

Research and Library Services



Northern Ireland Assembly

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# **AUTISTIC SPECTRUM DISORDER (ASD)**

**Research and Library Service**

This paper provides a background to Autistic Spectrum Disorder and highlights the difficulties in establishing prevalence rates for the condition. The paper also highlights the importance of Education and Health policies to support those with ASD. Finally, the paper addresses the development in the United States of America of ASD condition specific legislation.

Research Papers are compiled for the benefit of Members of The Assembly and their personal staff. Authors are available to discuss the contents of these papers with Members and their staff but cannot advise members of the general public.

## OVERVIEW

### AUTISTIC SPECTRUM DISORDER (ASD)

An Autistic Spectrum Disorder is a complex developmental condition that essentially affects the way a person communicates and relates to people. The term “autistic spectrum” is often used as the condition varies from person to person. Asperger's Syndrome is a condition at the more able end of the spectrum. At the less able end of the spectrum is Kanner's Syndrome also sometimes called 'classic autism'.<sup>1</sup>

People with autism generally experience three main areas of difficulty, which are commonly referred to as 'the triad of impairments'.

- Social interaction (difficulty with relationship, for example appearing aloof and indifferent to other people).
- Social communication (difficulty with verbal and non-verbal communication, for example not fully understanding the meaning of common gestures, facial expressions or tone of voice).
- Imagination (difficulty in the development of interpersonal play and imagination, for example having a limited range of imaginative activities, possibly copied and pursued repetitively).

### PREVALENCE

The National Autistic Society (NAS) has highlighted the complexity of determining prevalence rates as a result of: differences in diagnostic criteria; differences in terms used in relation to autism; and varied methodologies in epidemiological studies. In particular, the task of determining prevalence rates of autism in the UK are difficult to accomplish as there is no central recording by the UK Government and, indeed, very few epidemiological studies on which to make informed predictions.

### AUTISM AND EDUCATION

Ensuring that children and adults with autism have access to the amount and kind of education that is available to people who do not have autism may require a range of additional resources. In addition, children with autism may well have additional educational needs in order to enable them to develop important everyday life skills and knowledge that tend to be taken for granted but which enable people to live satisfactory lives

In November 2000, a Task Group on Autism in Northern Ireland was established to make recommendations on educational provision for children and young people with autism. In its report, the Task Group stressed the need for significant improvements in the following 3 main areas:

- access to multi-agency, multi-disciplinary diagnostic and assessment services;
- training for parents of, and people who work with, children and young people with ASD; and

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<sup>1</sup> Cited in Western Health and Social Services Board (2007) *Spectrum for Change – A Strategic Framework for Autistic Spectrum Disorders Services in the West*, April: 5.

- school-based and home-based educational and therapeutic provision.

The Task Group findings indicated that children and young people with ASD, and their families, need support from people employed by a variety of statutory and voluntary organisations. Over 40 recommendations to improve this support were included in the report

#### **AUTISM AND HEALTH**

Groups representing people with ASD state that the needs of persons with autism in the field of health care are not sufficiently taken into account. In addressing this perceived discrimination across the EU in terms of access to health care, Autism Europe has called for active measures that will enable people with autism '...to achieve the maximum of their unique potential, independence, and capacity for informed choice and self-advocacy.

On 5<sup>th</sup> September 2007 the Health Minister, Michael McGimpsey MLA, announced the launch of an Independent Review of Autism Services across Northern Ireland. The review group is tasked with providing the Minister with a report by the end of December 2007. By 31 March 2008, following public consultation, a final report on the group's findings, including an associated action plan with recommendations, will be produced, based on their findings, on how Health and Social Care services to both children and adults with autism might be improved.

#### **CONDITION SPECIFIC LEGISLATION**

Autism NI (PAPA) has called for the Assembly to pass condition specific legislation relating to ASD. ASD condition specific legislation has recently been passed in the US Congress and further legislative proposals have also been introduced. Whilst there is currently no condition specific legislation relating to persons with ASD in force in the UK, the potential exists for persons with ASD and those seeking to progress or defend their rights to rely on existing human rights, anti-discrimination and equality legislation.

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## DEFINITION AND CONDITION

An Autistic Spectrum Disorder is a complex developmental disability that essentially affects the way a person communicates and relates to people. The term “autistic spectrum” is often used as the condition varies from person to person. Asperger’s Syndrome is a condition at the more able end of the spectrum. At the less able end of the spectrum is Kanner’s Syndrome also sometimes called ‘classic autism’.<sup>2</sup>

Autism is a lifelong developmental disability that affects the way a person communicates and relates to people around them. Children and adults with autism have difficulty relating to others in a meaningful way. Their ability to develop friendships is generally limited as is their capacity to understand other people’s emotional expressions and feelings. It is a brain developmental disorder characterised by impairments in social interaction and communication as well as a tendency to engage in restricted and repetitive behaviour. These distinguishing traits, which are normally recognisable in the formative years of a child’s life, clearly define autism from milder autistic spectrum disorders (ASD).<sup>3</sup>

As the statement from the study group on Autism above suggests, due to the variation in conditions affecting those diagnosed with autism, the generally accepted practice is to refer to Autistic Spectrum Disorders (ASD). An increasingly prevalent condition within this spectrum is Asperger’s syndrome which is a form of autism used to describe people usually at the ‘higher functioning’ end of the autism continuum (see below).

### Characteristics of Autism

People with autism generally experience three main areas of difficulty, which are commonly referred to as ‘the triad of impairments’.

