



DEBATE PACK

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Waiting time standard for autism diagnosis

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Summary

This House of Commons Library debate pack briefing has been prepared in anticipation the debate entitled “Waiting time standard for autism diagnosis”, which is sponsored by Bambos Charalambous MP.

It provides background information on waiting times for autism diagnoses in England, as well as Government policy on autism in general, and diagnosis waiting times in particular. It also provides parliamentary material and recent press articles and notices for further information.

The House of Commons Library prepares a briefing in hard copy and/or online for most non-legislative debates in the Chamber and Westminster Hall other than half-hour debates. Debate Packs are produced quickly after the announcement of parliamentary business. They are intended to provide a summary or overview of the issue being debated and identify relevant briefings and useful documents, including press and parliamentary material. More detailed briefing can be prepared for Members on request to the Library.

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1. Background

1.1 Government policies on autism in England

Autism Act 2009

The [Autism Act 2009](#), which received Royal Assent in November 2009, placed statutory requirements on the Government to publish an adult autism strategy by April 2010, and associated statutory guidance for local authorities and local health bodies on supporting the needs of adults with autism by 31 December 2010.

Section 2(5) of the *Autism Act* stated that the guidance must cover, among other areas: the provision of relevant services for diagnosing autism; identification of the numbers of adults with autism at a local level and; training of staff who provide relevant services to adults with autism.

The *Autism Act 2009* began as a Private Members Bill introduced by Cheryl Gillan with backing from the National Autistic Society and other autism charities. It was the first disability-specific piece of legislation.

Adult autism strategy for England

As required under the *Autism Act 2009*, the Department of Health published the first autism strategy for England in March 2010: [Fulfilling and rewarding lives: the strategy for adults with autism in England](#).

The strategy focused on five core areas of activity:

- Increasing awareness and understanding of autism among frontline professionals
- Developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment
- Improving access for adults with autism to the services and support they need to live independently within the community
- Helping adults with autism into work, and
- Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.¹

A first year delivery plan was published on 2 April 2010, [Towards fulfilling and rewarding lives: the first-year delivery plan](#). This set out the governance structure and the actions, with timescales and responsibilities, to be taken in the first year to support the implementation of the adult autism strategy.

The Government committed to review the strategy after three years.

Statutory Guidance 2010

Following the General Election in 2010, the Coalition Government confirmed that it would fulfil the commitment in the *Autism Act* to consult on and publish statutory guidance for local authorities and NHS organisations to support the strategy's implementation.

In December 2010, the Department of Health published [Implementing Fulfilling and rewarding lives: Statutory guidance for local authorities and NHS organisations to support](#)

¹ Department of Health [hereafter DoH], ['Fulfilling and rewarding lives': the strategy for adults with autism in England](#), 3 March 2010, para 1.8

[implementation of the autism strategy](#). This provided guidance to local authorities, NHS bodies and NHS Trusts on the following key areas:

- Training of staff who provide services to adults with autism;
- Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services ;
- Planning in relation to the provision of services to people with autism as they move from being children to adults; *and*
- Local planning and leadership in relation to the provision of services for adults with autism.

Think Autism strategy 2014

In April 2014, the Department of Health published an update to the 2010 autism strategy: [Think Autism: fulfilling and rewarding lives, the strategy for adults with autism in England: an update](#). It builds on, rather than replaces, the 2010 strategy.

Think Autism sets out fifteen priority challenges for action from the perspective of people with autism and carers. The strategy focuses on the following areas:

- Building communities that are more aware of and accessible to the needs of people with autism, which have autism champions for change;
- Promoting innovative local ideas, services or projects which can help people in their communities through new models of care; *and*
- Focusing on how advice and information on services can be joined up better for people.

The Coalition Government announced a national investment in 2014/15 of £4.5million to deliver the objectives set out in the strategy.

As part of this, the Government launched an Autism Innovation Fund to develop creative and cost effective solutions, and find new models of good practice. Local authorities, NHS organisations, third sector organisation and commercial organisation could bid for:

- £1 million of revenue funding for autism innovation project bids
- £200,000 representing 6 months revenue funding for national co-ordination of autism awareness and the champions network. This funding was for third Sector/voluntary groups only.²
- Examples of successful Autism Innovation Fund projects are provided in the [Think Autism progress report](#) (January 2016).

The 2014 strategy also contained a commitment to improve the data available on autism. The Department of Health committed to work with Public Health England to establish a data and information working groups, including the Department for Work and Pensions, the Department for Education and others to report to the National Autism Programme Board to compile a list of data sources for local authorities on people with autism.

The strategy is overseen by the [Adult Autism Programme Board](#) and will be reviewed in five years.

In January 2016, the Department of Health produced a progress report on *Think Autism: Progress Report on Think Autism: the updated strategy for adults with autism in England*. The report summarises progress since the 2014 strategy and sets a number of new

² DoH, [The Autism Innovation Fund, national co-ordination of awareness and the champions network 2014/15](#).

actions, focusing on education, employment, the criminal justice system and better data reporting.

