autism*”<sup>44</sup>. The approach in the strategy does not depend on new investment but relies instead on ensuring mainstream services actively identify and respond to the needs of adults with autism focuses on five core areas of activity<sup>45</sup>:

- Increasing awareness and understanding of autism among frontline professionals;
- Developing consistent pathways for diagnosis in every area, followed by the offer of a personalised needs assessment;
- Improving access to the services and support which adults with autism need to live independently;
- Helping adults with autism into work, and
- Enabling local partners to plan and develop appropriate services for adults with autism.

The Scottish Government recently published its draft autism strategy, *Towards an Autism Strategy for Scotland* (September 2010), which sets out what the Scottish Government in partnership with users, carers and professionals proposes to do to meet the needs of people with ASD. The Autism Spectrum Disorder Reference Group that led earlier work in Scotland from 2002 and 2008 and took forward recommendations in the Public Health Institute of Scotland Needs Assessment of those with ASD<sup>46</sup> has been reconvened and will be expanded to provide national leadership for the strategy.

## 5. Clause 3 – Content of the Autism Strategy

Clause 3 sets out the proposed content of the autism strategy. This section of the paper reviews Clause 3 in the context of the content of existing strategies and action plans as already referred to above.

<sup>42</sup> Supporting people with autism through adulthood, National Audit office, June 2009

<sup>43</sup> *Fulfilling and rewarding lives* The Strategy for adults with autism in England (2010), Department of Health, March 2010, Ministerial Foreword, page 4

<sup>44</sup> *Fulfilling and rewarding lives* The Strategy for adults with autism in England (2010), Department of Health, March 2010, Ministerial Foreword, page 4

<sup>45</sup> *Fulfilling and rewarding lives* The Strategy for adults with autism in England (2010), Department of Health, March 2010, page 18

<sup>46</sup> Public Health Institute of Scotland Autistic Spectrum Disorders Needs Assessment Report, 2001, PHIS/NHS Scotland

**Clause 3(1)** states that the strategy ‘*must set out how the needs of persons with autism are to be addressed throughout their lives*’. In its current ASD Strategic Action Plan, The DHSSPS recognises that:

*ASD is a life long condition, and that whilst early interventions, assessment, diagnosis and support in childhood are absolutely essential, so too is coordinated planning into adulthood with the management of transition between childhood and adulthood of pivotal importance.*<sup>47</sup>

To deliver on the life long requirements the DHSSPS notes that the Action Plan requires

*The active involvement of individuals, families, carers, voluntary and community groups, together with representatives from other Northern Ireland departments to promote the development of complementary, co-ordinated services across other Departmental responsibilities including housing, education, employment,, social security and leisure activities.*<sup>48</sup>

In a lifelong approach, the points of transition in an individual’s life are recognised as important and one of the priorities of the DHSSPS Action Plan is the

*...development of multi-disciplinary, multi-agency approaches to intervention and support recognising the importance of points of transition, e.g. between adolescence and adulthood, to include the need for signposting and liaison with organisations responsible for education, housing, benefit support, employment and leisure activities*<sup>49</sup>

The strategy for Wales focuses in detail on the challenges of transitions for children and young people with ASD. It appears that it is in the area of transitions that the cross-cutting nature of services and co-operation between government departments, agencies, voluntary and community groups etc. becomes most required and most evident.

*...the Welsh Assembly Government has recently convened a multi-disciplinary Transition External Reference Group to take forward the recommendations made by the Education, Lifelong Learning and Skills Committee in their review of SEN – part three of which focused wholly on transition and the Equal Opportunity Committee’s review of services for disabled children and young people*<sup>50</sup>

One of the recommendations in the current draft Scottish Strategy is to ensure that the ASD Reference Group, in collaboration with autism service providers,

<sup>47</sup> Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09-2010/11, DHSSPS, June 2009, page 6

<sup>48</sup> Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09-2010/11, DHSSPS, June 2009, page 5

<sup>49</sup> Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09-2010/11, DHSSPS, June 2009, page 21

<sup>50</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 5, page 32

will identify the key determinants of service provision that result in improved quality of life for people with ASD across the spectrum and across the lifespan.<sup>51</sup>

Although the current DHSSPS Action Plan promotes inter-departmental co-ordination, it would seem that one of the aims of the proposed Bill is to ensure through legislation that this co-ordination across other departments happens in the manner required to deliver on the life long services for those with ASD. When reporting to the HSSPS Committee in 2008 on the Independent Review of Autism Services, Lord Maginnis, as Chair of the Review, noted that

*“ the one constraint on our inquiry was that we did not have authority – or any great welcome in some areas – when we tried to step outside the parameters that were dictated by the Department of Health, Social Services and Public Safety...there appears to be no desire for other departments to co-operate...unless that can be overcome difficulties will emerge in the future”.<sup>52</sup> |*