- Social interaction (difficulty with relationship, for example appearing aloof and indifferent to other people).
- Social communication (difficulty with verbal and non-verbal communication, for example not fully understanding the meaning of common gestures, facial expressions or tone of voice).
- Imagination (difficulty in the development of interpersonal play and imagination, for example having a limited range of imaginative activities, possibly copied and pursued and repetitively).

Other characteristic traits of autism include repetitive behaviour and resistance to change in routine.<sup>4</sup> This triad of impairments were identified within an authoritative piece of research conducted by Lorna Wing and Judith Gould in 1979. In attempting to evaluate the prevalence of autism in children (in the former London Borough of Camberwell) as defined by Leo Kanner in the 1940s (commonly referred to as

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<sup>2</sup> Cited in Western Health and Social Services Board (2007) *Spectrum for Change – A Strategic Framework for Autistic Spectrum Disorders Services in the West*, April: 5.

<sup>3</sup> Information accessed electronically from the National Autistic Society website at: <http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=225>

<sup>4</sup> The National Autistic Society – *What is Autism* – accessed electronically at: [http://www.nas.org.uk/content/1/c4/29/13/What%20is%20Autism%20flit%2007\\_03.pdf](http://www.nas.org.uk/content/1/c4/29/13/What%20is%20Autism%20flit%2007_03.pdf)

'Kanner or classic autism'), they identified a larger group of minors (about 15 per 10,000) who were affected by the 'triad of impairments' but did not fit into the traditional picture of classic autism but rather were identified within the broader autistic spectrum.<sup>5</sup> Significantly, determining the extent to which a child is affected by these three impairments of social interaction, communication and imagination has since formed a central element in the diagnosis of ASD, including Asperger's syndrome.

### **Asperger's Syndrome (AS)**

Autism is diagnosed on the basis of abnormalities in the areas of social development, communicative development, and imagination, together with marked repetitive or obsessional behaviour or usual narrow interests. Individuals with autism may have an IQ at any level. By convention, if an individual with autism has an IQ in the normal range (or above), they are said to have 'high functioning autism' (HFA). If an individual meets all of the criteria for HFA except communicative abnormality/history of language delay, they are said to have Asperger's syndrome (AS).<sup>6</sup>

Described by (Richard) Howlin as a form of 'social dyslexia', AS is often distinguished from other ASDs by reasonably competent linguistic and cognitive abilities with an average or high intellect which facilitates a high functioning form of autism (allowing those with AS to live independently). In explaining his reference to AS as social dyslexia, Howlin stresses that in each individual case, children will vary in their own unique expression of any processing disorder, be it AS or dyslexia. He goes on to state that, as the dyslexic child struggles with the alien world of print, so to the Asperger's child finds himself lost in reading social interaction and intent. In both stories, a naturally unfolding developmental process is stunted, leaving the child helpless, if left without support and understanding of the adult world.<sup>7</sup> This concept of an autistic child or adult living in an alien world was also affirmed by Wing in 1996 who stressed the importance of understanding the impact of the triad of impairments on their daily lives and for the need for non-autistic people ('neurotypicals'- name given by those on the autistic spectrum to those who aren't)<sup>8</sup> to attempt to imagine themselves in their world. According to Wing, "It is essential to understand the nature of autistic conditions. People with these disorders, because of their social impairments, cannot meet you half way. You have to make an imaginative leap into their world and try to see things from their point of view".<sup>9</sup>

### **PREVALENCE**

According to the National Autistic Society (NAS), the task of determining prevalence rates of autism in the UK is difficult to accomplish. Significantly the NAS highlights that 'there is no central recording by the UK Government and, indeed, very few epidemiological studies on which to make informed predictions. The available studies into this population are infrequent, expensive and problematic.'<sup>10</sup>

<sup>5</sup> National Autistic Society – How many people have autistic spectrum disorders?

<sup>6</sup> Baron-Cohen (2005) *Is Asperger's syndrome necessarily a disability?*: 4.

<sup>7</sup> Howlin (2003) *Asperger Syndrome: Social Dyslexia*, Connecting Lives Asperger Society of Michigan.

<sup>8</sup> Term cited in Saner, E (2007) 'It is not a disease, it is a way of life', *The Guardian*, 7<sup>th</sup> August.

<sup>9</sup> See Wing, L (1996) *The Autistic Spectrum: A Guide for Parents and Professionals*, Constable and Robinson.

<sup>10</sup> Wing, L. & Potter, D. (2007) *Notes on the prevalence of autism spectrum disorders* -

See National Autistic Society website at:

[www.nas.org.uk/nas/jsp/polopoly.jsp?d=364&a=2618&view=print](http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=364&a=2618&view=print)

NAS have indicated that the complexities associated with determining prevalence rates arise from three main causes:

- There are many difficulties in diagnosing people with these disorders. There is no medical test that can determine whether or not a person has autism. Diagnostic criteria are in terms of description of behaviour. The earliest criteria, suggested by Leo Kanner, were very narrow. The current standard classification systems (ICD<sup>11</sup>-10 and DSM-IV<sup>12</sup>) are much wider, even for the sub-group of 'childhood autism' (or 'autistic disorder' in DSM-IV). Professionals differ in the way they apply the criteria, even if they are theoretically, using one of the standard systems. Diagnoses may be recorded in different ways in case notes and centralised data collections.
- Diagnostic terms tend to be used in different ways. Sometimes the term 'autism' is used to mean Kanner's original group, sometimes it refers to the wider group called 'childhood autism' in ICD 10 and sometimes the whole autistic spectrum, including individuals described by Asperger. In any case, there is a very great deal of overlap among all the sub-groups names in ICD - 10 and DSM-IV and many individuals fit more than one diagnosis within the spectrum.
- In epidemiological studies of prevalence, case finding methods vary. Those that involve seeing, assessing and diagnosing every individual in the sample to be examined will tend to find higher numbers than studies that rely on using case notes of individuals who have already been given the diagnosis.<sup>13</sup>

