



National Audit Office

**MEMORANDUM FOR  
THE COMMITTEE OF  
PUBLIC ACCOUNTS**

**17 JULY 2012**

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Department of Health

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# Progress in implementing the 2010 Adult Autism Strategy

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National Audit Office

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Memorandum for the Committee of Public Accounts

# **Progress in implementing the 2010 Adult Autism Strategy**

The memorandum outlines the progress that has been made in implementing the commitments in the 2010 Adult Autism Strategy.

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## Contents

**Overview** 4

**Part One**

Introduction 7

**Part Two**

Progress in implementing the Adult Autism  
Strategy commitments 10

**Appendix One**

Local authority progress: results of the  
self-assessment exercise 27

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This report can be found on the National Audit Office website at [www.nao.org.uk](http://www.nao.org.uk)

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## Overview

1 The National Audit Office reported on *Supporting people with autism through adulthood*<sup>1</sup> in June 2009, making a range of recommendations aimed at achieving better outcomes for people with autism. The subsequent Committee of Public Accounts report,<sup>2</sup> published in October 2009, recommended that the Government should incorporate the National Audit Office's recommendations in its adult autism strategy *Fulfilling and rewarding lives* (the Strategy). The Strategy was launched in March 2010 with the aim of improving the lives of adults with autism.

2 The Committee also recommended that the National Audit Office should review progress in implementing the commitments made in the Strategy. This memorandum outlines the progress that has been made since the Strategy was published. It draws on evidence provided by the seven government departments and agencies with commitments in the Strategy and by The National Autistic Society and the Autism Alliance, a network of charities providing services to people with autism.

3 The Department of Health is the policy lead for autism but the cross-government nature of the Strategy means that responsibility for delivery is shared across a number of departments and there is no single point of accountability. In addition, much of the responsibility for implementing the commitments rests with local authorities and NHS bodies, which have the freedom to decide how best to design and deliver services for their local populations in line with the Government's localism agenda and changes to NHS structures.

### Progress to date

4 A key development was the establishment in April 2010 of the Adult Autism Strategy Programme Board (the Programme Board), whose members include government departments, people with autism, representatives of carers and autism charities. The Programme Board is responsible for overseeing progress against the Strategy and facilitating local delivery.

5 Considerable progress has been made in the two years since the Strategy was published: 24 of the 56 commitments have been implemented, and action has begun in response to most of the remainder. Our work indicates that 20 commitments have been partly implemented, two are on track and the remaining ten had not been implemented at the time of our work. Further action is therefore required for the commitments to be implemented in full. The Department of Health confirmed that it is committed to progressing the outstanding commitments ahead of a review of the Strategy in 2013.

1 Comptroller and Auditor General, *Supporting people with autism through adulthood*, Session 2008-09, HC 556, National Audit Office, 5 June 2009.

2 House of Commons Committee of Public Accounts, *Supporting people with autism through adulthood*, Fifteenth Report of Session 2008-09, HC 697, 15 October 2009.

**6** Considerable headway has been made in implementing the commitments designed to support delivery of the Strategy. Actions include: the publication of statutory guidance for local authorities; the development of a self-assessment tool for local authorities to measure progress; and the establishment of local autism partnership boards in 87 of the 152 local authorities.

**7** Reflecting the Government's increased focus on devolved delivery and local accountability, the Strategy has no central targets or timetable, and no ring-fenced funding. The commitment to publish a long-term delivery plan was not implemented as greater emphasis was placed on local planning and implementation.

**8** Training materials and guidance have been developed on a range of areas with, for example, the aim of improving awareness and understanding among staff working with people with autism; improving the transition between, and promoting reasonable adjustments to, services; and enhancing employment support to help people with autism into work. Although some data is available on the distribution and use of training material, no evidence has been collected on the impact the material has had in driving improvements in awareness of autism.

**9** Less progress has been made in improving access to social care assessments, personal budgets and diagnostic services in local authorities, which can all help adults with autism to access services and support. The National Institute for Health and Clinical Excellence published clinical guidelines for the diagnosis, referral and management of adults with autism in June 2012, which should help local authorities and the NHS design diagnostic pathways specifically for adults with autism.

**10** Effective local services and support are crucial in improving outcomes for people with autism. Some progress has been made on developing local support mechanisms, such as the appointment of autism leads to commission services and the development of regional delivery plans, designed to help local bodies to deliver relevant services. The National Institute for Health and Clinical Excellence is developing an Adult Autism Quality Standard, which is scheduled for publication in July 2013. The Quality Standard will aim to help service providers to assess and implement high standards of clinical performance and care, and commissioners to purchase high quality cost-effective services. In addition, better information on the number of adults with autism is needed to assist effective planning and commissioning of services. There is also scope to involve adults with autism and carers more in the design of services.

### **Looking ahead**

**11** When the Strategy was introduced, there was no national empirical baseline of service provision and outcomes for people with autism. This makes it difficult to track impact, to compare the position in different local areas or to hold central or local government to account. Establishing a clear empirical baseline could usefully form part of the review of progress which is due to be undertaken in 2013.

**12** Some data has been collected to assess the extent to which the Strategy has achieved its ultimate aim of improving the lives of adults with autism. A recent local authority self-assessment exercise generated information on progress, but by its nature the assessment is subjective and largely descriptive. To improve the comparability and reliability of the self-assessment tool, the Programme Board could draw on The National Autistic Society's database of key indicators of progress, which we consider uses simple, well defined questions. The Department of Health confirmed that it is committed to working with The National Autistic Society and other partners to refine and incorporate this data into the next self-assessment exercise.

**13** More generally, we see the Programme Board as having a key role to play in maintaining momentum and building on the progress made to date. The Programme Board will be leading the review of progress in 2013 and is considering how best to secure the views of people with autism and carers. The Review will be an opportunity for government to take stock, identify where commitments remain outstanding and consider where further action is required to realise the vision of improving the lives of adults with autism.



# Part One

## Introduction

### What is autism?

**1.1** Autism is a lifelong developmental disability, with people sharing three main areas of difficulty:

- communicating socially, particularly using and understanding facial expressions, tone of voice and abstract language;
- interacting socially such as recognising or understanding other people's emotions and feelings, and expressing their own; and
- understanding and predicting other people's behaviour, such as making sense of abstract ideas and imagining situations outside their daily routine.

