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Autism Bill

Bill 10 of 2008-09

The Bill is sponsored by Cheryl Gillan MP, who drew first place in the 2008/09 ballot for Private Members' Bills. It was presented on 21 January 2009, published on 13 February 2009, and its Second Reading debate is on 27 February 2009.

The Bill would require local authorities to collect and share information about people with autism, in order to assist in the provision of services. The Bill also contains measures to promote multi-agency working in the delivery of services, and the effective transition from child to adult services, for people with autism.

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Summary of main points

The *Autism Bill* is a Private Member's Bill introduced in the House of Commons by Cheryl Gillan with cross-party support. It was presented on 21 January 2009 and its Second Reading debate is due on 27 February 2009.

The Bill is intended to provide better information about the numbers of people with autism and their needs and to improve local planning and delivery of services. The Bill makes provisions in three main areas, relating to information gathering, the delivery of services to people with autism, and the transition to adult services:

- The Bill would require every local authority to maintain a register of autistic children within their area, and place a duty on the Secretary of State for Health to make regulations requiring local authorities and NHS bodies to collect data on the population of adults with autism.
- The Bill would require the Secretary of State for Children, Schools and Families to make regulations stating that children's services authorities must consider the need of children with autism, and the Secretary of State for Health to make regulations promoting the provision of services for adults with autism by local authorities and NHS bodies. The Bill would also require Welsh Ministers to promote the provision of services for adults with autism by local authorities and NHS bodies in Wales.
- The Bill would require local authorities to promote effective transition from child to adult services for young people with autism.

The Bill builds on two ten-minute rule bills introduced by Lee Scott (*Education (Children with Autism) Bill*, Bill 56, 2007-08) and Angela Browning (*Autism Bill*, Bill 111, 2007-08). The National Autistic Society has been involved in the drafting of the Bill and has provided its support, together with 14 other organisations working with people with autism.

This Research Paper notes the measures proposed by the Bill and provides background on autism spectrum disorders (ASDs) and their prevalence. It sets out the current statutory framework and Government policy for supporting people with autism. In particular it notes the Government's intention to publish a strategy for adults with autism later in 2009, and its commitment, made in a letter to MPs on 19 February 2009, to introduce statutory guidance and other measures, specifically addressing issues raised by the Bill. The details of the Government's proposals are still at an early stage and Cheryl Gillan has said that she will continue campaigning until the Government pledges to fully support people affected by autism.

The arrangements for the collection of data on autism are described in this Research Paper along with information on what data is currently available. It also sets out the evidence on outcomes for people with autism, and highlights some of the issues faced by children, young people and adults with the condition.

The Bill extends to England and Wales only.

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I The Bill

The *Autism Bill* is a Private Member's Bill introduced in the House of Commons by Cheryl Gillan on 21 January 2009 with cross-party support:

Autism Bill

Mrs. Cheryl Gillan, supported by Jon Cruddas, Mrs. Joan Humble, Roger Berry, Mr. Russell Brown, Mrs. Sharon Hodgson, Mr. Gordon Marsden, Mrs. Caroline Spelman, Mrs. Jacqui Lait, Angela Browning, Mr. Tim Boswell and Sandra Gidley, presented a Bill to make requirements relating to the collection and dissemination of information on people with autism; to make provision about support for people with autism; and for connected purposes: Bill read the First time; to be read a Second time on Friday 27 February and to be printed (Bill 10).¹

The Bill, which was published on 13 February 2009,² will have its Second Reading debate on Friday 27 February 2009.

The Bill is intended to provide better information about the numbers of people with autism and their needs and to improve local planning and delivery of services. The Bill makes provisions in three substantive areas. The first, which relates to information gathering, requires every local authority to maintain and share a register of autistic children within their area, and for the Secretary of State for Health to make regulations requiring local authorities and NHS bodies to collect data on the population of adults with autism. The second, which relates to services for children and adults with autism, requires the Secretary of State for Children, Schools and Families to make regulations stating that children's services authorities must consider the need of children with autism, and the Secretary of State for Health to make regulations promoting the provision of services and support for adults with autism by local authorities and NHS bodies. The Bill also requires Welsh Ministers to promote the provision of services and support for adults with autism by local authorities and NHS bodies in Wales. The third, requires local authorities to promote effective transition from child to adult services for young people with autism.

The Autism Bill builds on two ten-minute rule bills introduced by Lee Scott and Angela Browning.³ The drafting of the Bill has been assisted by the National Autistic Society and it is supported by a large number of organisations including: Autism Research Centre, Treehouse, Autism in Mind, Autism Education Trust, Autism Speaks and Research Autism. According to the National Autistic Society, 115 MPs are committed to attending the Second Reading debate on the Autism Bill.

Clause 1 seeks to introduce new sub-paragraphs 3, 4, 5 and 6 into paragraph 2 of Schedule 2 of the *Children Act 1989*.

¹ [HC Deb 21 January 2009 c754](#)

² [Autism Bill](#), Bill 10, Session 2008-09

³ Angela Browning's *Autism Bill* [Bill 111 2007-08] presented on 20 May 2008 and Lee Scott's *Education (Children with Autism) Bill* [Bill 56 2007-08] presented 16 January 2008.

Sub-paragraph 3 would require local authorities' register of disabled children to record how many are children with autism. Sub-paragraph 4 requires local authorities to provide the contents of the register to its 'relevant partners' on an annual basis. Sub-paragraphs 5 and 6 states that 'autism' has the same meaning as in Clause 7 of the Bill, and that 'relevant partners' are those referred to as relevant partners of a children's services authority, under section 10(4) of the *Children Act 2004*. The organisations set out in this section of the *Children Act 2004* are listed below:

- 10(4)(a) - where the authority is a county council for an area for which there is also a district council, the district council;
- (b) - the police authority and the chief officer of police for a police area any part of which falls within the area of the children's services authority;
- (c) - a local probation board for an area any part of which falls within the area of the authority;
- (d) - a youth offending team for an area any part of which falls within the area of the authority;
- (e) - a Strategic Health Authority and Primary Care Trust for an area any part of which falls within the area of the authority;
- (f) - a person providing services under section 114 of the Learning and Skills Act 2000 (c. 21) in any part of the area of the authority;
- (g) - the Learning and Skills Council for England.

Clause 2 of the Bill seeks to introduce new section 17(3)(c), 17(3)(d) and 17(3)(e) into the *Children Act 2004*.

Section 17 of the *Children Act 2004* allows the Secretary of State to make regulations requiring children's services authorities to publish a children and young person's plan. Section 17(3)(c) provides that these regulation include the children's services authority's assessment of the specific needs of children with autism, the services required to meet those needs, and the training requirements of relevant staff to ensure such services are delivered effectively. Section 17(3)(d) states that in making the above assessment children's services authorities must have regard to the views of children and young people with autism, and the views of their parents and carers.

Clause 3 of the Bill aims to promote effective transition from children's to adult services for young people with autism. It would insert a new sub-paragraph 7 at the end of Schedule 2 paragraph 2 of the *Children Act 1989*, requiring a local authority's director of children's services and director of adult services to review the register of disabled children at least once every three-month period, from the date the Act comes into force:

"...for the purpose of improving the planning of services for children and adults with autism and, in particular, their transition between children and adult services."

Clause 4 of the Bill introduces new sub-section 116(4A) into the *Local Government and Public Involvement in Health Act 2007*, to ensure that local authorities and Primary Care Trusts (PCTs) consider the requirements for services and support for adults with autism. Section 116 of the *Local Government and Public Involvement in Health Act 2007* requires a local authority and its partner PCT to prepare a joint strategic needs assessment for health and social care. The new sub-section 116(4A) would create an additional requirement for local authorities and PCTs to have 'particular regard to the

requirements for services and support of persons with autism' when preparing any assessment of relevant needs under this section.

Clause 5 of the Bill introduces a new duty for the Secretary of State for Health to promote the provision of services and support by local authorities and NHS bodies to adults with autism. Clause 5(2) explains that this duty would be preformed by making regulations, and Clause 5(3) sets out the specific items that the regulations must make provision for. These include training requirements, the provision of diagnostic and assessment services, and the sharing of good practice. Clause 5(3) also states that the regulations must make provision for the collection of data on the population of adults with autism and their requirements for services and support. Clause 5(4) sets out who the Secretary of State must consult before making regulations under this section. As well as local authority and NHS bodies, this includes people with autism, organisations that represent people with autism and people affected by autism (such as the National Autistic Society), and professionals delivering autism support services. Clause 5(5) states that local authorities and NHS bodies must promote independent living for persons with autism. Clause 5(6) and 5(7) state that regulations must be made by Statutory Instrument approved by both Houses of Parliament.

Clause 6 of the Bill extends similar duties to those contained in Clause 5 to Ministers of the National Assembly for Wales, although it does not prescribe the items that the regulations must make provision for (as in Clause 5(3)). As well as consulting all the individuals and bodies listed in Clause 5(4), under Clause 6(3)(f) Welsh Ministers must also consult 'organisations involved in research relating to care services for persons with autism.'

Clause 7 of the Bill defines certain key terms used in the Bill, particularly:

Autism - includes all autism spectrum disorders, including Asperger syndrome.

Autism support services - means services provided by local authorities and NHS bodies for the assessment, care and support of persons with autism.

Independent living - means persons with autism enjoying the same choice, freedom, dignity, control and substantive opportunities as persons who are not disabled.

Clause 8 of the Bill is a procedural clause.

Clause 9 of the Bill states that, if enacted, the legislation will be cited as the *Autism Act 2009* and will apply to England (Sections 1 to 5 and 7 to 9) and Wales (Section 6).