Statutory guidance 2015

In March 2015, the Government produced updated [statutory guidance](#) for local authorities and NHS organisations to support the implementation of *Think Autism*. The guidance covers the following areas:

- Training of staff who provide services to adults with autism
- Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services
- Planning in relation to the provision of services for people with autism as they move from being children to adults
- Local planning and leadership in relation to the provision of services for adults with autism
- Preventative support and safeguarding in line with the *Care Act 2014* from April 2015
- Reasonable Adjustments and Equality
- Supporting people with complex needs, whose behaviour may challenge or who may lack capacity
- Employment for adults with autism
- Working with the criminal justice system.

The guidance was revised to take account of responses to [a related consultation](#). It also takes into account progress made since the 2010 guidance, and recent legislation including the *Health and Social Care Act 2012*, the *Care Act 2014* and the *Children and Families Act 2014* which provided new duties for people with autism.

'No voice unheard, no right ignored' consultation

In March 2015, the Government published the consultation paper - '[No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions.](#)'

The consultation examined how people's rights and choices can be strengthened.

The scope of the consultation primarily related to:

- assessment and treatment in mental health hospitals for people (all age) with learning disability or autism;
- adult care and support, primarily for those with learning disability but also for adults with autism (and the links to support for children and young people); *and*
- all those to whom the Mental Health Act currently applies (including children and young people).³

The Government provided its response to the consultation in November 2015: [Government response to No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions](#). The Government set a series of proposals grouped into three implementation phases:

- early actions that seek to sustain momentum generated, chiefly through the use of existing powers and building on work currently underway ;

³ DoH, '[No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions.](#)' March 2015

- further changes, including proposed legislative changes that cannot be achieved via existing powers (and which relate principally to the *Mental Health Act 1983*); and
- a third phase, which explores more radical solutions to longer-term issues, as well as ongoing monitoring and review, and a commitment that the Government will intervene further, including through legislation if necessary, if the improvements sought continue not to be realised in practice.⁴

1.2 Waiting times for autism diagnosis

Autism diagnoses for children and young people

The National Institute for Health and Care Excellence (NICE) specifies in its clinical guidelines – [Autism Spectrum Disorder in Under 19s](#) – that, for children and young people, diagnostic assessment for autism should be started within three months of the referral from the patient’s GP or health visitor referral to the autism team.⁵ These are guidelines, however, and are therefore non-mandatory. Indeed, there is evidence that, in practice, waiting times can often last much longer.

As part of a research project conducted by academics from City and Goldsmiths, both University of London, a survey of a small number of parents about waiting times for autism diagnoses for children was conducted in 2012. Their figures, it should be noted, are calculated from when professional help was first sought. The same research project surveyed just over 1000 parents in 2012 and this yielded findings which showed:

The average delay between first contacting a healthcare professional and receiving a diagnosis was 3.6 years. However, we found that those children who were given the diagnosis of 'Asperger syndrome' tended to experience longer delays (over four years) than children who were given a diagnosis of 'autism' (between two and three years). This may be related to the signs of autism being more subtle in children who do not have intellectual impairments and who appear to show good language abilities.⁶

The findings from this study were published in a research article, entitled “[Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom](#)”.⁷

Autism diagnoses for adults

The NICE [Quality Standard on autism](#) recommends that people should have a diagnostic assessment for autism within three months of referral:

Quality statement

People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.

Rationale

There are several different routes by which someone with possible autism can be referred to an autism team for a diagnostic assessment. It is important that the assessment is conducted as soon as possible so that appropriate health and social care interventions, advice and support can be offered.⁸

⁴ DoH, [Government response to No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions](#), November 2015 para 6

⁵ NICE, [Autism spectrum disorder in under 19s: recognition, referral, and diagnosis \[CG128\]](#), *Clinical Guidance*, September 2011

⁶ “Results of our parent survey”, [Diagnosis of Autism project website](#)

⁷ Laura Crane, James W. Chester, Lorna Goddard, Lucy A. Henry and Elisabeth L. Hill, ‘[Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom](#)’, *Autism*, Vol. 20(2) (2016).

⁸ NICE, [NICE quality standard \[QS51\], Quality statement 1: Diagnostic assessment by an autism team](#), January 2014

In its 'Autism Diagnosis' campaign material, the National Autistic Society (NAS), an autism charity, has claimed that the average waiting time for a diagnosis is "over two years".⁹ This claim appears to have been based on a survey conducted as part of the aforementioned study by City and Goldsmiths. This survey found that, amongst a group of 128 autistic adults:

On average, the adults received a diagnosis around five years after concerns first emerged and two years after seeking professional help.

Encouragingly, adults diagnosed more recently experienced fewer delays.

The actual date when participants in this survey received their diagnosis will have varied greatly, so it is difficult to draw firm conclusions about recent waiting times, other than the general point that they are shorter for recent diagnoses.¹⁰

Public Health England Self-Assessment Framework

The Department of Health commissions Public Health England (PHE) each year to carry out a self-assessment exercise with local authority areas on progress they are making in implementing the Autism Strategy for Adults in England. Local authorities work with their local partners including Clinical Commissioning Groups (CCGs) to informally answer a range of questions.