Since Leo Kanner first described his classic autistic syndrome in the 1940s, a huge swathe of research has been conducted into this complex lifelong developmental disorder. Findings from the various pieces of clinical work have contributed to a significant broadening of the concept of autistic disorders. Indeed, the research around the development of a spectrum of autistic conditions, including classic autism and Asperger's syndrome have given rise to an increasing number of prevalence rates fuelling the perception at least of autistic conditions affecting a greater number of children and adults.

Without prevalence studies being conducted on adults, it is difficult to determine an accurate picture on the number of men and women above the age of 18 who are affected by ASD. However, according to an article written for the National Autistic Society, Wing and Potter have stated that while the indication from recent studies is that the figures cannot be precisely fixed it appears that a prevalence rate of around 1 in 100 is a best estimate of the prevalence of children [in the UK].<sup>14</sup>

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<sup>11</sup> ICD stands for International Classification of Diseases as stipulated by the World Health Organisation.

<sup>12</sup> DSM-IV stands for Diagnostic and Statistical Manual of Mental Disorders, Fourth edition.

<sup>13</sup> Wing, L. & Potter, D. (2007) *Notes on the prevalence of autism spectrum disorders* - See National Autistic Society website at:

[www.nas.org.uk/nas/jsp/polopoly.jsp?d=364&a=2618&view=print](http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=364&a=2618&view=print)

<sup>14</sup> See Wing, L. & Potter, D. (2007) *Notes on the prevalence of autism spectrum disorders* - See National Autistic Society website at:

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In a recent response to press coverage concerning research conducted by the Cambridge Autism Research Centre, its Director Professor Simon Baron-Cohen stated that, 'It is my view that any apparent rise in rates of autism is likely to be driven by five factors: better recognition, greater awareness, growth in service, a widening of the definition of autism and a shift towards viewing autism as a spectrum rather than a categorical condition.'

On 5th June 2004, the European Commission by way of oral answer to Kathy Sinnott MEP (Ireland) stated that there was 'no comprehensive or comparable data at EU level concerning the incidence or prevalence of this disease'. The Commission further stated that they would welcome project proposals in the area of autism.<sup>15</sup> In this context, the European Autism Information System project proposes to address the issues of a lack of systematic, consistent and reliable data about Autism and the lack of agreed and harmonised early detection tools.<sup>16</sup> As part of the project, the European Autism Alliance will be launched in the European Parliament building, Brussels, 17 October 2007. The EAA will be a sustainable association through which systematic, reliable and consistent data on autism can be obtained in the EU.<sup>17</sup>

### **Prevalence Rates in Northern Ireland**

PAPA has published estimates for Northern Ireland based on National Autistic Society published prevalence estimates for ASD. The *Report of the Task Group on Autism*,<sup>18</sup> published in April 2002, further extrapolated these figures to estimate the possible total prevalence of all ASD in years 1 to 12 of the school system in Northern Ireland as 91 per 10,000. The Task Group report, however, also contained an estimate of a prevalence rate of 27 per 10,000 children, though this was based on those children known by Education and Library Boards to have an ASD. The report concluded that the estimated prevalence rate of 27 per 10,000 in Northern Ireland was low. It added, however, that prevalence rates varied between Education and Library Board areas and were much higher for younger children than for older children. Seeking to explain these differences, the Task Group report linked them to the dates of establishment of comprehensive and broad-reaching diagnostic services in each area. The higher prevalence rate in the SEELB area, for example, was seen as potentially resulting from the relatively early establishment in the Down Lisburn Trust of a 'very active diagnostic clinic'.<sup>19</sup>

### **AUTISM AND EDUCATION**

Ensuring that children and adults with autism have access to the amount and kind of education that is available to people who do not have autism may require a range of additional resources. In addition, children with autism may well have additional educational needs in order to enable them to develop important everyday life skills and knowledge that tend to be taken for granted but which enable people to live satisfactory lives.<sup>20</sup>

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<sup>15</sup> [http://ec.europa.eu/health/ph\\_information/implement/wp/morbidity/docs/ev\\_20051212\\_co05\\_en.pdf](http://ec.europa.eu/health/ph_information/implement/wp/morbidity/docs/ev_20051212_co05_en.pdf)

<sup>16</sup> Website address <http://www.eais.eu/index.php>

<sup>17</sup> <http://www.eais.eu/fullnews.php?nid=11>

<sup>18</sup> Access report electronically at: [http://www.deni.gov.uk/index/7-special\\_educational\\_needs\\_pg/special\\_educational\\_needs\\_-\\_reports\\_and\\_publications-newpage-2/special\\_educational\\_needs\\_-\\_reports\\_and\\_publications-newpage-4.htm](http://www.deni.gov.uk/index/7-special_educational_needs_pg/special_educational_needs_-_reports_and_publications-newpage-2/special_educational_needs_-_reports_and_publications-newpage-4.htm)

<sup>19</sup> Above para 4.95 page 91

<sup>20</sup> Autism Europe (2003)