On 19 February 2009, Phil Hope MP, Minister for Care Services and Sarah McCarthy-Fry MP, Minister for Schools and Learners, wrote a joint letter to Members of Parliament setting out the actions the Government is taking to support children and adults with autism.⁴ These actions include the following measures specifically addressing issues raised by the Bill:

⁴ Letter from Phil Hope, Minister for Care Services, Department of Health, and Sarah McCarthy-Fry MP, Minister for Schools and Learners, DCSF, sent to Members of Parliament on 19 February 2009.

- A commitment to publish an adult autism strategy by December 2009, with new statutory guidance to ensure the delivery of the outcomes set out in the strategy.
- Measures to enable the collection of data on adults with autism, and to take forward research on the prevalence of autism.
- New statutory guidance for Children and Young People's Plans which clearly reflect the needs of disabled children, including those with autism.
- The publication of commissioning guidance and good practice guidance aimed at local authorities and the NHS.
- Funding for research on the transitions to adulthood of young people with autism.

The Ministers' letter states that the Government proposals will achieve the outcomes the Bill seeks to address without recourse to legislation. A more detailed account of the Government's announcement, and reactions to this, are set out in Section III of this Research Paper.

II Background

A. What is autism?⁵

In the context of this Bill the term autism refers to a group of disorders of development, known as autism spectrum disorders or ASDs, whose signs are first seen in early childhood. These lead to lifelong disabilities ranging from subtle difficulties with social functioning (such as Asperger syndrome) to severe behavioural, learning and communication problems (such as classic Kanner's autism).⁶

Diagnosis is based on observations of behaviour and tests of functioning, the interpretation of which inevitably leads to some variability and diagnostic uncertainty. Structured diagnostic protocols have helped to reduce this variability and continue to be refined but there is currently no genetic or other physiological test for autism. Autism is usually diagnosed in childhood but an increasing number of diagnoses, particularly of Asperger syndrome, are made in adolescence or adulthood.⁷

The International Classification of Diseases, version 10 (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders 4th edition (DSM-IV) define autism as involving three areas of impaired functioning:

- social – impaired, deviant and delayed or atypical social development, especially interpersonal development

⁵ The Parliamentary Office of Science and Technology have also produced a '[Postnote](#)' on Autism (Number 302 February 2008).

⁶ There has been a shift towards the use of the term "Autistic Spectrum Conditions" or ASC, but as ASD is the term used in most of the publications cited in this Research Paper this is used as the preferred term. Clause 7 of the *Autism Bill 2008-09* defines autism as including all ASDs, including Asperger syndrome; the terms autism and ASD are used interchangeably in this Research Paper.

⁷ Scottish Intercollegiate Guidelines Network (SIGN), [Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders](#), July 2007, p 11

- language and communication – impaired and deviant language and communication, verbal and non-verbal. Impairment in pragmatic aspects of language
- thought and behaviour – rigidity of thought and behaviour and impoverished social imagination. Ritualistic behaviour, reliance on routines, impairment of imaginative play.⁸

Historically, health services and public interest have focused on those with severe autism but it is increasingly clear that there are many more people who have milder forms of the disorder. The National Autistic Society has published a concise definition that may be more appropriate for many of those with autism:

Autism is a lifelong developmental disability that affects how a person communicates with other people. It also affects how they make sense of the world around them. The three main areas of difficulty are:

- social interaction - which can make it hard to form friendships.
- social communication - including using and understanding verbal and non-verbal language, such as gesture
- social imagination - including the ability to understand and predict intentions and behaviour.⁹

Approximately 30% of people with severe autism also have epilepsy and the condition is up to four times as common in males as it is in females. The cause of autism remains unknown. It is thought to be mainly genetic in origin but environmental factors are likely also to play a part.¹⁰

No specific drug treatment is available but there is some evidence that early behavioural and cognitive intervention programmes are effective in reducing later disability and improving ability.¹¹ Medication may be used to help manage specific problems such as anxiety, depression or hyperactivity.

There is no known 'cure' for autism and many of those with autism object to the use of a disease model for their condition.¹² The debate is further enriched by a recent paper at a meeting of the Royal College of Psychiatrists, suggesting that Charles Darwin had Asperger syndrome. In practice, support for those with autism focuses on preventing or managing disability by tailoring education, social support and employment services to their particular needs, and the needs of their families.

⁸ Scottish Intercollegiate Guidelines Network (SIGN), [Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders](#), July 2007, p3

⁹ National Autistic Society, [Autism Bill briefing notes](#) (accessed 19 February 2009)

¹⁰ Claims have been made that the MMR vaccine may cause autism. However, repeated studies have not shown any link and this is reflected in Department of Health guidance (Department of Health, [Top 10 myths & truths about MMR](#), August 2003).

¹¹ *ibid.*, p16

¹² National Autistic Society, [Is there a cure?](#) (accessed 19 February 2009)

B. Estimates of the prevalence of Autism spectrum disorders

There is no national register of people with autism as with the large majority of mental and physical conditions. This means estimates are from epidemiological studies or surveys on samples of the population. There are specific difficulties in making any estimate of the prevalence of ASD. According to Wing and Potter¹³ there are three main problems:

- Difficulties in diagnosis –There is no medical test for autism, diagnosis is based on descriptions of behaviour. Current classification systems are much wider than those for 'classic autism' and clinicians differ in how they apply these criteria.
- Different uses of diagnostic terms –Autism may be used to refer to just those with classic Kanner's autism, a wider definition of childhood autism or sometimes the whole autistic spectrum. People may not fit neatly into any single category or may fit into more than one.
- Different assessment methods –Studies based on case notes or individuals with a firm diagnosis tend to give lower prevalence rates than those which assess every individual in the sample.

They add that the rise in the number of people with ASD could be due to changes in referral pattern, diagnostic criteria and a general improvement in awareness of different aspects of ASD. There might have been real changes in prevalence, but there is no way of telling without further research.

These problems are highlighted in the prevalence data. The National Autistic Society (NAS) summary of research¹⁴ shows how prevalence estimates for children have evolved:

- 4.5 per 10,000 -Classic Kanner's autism (1966)
- 20 per 10,000 -An expanded definition which also included children impairments of social interaction, communication and imagination with a repetitive stereotyped pattern of activities (1979)
- 35 per 10,000 (and possibly as high as 71 per 10,000) –Asperger Syndrome (1993)
- 90 per 10,000 –Autism Spectrum Disorders (2005)¹⁵
- 116 per 10,000 - Autism Spectrum Disorders (2006)

A Medical Research Council review of autism research in 2001 concluded that according to recent reviews there was fairly good agreement that ASD affected around 60 children aged under 8 per 10,000, or 10-30 for more narrowly defined autism.¹⁶

¹³ L. Wing and D. Potter, (2002) *Notes on the prevalence of autism spectrum disorders*.
www.nas.org.uk/nas/jsp/polopoly.jsp?d=364&a=2618

¹⁴ *Statistics: how many people have autistic spectrum disorders?*, National Autistic Society
www.autism.org.uk/nas/jsp/polopoly.jsp?a=3527&d=235

¹⁵ Based on a reported rate of 0.9%. The actual observed rate was 0.89% or 89 per 10,000 and was rounded to one decimal place in the original report.

¹⁶ *MRC Review of Autism Research. Epidemiology and causes*, MRC (2001)

Some of the more recent studies give prevalence rates for the narrower definitions as well. NAS has stated that the best estimates are those which look at the entire spectrum rather than sub-groups. They currently use a rate of 1 in 100 (100 per 10,000) as a best estimate of prevalence in children and add that this can not be precisely fixed. A rate of 1 in 100 implies a population in the UK aged under 18 with ASD of 131,000.¹⁷ Without any studies of prevalence in adults it is very difficult to estimate a similar figure for the whole population, but as a 'very rough guide' NAS has estimated that it could be more than 500,000.¹⁸ To help put this figure in context of other conditions, there are thought to be 2.35 million people in England with diabetes or 4.6% of the population.¹⁹ Data on mental health conditions is less robust, but a survey in 2000 found 16% of adults had a common mental/neurotic disorder such as mixed anxiety and depressive disorder. 0.5% were thought to have had a probably psychotic disorder in the previous year.²⁰

Within the total number of people with ASD there will be large differences in the nature and severity of their condition and hence in whether they need additional support and if so how much. The difficulties in making any prevalence estimate were mentioned earlier. The ideal type of information at a national level to help plan services would be robust estimates of the prevalence of ASD overall and of the different sub-groups that have varying levels of service need.

Most of these results are based on small samples of the population which may, by chance, over or under estimate the prevalence of ASD for the population as a whole. This variability will be accounted for in the original research by calculating a range around the observed sample prevalence. This is the range within which the authors are reasonably certain that the prevalence rate of autism (however they define it) for the whole population lies.²¹ The central estimate or observed sample prevalence is the figure which normally gets reported, but it is important to be aware of the range as it is more likely to be accurate (include the 'true' rate) and it illustrates the underlying uncertainty in the estimate. The last two studies quoted above had central estimates of 89 and 116 per 10,000 respectively. Their ranges were 66-112 and 90-142 per 10,000 respectively.^{22 23} The extent of these ranges is plus or minus a couple of tenths of a percentage point, but when used to estimate national populations this equates to plus or minus more than 100,000 people.

