World Autism Awareness Day, 2 April 2018

Summary

World Autism Awareness Day is observed annually on 2 April. Autism is the name given to a range of conditions which affect a person's social interaction and communication skills. It is estimated that globally I in 160 children have autism and that in the UK the condition affects approximately I percent of the population. This Briefing summarises the condition, Government policy on the subject since 2010, and recent developments.

Background

On 18 December 2007, the United Nations General Assembly adopted Resolution 62/139, which designated 2 April as World Autism Awareness Day. The resolution invites all member states "to observe World Autism Awareness Day in an appropriate manner, in order to raise public awareness of autism". The resolution also "encourages member states to take measures to raise awareness throughout society [...] regarding children with autism". The theme for Autism Awareness Day 2018 is "empowering women and girls with autism", which seeks to highlight the particular challenges faced by women and girls with disabilities when accessing health and education services. 3

What is Autism?

Autism, also known as autism spectrum disorder (ASD), is the name for a range of conditions (including Asperger syndrome), which affect a person's social interaction and communication. It is a lifelong development condition which can present itself in a spectrum of behaviours, including: difficulty with communication and social skills; repetitive behaviour; highly focused interests; and sensory sensitivity. According to the World Health Organisation, the prevalence of autism "appears to be increasing globally" which may be the result of improved awareness, better diagnostic tools and improved reporting. The cause of autism is not fully known and is still being investigated; however, research suggests a combination of genetic and environmental factors may account for differences in development. Autism is incurable, but the condition can be managed with a combination of speech and language therapy, occupational therapy and educational support. According to the National Autistic Society, there is "a growing movement among activist adults who are on the autism spectrum who don't think in terms of 'curing' a disorder but instead of celebrating diversity".

Prevalence in the UK

According to the National Autistic Society, it has been estimated that 700,000 people in the UK, or approximately I percent of the population, have autism. The condition affects five times as many males as females. The National Autistic Society has published research evidence that shows:

- Between 44–52 percent of autistic people may also have a learning disability.
- 17 percent of autistic children have been suspended from school.

- 16 percent of autistic adults are in full-time paid employment.
- One in three autistic adults "are experiencing severe mental health difficulties due to a lack of support". 10

Government Policy

Health is a devolved matter, therefore this section focuses on government policy in England. The Autism Act 2009 was the first specific piece of legislation on the condition. The Act began as a private member's bill in the House of Commons and was sponsored in the House of Lords by Baroness Pitkeathley (Labour). The Act placed a duty on the Government to publish a national strategy and statutory guidance for local authorities and local health bodies in the implementation of the strategy. The resulting strategy, Fulfilling and Rewarding Lives, was published in March 2010. The strategy included a number of duties and recommendations covering areas including identification and diagnosis of autism, local service provision, and training of staff. In April 2014, the Government published an updated strategy, Think Autism. The updated strategy and revised guidance placed duties on public service providers in the areas of employment, welfare, criminal justice, transport and education services. On 14 January 2016, the Government published a progress report on the Think Autism strategy. Progress on the autism strategy is overseen by the Adult Autism Progress Board.

Recent Developments

In November 2017, the All Party Parliamentary Group on Autism, in association with the National Autistic Society, published the report <u>Autism and Education in England 2017</u>. ¹⁶ The report found that fewer than half of children with autism say they are happy at school, 42 percent of parents said that an assessment of their child's special educational needs was refused the first time it was requested, and 60 percent of young people said the main thing that would make school easier was a teacher who understands autism. ¹⁷ The report was debated in the House of Commons on 6 February 2018. During the debate, Nadhim Zahawi, Parliamentary Under Secretary of State for Education, defended the Government's policy relating to teacher training:

Our approach to initial teacher training ensures that newly qualified teachers are equipped to support children with special educational needs, including those with autism. To be awarded qualified teacher status, trainees must satisfy the teachers' standards, which include a requirement that they have a clear understanding of the needs of all pupils, including those with special educational needs.¹⁸

Nadhim Zahawi also defended the level of government funding provided to support special educational needs and disability (SEND) provision:

We have introduced a new series of joint inspections by Ofsted and the Care Quality Commission to see how well all local areas are fulfilling their responsibilities for children and young people with SEND, including those with autism [...] The Government have provided over £300 million to support local areas to implement the changes made to the SEND system [...] We have committed £23 million of additional funding to support strategic planning of high-needs provision. This will support local authorities in predicting local needs for education, health and care services for children and young people with SEN or disabilities.¹⁹