The latest PHE [Self-Assessment framework](#) found the following about local authorities' performance with regard to establishing local diagnostic pathways:

Seventy nine (52%) local authorities gave themselves the highest (green) rating for their establishment of a local diagnostic pathway. One hundred and two (67%) reported there was a specialist autism specific service. Sixty nine (45%) reported that diagnosis triggered an automatic offer of a CCA. Only 33 (22%) of local authorities reported having met the National Institute for Health and Care Excellence (NICE) recommended waiting times (QS51).¹¹

1.3 Government policies on autism diagnoses and waiting times

The Department of Health has said that many people with autism are likely to be undiagnosed or misdiagnosed.¹² A key action from the *Think Autism* strategy was that NHS England would help improve autism diagnostic services. The strategy set this as one of its 15 priority challenges for action:

I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.¹³

Think Autism states that each local area is expected to have a clear pathway to diagnosis and each Clinical Commissioning Group (CCG) should designate a health lead responsible for developing, maintaining, and promoting a diagnostic and treatment pathway.¹⁴ Local

⁹ See more on this below.

¹⁰ "Results of our adult survey", [Diagnosis of Autism project website](#)

¹¹ Public Health England, [Autism Self-Assessment Exercise 2016: Detailed Report and Thematic Analyses, June 2017](#), pages 8 and 158

¹² DoH, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 34

¹³ DoH, [Think Autism – Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update](#), April 2014, page 7

¹⁴ DoH, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 16

authorities, NHS bodies and Foundation Trusts are asked to undergo a self-assessment evaluation of their diagnosis pathway:

In every local area, the NHS is expected to have a pathway to diagnosis, just as the local authority should have a clear framework for assessing the care and support needs of adults with autism. We will continue to ask local authorities, NHS bodies and Foundation Trusts to assess their progress on developing and maintaining a pathway to diagnosis through the autism local area self-evaluation exercise.¹⁵

The statutory guidance states that the NICE guidance and NICE Quality Standard on autism represent best practice when developing diagnostic services.¹⁶

No formal statistics are collected of autism referrals, initial assessments or diagnoses. As mentioned above, however, the Department of Health does commission Public Health England each year to carry out a self-assessment exercise with local authority areas on progress they are making in implementing the Autism Strategy for Adults in England. Local authorities work with their local partners including CCGs to informally answer a range of questions.¹⁷ As committed to in *Think Autism*, work is being undertaken to improve data sources of autism, including diagnosis. Further information is available in the *Think Autism Progress Report* (see page 12).

The Department of Health has supported the work of the Joint Commissioning Panel (JCP) for Mental Health, co-chaired by the Royal College of Physicians and the Royal College of GPs. The panel is developing a guide to encourage commissioners to use a values-based commissioning model when planning diagnostic services, which was a recommendation in *Think Autism*.¹⁸

The autism statutory guidance states that NHS England local audit teams will assess the quality of autism diagnostic pathways and people's experiences of using them. Further information was given in a recent debate:

Diagnosis is of course a process which should be driven locally by clinical commissioning groups, working in partnership with their local authorities, to develop the right pathways to assessment and packages of care which result from a diagnosis. The noble Lord, Lord Hunt, and my noble friend Lady Browning talked about meeting targets and holding CCGs to account. The Department of Health and NHS England, along with the Association of Directors of Social Services, are visiting CCGs and local authorities. These visits aim to develop a better oversight of the challenges in securing timely diagnosis across all ages. They will consider data on waits, which are so essential, and the design of pathways [...]. They will also consider many of the critical issues raised so that they can make an effective assessment of how information is made available to the public, the links to mental health services and social care services, how initial referrals are triaged, and who provides leadership locally for autism support. NHS England will complete its work in April and then report to the cross-government autism programme board.¹⁹

In January 2015, the Royal College of General Practitioners also launched a training programme for its members to improve the diagnosis of autism and support.²⁰

¹⁵ DoH, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 15

¹⁶ DoH, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 16

¹⁷ [PO HL6524 \[on Autism\], 14 March 2016](#)

¹⁸ DoH, [Progress Report on Think Autism: the updated strategy for adults with autism in England](#), January 2016, page 38

¹⁹ [HL Deb 22 March 2016 cGC350](#)

²⁰ [HC Deb 5 January 2015 c130](#)

In July 2016, the then Health Minister, David Mowat, in answer to a PQ about lowering waiting times between referral and first assessment for a diagnosis of autism, provided the following information about the Government's developing policy on this issue:

To support local areas in addressing long waits, NHS England, supported by the Department and the Association of Directors of Adult Social Services, initiated a series of visits to clinical commissioning groups and local authorities. These visits aimed to develop a better idea of the challenges in securing timely autism diagnosis across all ages, looking at the variability in diagnosis times and sharing good practice to help areas to improve their service. NHS England submitted a report on the visits to the 16 June meeting of the Cross Government Autism Programme Board, which includes representatives of autism third sector organisations and people who have autism. NHS England will have further discussions with relevant organisations over the summer about actions in their report, including on the Clinical Commissioning Group Improvement and Assessment Framework, before reporting back to the Autism Programme Board.