C. Statutory framework for supporting people with autism

There are few specific references to autism or ASD in legislation, and the National Autistic Society notes that the only mention of autism in a UK Act of Parliament is in the

¹⁷ *Mid-2007 population estimates*, ONS

¹⁸ *Statistics: how many people have autistic spectrum disorders?*, National Autistic Society

¹⁹ www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/Diabetes/DH_074762

²⁰ *Psychiatric morbidity among adults living in private households*, 2000, ONS (2001)

²¹ This will normally be a 95% confidence interval. This is the range within which the population prevalence will lie 95% of the time.

²² Green H, et al, *Mental health of children and young people in Great Britain, 2004*, ONS (2005)

²³ Baird, G. et al (2006). *Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)*. *The Lancet*, 368 (9531), pp. 210-215.

Chronically Sick and Disabled Persons Act 1970.²⁴ However, legislation on Special Educational Needs (SEN), mental health services, and services for children and people with disabilities, may also extend to people with autism.

1. Guidance on how existing legislation applies to people with autism

Department of Health guidance, *Better services for people with an autistic spectrum disorder*, sets out how some existing legislation applies to people with ASDs:

Mental Capacity Act 2005

"...following implementation of the Mental Capacity Act, people must be assumed to have capacity to make decisions about the services provided or offered to them unless it has been demonstrated otherwise. This includes people with an ASD and those who may not find it easy to express their choice in words. This will provide people with an ASD much greater freedom to direct their own support. Use of "best interest principles" (i.e. decisions guided by what would be in a person's best interest) should guide decision making for the few people for whom choice is very difficult to ascertain."²⁵

Disability Discrimination Act 1995

"The Disability Discrimination Act and the new Disability Equality Duty [created by the Disability Equality Act 2005] underline the need for all services to understand, and respond to, the needs of disabled people. This means that day, employment, leisure and education services (as well as all other public services) must make reasonable adjustments to facilitate the inclusion of people with an ASD."²⁶

Carers Recognition and Services Act 1995

"In accordance with the Carers Recognition & Services Act 1995 carers should be made aware of their right to request an assessment. Social services should draw up a care plan for a carer in need of support and communicate it to their GP and primary care team."²⁷

2. Direct Payments and Individualised Budgets

The Department of Health guidance referred to above notes that the legislation on direct payments and individual budgets also applies to people with an ASD:

The expectation that everyone eligible for support should be offered direct payments clearly applies to people with an ASD. The importance of getting support right for people with an ASD combined with the poor performance of some traditional services means an increasing number of people are using direct payments and individualised budgets. People with an ASD may need specific

²⁴ Section 26 of the *Chronically Sick and Disabled Persons Act 1970*, which has been repealed, related to the special educational treatment of children with autism.

²⁵ Department of Health, *Better services for people with an autistic spectrum disorder: A note clarifying current Government policy and describing good practice*, November 2006, p9

²⁶ *ibid.*, p10

²⁷ *ibid.*, p22

support with managing some of the implications of new ways of working for example the social issues in managing staff and the systems developing around individualised budgets are developing to accommodate this.²⁸

Direct Payments were first introduced in 1997 under the *Community Care (Direct Payments) Act 1996* for working age adults. The aim of Direct Payments is to increase individuals' independence and choice by giving them control over the way the services they receive are delivered. Direct Payments are local council cash payments for people who have been assessed as needing help from social services, and who would like to arrange and pay for their own, independently contracted, care and support services instead of receiving them directly from the local council. They were extended to older people in 2000, and in 2001 to parents of disabled children and carers.²⁹ In 2003 regulations made under section 57 of the *Health and Social Care Act 2001* put a duty on councils to make Direct Payments to individuals who consented to, and were able to manage, them, with or without assistance.³⁰

One of the proposals set out in the Government's report *Aiming high for disabled children*³¹ was to pilot individual budgets for disabled children and young people. Following scoping work and building on existing practice in developing individual budgets for adults, a number of local authorities – with their PCT partners – will be invited to express an interest in becoming a disabled children individual budget pilot area, to test approaches to give young people and their families more control over their care.³²

3. Special Educational Needs (SEN)

The legal responsibilities of Local Education Authorities (LEAs)³³ and schools towards children with SEN are contained in the *Education Act 1996*, as amended by the *Special Educational Needs and Disability Act 2001*. A child has SEN if he/she has a learning difficulty which needs special educational provision to be made. In England there is a graduated approach to SEN with the following stages: 'School Action' where the school provides additional help, 'School Action Plus' where greater involvement of external specialists is needed, and for children who need the greatest amount of additional support this may lead to more formal arrangements for SEN provision through a statement of SEN. As noted above, within the total number of children with ASD there will be large differences in the nature and severity of the condition and hence in whether they need additional support such as a statement of SEN. (The National Autistic Society describes autism as a "developmental disability" rather than a learning difficulty.)

²⁸ *ibid.*, p24

²⁹ *Carers and Disabled Children Act 2000*

³⁰ *Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2003* (SI 2003/762). For further information about direct payments and individualised budgets see Library Research Paper, *Welfare Reform Bill: disabled people, child maintenance and birth registration [Bill 8 of 2008-09]*, and <http://www.in-control.org.uk>

³¹ Department for Education and Skills and HM Treasury, *Aiming high for disabled children: better support for families*, May 2007, paras 2.11 to 2.24

³² Department for Children, Schools and Families and Department of Health, *Healthy lives, brighter futures: The strategy for children and young people's health*, February 2009, para 6.64

³³ Education legislation uses the term 'local education authority' though local authority children's services are being integrated to reflect Government policy, which is to improve outcomes for children by promoting greater cooperation between agencies working with children. The post of Director of Children's Services was provided in the *Children Act 2004*.

Information about the number of children with SEN who also have ASD is given in Section IV of this Research Paper.

a. Transition for children with SEN

The statutory *Code of Practice on the Assessment and Identification of Special Educational Needs*³⁴ states that a 'transition plan' must be drawn up, and subsequently reviewed, for all children with statements of SEN from the age of 14. The Transition Plan should draw together information from a range of individuals within and beyond school in order to plan coherently for the young person's transition to adult life. Under Section 140 of the *Learning and Skills Act 2000*, the Connexions Service, on behalf of the Secretary of State for Education, must carry out needs assessments of pupils with SEN statements in the last year of school who want to go on to further education and training so that provision is developed that meet those needs.

Information on current statutory requirements to collect data on the number of disabled children and adults are set out in Section IV of this Research Paper.

D. Government guidance on supporting people with autism

There is little statutory guidance that specifically relates to the provision of services for people with autism. As can be seen from the section above, many of the Government's general policies, whether for SEN or for health and social services directed at children and the disabled, can apply to people with autism. However, the Government has recognised that some people with ASD who need services 'fall through the gaps created by traditional service boundaries.'³⁵ The National Autistic Society referred to this problem in their briefing on the *Autism Bill*:

There are key structural barriers preventing adults with autism from accessing the support that they desperately need. Local authorities tend to provide services via specific teams, with the teams categorised into client groups. Consequently, people with autism will usually come into contact with the learning disability team and/or the mental health team. However, as autism is a developmental disability and not a learning disability or a mental health problem, many people with autism, and particularly those with Asperger syndrome or high functioning autism find themselves "falling through the gap" between services that refuse to take responsibility for them.³⁶

In order to deal with this issue the Government has issued a number of guides and statements of best practice intended to clarify how existing policies apply to people with autism. The guidance, which is summarised below, can broadly be categorised as either dealing with services for children, or with services for adults.

³⁴ Department for Education and Skills, *Code of Practice on the Assessment and Identification of Special Educational Needs*, 2001, see para 9.51

³⁵ Department of Health, *Better services for people with an autistic spectrum disorder: A note clarifying current Government policy and describing good practice*, November 2006, p8

³⁶ National Autistic Society website, *Autism Bill briefing notes*

1. ***Autistic Spectrum Disorders: Good Practice Guidance (2002)***

Autistic Spectrum Disorders: Good Practice Guidance is a joint publication of what was then the Department for Education and Skills (DfES), the Department of Health and the Autism Working Group,³⁷ and is intended to raise awareness and standards of support for children with ASDs.³⁸ Although this was published in 2002 it remains the most substantial piece of guidance specifically dealing with services for children with ASD (and education services in particular). An account of more recent Government policy for children with autism is given in the sections on the Government's *National Service Framework for Children* and the child health strategy, *Healthy lives, brighter futures*, published on 12 February 2009, which follow on from this.

The guidance concentrates on educational provision as the education service tends to make the most sustained intervention for children with autism but it also aims to encourage a multi-agency approach across health, social services and education. The guidance sets out some of the education interventions used for children with ASDs and the wide variety of educational settings that might be appropriate:

At present in England, children with an ASD might attend an ordinary mainstream school or a special unit or school for children with learning difficulties or an autism-specialist school. A minority of children may attend residential schools offering a consistent programme both during and after normal school hours. Some children with an ASD are educated at home for a variety of reasons. The majority of children with an ASD will be recognised within a mainstream school as having additional or different needs from their peer group and will have an Individual Education Plan or individual targets and interventions planned as part of the class or school curriculum. Some may require more support than is usually provided from within a mainstream school's or early education setting's resources and may need a formal assessment, which, where necessary, leads to a Statement of Special Educational Needs, specifying their needs and the provision to meet them. Children whose needs are identified before statutory school age may receive a statement to support early intervention, either in specialist or mainstream settings, or in the home.³⁹

As noted above, although many children with autism will have a Statement of SEN this is not the case for all children with autism. Further information about the number of SEN pupils who have ASD as their primary need is given in Section IV of this Research Paper along with data on the types of schools they attend.