[http://www.autismeurope.org/portal/Portals/0/AE\\_EYPD\\_EDU\\_FINAL\\_2\\_ENG.pdf](http://www.autismeurope.org/portal/Portals/0/AE_EYPD_EDU_FINAL_2_ENG.pdf)

The Task Group on Autism in Northern Ireland was tasked with making recommendations on educational provision for children and young people with autism. The group members were educational practitioners with an interest and expertise in autism and included representatives from the non-governmental sector. Liaison between the group and the Task Force on Autism in the Republic of Ireland was facilitated by inclusion on each group of an education inspector from each jurisdiction.<sup>21</sup> In its report, the Task Group stressed the need for significant improvements in the following 3 main areas:

- access to multi-agency, multi-disciplinary diagnostic and assessment services;
- training for parents of, and people who work with, children and young people with ASD; and
- school-based and home-based educational and therapeutic provision.

The Task Group findings indicated that children and young people with ASD, and their families, need support from people employed by a variety of statutory and voluntary organisations. Over 40 recommendations to improve this support were included in the report.<sup>22</sup>

#### **AUTISM AND HEALTH**

Autism Europe, an advocacy group, believes that the needs of persons with autism in the field of health care are not sufficiently taken into account. In order to address what the organisation describes as discrimination taking place across the European Union in terms of access to health care it has called for active measures that will enable people with autism '...to achieve the maximum of their unique potential, independence, and capacity for informed choice and self-advocacy by providing:

- Access to appropriate, early, multi-disciplinary diagnosis and assessment, *in accordance with internationally accepted medical standards,*
- Access to appropriate, early, multi-disciplinary and continuous treatment, including social rehabilitation, *in accordance with internationally accepted medical standards,*
- Access to the ordinary health services that do exist and receive the care that is appropriate to his or her health needs, in accordance with the same standards afforded to other ill persons

The organisation particularly recommends the development of the following measures:

- Put in place quality care services for people with autism, as well as for all dependent persons
- Improve the existing indicators on specific health care services in order to be able to measure the proportion of children with autism or a

<sup>21</sup> [http://www.deni.gov.uk/executive\\_summary.pdf](http://www.deni.gov.uk/executive_summary.pdf)

<sup>22</sup> See [http://www.deni.gov.uk/index/7-special\\_educational\\_needs\\_pg/special\\_educational\\_needs\\_-\\_reports\\_and\\_publications-newpage-2/special\\_educational\\_needs\\_-\\_reports\\_and\\_publications-newpage-4.htm](http://www.deni.gov.uk/index/7-special_educational_needs_pg/special_educational_needs_-_reports_and_publications-newpage-2/special_educational_needs_-_reports_and_publications-newpage-4.htm)

complex dependency needs disability benefiting from adequate re-education programmes;

- Reinforce the initial and continuous training of health professionals on the internationally accepted diagnostic systems and evidence based treatments;
- Integrate the specific behavioural and communication features and needs of persons with autism or a complex dependency needs disability into the standard education systems by means of the continuous training of health professionals at all levels and not only as part of specialised training;
- Strengthen and adapt general healthcare services to the needs of persons with autism or a complex dependency needs disability, by providing specific support and facilities;
- In co-operation with parents associations, design and create international consensus documents for a medical care guide specific to autism, comprising protocols for the diagnostic process and medication as well as guide-lines for rehabilitative intervention;
- Systematically inform families on the health condition of their child and on the existing legislation and provisions that entitle them to ensure the best care for their children; and
- Systematically disseminate reliable information on state-of-the-art medical standards in relation to autism and other complex dependency needs disabilities.<sup>123</sup>

On 5<sup>th</sup> September 2007 the Health Minister, Michael McGimpsey MLA, announced<sup>24</sup> the launch of an Independent Review of Autism Services across Northern Ireland. The Independent review group, to be chaired by Lord Maginnis, will comprise five leading professionals from across GB and Ireland. The Review team reflects a relevant range of disciplines, including speech and language therapy, paediatrics, public health and leading researchers. The specific terms of reference for the Review are to:

- Map existing services provided by Health and Social Care organisations for both children and adults, and any transition period;
- Carry out a desktop literature review of relevant information;
- Examine the issues surrounding autism specific legislation in the context of the existing legislative provision in the Disability Discrimination Act and Section 75 of the Northern Ireland Act 1998, and make appropriate recommendations;
- Consult with key stakeholders and others as appropriate; and

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<sup>23</sup> Autism Europe (2003) Autism and Health Revised Position AE EYPD 2003 - 19/12  
[http://www.autismeurope.org/portal/Portals/0/AE\\_EYPD\\_HEALTH\\_FINAL\\_2\\_ENG.pdf](http://www.autismeurope.org/portal/Portals/0/AE_EYPD_HEALTH_FINAL_2_ENG.pdf)

<sup>24</sup> DHSSPS Press release accessed at <http://www.northernireland.gov.uk/news/news-dhssps/news-dhssps-050907-minister-for-health.htm>

- Produce a report with associated recommendations on how existing Health and Social Care services to both children and adults might be improved based on the findings of the review team.

The review group is tasked with providing the Minister with a report by the end of December 2007. By 31 March 2008, following public consultation, a final report on the group's findings, including an associated action plan with recommendations, will be produced, based on their findings, on how Health and Social Care services to both children and adults with autism might be improved.