In parallel, as recommended by the independent Mental Health Taskforce, the Department is undertaking a five year plan for the development of mental health data to be published by the end of the year. The plan will set out future requirements and timings for developing data to inform pathways of care, which will include requirements for autism in the Health and Social Care Information Centre Mental Health Services Data Set. Data on referrals or appointments for an autism diagnostic assessment are not currently captured in published mental health data.²¹

In September 2016, David Mowat, again in answer to a [PQ](#), provided updated information that NHS England had been working with NHS Digital to develop reporting from the new Mental Health Services Data Set:

This mandatory data set includes provision for the diagnosis of autism to be recorded, and reporting on these data has been prioritised. Experimental data reports on the number of people diagnosed with autism are expected to be published by the end of 2016.²²

The [latest](#) of these experimental reports on the number of people diagnosed with autism was published on 20 June 2017.²³ In August 2017, NHS Digital also published a data quality [report](#) on diagnostic codes which took account of autism, alongside other conditions. During the period between January and March 2017, it reported that providers had not 'coded' autism in 50.7% of expected patient episodes.²⁴

In November 2016, David Mowat also [confirmed](#) that early-years providers must have arrangements in place to identify children with special educational needs or disabilities, including autism, and that they must review progress of children aged between 2 and 3 years and provide parents with a short written summary of their child's development.²⁵

1.4 National Autistic Society campaign on autism diagnosis

There have been calls for the Government and NHS England to do more to lower waiting times for diagnoses of autism, as well as to improve data collection on NHS performance in diagnosing children and adults with autism, principally from the National Autistic Society (NAS). In 2015, the NAS launched a campaign – [Autism Diagnosis Crisis](#) – which called for the Government to “prioritise the reduction of autism diagnosis waiting times”.

²¹ [PO 42713 \[on Autism\], 18 July 2016](#)

²² [PO 45794 \[on Autism\], 19 September 2016](#)

²³ NHS Digital, [Mental Health Services Monthly Statistics: Final March 2017](#), 20 June 2017

²⁴ Idem., [Data Quality Report on Comorbidity Diagnostic Persistence](#), August 2017

²⁵ [PO 53960 \[on Autism: Children\], 24 November 2016](#)

The NAS conducted a survey in 2011 which, they claim, revealed the following information about the effects of late or no diagnosis of autism:

For children, parents tell us that without a diagnosis and full identification of need, they have struggled to get the right help for their son or daughter. Delays in getting the right help can have a negative impact on a child's education and development.

- 69% of parents in The National Autistic Society's survey said that their child's educational progress has suffered because of a lack of timely support.
- Three quarters said that a lack of support has harmed their child's social and communication skills.²⁶

Autistic adults who have not received a diagnosis find it hard to get the support they need, to live the life they choose, including help with daily living and getting and keeping a job. In a survey The National Autistic Society has done, over half of local authorities told us that they thought it was more likely people would get help if they had a diagnosis.

Being left without support can mean that people face social exclusion and anxiety, which can have negative effects on individuals' mental health. Research suggests that 16 – 35% of autistic adults have a comorbid psychiatric disorder. While not all of these are attributable to not getting a diagnosis, getting a timely diagnosis and appropriate support as a result, will reduce these numbers.

At the same time, the NAS claims that by investing in and improving autism diagnosis, "the NHS could save money that is currently spent on mental health services that result from autistic people not getting the support they need, as they have not got a diagnosis".

Overall, the campaign has proposed the following:

- NHS England should collect, publish and monitor key information on how long people are waiting for diagnosis, and how many people are known to their GP to have autism.
- NHS England should ensure that 'waiting times standards' on mental health currently in development reflect national guidance that no one waits longer than three months between referral and being seen for diagnosis.
- The Government must share in this commitment, ensuring that NHS England meets its aims. In order to do this, timely access to an autism diagnosis should be written into the Government's Mandate to NHS England.²⁷

Since the launch of this campaign, the NAS has lobbied the Department of Health and NHS Digital to change the Mental Health Services Dataset to enable diagnosis waiting times to be recorded and published, and to then use this data to shape the local services required by autistic people.

It has, similarly, lobbied NICE and NHS England to create a primary care register of autism. This, they claim, would enable commissioning bodies, such as CCGs and NHS England, to identify any issues which might hinder certain groups from accessing a diagnosis, as well as allow GPs to better support autistic children and adults locally.

NAS has provided a precis of their campaign and their lobbying achievements in preparation for this debate on [their website](#).

²⁶ National Autistic Society [hereafter NAS], [The Autism Diagnosis Crisis: Key Information](#) (2015); idem., Great Expectations (2011)

²⁷ NAS, [The Autism Diagnosis Crisis](#)

2. Parliamentary material

2.1 Written Questions

- [Autism: Children](#)

Asked by: Bruce, Fiona | **Party:** Conservative Party

To ask the Secretary of State for Health, what steps his Department is taking to promote and facilitate the diagnosis of autism in children between the ages of two and four years.

Answering member: David Mowat | **Party:** Conservative Party | **Department:** Department of Health

The National Institute for Health and Care Excellence guideline 'Autism spectrum disorder in under 19s: recognition, referral and diagnosis' recommends that an assessment for autism is begun within three months of referral and includes information on signs and symptoms of possible autism in pre-school children.