The guidance highlights the range of support that children with autism and their families require and states that there should be multi-agency co-operation in the delivery of services, particularly at the transition to adult services:

³⁷ The Autism Working Group was established by what was the Department for Education and Employment and included representation from central government, government agencies, parent groups, LEAs, early years, researchers and academics.

³⁸ Department for Education and Skills and the Department of Health, *Autistic Spectrum Disorders: Good Practice Guidance*, 2002

³⁹ *ibid.*, para 3.3 p14

ASDs are complex and will undoubtedly require the input of different agencies. There should be multi-agency co-operation and intervention which recognises the multiple demands ASDs place on providers. Interagency discussion is crucial and is particularly important at the pre-school stage and at the transition to adult services. For children with an ASD and their families to receive a co-ordinated flexible and seamless service, statutory, voluntary and independent providers need to link and liaise across organisational boundaries.⁴⁰

The guidance also states that there should be 'close liaison' between LEAs and health and social services in order that there should be:

...a clear picture of the size of the cohort of children with an ASD in an LEA or region and a clear inter-agency policy on provision for children with an ASD.⁴¹

2. *National Service Framework for Children, Young People and Maternity Services and the Autistic Spectrum Disorders Exemplar (2004)*

The *National Service Framework for Children, Young People and Maternity Services* (Children's National Service Framework or NSF) is a 10 year programme intended to stimulate long-term and sustained improvement in children's health.⁴² It sets national standards aiming to ensure fair, high quality and integrated health and social care from pregnancy, right through to adulthood. Standards that are particularly relevant to children with autism are Standard 4, *Growing Up into Adulthood* and Standard 8, *Disabled Children and Young People and Those with Complex Health Needs*. Standard 4 of the NSF provides:

All young people have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood.⁴³

Standard 8 provides:

Children and young people who are disabled or who have complex health needs receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives.⁴⁴

Supporting material was published alongside the NSF, including an 'exemplar' patient journey for a child with ASD. This illustrates how some of the key themes in the NSF are applied, from first identification and assessment of an ASD, through ongoing support (including benefits and respite care), and on to planning for transition to adulthood.⁴⁵

⁴⁰ *ibid.*, p17

⁴¹ *ibid.*, p16

⁴² Department for Education and Skills and the Department of Health, *National Service Framework for Children, Young People and Maternity Services*, September 2004

⁴³ Department for Education and Skills and the Department of Health, *The National Service Framework for Children, Young People and Maternity Services – Disabled Children and Young People and those with Complex Health Needs*, September 2004.

⁴⁴ *ibid.*

The All Party Parliamentary Group on Autism (APPGA) reported that there was an implementation gap between the policies recommended in the NSF and the reality of services at a local level. A survey of local authorities found that only 35% of officials and 10% of councillors said their authority used the autism exemplar chapter of the NSF.⁴⁶

3. *Healthy lives, brighter futures: The strategy for children and young people's health (2009)*

On 12 February 2009 the Government published the *Healthy lives, brighter futures: The strategy for children and young people's health*, which made special reference to children with autism.⁴⁷ The strategy reaffirms the Government's commitment to follow-up the recommendations of the Independent Review of Child and Adolescent Mental Health Services (CAMHS), including the recommendations on improving the access, quality and impact of mental health services for vulnerable children and young people, including those with autism. It also sets out how the Government intend to improve services for children with speech, language and communication needs, many of whom will have an ASD, following the recommendations of the Bercow Report on these service.⁴⁸

Healthy lives, brighter futures announced funding of £340 million, as part of Primary Care Trust allocations over 2008-09 to 2010-11, to support the NHS in delivering services for disabled children. This is in addition to the funding of £340 million, over the same three years (2008-9 to 2010-11), available through the *Aiming High for Disabled Children* (AHDC) programme to transform services for disabled children, including those with autism.⁴⁹ The AHDC programme is intended to improve short-breaks for disabled children and their families and autism is an area of focus of this work. The Government's *Short Breaks Implementation Guidance* under AHDC makes clear that children and young people with autistic spectrum disorders should not be disadvantaged in accessing short breaks.⁵⁰

4. *Better services for people with an autistic spectrum disorder: A note clarifying current Government policy and describing good practice (2006)*

In November 2006 the Department of Health published *Better services for people with an autistic spectrum disorder: A note clarifying current Government policy and describing good practice*.⁵¹ The note sets out the Government's expectations for the delivery of public services for adults (people aged 16 or over) with ASDs. It encourages people in

⁴⁵ Department of Health, *National Service Framework for Children Young People and Maternity Services: Autistic spectrum disorders*, September 2004

⁴⁶ All Party Parliamentary Group on Autism, *Policy into Practice: Implementation of the National service framework for children, young people and maternity services by local authorities*, July 2007

⁴⁷ Department for Children, Schools and Families and Department of Health, *Healthy lives, brighter futures: The strategy for children and young people's health*, February 2009

⁴⁸ Department for Children, Schools and Families, *The Bercow Report: A Review of Services for Children and Young People with Speech, Language and Communication Needs*, 2008. Following this the Department published *Better Communication: An Action Plan to Improve Services for Children and Young People with Speech, Language and Communication Needs* in December 2008

⁴⁹ Department for Children, Schools and Families and Department of Health, *Healthy lives, brighter futures: The strategy for children and young people's health*, February 2009, paras 6.25 and 6.61

⁵⁰ Department for Children, Schools and Families and Department of Health, *Short Breaks Implementation Guidance*, 2008, p16

⁵¹ Department of Health, *Better services for people with an autistic spectrum disorder: A note clarifying current Government policy and describing good practice*, November 2006

the social care and health services to develop local agendas for action but makes clear what services people with an ASD can expect, regardless of how services are configured. The note also provides examples of current best practice.

The introduction to *Better services for people with an autistic spectrum disorder* stresses that it does not introduce new policy but explains what existing policy means for local providers. In particular it focuses on the six adult national policies listed below, and summarises how these are relevant to the delivery of services to people with ASD:

- *Fair Access to Care: guidance on eligibility criteria for adult social care* (2002)
- *Valuing People: A New Strategy for Learning Disability for the 21st Century* (2001)⁵²
- *National Service Framework (NSF) for Mental Health* (1999) and the *National Service Framework for Mental Health – Five Years On* (2004)
- *Our Health, Our Care, Our Say: a New Direction for Community Services* (2006)
- *Improving the Life Chances of Disabled People* (2005)
- *NSF on Long Term (Neurological) Conditions* (2005)

The note also includes a section called *Growing into Adulthood*, which provides a cross cutting interpretation of policies for young people in transition from child to adult services.⁵³

The note refers to the difficulties that some people with autism face in falling through the gaps created by traditional service boundaries, such as those between health and learning disability services. It stresses that this is contrary to existing Government policy, and identifies ways to prevent this, such as joint working protocols between service providers.

The note states that it is the responsibility of the Director of Adult Social Services and/or the Director of Public Health to “identify, assess and meet the needs of the local adult population and this should include people with an ASD.” Although not a statutory requirement, existing policy states that they should also ensure there is *local data* about adults with ASD, and the note highlights a small number of examples of this happening.⁵⁴ It goes on to say that when commissioning services for people with ASD it is good practice to:

- Have a person centred commissioning strategy that create support solutions for each individual person
- Use this individual information to build a picture of the total local population of people with ASD.⁵⁵

⁵² In January 2009 the Government published *Valuing People Now: a new three-year strategy for people with learning disabilities*. Following comments during the consultation stage the strategy was strengthened to include specific references to the ‘most excluded groups of people’, such as people with ASDs.

⁵³ Department of Health, *Better services for people with an autistic spectrum disorder: A note clarifying current Government policy and describing good practice*, November 2006, p4

⁵⁴ *ibid.*, p7

⁵⁵ *ibid.*, p8

The following explanation of policy regarding the transition between child and adult services is set out in the note:

To meet the needs of young people in transition the policies state that health and social care commissioners should:

- Ensure each young person and their family/carers are supported by a single ‘trusted adult’ contact who will liaise with services, support, the young person and their family/carers.
- Have early access information about what the future may hold such as learning and employment, support services and opportunities for participation.
- Respect an individual young person’s preferences for daily structure, support and communication.
- Ensure that a consistent and skilled approach is taken across all services and support is offered as the young person grows into adulthood.
- Meet the statutory requirement to commence transition planning from the age of 14.

Approved Social Workers, assertive outreach teams, challenging behaviour teams and psychiatrists will be more confident and deliver better solutions if they understand the impact of major transition, crisis and change on people with an ASD.⁵⁶

III Proposals for an adult autism strategy and Government action to support people with autism

1. Adult autism strategy

In May 2008 the Department of Health announced its intention to publish a national autism strategy for adults, and that to inform this it would commission research into the prevalence of autism, and the specific transitional needs of young people with autism.⁵⁷

On 19 February 2009, Phil Hope MP, Minister for Care Services and Sarah McCarthy-Fry MP, Minister for Schools and Learners, wrote a joint letter to Members of Parliament explaining the action the Government is taking to support children and adults with autism. The Ministers state that the Government’s proposals “will achieve the outcomes the Bill seeks to address”, and that action is best taken without recourse to legislation:

We believe that this action is best taken without recourse to legislation, which risks restricting the flexibility of service commissioning and provision. Legislation could

⁵⁶ *ibid.*, p11

⁵⁷ Department of Health press release, [Department of Health announces Adult Autism Strategy](#), 8 May 2008

make delivery of change more difficult for children and adults who require personally tailored solutions depending on their individual needs.⁵⁸

The Ministers' letter set out details for the consultation on the strategy for adults with autism, and made a new commitment to issue statutory guidance to support this. A briefing note, accompanying the letter provided further information on this:

In April [2009], Phil Hope [Minister for Care Services, Department of Health] will launch a consultation on a strategy on services to support adults with autism. Our priority is to ensure we take account of the views of people with autism and their families, and service commissioners and providers, in producing the strategy.