The purpose of the Welsh Strategic Action Plan has been described as setting a clear direction of travel for the development of services in Wales by taking a person-centred approach to services and support for people with ASD and their families. It is acknowledged that this approach will only succeed with effective co-ordination at local, regional and national level<sup>53</sup> and has been described as a ‘whole nation’ model and a ‘pioneering comprehensive approach’ for delivering services and research into ASD.<sup>54</sup>

In Scotland, service redesign for people with autism commenced in 2001 with the Public Health Institute of Scotland (now NHS Health Scotland) carrying out an ASD Needs Assessment with the subsequent formation of the ASD Reference Group (referred to in the discussion of Clause 2 above) to take forward priorities for service improvement. The current draft strategy for Scotland *Towards an Autism Strategy for Scotland* (September 2010) notes the good work so far in Scotland and focuses on the ASD Reference Group now providing national leadership to promote good practice for local agencies working together and the advantages of sharing budgets. This direction would seem to cover all aspects of life for those with ASD and to encourage the development of services that cross health/social care, educational and skills development boundaries.

In the Republic of Ireland, the Disability Act 2005 has seen a change in the entitlements for individuals with disabilities including those with autism and there has been ongoing learning regarding best practice in terms of assessment

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<sup>51</sup> Towards an ASD Strategy for Scotland, The Scottish Government, 2010, page 45

<sup>52</sup> Committee for HSSPS, Official Report (Hansard), Independent Review of Autism Services, 3 July 2008

<sup>53</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Executive Summary

<sup>54</sup> News from Autism Cymru and Autism Speaks, [www.autismspeaks.org.uk](http://www.autismspeaks.org.uk), 9 November 2007



and intervention services for people with autism. Consultation by the Health Service Executive in relation to models of service provision, gaps in services and other issues has identified a number of issues for further consideration including the mapping of existing services, identification of gaps in service, identification of assessment tools and best practice in relation to 0-18 year olds and others.

Two subgroups have been formed, one to review the issues concerning children with autism spectrum disorders and the other to review issues relating to services to adults with autism spectrum disorders.

**Clause 3(2)** prescribes that the autism strategy for Northern Ireland shall include the health care, educational and social needs of persons with autism. The current DHSSPS Action Plan focuses primarily on health and social care services for those with ASD and is designed around five key themes as follows<sup>55</sup>:

Service redesign to improve care, including such areas as improving co-ordination of assessment, diagnosis, care and support; and development of specialist teams at local level linked to a regional multi-disciplinary ASD group;

Performance improvement of autism services, including reducing waiting times for assessment, diagnosis and treatment;

Training and raising awareness to support parents and professionals;

Improving communication and information provided to individuals and families; and

Effective engagement and partnership working within Government and with voluntary/community groups and other agencies as required.

The five themes are all linked to the central tenet of the Care Pathway for ASD (at Appendix 3). Standards and measurable performance indicators will be developed for key stages along the Care Pathway.

A key element of the service redesign is the development of local specialist teams and a HSC Trust led local integrated network in each of the five Trusts to assist in assessment, diagnosis and interventions with close linkage to the ASD regional group network, mentioned previously in the discussions of Clause 2. Nominated lead Directors and co-ordinators have been identified in each HSC Trust. The local multi-disciplinary network in each Trust will link to the ASD

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<sup>55</sup> Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09-2010/11, DHSSPS, June 2009, page s 12 -17

Regional Network Group, which is responsible for the development of the care pathway, regional standards and performance indicators.<sup>56</sup>

The overall direction for service redesign in the Action Plan for Wales is based on the specific approach recently taken in Wales for developing all health and social services based on the concept of a four level/four tier strategic conception of their functions. It *“recognises that it is neither appropriate nor feasible that all people with ASD should only be diagnosed, assessed and provided with interventions by the most specialised of services”*<sup>57</sup>:

Tier 1 = direct access to first level services;

Tier 2 = more specialised but essentially local assessments and interventions from a variety of sectors;

Tier 3 = Access to regional specialist services for those with complicated diagnosis and assessment or challenging and variable comorbidities; and

Tier 4 = More specialist inpatient services or access to residential schooling (e.g. those with very limited verbal communication skills).

It places emphasis on multi-disciplinary and holistic person-centred assessment for those diagnosed or suspected of having ASD and their families, with the *“recognition that a person may have special health, education or social needs”*.

The *key worker* is advocated in the Action Plan for Wales as *“identified staff are empowered to work with families, carers and professionals of people with ASD...usually a professional who already provides some service to the family or carers and takes on the co-ordination role additional to their core profession”*<sup>58</sup>.