## **LEGISLATIVE DEVELOPMENTS IN THE UNITED STATES OF AMERICA**

The United States of America has been at the forefront of passing legislation directed specifically at Autism. The Combating Autism Act of 2006<sup>25</sup> (the 2006 Act) was signed into law by President George Bush on 19<sup>th</sup> December 2006. In addition to the Combating Autism Act, two further condition specific bills have been introduced recently in congress, namely the Expanding the Promise for Individuals With Autism Act of 2007 and the Empowering Children with Autism through Education Act of 2007.

Whilst passage of the 2006 Act was supported by the majority of autism advocacy groups, it has been reported in online forums that some of those in the 'autism rights movement' opposed its provisions which were aimed at eliminating autism.<sup>26</sup> Such advocates believe that autism should be accommodated not combated.

### Combating Autism Act of 2006

The Combating Autism Act of 2006 is designed to enhance research, surveillance, and education regarding Autism Spectrum Disorder. In particular it:

*Authorizes Research Under NIH To Address The Entire Scope Of Autism Spectrum Disorder (ASD).*

*Authorizes Regional Centers Of Excellence For Autism Spectrum Disorder Research And Epidemiology. These Centers collect and analyze information on the number, incidence, correlates, and causes of ASD and other developmental disabilities. The Act also authorizes grants to States for collection, analysis, and dissemination of data related to autism.*

*Authorizes Activities To Increase Public Awareness Of Autism, Improve The Ability Of Health Care Providers To Use Evidence-Based Interventions, And Increase Early Screening For Autism. The Act authorizes the Secretary of Health and Human Services to:*

- Provide information and education on ASD and other developmental disabilities to increase public awareness of developmental milestones;

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<sup>25</sup> Public Law 109-416 – Dec 19, 2006.

[http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=109\\_cong\\_public\\_laws&docid=f:publ416.109.pdf](http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=109_cong_public_laws&docid=f:publ416.109.pdf)

<sup>26</sup> [http://en.wikipedia.org/wiki/Combating\\_Autism\\_Act](http://en.wikipedia.org/wiki/Combating_Autism_Act) (August 2007)

- Promote research into the development and validation of reliable screening tools for ASD and other developmental disabilities and disseminate information regarding those screening tools;
- Promote early screening of individuals at higher risk for ASD and other developmental disabilities as early as practicable;
- Increase the number of individuals who are able to confirm or rule out a diagnosis of ASD and other developmental disabilities;
- Increase the number of individuals able to provide evidence-based interventions for individuals diagnosed with ASD or other developmental disabilities; and
- Promote the use of evidence-based interventions for individuals at higher risk for ASD and other developmental disabilities as early as practicable.

The 2006 Act also calls on the Interagency Autism Coordinating Committee (IACC) to enhance information sharing. The IACC provides a forum to facilitate the efficient and effective exchange of information about autism activities, programs, policies, and research among the Federal government, several non-profit groups, and the public. The 2006 Act requires the IACC to provide information and recommendations on ASD-related programs, and to continue its work to develop and update annually a strategic plan for ASD research.<sup>27</sup>

During passage of the legislation, the Congressional Budget Office, estimated that implementation of the 2006 Act would cost \$4 million in 2007 and \$209 million over the 2007-2011 period (relative to estimated spending under the existing legislation).<sup>28</sup>

#### Expanding the Promise for Individuals With Autism Act of 2007

The Expanding the Promise for Individuals With Autism Act of 2007 was introduced into the Senate on the 20<sup>th</sup> March 2007 by Senators Clinton and Allard.<sup>29</sup> An identical Bill was introduced into the House of Representatives on 17<sup>th</sup> April 2007 by Representatives Doyle, Eliot Engel, Pickering and Smith.<sup>30</sup> The legislation amends existing legislation to require the Secretary of Health and Human Services to:

- Convene, on behalf of the Interagency Autism Coordinating Committee, a Treatments, Interventions, and Services Evaluation Task Force to evaluate evidence-based biomedical and behavioural treatments and services for individuals with autism;
- Establish a multi-year demonstration grant program for states to provide evidence-based autism treatments, interventions, and services.
- Establish planning and demonstration grant programs for adults with autism;

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<sup>27</sup> The Whitehouse (2006) Fact Sheet: Combating Autism Act of 2006 (24 August 2007) <http://www.whitehouse.gov/news/releases/2006/12/print/20061219-3.html>

<sup>28</sup> Congressional Budget Office (2006) <http://www.cbo.gov/ftpdoc.cfm?index=7469&type=0&sequence=0> (24 August 2007)

<sup>29</sup> S.937 <http://thomas.loc.gov/cgi-bin/query/D?c110:4:./temp/~c110obgLBR::> (August 2007)

<sup>30</sup> H.R.1881 <http://thomas.loc.gov/cgi-bin/query/D?c110:5:./temp/~c110obgLBR::> (August 2007)

- Award grants to states for access to autism services following diagnosis;
- Award grants to University Centers of Excellence for Developmental Disabilities to provide services and address the unmet needs of individuals with autism and their families;
- Make grants to protection and advocacy systems to address the needs of individuals with autism and other emerging populations of individuals with disabilities; and
- Award a grant to a national non-profit organization for the establishment and maintenance of a national technical assistance center for autism services and information dissemination.

The Bill also directs the Comptroller General to issue a report on the financing of autism services and treatments.