Following consultation, and working closely with the autism community to ensure that we focus on the key actions needed to deliver real change, we will produce the final strategy by December, accompanied by a supporting delivery plan.

We will explore the ways in which we can ensure delivery of the outcomes set out in the strategy; this will include statutory guidance, subject to consultation and assessment of benefits.⁵⁹

And, Phil Hope will establish clear leadership for delivery of the strategy at national, regional and local level, learning from the model set out in the Valuing People Now strategy for people with learning disabilities.

With the strategy's External Reference Group, chaired by the Chief Executive of the National Autistic Society, we have identified the priority headings for an adult autism strategy. These are:

- Health
- Social Inclusion, including employment
- Choice and Control
- Training

Health: we will identify the barriers to accessing specialist health interventions and mainstream healthcare services and propose action in the strategy to address this. This will be informed by the report of the study currently being taken forward by the National Audit Office which we expect to see in April.

Social inclusion: the strategy will address issues of employment for people with autism. This includes building on work to address the commitments in PSA 16 to support more of the most socially excluded groups of people into employment and the forthcoming learning disability employment strategy.

⁵⁸ Letter from Phil Hope, Minister for Care Services, Department of Health, and Sarah McCarthy-Fry MP, Minister for Schools and Learners, DCSF, sent to Members on 19 February 2009.

⁵⁹ Although this proposal is at an early stage, and subject to consultation, it has been suggested that statutory guidance could be made under Section 7 of the *Local Authority Social Services Act 1970*. Section 7(1) of the Act states that "Local authorities shall, in the exercise of their social services functions, including the exercise of any discretion conferred by any relevant enactment, act under the general guidance of the Secretary of State."

Choice and Control: We are commissioning work from the Social Care Institute for Excellence to publish evidence-based good practice guidance in Spring 2010. That will be informed by an analysis of existing research by early summer, and an in-depth knowledge review which will include field work exploring best practice.

Training: We will work with professional bodies to take action to address training issues. Skills for Care last week launched a national consultation to create new knowledge sets to support people who have an autistic spectrum condition with the aim of publishing in June the basic knowledge needed to support people with autism.⁶⁰

2. Other actions to support adults with autism

The briefing note sent to Members of Parliament on 19 February 2009 also listed other actions to support adults with autism, including the collection of data, issuing of good practice guidance, and taking forward research on the prevalence of autism, and on the transition to adult services, originally announced in May 2008:

We will address issues relating to the collection of data on adults with autism. As a first step we will engage with local communities, voluntary sector experts and carers to work out how to overcome existing problems with collecting information locally and we will develop proposals through the strategy to enable every locality to collect good data about the needs of people with autism living in the area.

Joint Strategic Needs Assessments (JSNAs) are a key mechanism for commissioners to understand the needs of local people and information included in JSNAs about people with autism is critical to ensuring better services are planned and commissioned locally. This year we will publish good practice guidance, which will set out what a good JSNA looks like, to help assessors identify the needs of people, like those with autism, who may be at risk of falling through the net.

In advance of that, work is already underway on a project bringing together exemplars from across the country sharing good practice focusing on specific client groups in JSNAs. This work will help improve the information local services can access to inform commissioning decisions.

We are commissioning **research on the prevalence of autism among adults**, and research on transitions. We remain committed to funding £300,000 (DH) for the prevalence work and £200,000 (DCSF) to look at young people with autism in transition to adult services.⁶¹

Further information was provided about how the publication of new commissioning guidance will address issues raised in the Bill, and about how the autism strategy and the strategy for adults with learning difficulties will be implemented:

⁶⁰ Briefing for MPs accompanying the letter from Phil Hope, Minister for Care Services, Department of Health, and Sarah McCarthy-Fry MP, Minister for Schools and Learners, DCSF, sent to Members on 19 February 2009.

⁶¹ *ibid.*

In April, Phil Hope will publish **Commissioning Guidance aimed at the NHS and local authorities**, to set out good practice for strategic planning of health and care services to meet the needs of adults with autism. This will address a number of issues raised in the Bill, for example, commissioning appropriate services, strategic needs assessments and consultation across the full autism spectrum.

In January, we published a strategy for adults with learning disabilities, *Valuing People Now*. The work to implement Valuing People Now, including Regional Boards, which will be up and running by April, will also secure **improved support for adults with autism who also have a learning disability**.

To support implementation of the strategy for adults across the whole autism spectrum, we will work through the Government Offices of the Regions to address what needs to be done in their regions to improve capacity and capability. This work will identify and address service improvements. It will include funding to support **implementation of the strategy at a regional level**, to ensure that the strategy makes a difference at the level at which services are experienced by people with autism.⁶²

3. Government action to support children with autism

The Ministers' letter to MPs explains that the Department for Children, Schools and Families is leading a complementary programme of work to improve provision for children with autism and their families. A number of the measures mentioned in the briefing sent to MPs and set out below were also mentioned in the strategy for children's health, *Healthy lives, brighter futures*, and covered in the previous section.⁶³ But the briefing also referred to proposals for new statutory guidance for Children and Young People's Plans which clearly reflect the needs of disabled children, including those with autism, and training to increase knowledge and awareness of autism in early years settings and schools.

The **Child Health Strategy**... makes specific reference to children with autism. Its focus on early engagement with a view to prevention and early intervention will benefit this group. The Strategy reaffirms the Government's commitment to follow-up the recommendations of the Independent Review of Child and Adolescent Mental Health Services (CAMHS), including recommendations on improving the access, quality and impact of mental health services for vulnerable children and young people, including those with autism. It also sets out how the Government will improve services for children with speech, language and communication difficulties – many of whom will be on the autism spectrum following the recommendations of the Bercow Review.

Through the **Aiming High for Disabled Children (AHDC)** programme, £340 million in revenue funding is being invested by DCSF over three years (2008-9 to 2010-11) to transform services for disabled children, including those with autism. The Government announced in the Child Health Strategy a further £340m, as part of PCT allocations over the same period, to support the NHS in delivering commitments for disabled children. The AHDC programme is improving short-breaks for disabled children and their families and autism is an area of focus of

⁶² *ibid.*

⁶³ Department for Children, Schools and Families and Department of Health, *Healthy lives, brighter futures: The strategy for children and young people's health*, February 2009

this work. The DCSF/DH Short Breaks Implementation Guidance under AHDC makes clear that a full service offer for a short breaks service should ensure that children and young people with autistic spectrum disorders are not disadvantaged in accessing short breaks.

Improving commissioning

We are **increasing funding to the Autism Education Trust (AET)** from £320,000 this year to £500,000 in 2009-10, primarily for working with local authorities, PCTs and the Commissioning Support Programme, which is jointly led by DCSF and DH to improve the commissioning of services for children with autism. This will include helping to improve the use of data on children with autism, which is a necessary component of effective commissioning.

Following the Apprenticeships, Skills, Children and Learning Bill, DCSF will consult on **new regulations and statutory guidance for Children and Young People's Plans (CYPPs)**. The consultation will consider how to make sure that the needs of disabled children, including children with autism, are properly reflected in this process, which in turn will ensure services in a range of areas – health, social care and education, for example – are all better tailored and integrated to meet the needs of autistic children.

Training and support

Improving awareness and knowledge of autism amongst those working in early years settings and schools is essential, so we are **improving training and support for professionals working in mainstream education**. In March, through the National Strategies, DCSF will be publishing DVD and online continuing professional development materials to help schools and early years providers meet the needs of children with autism as part of its Inclusion Development Programme (IDP). Publication will be followed by a dissemination strategy and monitoring by the National Strategies of the take up and use of the materials.⁶⁴

Further information regarding the Governments actions to improve services for children and adults with autism was published on the Department of Health website.⁶⁵

4. Reactions to the Government's proposals

In a press notice issued by the National Autistic Society the Chief Executive, Mark Lever, welcomed the Government's announcement and highlighted the role of the Private Member's Bill in bringing this about:

"The failure of many local authorities to recognise the needs of people with autism made it absolutely necessary to try and create an autism law. Today, thanks to the overwhelming level of support galvanised by Cheryl Gillan MP's Autism Bill from our campaigners, across all the political parties and the 15 other autism charities we have been working with; we have achieved our major political goals. This is a

⁶⁴ Briefing for MPs accompanying the letter from Phil Hope, Minister for Care Services, Department of Health, and Sarah McCarthy-Fry MP, Minister for Schools and Learners, DCSF, sent to Members on 19 February 2009.

⁶⁵ Department of Health website, [Government support to improve services for services for people with autism and their families](#), dated 20 February 2009

landmark victory which could also have a far wider reaching impact on others in the disabled community. We warmly welcome the announcement and look forward to hearing the Government categorically reaffirm their commitment to transforming the lives of people affected by autism when the bill is debated in Parliament on the 27 February.”⁶⁶

According to an article in *The Observer*, Phil Hope acknowledged that the Bill “has had an impact” on the Government’s proposals.⁶⁷

Cheryl Gillan, quoted in the National Autistic Society press notice, made the following comment:

“It was critically important to me that my Private Members’ Bill should cover an area that ordinarily would be overlooked –today’s announcement is a testament to the weight of support from my colleagues and autism campaigners. Without the right help autism can have a profound and sometimes devastating effect, so I will keep campaigning until I hear the Government pledge to fully support people affected by autism in Parliament. The real test will be in how they implement this package of measures in the long term.”⁶⁸

Prior to the Ministers’ letter on 19 February the National Autistic Society had provided a note on how the *Autism Bill* would ‘fit’ with the Government’s longstanding commitment to publish an autism strategy:

The Department of Health is already working on an Adult Autism Strategy: how does the Autism Bill fit with this?