There are now 22 identified ASD leads in Wales who are a point of contact for families and professionals at a local level.<sup>59</sup>

Outside of health and social care, some of the main areas the Welsh strategy focuses on are<sup>60</sup>:

- Mapping prevalence, needs and services by an ASD Champion to carry out this mapping exercise through the Children and Young People’s Partnerships and Local Health, Social Care and Well-being Strategy Groups as part of their wider mapping of needs and services, and needs assessments;

<sup>56</sup> Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09-2010/11, DHSSPS, June 2009, page s 17-18

<sup>57</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 4, page 23-24

<sup>58</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 3, page 19

<sup>59</sup> Statement by the Welsh Assembly Government on the ASD Strategic Action Plan for Wales, Deputy Minister for Social Services, 8 June 2010

<sup>60</sup> Autistic Spectrum Disorder (ASD) Services, NI Assembly, Research and Library Services, Research Paper, 42/09, November 2008, pages 7-8

- The Children and Young People's Partnerships and Local Health, Social Care and Well-being Strategic Partnerships supporting the establishment of an ASD co-ordinating group in each local area (multi-agency and including service users and carers);
- The publication of Quality Standards in Education for Pupils with ASD in 2008, by the Welsh Assembly Government; and
- Commissioners and service providers to ensure there are "*clear arrangements for transition between services for children and young people and adult services*"<sup>61</sup>. This is supported by a number of additional key transition workers to provide support to children and young people with SEN (including those with ASD) as they move through school to further education or the workplace.

Within the current English strategy for adults with ASD, two of the five core areas of focus are relevant to health and social care needs - the development of a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment, and improving access to the services and support needed to live independently in the community. Some of the main actions in these areas are linked to<sup>62</sup>:

- Increasing capacity around diagnosis as diagnosis is important for adults who have not had their condition recognised earlier in life;
- Ensuring diagnosis is recognised as a reason for a community care assessment;
- Development of a model care pathway to allow commissioners to develop referral and care pathways in their areas;
- Enabling adults with autism to benefit from personalisation of the social care, including access to direct payments; and
- Improving transition planning to give people with autism the right start in their adult life.

Of the remaining core areas two focus on the wider spectrum of needs including helping adults with autism into work by ensuring they can benefit from wider employment initiatives and engaging employers<sup>63</sup>; and enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities, such as enabling adults with autism to have greater choice and control over where and how they live.<sup>64</sup> The draft strategy for Scotland focuses on outlining what still needs to be done in Scotland to build on

<sup>61</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 1, page 4

<sup>62</sup> *Fulfilling and rewarding lives*' The Strategy for adults with autism in England (2010), Department of Health, March 2010, chapters 3 and 4

<sup>63</sup> *Fulfilling and rewarding lives*' The Strategy for adults with autism in England (2010), Department of Health, March 2010, page 49

<sup>64</sup> *Fulfilling and rewarding lives*' The Strategy for adults with autism in England (2010), Department of Health, March 2010, page 59

the work already achieved by the ASD Reference Group to date and lists 26 specific recommendations for action, many of which cover the areas of health, education and social needs people with autism, for example<sup>65</sup>:

Recommendation 5 – The ASD reference group in collaboration with autism service providers will identify the key determinants of service provision that result in improved quality of life for people with ASD, across the spectrum and across the lifespan;

Recommendation 10 – It is recommended that an assessment of national waiting lists is undertaken to clarify the extent of delays and the ASD Reference Group considers and responds to these findings;

Recommendation 12 – It is recommended that the ASD Reference Group explore the ways diagnostic processes for adults and children are different and how this should inform practice;

Recommendation 14 – It is recommended that agencies and services develop a menu of interventions including therapeutic interventions and counselling for children, young people and adults with an ASD;

Recommendation 20 – It is recommended that the supported employment framework for Scotland is evaluated in terms of its impact on employment and employability for people with autism; and

Recommendation 26 – It is recommended that good practice transition guidance is developed, building on from existing educational guidance, in order to support the lifelong challenges facing people with autism as they make daily and life-stage transitions.

**Clause 3(3)** prescribes that the strategy for Northern Ireland must set out how the needs of families and carers for persons with autism are to be addressed.

Within the current DHSSPS Action Plan, the principles of family support services for individuals with ASD and their families will be informed by the strategic context set out in *Families Matter: Supporting Families in Northern Ireland* (March 2009).<sup>66</sup> The Action Plan highlights the main aspects of family support as<sup>67</sup>:

- Needs led with a clear focus on the wishes of the family;
- Support services should be accessible and flexible in respect of location, timing, changing needs etc.;

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<sup>65</sup> Towards an ASD Strategy for Scotland, The Scottish Government, 2010, pages 59-62

<sup>66</sup> [http://www.nidirect.gov.uk/families\\_matter\\_strategy.pdf](http://www.nidirect.gov.uk/families_matter_strategy.pdf)

<sup>67</sup> Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09-2010/11, DHSSPS, June 2009, page s 11-12

- A range of support services should cover early years, pre and post diagnosis, befriending, social support, citizenship/learning for life and parenting programmes; and
- Measures of success should be built into the provision of family support services.