**1.2** Owing to variable identification rates and a lack of national data, it is difficult to quantify with certainty the number of people with autism. Recent estimates by The Health and Social Care Information Centre suggest that around one in one hundred adults in England (approximately 500,000 people in total) have autism.<sup>3</sup> Around half of these also have a learning disability (sometimes known as 'low-functioning' autism), while the rest do not ('high-functioning' autism, which includes Asperger Syndrome). Autism affects people in different ways – some can live relatively independently, in some cases without any additional support, while others require a lifetime of specialist care.

<sup>3</sup> The Health and Social Care Information Centre, *Estimating the prevalence of autism spectrum conditions in adults*, January 2012. Available at [www.ic.nhs.uk/webfiles/publications/005\\_Mental\\_Health/Est\\_Prev\\_Autism\\_Spectrum/Est\\_Prev\\_Autism\\_Spec\\_Cond\\_in\\_Adults\\_Report.pdf](http://www.ic.nhs.uk/webfiles/publications/005_Mental_Health/Est_Prev_Autism_Spectrum/Est_Prev_Autism_Spec_Cond_in_Adults_Report.pdf)

## The Government's Autism Strategy

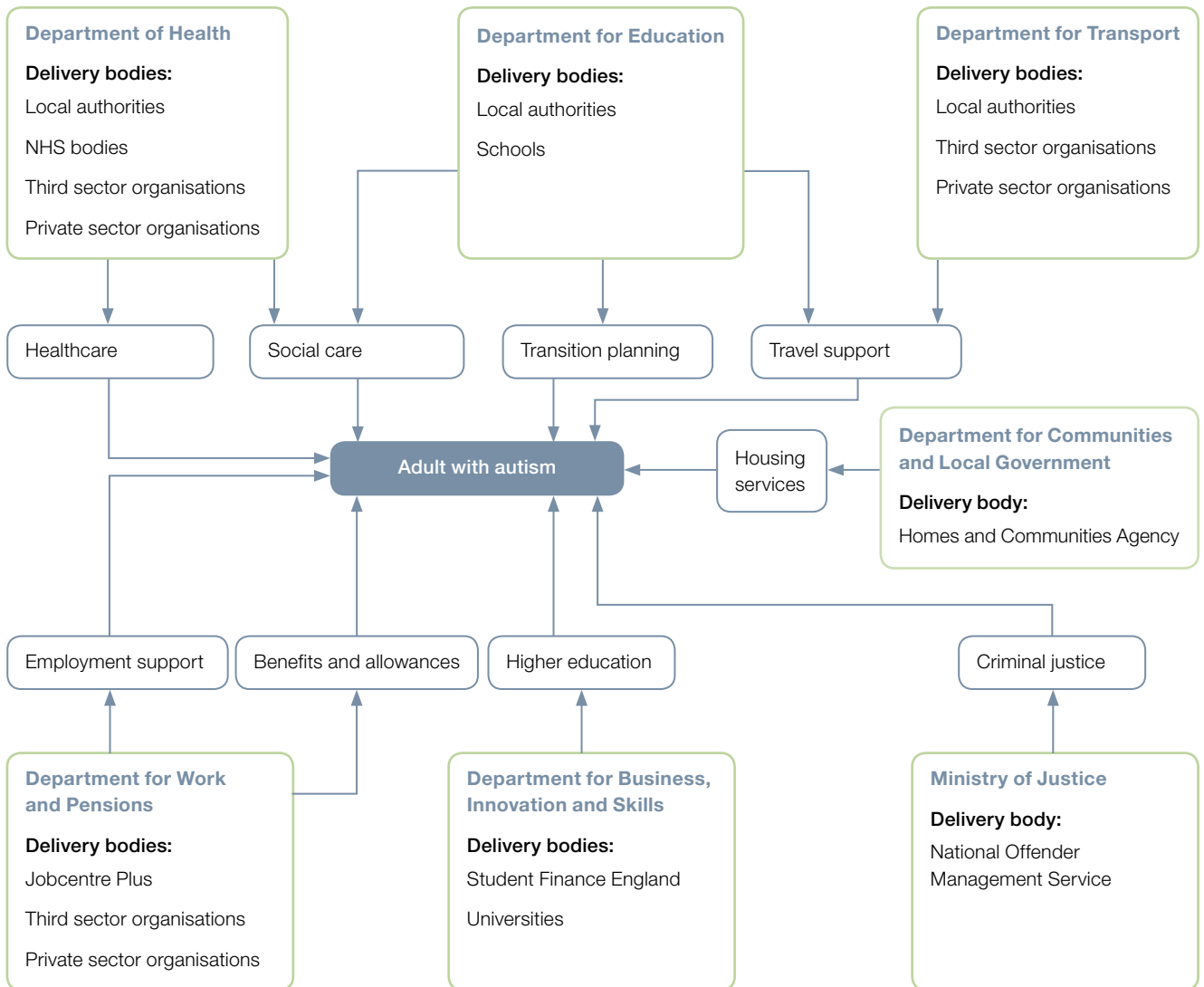
**1.3** The Autism Act 2009 required the Government to produce a Strategy and supporting statutory guidance. The Act was followed in 2010 by the Autism Strategy, which set out the Government's vision for autism services and five areas for action aimed at improving the lives of adults with autism:

- increasing awareness and understanding of autism;
- developing a clear, consistent pathway for diagnosis of autism;
- improving access for adults with autism to services and support;
- helping adults with autism into work; and
- enabling local partners to develop relevant services.

**1.4** Reflecting the range of support and services for people with autism, the Strategy set out commitments for seven central government departments and agencies: the Department of Health; the Department for Work and Pensions; the Department for Education; the Department for Business, Innovation and Skills; the Department for Transport; the Ministry of Justice; and the Homes and Communities Agency. The Department of Health is the lead policy department for autism, with delivery shared across a range of government departments and agencies and local health and social care service providers. **Figure 1** shows the service delivery arrangements for people with autism.

**Figure 1**

Service delivery arrangements for adults with autism by accountable department



Source: National Audit Office

## Part Two

### Progress in implementing the Adult Autism Strategy commitments

**2.1** This part sets out the progress that has been made in implementing the commitments in the Adult Autism Strategy. We confirmed the actions taken by departments. We did not, however, evaluate the quality or impact of the guidance and other material produced or the structures and programmes put in place.