Early-years providers must have arrangements in place to identify children with special educational needs or disabilities, including autism. In addition when a child is aged between two and three, early years practitioners must review progress and provide parents with a short written summary of their child's development, focusing in particular on communication and language, physical development and personal, social and emotional development.

Earlier this year, NHS England, supported by the Department and the Association of Directors of Adult Social Services, initiated a series of visits to clinical commissioning groups and local authorities aimed at a better idea of the challenges in securing timely autism diagnosis across all ages. To support the effective development of diagnostic services for autism, the Department is working with NHS Digital and system partners to ensure data on autism is included in future requirements for the Mental Health Services Data Set.

24 Nov 2016 | Written questions | Answered | House of Commons | 53960

Date tabled: 21 Nov 2016 | **Date for answer:** 24 Nov 2016 | **Date answered:** 24 Nov 2016

- [Autism](#)

Asked by: Cameron, Dr Lisa | **Party:** Scottish National Party

To ask the Secretary of State for Health, with reference to the findings of the Westminster Commission on Autism, A Spectrum of Obstacles: an inquiry into access to healthcare for autistic people, published in July 2016, if he will put in place annual health checks for people diagnosed with autistic spectrum disorder who find it difficult to communicate co-morbid physical health and mental health issues.

Answering member: David Mowat | **Party:** Conservative Party | **Department:** Department of Health

NHS England has been working with NHS Digital to develop reporting from the new Mental Health Services Data Set. This mandatory data set includes provision for the diagnosis of autism to be recorded, and reporting on these data has been prioritised.

Experimental data reports on the number of people diagnosed with autism are expected to be published by the end of 2016.

The National Health Service is taking action to increase the health checks and cancer screening programmes for people with learning disabilities, including those who also have autism. In 2015, NHS England commissioned the world's first Learning Disability Mortality Review Programme to support local areas to review deaths of people with learning disabilities and to use the information to improve service provision so that physical and mental health problems can be identified and addressed. Information from the programme will help with what more can be done to support regular health monitoring to address the health care needs of people diagnosed with autism.

In 2015, the Department reviewed and updated the autism statutory guidance for the NHS and local authorities in England. In line with this statutory guidance, local authorities and the NHS should be providing autism awareness training to all frontline staff in contact with adults with autism.

19 Sep 2016 | Written questions | Answered | House of Commons | 45794

Date tabled: 09 Sep 2016 | **Date for answer:** 13 Sep 2016 | **Date answered:** 19 Sep 2016

- [Autism](#)

Asked by: Berger, Luciana | **Party:** Labour Party · Cooperative Party

To ask the Secretary of State for Health, if he will take steps to ensure that the updated 2017-18 deliverables under the Government's Mandate to NHS England include specific actions to reduce autism diagnosis waiting times.

Answering member: David Mowat | **Party:** Conservative Party | **Department:** Department of Health

The current mandate for 2016-17 was published in December 2015, and sets out NHS England's objectives and budget to 2020 to provide stability and support the National Health Service to plan more effectively to deliver our long-term aims.

The Secretary of State must publish a mandate each year, which allows the Government to ensure it remains current and to agree new annual deliverables. The Department will consult on any significant changes that may be necessary, including to the mental health, learning disability and autism objective and deliverables. The mandate for 2017-18 will be published and laid before Parliament in the autumn.

19 Jul 2016 | Written questions | Answered | House of Commons | 42869

Date tabled: 14 Jul 2016 | **Date for answer:** 19 Jul 2016 | **Date answered:** 19 Jul 2016

- [Autism](#)

Asked by: Smith, Cat | **Party:** Labour Party

To ask the Secretary of State for Health, with reference to the last meeting of the National Autism Programme Board, what steps his Department is taking to ensure that waiting times between referral and first assessment for a diagnosis of autism are included in the HSCIC Mental Health Services Data Set, which now includes the Child and Adolescent Mental Health Services data set.

Answering member: David Mowat | **Party:** Conservative Party | **Department:** Department of Health

To support local areas in addressing long waits, NHS England, supported by the Department and the Association of Directors of Adult Social Services, initiated a series of visits to clinical commissioning groups and local authorities. These visits aimed to develop a better idea of the challenges in securing timely autism diagnosis across all ages, looking at the variability in diagnosis times and sharing good practice to help areas to improve their service. NHS England submitted a report on the visits to the 16 June meeting of the Cross Government Autism Programme Board, which includes representatives of autism third sector organisations and people who have autism. NHS England will have further discussions with relevant organisations over the summer about actions in their report, including on the Clinical Commissioning Group Improvement and Assessment Framework, before reporting back to the Autism Programme Board.

In parallel, as recommended by the independent Mental Health Taskforce, the Department is undertaking a five year plan for the development of mental health data to be published by the end of the year. The plan will set out future requirements and timings for developing data to inform pathways of care, which will include requirements for autism in the Health and Social Care Information Centre Mental Health Services Data Set. Data on referrals or appointments for an autism diagnostic assessment are not currently captured in published mental health data.