In addition a key action is the production of a communication plan to provide information to people with ASD, their families and carers on developmental milestones, innovative ways of supporting individuals with ASD, and access to information on disability and services.<sup>68</sup>

The Family and Carer support services section<sup>69</sup> of the Welsh Strategy focuses specifically on the role that families and carers play in caring for (including a therapeutic input), advocating for and supporting people with ASD,

*There is abundant evidence that families provide the mainstay of day-to-day care for their relatives who have ASD. They should receive effective and appropriate services and support that are flexible and responsive to the breadth and depth of their needs and circumstances.*<sup>70</sup>

Within the English Strategy for adults, providing relevant information to adults with autism and their families at the point of diagnosis has been identified as a key matter, including information about autism and information about sources of help for the individual and their family, from telephone help lines to local voluntary groups. Statutory guidance is to provide the detail of the type of information required.<sup>71</sup>

The current draft strategy for Scotland sees individuals, families and carers as co-producers of planning and decision-making about the best use of funding for ASD services in the “tight financial climate”<sup>72</sup> and highlights the success to date of its Local Area Coordination and ASD Co-ordinator/Lead Officer posts. The Local Area approach promotes the rights of people with support needs to live ordinary lives within their local communities. Local Area Co-ordinators engage “*with the most isolated people within our communities, in many cases people on the autism spectrum, who may not be accessing social care services*”. In addition there is also support for those with ASD from several ASD Co-ordinator posts.<sup>73</sup>

<sup>68</sup> Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09-2010/11, DHSSPS, June 2009, page s 34-35

<sup>69</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, pages 41-43

<sup>70</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, paragraph 78, page 42

<sup>71</sup> *Fulfilling and rewarding lives* The Strategy for adults with autism in England (2010), Department of Health, March 2010, page 38

<sup>72</sup> Towards an ASD Strategy for Scotland, The Scottish Government, 2010, page 7

<sup>73</sup> Towards an ASD Strategy for Scotland, The Scottish Government, 2010, page 24

**Clause 3(4) and (5)** deal with the issue of awareness. Clause 3(4) prescribes that the autism strategy for Northern Ireland must set out proposals for promoting an autism awareness campaign and Clause 3(5) the steps the DHSSPS proposes to take to ensure that all Northern Ireland Civil Service staff who deal directly with the public are given autism awareness training. It is worth noting that Clause 3(5) as written does not appear to cover the public servants who deal directly with the public in relation to ASD who are not Civil Servants, for example, teachers and health and social care professionals.

‘Training and raising awareness’ is one of the five key themes of the current DHSSPS Action Plan. It is being delivered by the Regional ASD Group in collaboration with Local ASD Network and partner organisations via an ASD Training Strategy with the aim of sharing best practice and promoting early recognition of ASD and knowledge of referral pathways for GPs, health visitors, school nurses etc. The training aspect is specialist training for staff in frontline posts and options such as internet based support systems for training parents and professionals.<sup>74</sup>

Within the Welsh Strategy, commissioners and service providers in health, social care and education sectors are to support the provision of ASD awareness training for all professionals who may come into contact with people with ASD. This is to include consideration of the development of a web-based self-instructional awareness training package for families and practitioners in Wales. In addition, professionals in the following services are to receive awareness training:

- Job Centres, Careers Offices and Employment Training Agencies;
- Further and Higher Education Institutions;
- The Youth and Criminal Justice System;
- Leisure Services; and
- Commissioners of Services.<sup>75</sup>

One of the five core themes of the English Strategy for adults is ‘increasing awareness and understanding of autism among front-line professionals’ in line with the needs of their job with specialist training for staff in health and social care. The Department of Health, through statutory guidance, plans to work with partners to develop effective training modules and approaches which can be used by local authorities and primary care trusts to create training programmes locally. It is also “expected that autism awareness training is included in the

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<sup>74</sup> Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09-2010/11, DHSSPS, June 2009, page s 32-33

<sup>75</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, page 12

equality and diversity planning and single equality schemes of all central government departments”.<sup>76</sup>

A key development in this area in Scotland was in 2006 when the Scottish Government funded the National Autistic Society in 2006 to develop a complementary information resource, Next Steps, which was distributed through educational settings when a child is believed to have ASD. The pack aims included<sup>77</sup>:

- Increase understanding, knowledge and awareness of autism spectrum disorder (ASD);
- Ensure that parents, families and individuals with an ASD can access relevant information and services; and
- Improve general awareness of autism and provide advice to health, education and care professionals working in the field.