#### **Central support structures, accountability and monitoring**

##### Central support structures

**2.2** The Strategy aimed to put in place central structures and statutory guidance to support implementation of specialist services and joint working by local commissioners – local authorities and primary care trusts, responsible for planning and funding services for people with autism – and public, private and third sector delivery organisations, responsible for providing services for people with autism.

**2.3** Significant progress has been made against most of these commitments. Of the seven commitments in this area, five have been achieved, one partly achieved and one not achieved (**Figure 2**).

**2.4** The National Autistic Society and the Autism Alliance sit on the Adult Autism Strategy Programme Board and welcome its establishment. The Department publishes the minutes of Programme Board meetings on its website<sup>4</sup> and plans to link these to its autism web pages to make them easier to access. The National Autistic Society also raised concerns that, while all departments with commitments in the Strategy sit on the Programme Board, there is a tendency for them to view the Strategy as a Department of Health project, which limits progress.

**Figure 2**

## Progress against Strategy commitments for central support structures

Accountable department	Commitment	Action taken	Date achieved	Progress
Department of Health	Create Learning Disabilities Observatory to improve information on the health and well-being of people with learning disabilities across England.	The North East Public Health Observatory, the Centre for Disability Research (Lancaster University) and the National Development Team for Inclusion (a not-for-profit organisation) formed the Learning Disabilities Observatory.	March 2010	Achieved
Department of Health	Establish Adult Autism Strategy Programme Board to oversee national progress against the Strategy; provide overall direction and governance; and consider how to facilitate local delivery.	The Adult Autism Strategy Programme Board was established. Members include government departments with commitments in the Strategy, people with autism, parent-carer representatives, clinicians, The National Autistic Society and the Autism Alliance.	March 2010	Achieved
Department of Health	Publish First Year Delivery Plan setting out governance structure, responsibilities and priority actions from the Strategy to be completed within the first 12 months.	The First Year Delivery Plan was published. However, two of the six Delivery Plan actions for the Programme Board were not completed (annual report and national communications campaign) due to the move towards local planning, implementation and delivery.	April 2010	Achieved
Department of Health	Publish a further delivery plan, giving more detailed plans for the longer term.	The longer term delivery plan was cancelled. The Department of Health reported that this was due to the Government's greater focus on local planning, implementation and delivery. The Department has developed a work plan and risk register for 2012, which it intends to publish on its website.	–	Not achieved
Department of Health	Publish statutory guidance for local authorities and NHS organisations, mandated by the Autism Act, to support implementation.	The Department published the statutory guidance.	December 2010	Achieved
Department of Health	Issue self-assessment tool to local authorities to assess progress in implementing the statutory guidance.	The Department issued a self-assessment tool to local authorities.	April 2011	Achieved
Department of Health	Establish local autism partnership boards.	The Department does not collect data on whether local autism partnership boards have been established. The National Autistic Society reported that, as of December 2011, partnership boards have been set up in 87 of 152 local authorities, although the quality of the boards and the resources available to them is variable. The boards include people with autism, carers, local authorities, primary care trusts and service providers.	December 2011	Partly achieved

Source: National Audit Office analysis of departmental and charitable sector responses

## Accountability and the monitoring of progress

**2.5** Due to the cross-government nature of the Autism Strategy, responsibility for delivery is shared across a number of departments and there is no single point of accountability. The Department of Health is the policy lead on autism, and supports the Programme Board to provide leadership and oversee progress. The Programme Board is chaired by the Minister for Care Services and the Director General for Social Care from the Department of Health.

**2.6** Individual departments are accountable for delivering specific Strategy commitments and providing the necessary resources. In addition, responsibility for implementing many of the commitments rests with the NHS and local authorities, who have freedom to decide how best to design and deliver local services. The Department of Health and other accountable departments do not collect data on whether, or how, the commitments have been implemented at local level. In this memorandum, we have therefore drawn on data provided by The National Autistic Society, which maintains a database of key indicators of progress collected by its regional team and directly from local authorities. The database was compiled in January 2012 and has since been updated on an ad hoc basis. This memorandum reflects the most recent data (as at May 2012).

**2.7** In addition, in early 2012 the Learning Disabilities Observatory collated some information on local progress using returns from the local authority self-assessment tool developed by the Department of Health (Figure 2). The tool draws on the Department's publication *Fulfilling and rewarding lives: evaluating progress*, which includes seven outcomes and three service ambitions. A total of 135 of 152 local authorities responded to the self-assessment exercise.

**2.8** The high level results of the self-assessment show that significant further progress is required if the objectives of the Strategy are to be achieved (Appendix One). We do, however, have concerns about the quality of the self-assessment tool and the robustness of the information generated. In particular, the tool has not set out criteria for its 'red/amber/green' scoring system so it is unclear that local authorities have responded to the questions in a consistent and reliable fashion. The Learning Disabilities Observatory published fuller results from the self-assessment exercise in July 2012.

**2.9** The Programme Board recently changed its terms of reference from developing governance structures to monitoring progress on implementation. It is currently considering how it will fulfil its commitment to review progress in 2013, but this will be difficult without an empirical baseline of the quality of service provision and outcomes for people with autism. Data collected by autism charities may help to support the 2013 review, including The National Autistic Society's monitoring database.

**2.10** The Strategy and statutory guidance set standards for service access and quality, with accountability mechanisms to be decided locally. The Government's intention is for local commissioners and service providers to be held to account by local populations, with charities such as The National Autistic Society and members of the Autism Alliance taking an active role.

**2.11** The National Autistic Society and Centre for Public Scrutiny have developed a guide for local authority overview and scrutiny committees on how to assess progress in implementing the Strategy. Commissioners can hold delivery organisations to account via contracts setting out duties and reasonable adjustments for people with autism. Ultimately, where local services are not in line with statutory guidance, service users could request a judicial review, although in reality this is likely to be a very rare occurrence. The National Autistic Society and the Autism Alliance reported that in their experience local commissioners and providers are rarely explicitly held to account for implementing the Strategy.

### **Increasing awareness and understanding of autism**

**2.12** It is important that health professionals and other frontline staff have a good understanding of autism to enable them to recognise the condition and respond effectively when they are working with people with autism. The Strategy includes a range of commitments to provide guidance and training aimed at increasing awareness and understanding of autism.