18 Jul 2016 | Written questions | Answered | House of Commons | 42713

Date tabled: 13 Jul 2016 | **Date for answer:** 18 Jul 2016 | **Date answered:** 18 Jul 2016

- [Autism: Diagnosis](#)

Asked by: Gillan, Mrs Cheryl | **Party:** Conservative Party

To ask the Secretary of State for Health, what the average time taken for autism diagnosis was by age and gender at time of diagnosis for each year from 2013.

Answering member: Alistair Burt | **Party:** Conservative Party | **Department:** Department of Health

We do not centrally collect data from the National Health Service on waiting times for an assessment of autism.

The National Institute for Health and Care Excellence clinical guideline on autism diagnosis states that a diagnostic assessment should start within 12 weeks of referral.

NHS England and the Association of Directors of Social Services have undertaken a series of visits to clinical commissioning groups to identify best practice on diagnosis and support.

24 May 2016 | Written questions | Answered | House of Commons | 37620

Date tabled: 19 May 2016 | **Date for answer:** 24 May 2016 | **Date answered:** 24 May 2016

- [Autism: Diagnosis](#)

Asked by: Godsiff, Mr Roger | **Party:** Labour Party

To ask the Secretary of State for Health, if he will ask NHS England to collect data on autism diagnosis waiting times.

Answering member: Alistair Burt | **Party:** Conservative Party | **Department:** Department of Health

NHS England and the Association of Directors of Adult Social Services, supported by the Department, undertook a series of visits to clinical commissioning groups and local authorities recently. These visits aimed to develop a better strategic oversight of the challenges in securing timely diagnosis across all ages and to share good practice. NHS England will report to the Cross Government Autism Programme Board in June on its findings and that report and discussion will be made public.

As recommended by the independent Mental Health Taskforce, the Department is undertaking a five year plan for the development of mental health data to be published by the end of this year. The plan will set out future data requirements and timings for developing data to inform pathways of care which will include data requirements for autism.

10 May 2016 | Written questions | Answered | House of Commons | 36566

Date tabled: 04 May 2016 | **Date for answer:** 09 May 2016 | **Date answered:** 10 May 2016

- [Autism: Children](#)

Asked by: Berger, Luciana | **Party:** Labour Party · Cooperative Party

To ask the Secretary of State for Health, what the average waiting time for children between referral for an autism diagnosis and first diagnostic appointment was in each clinical commissioning group and primary care trust area in each year since 2010.

Answering member: Alistair Burt | **Party:** Conservative Party | **Department:** Department of Health

The Department does not collect this information centrally.

No formal statistics are collected of autism referrals, initial assessments or diagnoses. The Department does however commission Public Health England each year to carry out a self-assessment exercise with local authority areas on progress they are making in implementing the Autism Strategy for Adults in England.

NHS England has almost completed a programme to visit clinical commissioning groups (CCGs) to identify and share good practice in accessing timely autism diagnosis. NHS England with support from the Association of Directors of Adult Social Services has visited a selection of areas to talk to CCGs and local authorities about their Autism Diagnostic Care Pathways and post diagnostic support. A report on this work will go initially to the June meeting of the Cross Government Autism Programme Board.

19 Apr 2016 | Written questions | Answered | House of Commons | 34105

Date tabled: 14 Apr 2016 | **Date for answer:** 19 Apr 2016 | **Date answered:** 19 Apr 2016

- [Autism](#)

Asked by: Lord Maginnis of Drumglass | **Party:** Independent Ulster Unionist

To ask Her Majesty's Government whether health managers and practitioners in England have had access to the 2008 Department of Health, Social Services and Public Safety Independent Review of Autism Services or to any similar independent guidance regarding appropriate timescale targets for moving from initial autism referrals to diagnosis and appropriate care.

Answering member: Lord Prior of Brampton | **Party:** Conservative Party | **Department:** Department of Health

No formal statistics are collected of autism referrals, initial assessments or diagnoses. The Department does however commission Public Health England each year to carry out a self-assessment exercise with local authority areas on progress they are making in implementing the Autism Strategy for Adults in England. Local authorities work with their local partners including clinical commissioning groups (CCGs) to informally answer a range of questions.

In the exercise based on 2013 data, all 152 local authority areas replied but some did not answer all the questions. Areas were asked how many adults have completed the diagnostic pathway in the preceding year and 111 reported a total of 4,677. They were also asked the length of the average wait for referral to diagnostic services and 117 answered this question. The average of these figures, weighted for the population in the responding areas, was 27.9 weeks.

The exercise based on 2014 data saw 149 areas respond. They were asked how many adults had received a diagnosis of an autistic spectrum condition in the preceding year and 128 reported a total of 5,109. Areas were also asked the length of the average wait between referral and assessment for all adults and 135 answered this question. The average of these figures, similarly weighted, was 19.6 weeks. Information on the waiting time between autism referrals and initial assessments, and between initial assessments and diagnosis, was not collected during these exercises. The next exercise will be launched later in the spring.

The number of children and young people diagnosed with autism by the National Health Service is not collected centrally. Latest figures from the School Census (2015) state that there were 90,775 pupils with an autistic spectrum condition at state funded schools and non-maintained special schools in England. This has increased from a total of 56,250 in 2010 who were recorded as having a primary need of autism, but it is not directly comparable to the 2015 figures because of a change in collection methodology.