The draft strategy for Scotland also refers to the advantage of having the Lead Officer posts, referred to above, in gaining increased public awareness of autism and in developing and sustaining local supports. It recommends that the ASD Reference Group for Scotland explores the benefits of the Lead Officers to establish how rollout across Scotland might be best achieved.<sup>78</sup>

Clause 2 (6) provides that the Department may make regulations as regards the content of the autism strategy. Both the Autism Act 2009 and the Autism (Scotland) Bill contain provisions which require the Secretary of State and the Scottish Ministers respectively to issue guidance relating to implementation of the relevant strategies. Before publishing guidance, consultation must take place with and in each case guidance must address:

- (a) the provision of relevant services for the purpose of diagnosing autistic spectrum conditions
- (b) the identification of persons with such conditions;
- (c) the assessment of the needs of persons with such conditions for relevant services;
- (d) planning in relation to the provision of relevant services to persons with autistic spectrum conditions as they move from being children to adults;

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<sup>76</sup> *Fulfilling and rewarding lives* The Strategy for adults with autism in England (2010), Department of Health, March 2010, page 31

<sup>77</sup> Towards an ASD Strategy for Scotland, The Scottish Government, 2010, page 17

<sup>78</sup> Towards an ASD Strategy for Scotland, The Scottish Government, 2010, page 53, Recommendation 18

- (e) other planning in relation to the provision of relevant services to persons with autistic spectrum conditions;
- (f) the training of staff who provide relevant services to persons with such conditions;
- (g) local arrangements for leadership in relation to the provision of relevant services to persons with such conditions

It should be noted that the references to 'persons' relate to adults only under the Autism Act 2009.

## 6. Financial Effects of the Bill

The Explanatory and Financial Memorandum of the Autism Bill states that the bill will not have significant financial implications. The implementation of any strategy is where the main financial implications lie.

The Financial Memorandum of the Autism (Scotland) Bill places the cost of the Bill at 'no more than £5,000' for the Scottish Government to prepare, consult on, and publish an autism strategy. It does not infer the costs of implementing the Bill's provisions.<sup>79</sup>

The current DHSSPS Action Plan is supported by an extra £2.02 million to underpin the three year plan (2008/09-2010/11). This forms part of the additional resource of £17million for learning disability services including respite care. The DHSSPS advocates that the Action Plan directs resources to front-line services and encourages the reorganisation of existing service capacity where possible.<sup>80</sup> In a news release on 29<sup>th</sup> November 2010, the Minister for Health, Social Services and Public Safety announced an additional £100,000 to develop specialist adult diagnostic services in addition to the extra investment of £1.54million which was made over the 2009 – 2011 period bringing the recurrent total new investment for autism services to £1.64million from April 2011.<sup>81</sup>

The Welsh Government has committed £5.4 million to the implementation of its Strategic Action Plan over the first three years of the 10-year plan. From 2007-08, the recurrent sum of £1.7 million has continued to be available through the

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<sup>79</sup> SPICe Briefing, Autism (Scotland) Bill, 5 November 2010, page 22

<sup>80</sup> Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09-2010/11, DHSSPS, June 2009, page 20

<sup>81</sup> DHSSPS News Release, McGimpsey announces £100k funding to boost autism services, 29<sup>th</sup> November 2010



revenue support grant to local authorities, specifically to develop specialist services for children with autism.<sup>82</sup>

The Strategy for adults with autism in England has a different approach and “*does not depend on new investment*”, rather the aim is to identify how to make existing policies work better for adults with autism and relies on ensuring that mainstream services actively identify and respond to the needs of adults with autism. This approach “*reflects the fact that there is already a wealth of government policy and initiatives that should support adults with autism*”.<sup>83</sup>

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<sup>82</sup> Statement by the Welsh Assembly Government on the ASD Strategic Action Plan for Wales, Deputy Minister for Social Services, 8 June 2010

<sup>83</sup> *Fulfilling and rewarding lives* The Strategy for adults with autism in England (2010), Department of Health, March 2010, page 19, paragraph 1.22-1.23

Appendix 1 Provisions of the Autism Act 2009, the Autism (Scotland) Bill and the Autism (Northern Ireland) Bill that refer to the provision of an autism strategy.