**2.13** Overall, progress in implementing these commitments is mixed. Of the 12 commitments in this area three have been achieved, four partly achieved, and five not achieved (**Figure 3** overleaf). While some guidance and training materials have been developed, no data is available on the impact they have had in improving awareness and understanding. The Department of Health confirmed that it is committed to making progress against the outstanding commitments.

**Figure 3**

## Progress against Strategy commitments to increase awareness among frontline professionals

Accountable department	Commitment	Action taken	Date achieved	Progress
Department of Health	Outline best practice examples for delivering autism awareness training in health and social care in the statutory guidance.	The statutory guidance outlines examples for delivering autism awareness training, but these are limited and the Department of Health confirmed that this work was not well advanced when the guidance was issued.	December 2010	Partly achieved
Department of Health	Produce an At a Glance Personalisation Briefing on autism to drive forward the personalisation agenda.	The Social Care Institute for Excellence and The National Autistic Society published a joint briefing on the personalisation of social care for adults with autism.	February 2010	Achieved
Department of Health	Develop training materials, such as online resources and information about autism, in partnership with health and social care professional bodies.	The Department of Health commissioned (£500,000) the Royal College of GPs and the Royal College of Nursing to develop training material for health and social care professionals. The Department reported that the Royal College of GPs e-learning course had 709 users at November 2011; and that the Royal College of Nursing had distributed its autism guide to 413,000 members.	–	Achieved
Department of Health	Include autism awareness in the core training curricula for doctors, nurses and other clinicians.	The Department of Health is in discussion with the Royal Colleges and professional bodies about how to incorporate autism awareness into the core training for clinical staff. There is, however, no date for implementing changes.	–	Not achieved
Department of Health	Work with primary care trusts and local authorities to identify priority groups for training.		–	Not achieved
Department of Health	Ensure that autism awareness training is available to everyone working in health or social care and work with partners to develop effective training modules which can be used by local authorities and primary care trusts to create local training programmes.	The Department of Health has not worked with primary care trusts or local authorities to identify priority groups for training or to develop effective training modules.	–	Not achieved
Department of Health	All local authorities should ensure that staff conducting community care assessments receive autism awareness training.	The Department of Health does not know whether local authorities have ensured that assessors received autism awareness training. However, The National Autistic Society reported that 29 of 152 local authorities had awareness training in place for assessors.	–	Not achieved
Department of Health	Include autism awareness training within general equality and diversity training programmes across all health and social care frontline services and provide examples of how to deliver this training in the statutory guidance.	Examples of best practice training delivery were outlined in the statutory guidance, but no information is available on the extent to which local authorities cover autism within general equality and diversity training. The National Autistic Society reported that 33 of 152 local authorities have held autism awareness events for staff.	December 2010	Partly achieved



**Figure 3** *continued*

## Progress against Strategy commitments to increase awareness among frontline professionals

Accountable department	Commitment	Action taken	Date achieved	Progress
Ministry of Justice and Department of Health	Ensure that autism awareness training is available to all staff in the criminal justice sector.	The Department of Health issued training material to professionals working with offenders with autism, including the <i>Positive Practice, Positive Outcomes</i> handbook. The Department reported that a paper outlining what relevant departments have done and highlighting good practice will be presented to the Programme Board in July 2012.	March 2011	Partly achieved
Department for Work and Pensions	Provide autism awareness training to all Disability Employment Advisers.	The Department for Work and Pensions, in partnership with the Hidden Impairment National Group, <sup>1</sup> developed an online 'Hidden Impairments Toolkit' (including some guidance on autism) to enable Disability Employment Advisers and Jobcentre Plus staff to better support adults with a disability. The Department confirmed that all new advisers receive formal autism training and have done so since 2005. It also revised learning material for advisers to refer to the Autism Strategy and reiterate that they should make contact with other departmental staff with links to local autism forums. However, The National Autistic Society raised concerns about how effective these measures have been in raising awareness of autism and advocated more in-depth training for advisers.	February 2010	Achieved
Department for Work and Pensions	Work with employer organisations to raise awareness of the benefits of employing people with autism.	The Department for Work and Pensions reported that it is working with employer organisations to raise awareness of the benefits of employing people with autism, and the adjustments needed. It meets with employers twice a year to take this work forward. It has also produced, with The National Autistic Society and a range of employers, guidance entitled 'Untapped talent', which was launched in March 2012.	–	Partly achieved
Central government departments	Include autism awareness training in equality and diversity planning and single equality schemes of all central government departments.	It is not clear what progress has been made on this commitment, although the Department for Work and Pensions reported that some information for staff is provided on its intranet site. The Department of Health reported that it will follow up progress on this commitment by meeting with departmental Equality and Diversity Leads.	–	Not achieved

**NOTE**

<sup>1</sup> The Hidden Impairment National Group was established by Jobcentre Plus in February 2010 to improve the skills and knowledge of Jobcentre Plus staff and is attended by leading medical professionals, disability specific organisations (e.g. The National Autistic Society) and people with 'hidden impairments'.

Source: National Audit Office analysis of departmental and charitable sector responses

## Developing a clear, consistent pathway for diagnosis

**2.14** A formal clinical diagnosis can help adults with autism to access services and support. It is therefore important to develop clear and consistent pathways for the diagnosis and referral of people with autism. The Strategy includes a number of commitments aimed at improving: guidance on diagnostic pathways; access to social care assessments; and the quality of diagnostic services in local authorities.

**2.15** While progress on developing guidance has been good, less progress has been made in improving access to social care assessments and diagnostic services in local authorities. Of the nine commitments in this area, five have been achieved, two have been partly achieved, and two not achieved (**Figure 4**).