It is extremely welcome that the Government have committed to producing a national adult autism strategy later in the year. However, if the lives of people with autism of all ages are really to improve, change must happen at ground level. Unfortunately, despite the national progress, local authorities across the UK have completely failed to meet the needs of people in their area and so legislation is necessary to address this.⁶⁹

5. Welsh Assembly Government’s autism strategy

The Welsh Assembly Government, working with voluntary and statutory sector organisations, established an all-age *Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales*.⁷⁰ This was published in April 2008, and has been described as “the World’s first” national strategy for autism. The strategic plan sets out actions for the development of services in Wales, including the mapping of needs and services. The Welsh Assembly Government has announced funding of £1.8 million for 2008-09 to support this purpose.

⁶⁶ National Autistic Society website, [Landmark victory for autism campaigners](#), 23 February 2009

⁶⁷ M O’Hara, “We’re failing autistic people, minister admits”, *The Observer*, 22 February 2009

⁶⁸ National Autistic Society website, [Landmark victory for autism campaigners](#), 23 February 2009

⁶⁹ National Autistic Society website, [The Autism Bill: frequently asked questions](#)

⁷⁰ Welsh Assembly Government, [Autistic Spectrum Disorder \(ASD\) Strategic Action Plan for Wales](#), April 2008

During a short House of Lords debate on autism Baroness Thornton, speaking for the Government, stated that the UK Government had been involved in the consultation on the *Strategic Action Plan for Wales* and would monitor its implementation:

We welcome the opportunity to be involved in the consultation on the strategy being taken forward by the Welsh Assembly. I have stated that we are in discussion with Welsh Assembly officials and will monitor closely the implementation of the strategy to see what lessons may be learnt.⁷¹

IV What data on autism is currently collected in the public sector?

A. Routine data collection

There is no specific routine data collection across the country on or about people with ASD. Some data is picked up in more general statistics on services people receive from the public sector related to their condition. The large majority of this information is for children and there are varying degrees of coverage and usefulness.

1. Children with identified Special Educational Needs (SEN) in school

As noted earlier, a child has SEN if they have a learning difficulty which needs special educational provision to be made. In England there is a graduated approach to SEN with the following stages: 'School Action' where only the school provides additional help, 'School Action Plus' where greater involvement of external specialists is needed, and for children who need the greatest amount of additional support this may lead to more formal arrangements for SEN provision through a statement of SEN.

Information on the number of pupils with SEN has been collected for many years. Since 2004 the primary and secondary type of need has also been collected for pupils at School Action Plus and those with statements. This includes 'Autistic Spectrum Disorder' and hence school pupils with ASD (at these SEN stages) can be identified.

This data is collected at pupil level and hence can be further analysed by other pupil characteristics and performance data. It does not give any information on what actually happens in the classroom on a day-to-day basis. Type of need data is collected for pupils all state funded primary, secondary and special schools and non-maintained special schools. It is not collected for pupils at independent special schools, other independent schools or maintained Pupil Referral Units and Hospital Schools.

The Department for Children, Schools and Families (DCSF) publishes the number of pupils by primary type of need, school type and by LEA in its annual statistical bulletin on SEN. It also publishes Key Stage 2 and GCSE attainment by type of need. While the type of need data has some limitations in terms of its coverage and the scope of what is

⁷¹ HL Deb 19 March 2008 c335

routinely published, it covers the large majority of pupils who have identified ASD⁷² and through the National Pupil Database provides a valuable resource to look at pupil progress, outcomes and characteristics.⁷³

a. National prevalence

The table opposite gives national totals for pupils with identified ASD since this data collection started. Numbers have increased steadily over this period and by a total of more than 50% to 47,300 in 2008. This increase could be due to changes identification/classification rather than a real underlying increase over this period. The number of pupils with ASD increased faster than the total number of pupils with SEN at this level. The total number in 2008 was 0.63% of all pupils at these schools or 0.58% if we include all pupils at all schools in England.⁷⁴ In January 2008 there were a further 7,800 pupils with ASD as their secondary need. Thus the total number of SEN pupils at School Action Plus or with a statement who had identified ASD was just over 55,000 or 0.73% of pupils at these schools.⁷⁵

SEN pupils with ASD as their primary need, England

January each year

	Number ^a	% of SEN pupils ^a	% of school population ^b
2004	31,260	5.3%	0.41%
2005	35,640	6.0%	0.47%
2006	39,140	6.4%	0.52%
2007	43,120	6.9%	0.57%
2008	47,300	7.2%	0.63%

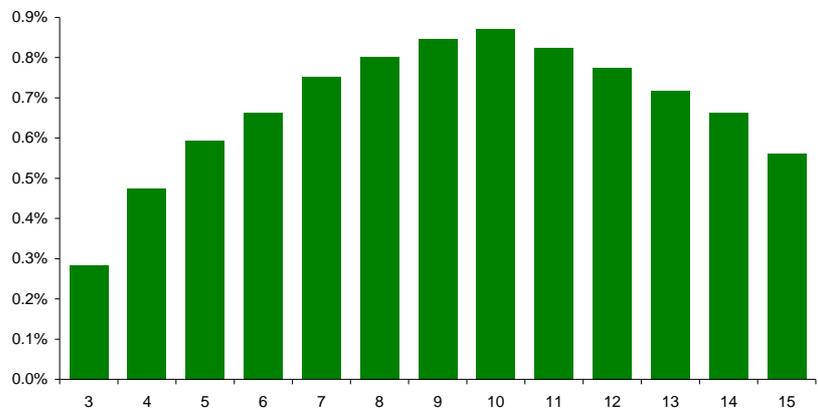
(a) Includes pupils with statements or at school action plus in state funded primary, secondary and special schools and non-maintained specials

(b) Based on headcount. School coverage matches type of need data

Source: *Special Educational Needs in England: January 2008, DCSF, and earlier*

In January 2008 86% of pupils with identified ASD were boys. This finding is consistent with research findings. The chart opposite looks at ASD rates by age and includes all those with ASD as their primary or secondary need. Peak rates were for those age 10 at 0.87% but the pattern by age is very clear with a distinctive ‘wave’ shape. Rates increased throughout the primary age groups as these pupils’ needs are identified and they are placed into the relevant SEN stages. There is a similar pattern across all SEN types. The reason for the declining rates through the

Prevalence of identified ASD by age, England 2008
As a % of all pupils of that age in all schools



Sources: *Pupil Characteristics and Class Sizes in Maintained Schools in England: January 2008 (Provisional)*, DCSF; Unpublished DCSF data

⁷² Research has shown that 97% of children and young people with ASD had identified SEN and 84% had stated SEN –ONS (2005)

⁷³ When pupil level data is released to outside bodies for education research the sensitive personal details are not included unless access is specifically requested and approved, as set out above. Restricted information includes personal details –name, age, date of birth, address- but also their type of SEN. All outside bodies that request NPD data need to sign a confidentiality statement even if they do not need any restricted data.

⁷⁴ *Pupil Characteristics and Class Sizes in Maintained Schools in England: January 2008 (Provisional)*, DCSF. Additional national tables.

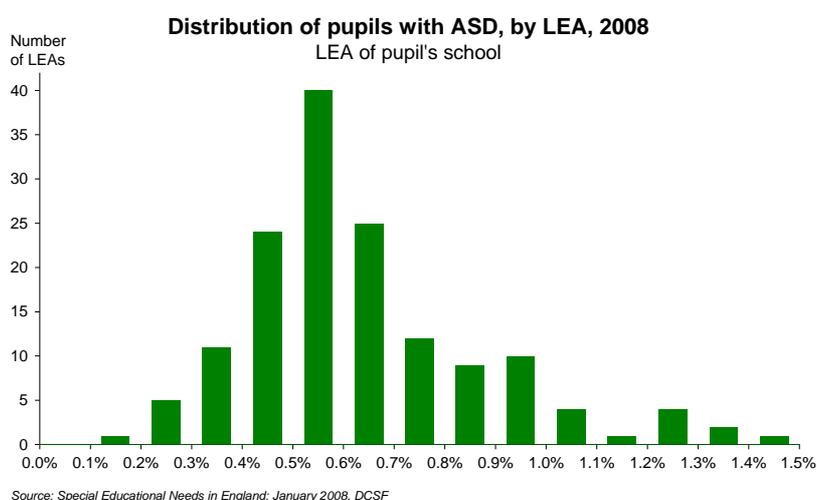
⁷⁵ Unpublished DCSF data

secondary school ages is less clear. It could in part be due to the overall increase in the identification of ASD in schools if this were largely concentrated in younger pupils. If this were the case we would expect this wave shaped pattern to shift across and see a less obvious drop off at older age groups in the future.