		<b><i>Autism Act</i></b>	<b><i>Scotland</i></b>	<b><i>Northern Ireland</i></b>
Strategy preparation and publication		Strategy to improve provision 1(1)	Strategy to improve provision 1(1)	Strategy 2(1)
Timescale		By 1 April 2010 1(3)	Within 4 months 1(3)	Not less than 2 years 2(1)
Review and revision		Publish if revised 1(5)	Publish if revised 1(5)	Publish revised strategy every 7 years
Consultation		With such persons as considered appropriate 1(6)	Consult and seek participation of appropriate stakeholders 1(6)	Consult NI Departments 2(2)
Data				Must be provided by every HSC trust 2(4)
Guidance/content		Guidance to local authorities and NHS bodies 2(1)	Guidance to local authorities and NHS bodies 2(1)	Strategy content 3(6)
Monitoring		Review effectiveness 2(4)	Review effectiveness 2(4)	Department to monitor implementation 2(6); report every three years 2(9)
Strategy/guidance content	Diagnosis	Relevant services for diagnosis 2(5)(a)	Relevant services for diagnosis 2(5)(a)	
	Identification	Adults with ASD 2(5)(b)	Adults with ASD 2(5)(b)	
	Needs	Assessment of needs of adults with ASD 2(5)(c)	Assessment of needs of adults with ASD 2(5)(c)	
	Planning	Provision of services 2(5)(d-e)	Provision of services 2(5)(d-e)	
	Training	For staff who provide services 2(5)(f)	For staff who provide services 2(5)(f)	For staff who have contact with people with ASD 3(5)
	Leadership	Local arrangements for provision of services 2(5)(g)	Local arrangements for provision of services 2(5)(g)	
	Addressing of needs			How needs are to be addressed 3(1-2); and those of family and/or carers 3(3)
	Awareness raising			Awareness campaign 3(4)

## Appendix 2: World Health Organisation Definition of Pervasive Developmental Disorders

### F84 PERVASIVE DEVELOPMENTAL DISORDERS

#### F84.0 Childhood autism

A. Presence of abnormal or impaired development before the age of three years, in at least one out of the following areas:

- (1) receptive or expressive language as used in social communication;
- (2) the development of selective social attachments or of reciprocal social interaction;
- (3) functional or symbolic play.

B. Qualitative abnormalities in reciprocal social interaction, manifest in at least one of the following areas:

- (1) failure adequately to use eye-to-eye gaze, facial expression, body posture and gesture to regulate social interaction;
- (2) failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities and emotions;
- (3) A lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people's emotions; or lack of modulation of behaviour according to social context, or a weak integration of social, emotional and communicative behaviours.

C. Qualitative abnormalities in communication, manifest in at least two of the following areas:

- (1) a delay in, or total lack of development of spoken language that is not accompanied by an attempt to compensate through the use of gesture or mime as alternative modes of communication (often preceded by a lack of communicative babbling);
- (2) relative failure to initiate or sustain conversational interchange (at whatever level of language skills are present) in which there is reciprocal to and from responsiveness to the communications of the other person;
- (3) stereotyped and repetitive use of language or idiosyncratic use of words or phrases;
- (4) abnormalities in pitch, stress, rate, rhythm and intonation of speech;

D. Restricted, repetitive, and stereotyped patterns of behaviour, interests and activities, manifest in at least two of the following areas:

- (1) an encompassing preoccupation with one or more stereotyped and restricted patterns of interest that are abnormal in content or focus; or one or more interests that are abnormal in their intensity and circumscribed nature although not abnormal in their content or focus.
- (2) apparently compulsive adherence to specific, non-functional, routines or rituals;
- (3) stereotyped and repetitive motor mannerisms that involve either hand or finger flapping or twisting, or complex whole body movements;
- (4) preoccupations with part-objects or non-functional elements of play materials (such as their odour, the feel of their surface, or the noise or vibration that they generate);
- (5) distress over changes in small, non-functional, details of the environment.

E. The clinical picture is not attributable to the other varieties of pervasive developmental disorder; specific developmental disorder of receptive language (F80.2) with secondary socio-emotional problems; reactive attachment disorder (F94.1) or disinhibited attachment disorder (F94.2); mental retardation (F70-F72) with some associated emotional or behavioural disorder; schizophrenia (F20) of unusually early onset; and Rett's syndrome (F84.2).

#### F84.1 Atypical autism

- A. Presence of abnormal or impaired development at or after age three years (criteria as for autism except for age of manifestation).
- B. Qualitative abnormalities in reciprocal social interaction or in communication, or restricted, repetitive and stereotyped patterns of behaviour, interests and activities (criteria as for autism except that it is not necessary to meet the criteria in terms of number of areas of abnormality).
- C. The disorder does not meet the diagnostic criteria for autism (F84.0).

Autism may be atypical in either age of onset (F84.11) or phenomenology (84.12), these two types being differentiated with a fifth character for research purposes. Syndromes that are atypical in both respects should be coded F84.12.

#### F84.10 Atypicality in age of onset

- A. Does not meet criterion A for autism. That is, abnormal or impaired development is evident only at or after age three years.
- B. Meets criteria B, C, D and E for autism (F84.0).

#### F84.11 Atypicality in symptomatology

A. Meets criterion A for autism (i.e. presence of abnormal or impaired development before the age of three years).

B. Qualitative abnormalities in reciprocal social interactions or in communication, or restricted, repetitive and stereotyped patterns of behaviour, interests and activities (criteria as for autism except that it is not necessary to meet the criteria in terms of number of areas of abnormality).