**Figure 4**

Progress against Strategy commitments to develop consistent pathways for diagnosis of autism

Accountable department	Commitment	Action taken	Date achieved	Progress
<b>Guidance on referral and care pathways for people with autism</b>				
Department of Health	Publish new clinical guidelines covering diagnosis, referral and management of autism among children and young people.	The National Institute for Health and Clinical Excellence published clinical guidelines covering children and young people with autism.	September 2011	Achieved
Department of Health	Publish new clinical guidelines covering diagnosis, referral and management of autism among adults.	The National Institute for Health and Clinical Excellence published clinical guidelines covering adults with autism. <sup>1</sup>	June 2012	Achieved
Department of Health	Local commissioners should review local diagnostic processes against the forthcoming clinical guideline, which will set out a model care pathway(s), to develop referral and care pathways.	The Department of Health does not collect data on whether local commissioners have reviewed local diagnostic processes. Members of the Autism Alliance reported that the National Institute for Health and Clinical Excellence clinical guidelines for children and young people were being applied in some local areas, although others were awaiting the publication, in June 2012, of the guidelines for adults before designing diagnostic pathways. The National Autistic Society reported that 27 of 152 local authorities have established diagnostic pathways. It also raised concerns about the extent to which these pathways will comply with the forthcoming clinical guidelines for adults and about the length of time people wait for a formal diagnosis of autism.	–	Partly achieved
Department of Health	Revise the Fair Access to Services guidance to promote fair and transparent implementation of eligibility criteria for social care.	The Department of Health issued revised Fair Access to Services guidance to cover the application of eligibility criteria for social care and its impact on applicants.	February 2010	Achieved
Department of Health	Developing an online training resource for social care staff to ensure that eligibility criteria are applied more consistently.	The Social Care Institute for Excellence published generic (rather than autism specific) guidance and online training for those involved in applying the eligibility criteria.	April 2010	Achieved

**Figure 4** *continued*

## Progress against Strategy commitments to develop consistent pathways for diagnosis of autism

Accountable department	Commitment	Action taken	Date achieved	Progress
<b>Access to social care assessments</b>				
Department of Health	Link diagnosis to an assessment of individual need in line with the NHS and Community Care Act 1990, requiring local authorities to assess any person who may be in need of community care services.	The Department reiterated these two commitments in the statutory guidance, and confirmed that adults with suspected autism do not need to wait for diagnosis to request a community care assessment. However, The National Autistic Society and the Autism Alliance reported that community care referral assessments are rare, but should increase following publication of the National Institute for Health and Clinical Excellence adult guidelines in June 2012. A survey <sup>2</sup> by The National Autistic Society in May 2012 found that 61 per cent of people with autism had not had an adult needs assessment from a local authority, and 80 per cent of carers had not had a needs assessment.	–	Not achieved
Department of Health	Ensure an autism diagnosis triggers an assessment of carer needs, in line with the Carers Equal Opportunities Act 2004.		–	Not achieved
<b>Diagnostic services in local authorities</b>				
Department of Health	Local areas should appoint a lead professional to develop diagnostic and assessment services for adults with autism.	Many local authorities have appointed an overall autism lead to develop and commission autism services (Figure 2), although The National Autistic Society reported that only 17 of 152 local authorities appointed a specific diagnostic lead. While statutory guidance clearly defines the two roles there is no clear distinction made in the Strategy, leaving it open to interpretation.	–	Partly achieved
Department of Health	Outline in the Department's statutory guidance to local authorities the information adults with autism and carers should receive after diagnosis.	The statutory guidance outlines information adults with autism and carers should receive following diagnosis including on local autism support and voluntary services; national autism representative groups; and the 'Living with Autism' section of the NHS Choices website.	December 2010	Achieved

**NOTES**

1 National Institute for Health and Clinical Excellence, June 2012, *Autism: recognition, referral, diagnosis and management of adults on the autism spectrum*. Available at <http://publications.nice.org.uk/autism-recognition-referral-diagnosis-and-management-of-adults-on-the-autism-spectrum-cg142>

2 The National Autistic Society, *The way we are: autism in 2012*, May 2012. Available at [www.autism.org.uk/Get-involved/50th-birthday/Survey-report.aspx](http://www.autism.org.uk/Get-involved/50th-birthday/Survey-report.aspx)

## Improving access to services and support

**2.16** Mainstream public services can be inaccessible for adults with autism, as many are sensitive to light and noise and experience difficulties with communication. The Strategy therefore includes a number of commitments aimed at ensuring that adults with autism can fully benefit from mainstream public services to live independently. It includes commitments to: improve the transition between child and adult services; make reasonable adjustments to services; and enable access to personalised social care.

**2.17** Good progress has been made on developing guidance, although there is little evidence to date about the impact it has had in improving access to services and support. There has been less progress on the personalisation of social care. Of the 11 commitments in this area, five have been achieved, two are on course to be achieved, three were partly achieved and one not achieved (**Figure 5**).

**Figure 5**

Progress against Strategy commitments to improve access to services and support

Accountable department	Commitment	Action taken	Date achieved	Progress
<b>Improving transition services</b>				
Department of Health and Department for Education	Explore the experience of the transition between child and adult services for young people with autism and their families.	The Department for Education and the Department of Health have commissioned research, due to be published in August 2012, exploring the experiences of young people with autism and carers of the transition between child and adult services. The findings will be used to inform good practice for transition services.	August 2012	On course to be achieved
Department for Education	Deliver a support programme to improve transition planning in local authorities.	The Department for Education spent £19 million on the 'Transition Support Programme', which provided every local authority with funding and support for local advisers to implement the minimum transition standards, set out in the statutory guidance, for disabled people from age 14 as they approach school leaving age.* A review of the Programme by the Department for Education indicated significant improvements with all but one local authority meeting the standard in 2011 compared to 44 of 152 meeting the standard in 2008.	2008 to 2011	Achieved
<b>Making reasonable adjustments to services</b>				
Department of Health	Local authorities should support volunteer and third sector groups in planning and commissioning advocacy and buddy schemes.	The Department does not monitor the extent to which local authorities are supporting volunteer and third sector groups in this regard. The National Autistic Society reported that Autism Strategy Groups are in place, with strong involvement from third sector organisations.	December 2010	Achieved