If we assume that the peak prevalence rates shown above are a better guide to the real level of prevalence (lower rates at younger ages reflect a lag in identification and/or moving children to the appropriate SEN stage and the drop off at older ages is a temporary pattern) then this gives a rate of around 0.8%. This is closer to the prevalence rates seen in the research quoted by the National Autistic Society and their best estimate of 1 in 100 children. It is still below these figures but this should be expected as the SEN data exclude pupils with ASD at the School Action stage and pupils some schools.

b. Local variations

The rate of pupils with ASD varied at the Local Education Authority (LEA)⁷⁶ level from 0.16% to 1.44%, or around one quarter of the national rate to more than double. This distribution is illustrated opposite. Some local variation should be expected, especially in smaller LEAs where small chance variations can have a greater proportionate impact. However,



the LEAs at the extremes and those with similar rates were not all particularly small and they did not all have similarly extreme numbers of pupils with other types of SEN. Regional rates varied from 0.53% in the North West to 0.75% in the South East. Given this it is likely that variations in local procedures and practices in identifying pupils with SEN/ASD are in part responsible for the relatively large local differences. The chart shows that the most common rate was 0.5-0.6% and the national average (mean) is dragged up by the authorities at the extreme high end.

c. Placement

The table below looks at the total number of pupils with identified ASD in 2008 by their SEN level and school type. This shows that just less than three-quarters of these pupils had a statement of SEN. The large majority of pupils with ASD at School Action Plus were in mainstream schools. A smaller majority of those with statements were in mainstream schools (60% v 40%). When numbers of pupils with ASD were compared to the whole population then rates in special schools approached 16% or around 13 pupils for the average sized special school. Rates in primary and secondary schools were both

⁷⁶ The rate is based on pupils at schools within an LEA, rather than the pupils' home LEA, so may be affected by the level of special provision and particularly the number of special schools approved for ASD provision within the LEA.

below 0.5% or around one pupil per average sized primary and four for the average sized secondary school.⁷⁷

School type of SEN pupils with ASD as their primary need

January 2008

	School Action Plus			Statement			Total		
	number	% of total	% of all pupils	number	% of total	% of all pupils	number	% of total	% of all pupils
Primary	7,770	61%	0.19%	11,650	34%	0.28%	19,420	41%	0.48%
Secondary	4,760	37%	0.14%	8,930	26%	0.27%	13,690	29%	0.42%
Special ^a	230	2%	0.26%	13,970	40%	15.61%	14,200	30%	15.87%
Total^a	12,750	-	0.17%	34,550	-	0.46%	47,300	-	0.63%

(a) Includes maintained and non-maintained specials

Source: *Special Educational Needs in England: January 2008, DCSF, and earlier*

d. Wales

Similar information is also collected for pupils with ASD in Wales. In January 2008 there were 2,743 pupils in Wales⁷⁸ with SEN whose major identified need was ASD. This was 0.60% of the population in these schools, a very similar rate to that seen in England. 27% of these pupils were taught in special schools. A new classification of needs was introduced in 2008 and ASD replaced 'autism'.⁷⁹ Therefore trend data may not accurately reflect underlying changes.

2. Local authority registers of disabled children and adults

All local authorities with social service responsibilities are required to keep a register of people with disabilities in their local area, but as the following written answer states these are not thought to be an accurate source of information:⁸⁰

Andrew George: To ask the Secretary of State for Health what percentage of (a) Cornwall's and (b) England's (i) total, (ii) adult and (iii) child population was registered disabled on the latest date for which figures are available.

Mr. Ivan Lewis: Each local authority is required by law to maintain a register of disabled people living within its area for the purposes of planning and providing social services. However, registration is entirely voluntary, therefore the information held does not accurately represent the prevalence of disability. This information is not held centrally.

People with disabilities or their parents/carers have no direct incentive to be on local authority registers – they are not linked to services or benefit entitlement.

⁷⁷ *Pupil Characteristics and Class Sizes in Maintained Schools in England: January 2008 (Provisional)*, DCSF. Additional national tables.

⁷⁸ Maintained primary, secondary and special schools. Includes pupils with and without statements. The number of pupils at independent schools with statements whose major need is 'autism' is also recorded.

⁷⁹ StatsWales: www.statswales.wales.gov.uk

⁸⁰ HC Deb 4 July 2007 c1103W

This view about the coverage of the data on these registers was supported by research for the DCSF. It asked local authorities to give a best estimate of the number of children with disabilities in their local area. Rates varied across authorities from 0.3% to 17.9%. Some authorities based this figure on an estimate, others on a count from one of various different sources of data. Overall 23 authorities (21% of respondents) used their Children Act Register as the source of their best estimate. Authorities were more likely to use SEN data (52%) or make an estimate (29%) than use this register. In addition 12% of responding authorities did not include ASD in their definition of disability.⁸¹ It was not clear whether these authorities meant all or only some children with ASD would not be included.

The NAS has surveyed all local authorities in Great Britain to ask whether they have systems in place to accurately record the number of adults with autism. Of the 103 local authorities that have so far responded: Two have been given the highest rating, two have been given the middle rating –generally some information is collected and/or new systems are to be introduced and the authority recognises the issue- and the remaining 51 were given the lowest rating –generally no estimates made and no systems in place to count adults with autism. Results were generally better in Wales. 17 of the 22 local authorities responded, three received the top rating, nine received the middle and five the lowest rating.⁸²

The Government relies on surveys and the Census for information on the prevalence of disabilities across the country and for sub-national variations. These can use a number of different definitions of disability, but they are all functional rather than condition specific. For instance the Census asks respondents if they have a limiting long-term illness. Other surveys ask for a definition that approximates to the Disability Discrimination Act definition, a person who has:⁸³

...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

3. Children receiving services form local authority social service departments

Results from an occasional national census of activity and expenditure by social service departments in England on 'Children in Need' (those known by their local authority to need services) give an indication of the numbers of children with autism who receive such support. Children are classified as such if they have had a diagnosis of autism or ASD from a medical practitioner, but the results of the survey explicitly exclude children with Asperger Syndrome. The most recent data was collected by all authorities for a typical week in February 2005. This found that 6,700 children with autism were receiving support from social services; around 3% of all supported children. 2,500 of these children were looked after by their local authority. Expenditure on these children was £2.8 million in the week in question and three-quarters of this was on the looked after children. This would imply total expenditure of just under £150 million for a full year if the week in

⁸¹ Mooney A. et al (2008), *Disabled Children: Numbers, Characteristics and Local Service Provision*, DCSF research report RR-042

⁸² National Autistic Society, [Local authority progress tables](#)

⁸³ The *Disability Discrimination Act* 1995

question was typical.⁸⁴ A slightly different census will run for sixth months from October 2008.

4. Adults

The Government does not make any estimate of the proportion of the adult population with autism.⁸⁵ There is no survey of adults receiving support from social services that identifies those with ASD. In May 2008 the Department of Health announced £0.5 million for research into the number of adults with autism and their specific transitional needs. This research will inform the Government's first ever autism strategy for adults which is due to be published in 2009.⁸⁶

B. One-off surveys

The Office for National Statistics report *Mental health of children and young people in Great Britain, 2004*,⁸⁷ is the most recent large scale survey of the prevalence of autism. The survey looked at children aged 5-16 and also asked questions of their parents and teachers. The overall prevalence of ASD was 0.89% (89 per 10,000) with a range of 0.66%-1.12%. Prevalence was clearly higher in boys than girls (1.4% v 0.3%) and this result was statistically significant. The observed rate was slightly higher among 5-10 year olds (1.02%) than 11-16 year olds (0.76%), but the difference was not statistically significant.

The report also looked at various characteristics of children with ASD and their families. This found little or no differences in those with or without ASD in age, ethnicity, family size/composition, housing type or area characteristics. Children with ASD were more likely to have parents with qualifications above GCSE level, live in a household where no one worked and were less likely to live in low income households. Just under one-third of children with ASD in the survey had another recognisable mental disorder. 97% had been identified with SEN and 84% had statemented SEN. This survey also looked at various indicators of difficulties faced by these children and other outcome indicators. These are summarised later on in this research paper.

Equivalent earlier surveys did not separately identify the prevalence of ASD. A follow-up survey carried out in 2007 did not look to update the prevalence figure but instead looked at a small sample of individuals to see whether any had grown into or out of ASD.⁸⁸ Official surveys of the mental health of adults have so far not separately identified adults with ASD.

⁸⁴ *Children in Need in England: Results of a survey of activity and expenditure as reported by Local Authority Social Services' Children and Families Teams for a survey week in February 2005: Local Authority tables and further national analysis*, DCSF

⁸⁵ HC Deb 20 February 2008 c802W

⁸⁶ Department of Health press release 8 May 2008, *Department of Health announces Adult Autism Strategy*

⁸⁷ ONS 2005

⁸⁸ *Three years on: Survey of the emotional development and well-being of children and young people*, ONS

C. Finance

There is no centrally collected information on expenditure on people with autism by (adult) social service departments,⁸⁹ Primary Care Trusts,⁹⁰ or the wider NHS.⁹¹ Some data is published on expenditure by schools and Local Education Authorities on pupils with SEN as a whole. This is not broken down by type of need to give a separate figure for pupils with ASD. Funding for local bodies is only rarely linked to or for people with specific conditions. Local bodies are generally viewed as best able to decide on local priorities. Their own spending is either not identifiable down to individual conditions or not reported at a detail sufficient to give figures for ASD. This leaves funding for research and voluntary groups as the only identifiable areas of public expenditure on autism.