C. Meets criterion E for autism.

D. Does not meet the full criteria B, C and D for autism (F84.0).

#### F84.12 Atypicality in both age of onset and symptomatology

A. Does not meet criterion A for autism. That is abnormal or impaired development is evident only at or after the age of three years.

B. Qualitative abnormalities in reciprocal social interactions or in communication, or restricted, repetitive and stereotyped patterns of behaviour, interests and activities (criteria as for autism except that it is not necessary to meet the criteria in terms of number of areas of abnormality).

C. Meets criterion E for autism.

D. Does not meet the full criteria B, C and D for autism (F84.0).

#### F84.2 Rett's syndrome

A. Apparently normal prenatal and perinatal period and apparently normal psychomotor development through the first six months and normal head circumference at birth.

B. Deceleration of head growth between five months and four years and loss of acquired purposeful hand skills between six and 30 months of age that is associated with concurrent communication dysfunction and impaired social interactions and appearance of poorly coordinated/unstable gait and/or trunk movements.

C. Development of severely impaired expressive and receptive language, together with severe psychomotor retardation.

D. Stereotyped midline hand movements (such as hand wringing or washing) with an onset at or after the time that purposeful hand movements are lost.

#### F84.3 Other childhood disintegrative disorder

A. An apparently normal development up to the age of at least two years. The presence of normal age-appropriate skills in communication, social relationships, play, and adaptive behaviour at age two years or later is required for diagnosis.

B. A definite loss of previously acquired skills at about the time of onset of the disorder. The diagnosis requires a clinically significant loss of skills (and not just a failure to use them in certain situations) in at least two out of the following areas:

- (1) expressive or receptive language;
- (2) play;
- (3) social skills or adaptive behaviour;
- (4) bowel or bladder control;
- (5) motor skills.

C. Qualitatively abnormal social functioning, manifest in at least two of the following areas:

- (1) qualitative abnormalities in reciprocal social interaction (of the type defined for autism);
- (2) qualitative abnormalities in communication (of the type defined for autism);
- (3) restricted, repetitive and stereotyped patterns of behaviour, interests and activities including motor stereotypies and mannerisms;
- (4) a general loss of interest in objects and in the environment.

D. The disorder is not attributable to the other varieties of pervasive developmental disorder; acquired aphasia with epilepsy (F80.6); elective mutism (F94.0); schizophrenia (F20-F29); Rett's syndrome (F84.2).

#### F84.4 Overactive disorder associated with mental retardation and stereotyped movements

A. Severe motor hyperactivity manifest by at least two of the following problems in activity and attention:

- (1) continuous motor restlessness, manifest in running, jumping and other movements of the whole body.
- (2) marked difficulty in remaining seated: will ordinarily remain seated for a few seconds at most except when engaged in a stereotypic activity (see criterion B).
- (3) grossly excessive activity in situations expecting relative stillness.
- (4) very rapid changes of activity, so that in general activities last for less than a minute on end (occasional longer periods on highly favoured activities do not exclude this; and very long periods spent in stereotypic

activities can also be compatible with this problem being present at other times).

B. Repetitive and stereotyped patterns of behaviour and activity manifest by at least one of the following:

(1) fixed and frequently repeated motor mannerisms: these may involve either complex movements of the whole body or partial movements such as hand-flapping.

(2) the excessive and non-functional repetition of activities that are constant in form: this may be play with a single object (e.g. running water) or a ritual of activities (either alone or involving other people).

(3) repetitive self-injury.

C. IQ less than 50.

D. An absence of the autistic type of social impairment, i.e. the child must show at least three of the following:

(1) developmentally appropriate use of eye gaze, expression, and posture to regulate social interaction.

(2) developmentally appropriate peer relationships that include sharing of interests, activities, etc.

(3) at least sometimes approaches other people for comfort and affection.

(4) can sometimes share other people's enjoyment. Other forms of social impairment, e.g. a disinhibited approach to strangers, are compatible with the diagnosis.

E. Does not meet diagnostic criteria for autism (F84.0 and F84.1), childhood disintegrative disorder (F84.3) or hyperkinetic disorders (F90.-).

#### F84.5 Asperger's syndrome

A. A lack of any clinically significant general delay in spoken or receptive language or cognitive development.

Diagnosis requires that single words should have developed by two years of age or earlier and that communicative phrases be used by three years of age or earlier. Self-help skills, adaptive behaviour and curiosity about the environment during the first three years should be at a level consistent with normal intellectual development. However, motor milestones may be somewhat delayed and motor clumsiness is usual (although not a necessary diagnostic feature). Isolated special skills, often related to abnormal preoccupations, are common, but are not required for diagnosis.

B. Qualitative abnormalities in reciprocal social interaction (criteria as for autism).

C. An unusually intense circumscribed interest or restricted, repetitive, and stereotyped patterns of behaviour, interests and activities (criteria as for autism; however it would

be less usual for these to include either motor mannerisms or preoccupations with part-objects or non-functional elements of play materials).