**Figure 5** *continued*

## Progress against Strategy commitments to improve access to services and support

<b>Accountable department</b>	<b>Commitment</b>	<b>Action taken</b>	<b>Date achieved</b>	<b>Progress</b>
Department for Transport	Make travel training available nationwide for all adults with autism that would benefit from it.	The Department for Transport published a good practice guide for establishing a travel training scheme for adults with a disability. It is not clear, however, whether travel training is available nationwide and The National Autistic Society is concerned that, despite the guidance, training is rarely available to adults with autism*.	May 2011	Partly achieved
Department for Work and Pensions	Ensure Jobcentre Plus advisers are aware both of the need to make suitable adjustments for adults with autism and of the kinds of adjustments that may be beneficial.	Jobcentre Plus issued online guidance for its personal advisers on reasonable adjustments to Jobcentre Plus services via the Hidden Impairments Toolkit (Figure 3)*. In addition, The National Autistic Society and the Autism Alliance, in partnership with the Hidden Disabilities National Group, are working with Jobcentre Plus to increase autism awareness among personal advisers.	June 2011	Achieved
Department for Business, Innovation and Skills	Clarify the types of support that students with autism can pay for with their Disability Students Allowance.	Student Finance England issued guidance to its internal assessors clarifying that social mentoring can be funded through the Disability Students Allowance for students with autism.	December 2011	Achieved
Department for Communities and Local Government	Incorporate best practice on housing design for adults with autism in the Homes and Communities Agency's non-mainstream housing design guidance.	The Homes and Communities Agency published guidance on housing design for adults with autism, as one aspect of the design and refurbishment of non-mainstream housing. The guidance is available online for investment partners, local authorities, designers and developers. <sup>2</sup>	January 2012	Achieved
Department of Health	Deliver guidance for mental health and learning disability services to indicate physical and communication adjustments.	The Department of Health is to revisit guidance for mental health and learning disability services to indicate the types of physical and communication adjustments that should be made for people with autism, and will report to the Programme Board. Examples of adjustments made by health services have been collected by the Learning Disabilities Observatory.	2012	On course to be achieved
Department of Health and Ministry of Justice	Ensure that teams that work within criminal justice agencies, such as the Criminal Justice Liaison Teams, have access to expertise to support adults with autism.	A national programme is underway with the aim of providing access to a liaison and diversion service to all police custody suites and criminal courts by the end of 2014. The programme will cover a wide range of health issues, including autism*.	Scheduled for completion in 2014	Partly achieved

*continued overleaf*

**Figure 5** *continued*

## Progress against Strategy commitments to improve access to services and support

Accountable department	Commitment	Action taken	Date achieved	Progress
<b>Enabling access to personalised care</b>				
Department of Health	Adults with autism are able to access personal budgets and direct payments, in line with the assessment of their needs.	The Department of Health does not have systematic evidence of the extent to which adults with autism are able to access personal budgets, although provided anecdotal evidence of progress in Cambridge, Bury and Nottingham. The National Autistic Society and members of the Autism Alliance raised concerns about access to personal budgets due to, for example, a lack of understanding of the complexity of the needs of people with autism.	2012	Partly achieved
Department of Health	Extend the programme of Payment by Results, which pays hospitals for the activity they do in each speciality, for Mental Health to include adults with autism more effectively.	At the time of our work, the Department of Health was considering how to extend Payment by Results to include adults with autism more effectively.	–	Not achieved

**NOTES**

- 1 Action taken labelled with an asterisk (\*) is generic to learning disabilities rather than autism specific.
- 2 [www.homesandcommunities.co.uk/non-mainstream-housing-design-guidance](http://www.homesandcommunities.co.uk/non-mainstream-housing-design-guidance)

Source: National Audit Office analysis of departmental and charitable sector responses

## Helping adults with autism into work

**2.18** Adults with autism are currently significantly under-represented in the labour market, which has a detrimental impact on their financial circumstances and social inclusion. The Strategy includes commitments aimed at increasing the number of adults with autism in work through the provision of: guidance and training to employers and employment support services; and ensuring adults with autism benefit from employment initiatives.

**2.19** Of the seven commitments in this area, three have been achieved, three partly achieved and one has not been achieved (**Figure 6**). It is not clear what impact the commitments have had in helping adults with autism into work. The National Autistic Society's survey in May 2012 of people with autism found that 10 per cent were receiving employment support. In addition, a third of respondents aged between 16 and 24 were not in education, employment or training, and 41 per cent of those over age 55 had been without a paid job for more than ten years.

**Figure 6**

## Progress against Strategy commitments to help adults with autism into work

Accountable department	Commitment	Action taken	Date achieved	Progress
<b>Guidance and training to employers and employment services</b>				
Department for Work and Pensions	Treble the capacity of the Pathways Advisory Services pilots to test placing Jobcentre Plus advisers in GP surgeries.	The three-year £1.2 million pilot funded 15 Jobcentre Plus advisers in ten GP surgeries between 2008 and March 2011 when the pilot concluded. No new advisers were recruited in the final year of the pilot. This did not meet the Department's commitment to treble capacity.	2011	Not Achieved
Department for Work and Pensions	Examine how Jobcentre Plus customer services address the needs of people with autism.	The Department for Work and Pensions developed an online Hidden Impairment Toolkit (Figure 3) for Disability Employment Advisers and Jobcentre Plus staff highlighting difficulties experienced by people with autism and suggesting support. It also encouraged existing Disability Employment Advisers to undertake formal autism awareness training before the end of 2010; all new advisers have done so since 2005.	–	Achieved
<b>Initiatives to support adults with autism into work</b>				
Department for Work and Pensions	Offer a job coach through the Department's Access to Work programme.	Jobcentre Plus has funded job coaches for people with autism to help them settle into and cope with changes at work. However, The National Autistic Society reported that it is not aware of any examples where the appointment of a job coach has resulted in a person with autism finding employment.	October 2010	Achieved
Department for Work and Pensions	Ensure employment programmes work for young people with autism, and that the choices and support they are offered reflect their specific needs.	The Department for Work and Pensions considers that the Hidden Impairments Toolkit (Figure 3), promoted through the Hidden Impairment National Group, will help to achieve this commitment. However, The National Autistic Society reported that it had not seen evidence that the Toolkit had improved employment opportunities. The Department subsequently reported that its work with employers will take further action on this commitment in partnership with The National Autistic Society and Research Autism.	June 2011	Partly achieved
Department for Work and Pensions	Replace specialist disability provision, such as the Job Introduction Scheme, with a pan-disability Work Choice programme to help long-term disabled people, including those with autism into work.	The Department for Work and Pensions delivered the Work Choice programme to provide tailored employment support. Participation in the programme is voluntary and is not dependent on a successful benefits claim. The National Autistic Society reported, however, that disabilities are not recorded in sufficient detail to identify whether individuals with autism, who can often be more difficult to help, are in practice being helped by the programme.	October 2010	Achieved