#### Empowering Children with Autism through Education Act of 2007

The Empowering Children with Autism through Education Act of 2007<sup>31</sup> was introduced in the House by Representative Yarmuth on 7<sup>th</sup> June 2007. The provisions of the Bill require the establishment of a task force to identify and disseminate evidence-based educational strategies and promising best practices to improve the quality of learning for individuals with autism. These include:

- Learning models, interventions, and services that demonstrate improvements in reading, writing, and math proficiency for individuals with autism.
- The cost-effectiveness of these learning models, interventions, and services, and their applicability for local education agencies.
- Professional development needs of educators who serve individuals with autism.
- Methods for incorporating State-, local- and community-based programs and services into the classroom to provide comprehensive support for individuals with autism.
- Identification of barriers to successful implementation of programs and services related to the education of and provision of services to children with autism and recommendations to address those barriers.
- Dissemination of findings to Congress, all relevant agencies, and States and United States territories to improve the quality of learning for individuals with autism.

#### **UK HUMAN RIGHTS, ANTI-DISCRIMINATION, AND EQUALITY LEGISLATION**

Whilst there is currently no condition specific legislation<sup>32</sup> relating to persons with ASD in force in the UK, the potential exists for persons with ASD and those seeking to progress or defend their rights to rely on existing human rights, anti-discrimination and equality legislation. In a number of cases such legislation places a statutory duty on public authorities to promote equality of opportunity between persons with a disability and persons without.

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<sup>31</sup> H.R. 2609 <http://thomas.loc.gov/cgi-bin/query/z?c110:H.R.2609>: **(August 2007)**

<sup>32</sup> A non-binding condition specific declaration on the rights of people with Autism was however adopted by the European Parliament in 1996.  
[http://www.iol.ie/~isa1/charter\\_of\\_rights.htm](http://www.iol.ie/~isa1/charter_of_rights.htm)

### The European Convention on Human Rights and the Human Rights Act 1998

The European Convention for the Protection of Human Rights and Fundamental Freedoms<sup>33</sup> (also known as the European Convention on Human Rights, the Convention, or ECHR) and its enforcement by the European Court of Human Rights provides a potential legal route for those seeking to progress or defend the rights of people with ASD. The ECHR, which was ratified by the United Kingdom in 1951 and entered into force in 1953, sets forth a number of fundamental civil and political rights and freedoms that Parties undertake to secure to everyone within their jurisdiction. The Human Rights Act 1998<sup>34</sup>, which came into force in October 2000, has made rights from the ECHR (the Convention rights) enforceable in UK courts. In October 2004, the European Court of Human Rights found that a 48 year old autistic man, who was admitted to a psychiatric hospital in 1997 for four months, had been deprived of his liberty in breach of Article 5(1) and denied the right to have the lawfulness of his detention determined by a court under Article 5(4).<sup>35</sup>

An Additional Protocol<sup>36</sup> to the ECHR added new fundamental rights to those protected under the Convention, namely the right to peaceful enjoyment of property, the right to education, and the right to free elections by secret ballot. Article 2 of the Additional Protocol – 'Right to Education' states that:

No person shall be denied the right to education. In the exercise of any functions which it assumes in relation to education and to teaching, the State shall respect the right of parents to ensure such education and teaching in conformity with their own religious and philosophical convictions.

The United Kingdom, however, whilst ratifying the additional protocol, made the following Reservation at the time of signature in 1952.

... in view of certain provisions of the Education Acts in the United Kingdom, the principle affirmed in the second sentence of Article 2 is accepted by the United Kingdom only so far as it is compatible with the provision of efficient instruction and training, and the avoidance of unreasonable public expenditure.<sup>37</sup>

### The European Social Charter

The European Social Charter (the Charter), which complements the ECHR, is designed to guarantee social and economic human rights. It was adopted in 1961

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<sup>33</sup> <http://conventions.coe.int/Treaty/Commun/QueVoulezVous.asp?NT=005&CM=8&DF=9/5/2007&CL=ENG>

<sup>34</sup> <http://www.opsi.gov.uk/acts/acts1998/19980042.htm>

<sup>35</sup> H.L. v. United Kingdom (N° 45508/99) 5 October 2004 [Section IV]  
<http://cmiskp.echr.coe.int/tkp197/view.asp?item=1&portal=hbkm&action=html&highlight=45508/99&sessionid=2025780&skin=hudoc-en>

<sup>36</sup> Protocol to the Convention for the Protection of Human Rights and Fundamental Freedoms CETS No.: 009  
<http://conventions.coe.int/Treaty/Commun/QueVoulezVous.asp?NT=009&CM=8&DF=9/5/2007&CL=ENG>

<sup>37</sup> <http://conventions.coe.int/Treaty/Commun/ListeDeclarations.asp?NT=009&CM=8&DF=9/5/2007&CL=ENG&VL=1>

and revised in 1996. The European Committee of Social Rights (ECSR) is the body responsible for monitoring compliance in the states party to the Charter. Compliance is based on a monitoring procedure based on national reports and a collective complaints procedure.

### **National Reports**

Every year the States Parties submit a report indicating how they implement the Charter in law and in practice. Each report concerns some of the accepted provisions of the Charter.

The Committee examines the reports and decides whether or not the situations in the countries concerned are in conformity with the Charter. Its decisions, known as “conclusions”, are published every year.

If a state takes no action on a Committee decision to the effect that it does not comply with the Charter, the Committee of Ministers addresses a recommendation to that state, asking it to change the situation in law and/or in practice.

The Committee of Ministers’ work is prepared by a Governmental Committee comprising representatives of the governments of the States Parties to the Charter, assisted by observers representing European employers’ organisations and trade unions.

### **Collective Complaints Procedure**

Under a protocol<sup>38</sup> opened for signature in 1995, which came into force in 1998, complaints of violations of the Charter may be lodged with the European Committee of Social Rights.