New statutory guidance was issued in England in March 2015 to support implementation of the Adult Autism Strategy. This set out what people seeking an autism diagnosis can expect from local authorities and NHS bodies. The National Institute for Health and Care Excellence has published three clinical guidelines on autism and a quality standard to assist health managers and practitioners in developing services. This includes a recommendation that an assessment is started within three months of the referral. NHS England has commenced a programme to visit CCGs to identify and share good practice in accessing autism diagnosis, and look at possible barriers. NHS England will complete a report on this by the end of April 2016.

14 Mar 2016 | Written questions | Answered | House of Lords | HL6526

Date tabled: 29 Feb 2016 | **Date for answer:** 14 Mar 2016 | **Date answered:** 14 Mar 2016

- [Autism](#)

Asked by: Baroness Hodgson of Abinger | **Party:** Conservative Party

To ask Her Majesty's Government what steps they are taking to reduce waiting times for autism diagnosis.

Answering member: Lord Prior of Brampton | **Party:** Conservative Party | **Department:** Department of Health

The number of children, young people and adults diagnosed with autism by the National Health Service is not collected centrally. Latest figures from the School Census (2015) state that there were 90,775 pupils with an autistic spectrum disorder at state funded schools and non-maintained special schools in England. This has increased from a total of 56,250 in 2010 who were recorded as having a primary need of autism, but it is not directly comparable to the 2015 figures because of a change in collection methodology. Local authority areas provide information for Public Health England's annual self-assessment exercise on implementing the Autism Strategy. This includes the number of adults receiving an autism diagnosis but because information is submitted on a voluntary basis a complete total for England is not available.

The Department has discussed with NHS England the difficulties that people on the autistic spectrum can have in getting an appropriate diagnosis and support in a timely manner. NHS England has commenced a programme to visit clinical commissioning groups to identify and share good practice in accessing autism diagnosis, and look at possible barriers. The Department is funding the Association of Directors of Adult Social Services to support this work. NHS England will complete a report on this by the end of April 2016.

The Department is also encouraging the autism third sector to work together and the four charity representatives on the Cross Government Autism Programme Board, which oversees the implementation of the Autism Strategy, gave presentations at the meeting on 18 February on work they are doing to increase public awareness. The charities are the National Autistic Society, the Autism Alliance UK, Autism Plus and Ambitious about Autism. The Autism Alliance UK is also being funded by the Department to undertake work with national and local organisations, to make reasonable adjustments to services and to train staff to be aware of what autism can mean to individuals who have the condition and their families.

The Health and Social Care Information Centre's publication *Estimating the Prevalence of Autism Spectrum Conditions in Adults - Extending the 2007 Adult Psychiatric Morbidity Survey (APMS)* gave the overall prevalence of autism in England as 1.1% (95% confidence interval 0.3% to 1.9%). Among adults with learning disabilities living in private households whose learning disability was sufficiently severe that they could not have taken part in the 2007 APMS, the prevalence of autism was 35.4% (95% confidence interval 24.7% to 46.2%). Among adults with mild or severe learning disabilities living in communal care establishments, the prevalence of autism was 31% (95% confidence interval 23.9% to 38%). Detailed supporting information regarding the underlying data and how figures have been derived is found within the detail of the report, a copy of which is attached.

The APMS was repeated in 2014 and findings are scheduled to be published in September 2016.

07 Mar 2016 | Written questions | Answered | House of Lords | HL6254

Date tabled: 22 Feb 2016 | **Date for answer:** 07 Mar 2016 | **Date answered:** 07 Mar 2016

- [Autism](#)

Asked by: Long Bailey, Rebecca | **Party:** Labour Party

To ask the Secretary of State for Health, if he will take steps to improve the current waiting time after referral for a diagnostic assessment for autism.

Answering member: Alistair Burt | **Party:** Conservative Party | **Department:** Department of Health

The Department has discussed with NHS England the difficulties that some people on the autistic spectrum can have in getting an appropriate diagnosis and support in a timely manner. NHS England has commenced a programme to visit clinical commissioning groups (CCGs) to identify and share good practice in accessing timely autism diagnosis. NHS England with support from the Association of Directors of Adult Social Services is to visit a selection of areas to talk to CCGs and local authorities about their Autism Diagnostic Care Pathways and post diagnostic support. A report on the work will be completed by the end of April 2016.

22 Feb 2016 | Written questions | Answered | House of Commons | 26422

Date tabled: 09 Feb 2016 | **Date for answer:** 22 Feb 2016 | **Date answered:** 22 Feb 2016

- [Autism: Lincolnshire](#)

Asked by: McCartney, Karl | **Party:** Conservative Party

To ask the Secretary of State for Health, what steps his Department and NHS England are taking to ensure that autism diagnosis waiting times for (a) children and (b) adults in Lincolnshire NHS Trust area meet NICE guidance.