*continued overleaf*

**Figure 6** *continued*

## Progress against Strategy commitments to help adults with autism into work

Accountable department	Commitment	Action taken	Date achieved	Progress
Department for Work and Pensions	As part of the Department's Work, Recovery and Inclusion initiative, internships and cover for episodic absences should be available to support adults with autism.	Ten new work placements (internship sites) were established in 2010-11 bringing the total to 14, but according to the Department for Work and Pensions only 25 people with autism have been helped into working 16 hours or more per week. The National Autistic Society and the Autism Alliance raised concerns that there is little provision of internships and short-term cover for adults with autism. The Department for Work and Pensions set out plans in July 2012 to extend its Access to Work programme to young disabled people undertaking work experience under the Youth Contract. The Department considers that this will help disabled people into mainstream placements.	Ongoing	Partly achieved
Department for Work and Pensions	Establish eight local pilots under the Right to Control scheme to test the effectiveness of individual budgets in accessing employment services for adults in receipt of social care.	Seven of the eight pilot sites have been established and are due to run until December 2012. The Department for Work and Pensions reported that their internal Office for Disability Issues will evaluate the pilots in spring 2013 in conjunction with the Department of Health and Department for Communities and Local Government. The National Autistic Society noted that the lack of data on adults with autism within local authorities could make it difficult to establish the impact of individual budgets on people with autism.	December 2012	Partly achieved

Source: National Audit Office analysis of departmental and charitable sector responses

## Enabling local authorities, the NHS and third sector organisations to deliver relevant services

**2.20** The key to enabling adults with autism to play a fuller part in their communities lies in effective local services and support. Much of the responsibility for implementing the Strategy rests with local organisations, and the Strategy emphasises the importance of local authorities, the NHS and third sector organisations working together to develop: services reflecting local priorities, supported by guidance on effective service models; data to plan autism services; and support mechanisms for local delivery.

**2.21** Progress in this area is mixed, with some progress on developing guidance and support mechanisms, but less progress in implementing local commissioning plans or enabling adults with autism to have greater choice and control over how they live. Of the ten commitments in this area, three have been achieved and seven partly achieved (**Figure 7**).



**Figure 7**

Progress against Strategy commitments to enable local authorities, NHS and third sector organisations to deliver relevant services

<b>Accountable department</b>	<b>Commitment</b>	<b>Action taken</b>	<b>Date achieved</b>	<b>Progress</b>
<b>Guidance for local partners</b>				
Department of Health	Provide best practice examples of possible structures for local autism partnerships in the First Year Delivery Plan.	The Department's First Year Delivery Plan provided examples of local autism partnership board structures, which bring together people with autism, carers, local authorities, primary care trusts and service providers. The National Autistic Society reported that 87 of 152 local authorities had established autism partnership boards.	April 2010	Achieved
Department of Health	Provide best practice examples in the Department's statutory guidance of effective service models and cost-effective ways to develop services locally.	The statutory guidance includes examples of cost-effective ways to develop local services including local joint teams from health and social care to assist adults with autism through diagnosis, health management, and day-to-day living. The National Autistic Society provides further examples on its website.	December 2010	Achieved
<b>Information to plan and commission autism services</b>				
Department of Health	Report findings in 2011 of the Department of Health funded study into rates of autism across adults in England.	The Health and Social Care Information Centre published adult autism prevalence rates for England in January 2012 based on a research project that built on its broader 2007 Adult Psychiatric Morbidity survey. However, our review of the results raises concerns about the robustness of national level estimates due to the small sample size and narrow geographic coverage.	January 2012	Partly achieved
Department of Health	Review the Department's Joint Strategic Needs Assessment core data set and include estimates of numbers of adults with autism in the revisions.	A Joint Strategic Needs Assessment provides an assessment of the health and social care needs of a local population to inform the commissioning of health and social care services within local authority areas. The Department of Health produced a core data set in 2008, which provides a list of indicators which local authorities should use in preparing their Joint Strategic Needs Assessment. The data set excluded indicators for the number of people with autism, and has not been updated using the 2012 autism prevalence rates.	July 2011	Partly achieved

*continued overleaf*

**Figure 7** *continued*

Progress against Strategy commitments to enable local authorities, NHS and third sector organisations to deliver relevant services

<b>Accountable department</b>	<b>Commitment</b>	<b>Action taken</b>	<b>Date achieved</b>	<b>Progress</b>
	<i>Relates to commitment from previous page</i>	In July 2011, the Department of Health published a Joint Strategic Needs Assessment data inventory. This can be used by local authorities to generate Joint Strategic Needs Assessments, and includes quantitative and qualitative indicators for both the physical and mental health of children and adults. The inventory included an indicator on the projected number of people with autism. However, The National Autistic Society reported that only 32 of 152 local authorities included autism in Joint Strategic Needs Assessments.		
Department of Health	Develop a protocol by December 2010 for information that should be recorded, how it should be shared with other services, and how to compile local data about numbers of adults with autism into centrally collated data about rates of autism.	The protocol was partly incorporated into the local authority self-assessment tool, but The National Autistic Society reported that the tool does not clarify what information should be recorded and how it should be shared by other services. The Department of Health reported that it is exploring, with the NHS, local authorities and The National Autistic Society, ways to encourage local areas to include autism in their Joint Strategic Needs Assessments. The Information Centre for Health and Social Care has also recently begun a consultation on changing the equality classifications for the standard social care data collected by local authorities. In future, 'autism' could be included as a standard equality classification, which would improve data collection on adults with autism.	–	Partly achieved
<b>Implementing mechanisms to support local delivery</b>				
Department of Health	Local authorities should appoint a joint commissioner ('autism lead') with responsibility for commissioning health and social services for adults with autism.	The Department of Health does not collect data on whether local authorities have appointed an autism lead for commissioning services for people with autism. The National Autistic Society reported that autism leads have been appointed in 115 of 152 local authorities.	–	Partly achieved
Department of Health	Develop regional delivery plans, demonstrating how autism partnership regions will respond to the national autism delivery plan.	All nine regional autism partnerships have a regional delivery plan responding to national delivery plan requirements. The National Autistic Society confirmed that partnership meetings between strategic health authorities, local government offices, deputy regional directors of social care and other key stakeholders had taken place in every region.	October 2011	Achieved

**Figure 7** *continued*

Progress against Strategy commitments to enable local authorities, NHS and third sector organisations to deliver relevant services