V Evidence on outcomes and difficulties faced by people with autism

A. Children

a. Survey results

The Office for National Statistics report *Mental health of children and young people in Great Britain, 2004*, combined results from the 2004 and 1999 surveys and found worse results across some indicators for children with ASD compared to other children. Compared to all children surveyed those with ASD had:⁹²

- No difference in levels of absence from school
- Higher levels of exclusion (27% v 4%)
- Higher likelihood of being behind in overall intellectual development (72% v 24%)
- Parents reporting higher levels of self harm (25% v 2%)
- Higher levels of other mental disorders (30% v 9%)

During a Westminster Hall debate on children and young people with autism, John Bercow MP referred to the relatively higher levels of exclusions for children with autism. He also expressed concern about the 'unofficial' exclusion of children with autism:

Significantly, however, there is an additional and more disturbing phenomenon—not merely exclusion of an official kind but unofficial, informal, sometimes internal and frequently if not invariably unrecorded exclusions of children and young people. I refer in this context to the TreeHouse constructive campaigning parent support project survey report following research conducted between January and July 2007, the results of which, in summary or detailed form, have recently winged their way to the Minister of State. That report found, alarmingly, that 43 per cent. of

⁸⁹ HC Deb 4 June 2008 c1025-6W

⁹⁰ HC Deb 27 February 2008 c1732W

⁹¹ HC Deb 27 February 2008 c1732W

⁹² ONS 2005. Chapter 8.

respondent parents said that their child had been excluded from school at least once, and possibly more than once, in the previous 12 months.⁹³

A review of educational provision for children and young people with autism was carried out for the Autism Education Trust⁹⁴ by researchers at the University of Birmingham. The review found that there was significant scope for improvement in local outreach and support services and how outcomes for children are monitored.⁹⁵ As noted in the Government's announcement on the autism strategy, the Department for Children, Schools and Families has increased its funding for the Autism Education Trust from £320,000 in the financial year 2008-09 to £500,000 in 2009-10. This is intended to support the Trust in working with local authorities and Primary Care Trusts to improve commissioning of services for children with autism.⁹⁶

b. GCSE results

The table below compares the GCSE attainment of pupils with identified ASD to all pupils in maintained schools and other pupils with SEN. On average those with ASD outperformed other pupils with SEN at the same level. They had the best results by type of need after those with hearing or visual impairments and those with physical disabilities.

GCSE^a attainment of SEN pupils with ASD as their primary need, England^b

2006/07

	Pupils at the end of KS 4	% achieving		
		5+ grades A*-C	5+ grades A*-C inc. English and Maths	Any passes
All pupils	598,930	63.5	47.8	98.2
SEN pupils				
School Action	70,705	33.6	16.7	97.8
School Action Plus	35,085	21.6	10.9	93.0
<i>of which ASD as primary need</i>	657	46.7	30.9	98.5
Statemented	23,570	10.7	5.2	82.8
<i>of which ASD as primary need</i>	2,351	22.3	13.7	81.4
<i>All SEN pupils with ASD as their primary need^c</i>	<i>3,008</i>	<i>27.6</i>	<i>17.5</i>	<i>85.1</i>

(a) Includes equivalent examinations

(b) Maintained schools only

(c) Pupils at School Action Plus and statemented only

Source: *Attainment by Pupil Characteristics, in England 2007/08, DCSF*

⁹³ HC Deb 8 October 2008 cc75-6WH

⁹⁴ The Autism Education Trust was established by the voluntary sector in November 2007, with funding from the Department for Children, Schools and Families, to improve the co-ordination and provision of services for children with autism.

⁹⁵ *Educational provision for children and young people on the autism spectrum living in England: a review of current practice, issues and challenges*, Autism Centre for Education and Research, University of Birmingham, November 2008. The review and a press release issued by the Autism Education Trust are available from the [National Autism Societies website](#).

⁹⁶ For further information see *Healthy lives, brighter futures: The strategy for children and young people's health*, February 2009, para. 6.56

Their results were clearly below the national averages for all pupils in maintained schools and those with statements performed less well than those at School Action Plus, as we would expect. Overall just over one-quarter of pupils with identified ASD achieved five or more good grades at GCSE. These figures are based on all pupils at the end of Key Stage 4 (year 11) whether they entered any examinations or not. The only pupils that are not included are those who are held back a year or more who then leave school before the end of Key Stage 4.

B. Adults

Results of the National Autistic Society's *I Exist* survey were published in early 2008.⁹⁷ This survey focussed on the experiences and needs of adults with autism and asked questions of these adults and their parents/carers where appropriate. Some of the key findings were:

- 63% of respondents thought they did not receive enough support to meet their needs
- 42% had had an assessment of their needs by their local authority since becoming an adult. Rates were lower for older adults and those with Asperger syndrome.
- Among those who have had problems receiving support the most common explanations from their local authority were not fitting into the mental health or learning disability categories, lack of funding and no appropriate services provided by the authority (all 40-45%).
- 82% of the parents/carers of adults with autism said their son/daughter needed some daily support to live independently.
- 20% of adults were receiving daily support
- 15% were in full-time employment and 34% were working in some capacity (including voluntary work)
- 61% relied on their family for financial support.
- 14% lived in their own dwelling with support

This survey had responses from 1,400 adults with autism or their parents/carers. Any such survey needs a way to identify its target respondents. It would be impractical and prohibitively expensive to obtain responses from this many adults with autism from a random sample of the whole population. The survey was sent out to NAS members, organisations in the autism services directory and was available to complete online on their website.

a. Entrants to further and higher education

Students in the further education sector complete a questionnaire which includes questions about learning difficulties and disabilities, but does not separately identify autism or ASD. Students who enter university also complete a questionnaire, but this separately lists ASD. In 2006/07, 420 UK students starting undergraduate courses said they had ASD, or 0.06% of all new UK entrants. The number of new students with ASD has increased steadily since this category was first introduced in 2003/04.⁹⁸ It is probable

⁹⁷ *I Exist. The message from adults with autism in England*, National Autistic Society

⁹⁸ *Students in higher education institutions*, various years, Higher Education Statistics Agency (HESA)

that such self-assessments do not give a completely accurate guide to the real rate of ASD among these students or how it has changed over time.

C. Transition from child to adult services

The transition to adulthood has been identified as a potentially difficult time for young people who require support from health and social services. The need for effective transition planning was highlighted in the *National Service Framework for Children, Young People and Maternity Services* in Standard 4, *Growing Up into Adulthood*.⁹⁹ The Commission for Social Care Inspection published a report, *Growing Up Matters*, that called for better transition planning for young people with complex needs.¹⁰⁰

The National Autistic Society's briefing on the Autism Bill commented on the factors that can make the transition to adulthood particularly difficult for young people with autism:

The transition from school to adulthood can be a particularly difficult time for young people with autism, as they tend to rely on structure, routine and rules and may find it difficult to adapt the 'rules' they have learned in one context to new relationships or situations. Consequently effective support and early planning is often vital for a successful transition from school life to adulthood. Transition planning requires a high degree of inter-agency co-operation, and this is often where difficulties arise.¹⁰¹

In May 2008 the Department of Health announced funding of £200,000 for research into the period of transition to adult life to inform the Government's proposed autism strategy for adults.¹⁰² The transitions research will focus on young peoples' experiences, including their mental health needs, their social care and housing needs, further education needs, opportunities for leisure and access to transport, and the ease of access to services.

The Government's child health strategy, *Healthy lives, brighter futures*, referred to the £19 million 'Transition Support Programme' which was launched in December 2008. This programme is intended to:

...tackle the barriers that prevent local authorities and PCTs from meeting their duties towards disabled young people to ensure that they experience a smooth transition to adult life, with the right support to make choices that other young people take for granted. The programme will focus on those with the most complex needs, including children with autism whose needs services can struggle to meet.¹⁰³

⁹⁹ Department of Health, *National Service Framework for Children, Young People and Maternity Services*, 2004

¹⁰⁰ Commission for Social Care Inspection, *Growing Up Matters: Better transition planning for young people with complex needs*, January 2007

¹⁰¹ National Autistic Society website, *Autism Bill briefing notes*

¹⁰² Department of Health press release, *Department of Health announces Adult Autism Strategy*, 8 May 2008

¹⁰³ Department for Children, Schools and Families and Department of Health, *Healthy lives, brighter futures: The strategy for children and young people's health*, February 2009, para 6.65

a. Parliamentary material

During a Westminster Hall debate on children and young people with autism on 8 October 2008, John Bercow MP referred to comments by the Commission for Social Care Inspection that transition services from secondary school to post-16 are ‘a nightmare’:

...If right hon. and hon. Members think that the situation is not great at the primary level and tends to deteriorate further at secondary level, they have seen nothing unless they reflect on the phenomenon of the paucity of provision post-16. The Commission for Social Care Inspection said that transition services from secondary school to post-16 are “a nightmare”.

Mr Bercow went on to comment on initiatives to improve transition services taking place in Barnet:

We should pay tribute to, champion and celebrate good work. Let me refer, therefore, to the National Autistic Society Barnet branch, working in conjunction with Aimhigher. It provides information, support and guidance to children and young people seeking to enter further or higher education. It has pioneered—it is a trailblazer—fantastic transition schools that assist in this important public policy objective. It runs a disabled students ambassador scheme, and the programme as a whole won the voluntary sector organisation of the year award at the London education partnership awards in 2007. That shows what can be achieved in the interests of the child or young person with application, creativity, vision and persistence.¹⁰⁴

In November 2008 the Department for Children, Schools and Families Minister, Sarah McCarthy-Fry, answered a series of questions about the provision of transition services to young people with autism:

Sarah McCarthy-Fry: I entirely agree that we should be examining the transition to adulthood, particularly for young people with autism. The hon. Gentleman may be aware that in May the Department of Health announced the development of an autism strategy for adults and the transition to adulthood, and we shortly expect the outcome of the tendering for that. I agree that this is vital, because it is no good training children through school if we then do not manage the crucial transition stage of getting them on to further education and eventual employment.¹⁰⁵

¹⁰⁴ HC Deb 8 October 2008 c78WH

¹⁰⁵ HC Deb 17 November 2008 c8