Answering member: Alistair Burt | **Party:** Conservative Party | **Department:** Department of Health

NHS England advises that, from 1 April 2016, Lincolnshire West Clinical Commissioning Group will be commissioning an integrated diagnostic pathway for adults with autism spectrum disorder. Performance measures will include a target maximum 12-week waiting time, to ensure that National Institute for Health and Care Excellence guidelines are met.

A review of services for children is also planned as part of the Lincolnshire All Age Autism Strategy, which will include the development of a clearly defined integrated pathway for diagnostic assessment and post-diagnostic support for this age group.

10 Feb 2016 | Written questions | Answered | House of Commons | 25310

Date tabled: 02 Feb 2016 | **Date for answer:** 04 Feb 2016 | **Date answered:** 10 Feb 2016

- [Autism](#)

Asked by: Twigg, Derek | **Party:** Labour Party

To ask the Secretary of State for Health, what steps his Department and NHS England are taking to ensure that autism diagnosis waiting times for (a) children and (b) adults meet NICE guidance (a) in Halton and (ii) nationally.

Answering member: Alistair Burt | **Party:** Conservative Party | **Department:** Department of Health

The Department issued new statutory guidance in March this year for local authorities and National Health Service organisations to support the continued implementation of the 2010 Autism Strategy, as refreshed by its 2014 Think Autism update. This sets out what people seeking an autism diagnosis can expect from local authorities and NHS bodies.

The Department has also discussed with NHS England the difficulties that people on the autistic spectrum can have in getting an appropriate diagnosis in a timely manner. With support from the Department, NHS England and the Association of Directors of Social Services will undertake a series of visits to clinical commissioning groups (CCGs) to discuss good practice in meeting the National Institute for Health and Care Excellence (NICE) Quality Standard 51 Autism, and those that do not, with the aim of supporting more consistent provision. The Quality Standard, which applies to children, young people and adults, recommends that there should be a maximum of three months between a referral and a first appointment for a diagnostic assessment for autism. We expect the NHS to be working towards meeting the recommendations.

We understand that NHS Halton CCG is working on improvements to the paediatric neurological pathway which incorporates children with autism. This will see the Child Development Centre (CDC) in Halton become a single access point of assessment for the most complex children. It is expected that the CDC will ensure that the first appointment for a child referred to them is well within the three months recommended by NICE.

The service commissioned by Halton CCG will also comply with NICE guidelines by ensuring that the appropriate mix of clinicians is available for a multi-disciplinary assessment, which also includes Child and Adolescent Mental Health Services.

In regard to adults, NHS Halton CCG is currently meeting its statutory requirements with autism by purchasing a diagnostic service on a cost per case basis from our provider of mental health services, 5 Boroughs Partnership NHS Foundation Trust. The CCG is working with other partners who receive the same service from the same provider with a view to pooling resources to commission a diagnostic and post diagnostic service.

16 Dec 2015 | Written questions | Answered | House of Commons | 19405

Date tabled: 09 Dec 2015 | **Date for answer:** 14 Dec 2015 | **Date answered:** 16 Dec 2015

Subject: Autism; Diagnosis; Health services

2.2 Debates

[HC Deb, 28 April 2016 cc1573-1631](#) (World Autism Awareness Week)

[HC Deb 8 March 2016 cc55WH-65WH](#) (Autism Diagnosis Waiting Times)

3. Press articles and notices

[Debate on diagnosis waiting times next week](#)

The National Autistic Society, 8 September 2017

[Norfolk autism assessment wait time 'up to two years'](#)

BBC News, 1 September 2017

[Autistic children self-harm warning over slow diagnosis](#)

BBC News, 10 July 2017

[Adults with autism facing longer waits for assessments](#)

Community Care, 5 July 2017

[Good news on diagnosis in South West London](#)

The National Autistic Society, 2 June 2017

[Autism diagnoses 'could be reduced under NHS plan'](#)

BBC News, 27 May 2017

[NHS proposals to reduce autism diagnoses in south west London 'deeply concerning', warns charity](#)

The Independent, 30 May 2017

[An Early Autism Diagnosis Changed My Daughter's Life](#)

The Huffington Post UK, 21 April 2017

[Why Are We \(Still\) Waiting? Delaying Autism Assessment Isolates Parents And Puts Children At Risk](#)

The Huffington Post UK, 19 April 2017

[Lengthy delays for autism assessments in York](#)

The Press, 6 March 2017

[Autism assessment waiting lists now at crisis level, says MLA](#)

The Belfast Telegraph, 22 December 2016

[Schools struggle as autism diagnoses rise 25 per cent](#)

Schools Week, 16 December 2016

['All my life suddenly made sense': how it feels to be diagnosed with autism late in life](#)

The Guardian, 19 November 2016

[NHS England 'must monitor waits for autism diagnosis'](#)

BBC News, 2 February 2016

4. Further reading

- House of Commons Library CBP 7172, [Autism: Overview of Policy and Services](#)
- HM Government, [Think Autism: Fulfilling and Rewarding Lives, the Strategy for Adults with Autism in England—An Update](#), April 2014
- Department of Health, [Statutory Guidance for Local Authorities and NHS Organisations to Support Implementation of the Adult Autism Strategy](#), March 2015
- National Autistic Society, [The Autism Diagnosis Crisis: Key Information](#), 2015

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