D. The disorder is not attributable to the other varieties of pervasive developmental disorder; schizotypal disorder (F21); simple schizophrenia (F20.6); reactive and disinhibited attachment disorder of childhood (F94.1 and .2); obsessional personality disorder (F60.5); obsessive-compulsive disorder (F42).

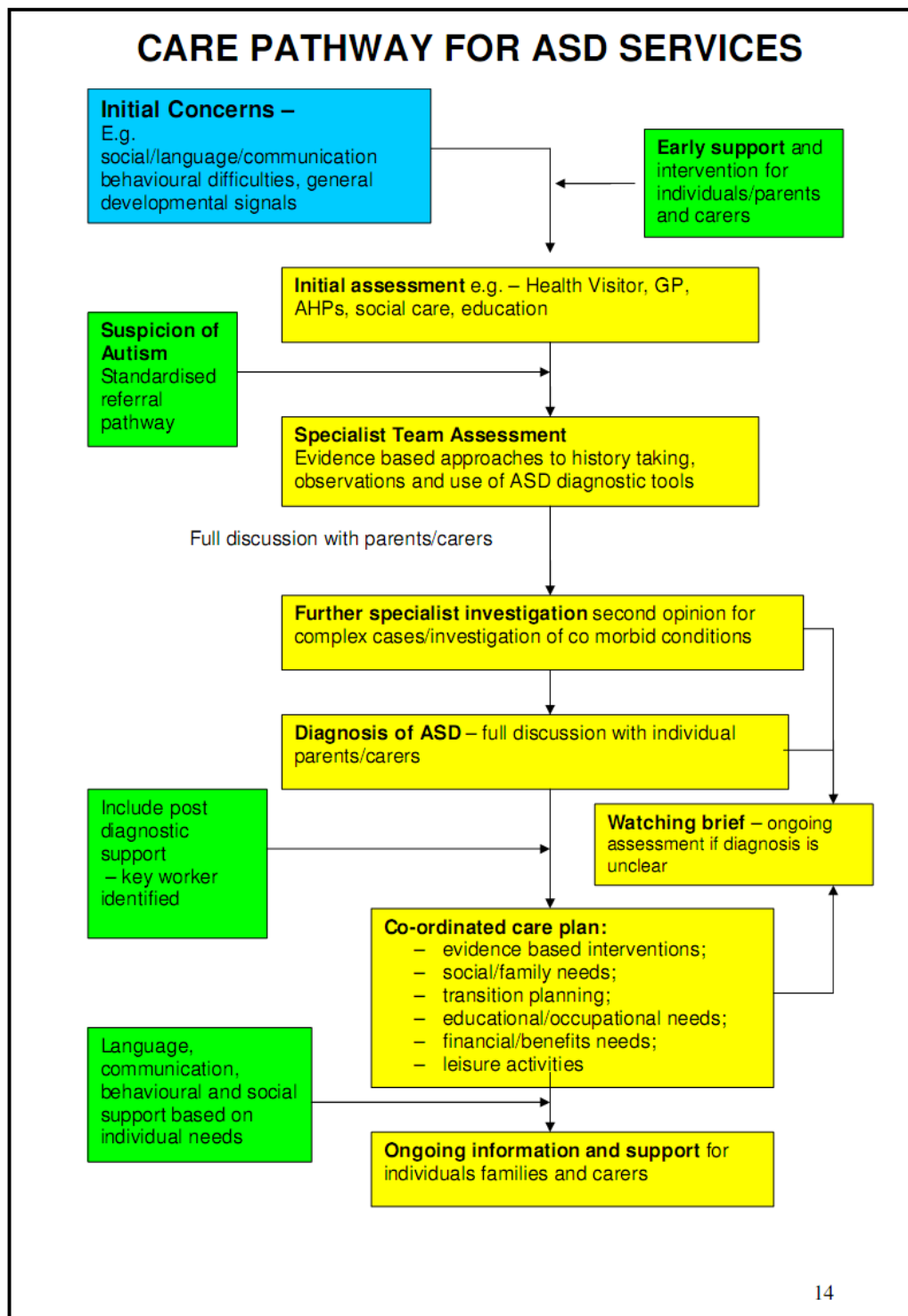
#### F84.8 Other pervasive developmental disorders

#### F84.9 Pervasive developmental disorder, unspecified

This is a residual diagnostic category that should be used for disorders which fit the general description for pervasive developmental disorders but in which a lack of adequate information, or contradictory findings, means that the criteria for any of the other F84 codes cannot be met.



## Appendix 3 – Care Pathway for ASD Services in Northern Ireland<sup>84</sup>



<sup>84</sup> Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09-2010/11, DHSSPS, June 2009, page 14