In the case of all states that have accepted the procedure those organisations which are entitled to lodge complaints with the Committee:

1. European Trade Union Confederation (ETUC), Union of Industrial and Employers’ Confederations of Europe (UNICE) and International Organisation of Employers (IOE).
2. Non-governmental organisations (NGOs) with participative status with the Council of Europe which are on a list drawn up for this purpose by the Governmental Committee; and
3. Employers’ organisations and trade unions in the country concerned.

In the case of states which have also agreed to this, National NGOs may also be entitled to lodge complaints.

Autism Europe<sup>39</sup> used the collective complaint procedure to denounce the French government for the non-provision of education to people with autism due to the lack of integration in mainstream education on the one hand and the dramatic shortage of specialised educational institutions on the other hand. The European Committee of

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<sup>38</sup> Additional Protocol to the European Social Charter Providing for a System of Collective Complaints (ETS No. 158)

<http://conventions.coe.int/Treaty/Commun/QueVoulezVous.asp?NT=158&CM=8&DF=9/5/2007&CL=EN>

<sup>39</sup> <http://www.autismeurope.org/>

Social Rights in November 2003 found that France was had failed to fulfill its educational obligations to persons with autism under the European Social Charter. This decision, was analysed by the Council of Europe's Committee of Ministers which upheld the collective complaint on 10 March 2004.<sup>40</sup>

Autism Europe relied on the revised charter for the substance of its complaint and the additional protocol to enable it to lodge the complaint with the European Committee of Social Rights. Whilst states such as France, Belgium, and Sweden have ratified the Revised charter and the additional protocol allowing collective complaints, the UK has done neither.<sup>41</sup>

## **DISABILITY DISCRIMINATION LEGISLATION**

The Equality Commission for Northern Ireland website highlights the following legislation which provides protection for disabled people against discrimination on the grounds of disability: the Disability Discrimination Act 1995<sup>42</sup> (DDA) as amended by the Disability Discrimination Act 1995 (Amendment) Regulations (Northern Ireland) 2004;<sup>43</sup> the Disability Discrimination (Transport Vehicles) Regulations 2005;<sup>44</sup> the Disability Discrimination (Northern Ireland) Order 2006;<sup>45</sup> the Special Educational Needs and Disability Order (Northern Ireland) 2005 (SENDO);<sup>46</sup> and the Special Educational Needs and Disability Order (Northern Ireland) 2005 (Amendment) (Further and Higher Education Regulations (Northern Ireland) 2006<sup>47</sup>. This body of legislation provides protection in the areas of: employment and vocational training; goods, facilities and services; education; and premises.

The DDA defines disability as “a physical or mental impairment which has a substantial and long-term adverse effect on a person’s ability to carry out normal day-to-day activities”. A person with autism who seeks to rely on the DDA and related legislation will, therefore, have to meet this definition of disability. Schedule 1 para 4 (1) of the DDA states 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

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<sup>40</sup> <http://www.autismeurope.org/portal/Default.aspx?tabid=644>

<sup>41</sup> A complete list of Council of Europe treaties and access to up to date information on signatories is available at <http://conventions.coe.int/Treaty/Commun/ListeTraites.asp?CM=8&CL=ENG>

<sup>42</sup> <http://www.opsi.gov.uk/acts/acts1995/1995050.htm>

<sup>43</sup> <http://www.opsi.gov.uk/Sr/sr2004/20040055.htm>

<sup>44</sup> <http://www.opsi.gov.uk/si/si2005/20053190.htm>

<sup>45</sup> <http://www.opsi.gov.uk/SI/si2006/20060312.htm>

<sup>46</sup> <http://www.opsi.gov.uk/si/si2005/20051117.htm>

<sup>47</sup> <http://www.opsi.gov.uk/Sr/sr2006/20060332.htm>

- (h) perception of the risk of physical danger.<sup>48</sup>

A case heard before the Employment Tribunal in England highlighted the potential difficulty for persons with autism seeking to meet the statutory definition of having a disability. The case involved a person with Asperger's Syndrome and Autism and the Employment Tribunal was required to rule on whether or not he satisfied the statutory definition of disability. The Employment Tribunal noted the absence of a specific factor in schedule 1 para 4 relating to conditions adversely affecting a person's ability to communicate or interact with other people and concluded that the applicant's conditions did not satisfy the statutory definition of disability. The Disability Rights Commission notes that the case presented an opportunity for the Employment Appeal Tribunal to clarify an unclear area of the law and thereby determine whether a significant number of people with Autism and Asperger's syndrome have effective protection under the DDA as it is presently framed. The DRC also argued that the case provided a vivid example supporting its recommendation for legislative change to incorporate the ability of a person to communicate and interact with others within the factors listed in Schedule 1, paragraph 4. The decision of the ET was appealed to the Employment Appeal Tribunal and the appeal, which was heard in January 2004, was successful. The EAT held the condition fits within the ability to understand, which covered understanding of broad human social interaction. The case was remitted back to the original Employment Tribunal to consider whether the adverse effect of the condition on the client's ability to understand is adversely affected to a substantial extent. However, a settlement was reached prior to the hearing.<sup>49</sup>

### **Statutory Duties on Public Authorities**

The DDA (as amended by Article 5 of the Disability Discrimination (Northern Ireland) Order 2006) requires Public Authorities, when carrying out their functions, to have due regard to the need to:

- promote positive attitudes towards disabled people; and
- encourage the participation of disabled people in public life.