Labour MP for Enfield, Bambos Charalambous, asked Maria Caulfield (Conservative MP for Lewes), who had secured the debate and had co-chaired the inquiry which produced the report, whether there was a

role for school support staff (such as speech therapists, child psychologists, and other health professionals) in diagnosing children with autism.²⁰ Maria Caulfield responded by stating that the report recommended the Government should produce a national autism strategy by 2019, which would address the issue of training for all school staff:

This is absolutely about not just teachers, but the whole support staff. Our report calls on the Government to introduce a national autism strategy by the end of 2019, which should include training for school staff, the provision of a specialist curriculum for all pupils who need one, and measures to reduce bullying and promote inclusion in schools.²¹

In response, the Government spokesperson, Nadhim Zahawi, stated that the report's recommendations would "inform our current consideration of our strategy for achieving this in 2018–19 and beyond".²²

On 8 February 2018, it was reported that a safeguarding review of Mendip House, a care home for those with autism in Somerset run by the National Autistic Society, had revealed cases of bullying and abuse of residents by staff.²³ The home has now closed and the National Autistic Society has released a statement in which it apologised to the residents and set out details of how it had implemented improvements to its procedures and services.²⁴

On 19 February 2018, the press reported the findings of a study in which "scientists have taken the first steps towards [developing] a new blood and urine test for autism". The study compared samples taken from children with and without autism, and found increased levels of protein damage in those with the condition. The research may result in a biological test for autism, which at present can only be diagnosed following behavioural assessment. However, other researchers have expressed caution in the findings of the study. The NHS has published a review which highlighted limitations with the study, including the small number of children studied and the fact that the blood and urine samples were only taken on one occasion. The NHS review concluded that the findings "are of interest but for the foreseeable future the way ASD is diagnosed will remain unchanged". Following the press reports, Jim Shannon (DUP MP for Strangford) tabled a written question asking if the NHS planned to make available a blood and urine test for autism. In response, Caroline Dinenage, Minister of State at the Department of Health and Social Care, stated:

There are no current plans for the National Health Service to offer a blood and urine test for autism [...] The National Institute for Health and Care Excellence (NICE) is the independent expert body responsible for developing robust guidance for the NHS to support it in designing autism services, including diagnostic services that are in line with the best available evidence. NICE routinely reviews its guidance to ensure it reflects the latest evidence.²⁷

Further Information

- John Donvan and Caren Zucker, In a Different Key: The Story of Autism, 2016
- Janine Booth, Autism Equality in the Workplace: Removing Barriers and Challenging Discrimination,
 2016

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¹ United Nations General Assembly, 'Resolution 62/139—World Autism Awareness Day', 18 December 2007, p 2.

³ United Nations, 'World Autism Awareness Day', accessed 22 March 2018.

⁴ National Autistic Society, 'What is Autism?', accessed 22 March 2018.

⁵ World Health Organisation, 'Autism Spectrum Disorders', accessed 22 March 2018.

⁶ National Autistic Society, 'What is Autism?', accessed 22 March 2018.

⁷ NHS Choices, '<u>Autism Spectrum Disorder (ASD)</u>', accessed 22 March 2018.

⁸ National Autistic Society, 'Autism Facts and History', accessed 22 March 2018.

⁹ ibid.

¹⁰ ibid.

¹¹Autism Act 2009, sections I and 2.

¹²Department of Health, *Fulfilling and Rewarding Lives: The Strategy for Adults With Autism in England*, 3 March 2010.
¹Department of Health, "Think Autism": An Update to the Government Adult Autism Strategy", 2 April 2014.

¹⁴Department of Health, 'Progress Report on Strategy for Adults With Autism', 14 January 2016.

¹⁵Department of Health, 'Adult Autism Programme Board', accessed 22 March 2018.

¹⁶ National Autistic Society, 'We Launch Held Back, Our New Education Campaign', 29 November 2017.

¹⁷ All Party Parliamentary Group on Autism, Autism and Education in England 2017, p. 4.

¹⁸ HC *Hansard*, 6 February 2018, col 1469.

¹⁹ ibid, col 1472.

²⁰ ibid, col 1467.

²¹ ibid.

²² ibid, col 1472.

²³ Steven Morris, 'Somerset Care Home Staff Bullied Autistic Residents, Review Finds', Guardian, 8 February 2018.

²⁴ National Autistic Society, 'Our Response to Mendip House Safeguarding Adults Review Report', accessed 22 March 2018.

²⁵ BBC News, 'Autism: Scientists Take 'First Steps' Towards Biological Test', 19 February 2018.

²⁶ NHS Choices, 'New Blood Test for Autism a Long Way Off', 19 February 2018.

²⁷ House of Commons, 'Written Question: Autism: Screening', 5 March 2018, 129672.