<b>Accountable department</b>	<b>Commitment</b>	<b>Action taken</b>	<b>Date achieved</b>	<b>Progress</b>
Department of Health	Develop local commissioning plans for services for adults with autism.	The Department of Health does not collect data on whether local commissioning plans for services for people with autism have been developed. The National Autistic Society reported that 35 of 152 local authorities have developed a local commissioning plan and the Department confirmed that more work is needed to broaden existing plans to include people with autism.	–	Partly achieved
Department of Health	Seek views of adults with autism and carers to inform the design of local services.	There is no clear evidence of the extent to which the views of adults with autism and carers have informed the planning and delivery of local services, although the local authority self-assessment tool does include a related indicator. Some areas such as the East Midlands Regional Partnership include representatives for people with autism and carers. The National Autistic Society reported progress in developing local planning groups, although the involvement of people with autism and carers is not always guaranteed.	–	Partly achieved
Department for Work and Pensions	Review ways to build the capacity of local disabled organisations.	The Office for Disability Issues, part of the Department for Work and Pensions, reviewed ways to build the capacity of disabled organisations, including those that support adults with autism. It has a Disabled People User Led Organisation Programme, with a £3 million budget over four years, to support and develop user led organisations. To date it has awarded over £124,000 to 13 organisations, although none are autism groups.	July 2011	Partly achieved

Source: National Audit Office analysis of departmental and charitable sector responses

**2.22** In addition, the National Institute for Health and Clinical Excellence is due to publish an adult autism quality standard in July 2013. The quality standard will be reflected in the new Commissioning Outcomes Framework which will inform payment mechanisms and incentive schemes such as the Quality Outcomes Framework.<sup>5</sup> The quality standard will aim to embed the needs of adults with autism into the health and social care system by helping:

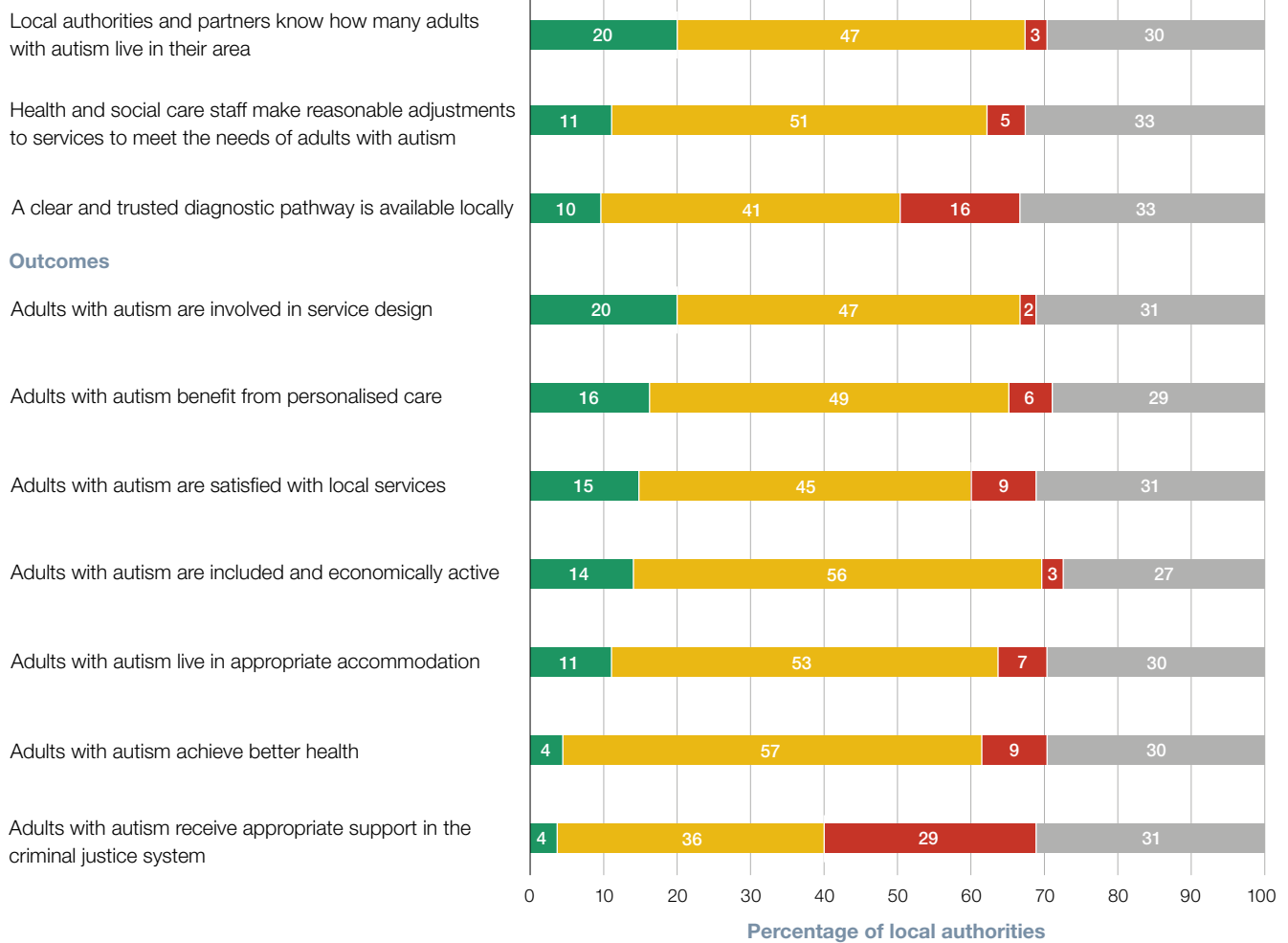
- health and social care professionals to base decisions on the latest evidence and best practice;
- people with autism to understand what service they should expect from health and social care providers;
- service providers to assess and implement high standards of clinical performance and care; and
- commissioners to purchase high quality and cost-effective services.

# Appendix One

Local authority progress: results of the self-assessment exercise

**Figure 8**  
Summary results of the local authority self-assessment exercise

**Service ambitions**



■ Achieved ■ In progress ■ No plan ■ No response

**NOTES**

- 1 A total of 135 of 152 local authorities responded to the self-assessment exercise in March 2012.
- 2 We have based this analysis on the top level results for each of the outcomes and service ambitions in the self-assessment exercise.
- 3 Percentage totals may not add to 100 due to rounding.

Source: National Audit Office analysis of autism self-assessment framework results, March 2012



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National Audit Office

Published online: [www.nao.org.uk](http://www.nao.org.uk)

Design and Production by

NAO Communications

DP Ref: 009919-001