Public Authorities are also under a duty to submit Disability Action Plans (DAP) to the Equality Commission for Northern Ireland explaining how they propose to fulfill these 'disability duties' in relation to their functions.

Under Section 75 of the Northern Ireland Act 1998,<sup>50</sup> public authorities in carrying out their functions relating to Northern Ireland are also under a statutory duty to have due regard to the need to promote equality of opportunity between persons with a disability and persons without and between persons of different religious belief,

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<sup>48</sup> Schedule 1 Para 4 (2) Regulations may prescribe (a) circumstances in which an impairment which does not have an effect falling within sub-paragraph (1) is to be taken to affect the ability of the person concerned to carry out normal day-to-day activities; (b) circumstances in which an impairment which has an effect falling within sub-paragraph (1) is to be taken not to affect the ability of the person concerned to carry out normal day-to-day activities.

<sup>49</sup> [http://www.drcgb.org/the\\_law/drc\\_legal\\_cases/impairment/mental\\_health\\_service\\_users\\_an/appeal\\_against\\_an\\_employment\\_t.aspx](http://www.drcgb.org/the_law/drc_legal_cases/impairment/mental_health_service_users_an/appeal_against_an_employment_t.aspx)

<sup>50</sup> <http://www.opsi.gov.uk/acts/acts1998/19980047.htm>

political opinion, racial group, age, marital status or sexual orientation; between men and women generally; and between persons with dependants and persons without.

### **Disability or Difference**

In the context of condition specific legislation it is important to note the growing (particularly online) debate around autism as a difference rather than disability. Those who support the former conception of ASD argue that those seeking a cure for autism are misguided and that it is more important and equitable to seek to create the conditions in which a person with ASD can use their unique skills and perceptions in useful ways. Aspies for Freedom<sup>51</sup> is an example of an organisation which in broad terms advocates this position. Adopting the view of ASD as essentially a disability, organizations such as Autism Speaks and Cure Autism Now<sup>52</sup> promote an alternative disability focused conceptualisation.

In a recent paper titled 'Is Asperger's syndrome necessarily a disability?', Professor Simon Baron-Cohen<sup>53</sup> concluded that "...the term 'difference' in relation to AS is a more neutral, value-free, and fairer description, and that the term 'disability' better applies to the lower functioning cases of autism". The paper also recognised, however, that "...the term 'disability' may need to be retained for AS as long as the legal framework only provides financial and other support for individuals with a disability".<sup>54</sup>

Likewise, the Task Group on Autism in Northern Ireland report highlighted the importance that identification of a disability may play in accessing additional support.

The Warnock Report (1978) encouraged professionals in the field of education to assess and detail the special educational needs of children rather than label them as members of a category. Subsequent legislation abandoned the use of category labels such as ESN (educationally subnormal), Maladjusted, Delicate etc. Many educationalists saw this as a progressive step, and perceived the medical model, i.e. diagnosing and labelling, to be one which was not appropriate in the field of education. Over time, however, diagnosis and labelling have become commonplace again. These labels are generally applied by medical professionals but it is often educational professionals who are challenged to provide appropriate educational solutions for the problems being experienced by the child. Medical labels are now extensively used in educational contexts, eg Attention Deficit with Hyperactivity Disorder, Dyspraxia, and, of course, Autism, Asperger syndrome, and Autistic Spectrum Disorders (ASD).

A key reason for the resurgence of diagnostic labels may be that it is frequently easier to argue for extra resources if the child has a named disability of some form, rather than a list of special educational needs. An equally compelling reason is that parents and some people with ASD put value on having a diagnosis. This presents a professional dilemma for

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<sup>51</sup> Website address <http://www.aspiesforfreedom.com/>

<sup>52</sup> Website address <http://www.autismspeaks.org/>

<sup>53</sup> Director of the Autism Research Centre (ARC) which is situated within the School of Clinical Medicine in the Department of Psychiatry, Section of Developmental Psychiatry, at the University of Cambridge.

<sup>54</sup> Baron-Cohen S. (2002) Focus on Autism and Other Developmental Disabilities Volume 17, Number 3, 1 September 2002 , pp. 186-191(6)

those, such as educational psychologists, who are committed to the principles of equity and of making provision according to need rather than making provision according to label. The autistic spectrum is a very wide one. Some children on the spectrum do not need resources beyond what the ordinary mainstream school can provide, and at the other extreme, some can overstretch the resources of even the most generously-provided special school. Most educational psychologists therefore focus on examining the special educational needs of the child and leave the diagnosis and application of the label to health professionals. They would hold the view that the presence of a diagnosis of ASD does not, per se, clarify what, if any, special educational needs the child will have. On the other hand, close examination of the diagnostic criteria for ASD reveals that the condition is one which is very much a psychological disorder related to impairments of perception, thinking, imagining, feeling, and communicating, and this suggests that the main form of “treatment” for the child will be educational in nature.<sup>55</sup>

**10<sup>th</sup> September 2007**

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<sup>55</sup> Task Group on Autism (2002) report electronically at: [http://www.deni.gov.uk/index/7-special\\_educational\\_needs\\_pg/special\\_educational\\_needs\\_-\\_reports\\_and\\_publications-newpage-2/special\\_educational\\_needs\\_-\\_reports\\_and\\_publications-newpage-4.htm](http://www.deni.gov.uk/index/7-special_educational_needs_pg/special_educational_needs_-_reports_and_publications-newpage-2/special_educational_needs_-_reports_and_publications-newpage-4.htm) paras 3.42 - 3.43