

# 'Fulfilling and rewarding lives'



The strategy for adults with autism in England (2010)

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easy read, Braille, large print and audio.*

# FOREWORD FROM THE SECRETARY OF STATE FOR HEALTH



It has taken time for society to understand autism and sadly, too many lives have not been as fulfilled as they might have been, as people have fallen between the cracks. This strategy is about making faster progress in the future to improve the lives of people with autism and their families.

This Government's ambition – backed up by a wealth of programmes and investments – is to unlock aspiration and make a reality of genuine equality of opportunity for all. The publication of this first national autism strategy for England is a significant and important step to delivering that vision for adults with autism.

Autism is sometimes described as a 'hidden disability', not only because it has no physical signs, but also because adults with autism are some of the most excluded, and least visible, people in the UK.

We know profound change is long overdue. Too many adults with autism are unemployed, struggling to get by on benefits and reliant on the care and support of their parents – both financially and for practical help.

The Autism Act 2009, building on the Bill brought by Cheryl Gillan MP, showed our collective commitment to improve the lives of people with autism and their families – and it has been backed by a range of actions across government to boost the profile of autism across public services.

But our long-term vision goes beyond this. Through this strategy, we want to capitalise on the momentum already gathering in public services so that adults with autism experience real improvements and more opportunities to lead fulfilling and rewarding lives. We want them to receive the right diagnosis as early as possible and access support if they need it, and to know that they can depend on mainstream public services to treat them fairly as individuals.

And, crucially, we will also ensure there is more effective, more tangible support for the families and carers that do so much for adults with autism; they must not be allowed to struggle on without our help.

But real success will depend ultimately not only on transforming services, but on changing attitudes across our society. We need to build public and professional awareness and reduce the isolation and exclusion that people with autism too often face.

Achieving these ambitions won't be easy and will take time. But this strategy is a bold and necessary starting point on an absolutely vital journey to improve the lives of adults with autism.

A handwritten signature in black ink that reads "Andy Burnham". The signature is written in a cursive, slightly slanted style.

Rt Hon Andy Burnham,  
Secretary of State for Health



# MINISTERIAL FOREWORD

The Autism Act 2009 was a unique and groundbreaking piece of legislation. It signalled a new commitment across government to transforming the way public services support adults with autism. But, more importantly, it is the foundation stone for a wider programme of activity across the public sector, designed to drive that change.

This national autism strategy – the first ever created in England – is the next major landmark in this process. It represents a shared approach towards a common goal: a society that not only accepts and understands autism, but also provides real opportunities for adults with autism to live fulfilling and rewarding lives.

The strategy is built on a fundamental recognition: too many people with autism are missing out on the chance of the quality of life that others enjoy. This is a denial of their potential, their personal aspirations, their hopes for the future. It places a heavy burden on their families, and, as many have pointed out, a heavy burden on the UK economy too.

We know that change will be a long-term process. While the Autism Act, and our vision, indicate our ambition, this strategy brings a practical approach. Building on the progress we have made in improving services for children with autism, it focuses on laying the foundations for the change we seek: raising awareness of autism, particularly across public services; increasing the availability and consistency of diagnosis; taking steps to make services more accessible for adults with

autism, putting personalisation – across all services – at the core of our approach; and looking directly at the challenges faced by adults with autism in getting into work and keeping a job, as part of our wider goal of achieving full employment.

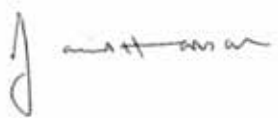
Above all, the strategy seeks to put the needs of adults with autism on the map in every area, so that throughout England the right services can be developed, commissioned and shaped to meet those needs.

Together, these foundations can underpin a wider process of cultural and social change, which is essential to realising our vision. Equally essential is the principle of collaboration across public services, shaping those services around the needs of adults with autism, across the whole of the autistic spectrum. We know that there are already many examples of outstanding services around the country that provide the support adults with autism need. We need to learn from them, both to support the direction we take in the future and to further improve mainstream services, to accelerate progress towards our goal.

Phil Hope,  
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Diana Johnson,  
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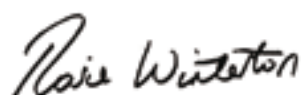
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Rosie Winterton,  
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Local Government



Claire Ward,  
Parliamentary  
Under-Secretary of  
State for Justice



# EXECUTIVE SUMMARY

- 1 The Government's vision is that 'All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.'
- 2 Despite the significant strides made over the last decade to reduce inequality across the UK, we know that adults with autism remain socially and economically excluded. They, and the people who care for them, have often been badly let down by public services which have failed to recognise or respond to their needs.
- 3 While we know that some adults with autism do live fulfilling lives, making successful and important contributions to their communities, the economy and their own families, currently too many adults with autism are not able to do this. Too many are dependent on benefits for their income and on the care and support of their families, not only for housing but simply to cope with their everyday lives. For those without this support, the outlook is worse: the risk of severe health and mental health problems, homelessness, and descent into crime or addiction. The costs in financial terms to public services are enormous: the costs in emotional terms for both adults with autism and their families more devastating still.
- 4 By improving the lives of adults with autism, by enabling them to live independently, supporting them into work and while at work, and by identifying their health needs earlier, the impact will be immense.
- 5 The landmark Autism Act 2009 is a symbol of the Government's commitment to achieving our vision and delivering such an impact within our society. The first ever piece of legislation designed to address the needs of one specific impairment group – adults with autism – it has already triggered a response, across government and public services, that is beginning to drive change. This strategy builds on that, setting a direction for long-term change to realise our vision but also identifying specific areas for action over the next three years. It also draws on the findings of the National Audit Office (NAO) report *Supporting people with autism through adulthood*.<sup>1</sup>
- 6 The strategy is underpinned by the fundamental principles of equality and human rights. It takes as its starting point the breadth of government policy – from health to social care to employment to justice to communities – that already should support adults with autism,

1. National Audit Office (2009) *Supporting people with autism through adulthood*. Report by Comptroller and Auditor-General HC 556 Session 2008–09. Throughout the rest of this document, this is referred to as 'the NAO report'.



- and seeks ways to ensure that this policy framework addresses their real needs. This policy framework is wholly transforming the way public services are planned, commissioned and delivered. In many areas, the changes introduced are beginning to have an impact on people's lives, including the lives of adults with autism. We believe it is important that these changes form the basis of the improved services and support available to adults with autism.
- 7 This not only reflects the current economic situation, where every public sector organisation is facing budget restrictions and is required to do more with less, but is also in line with the Government's overall policy direction of reducing statutory requirements and encouraging frontline staff to develop services and solutions to meet local needs. While we recognise that these factors make it a difficult time for public services to respond to a new strategy, we can no longer ignore the moral imperative to address the unmet needs of so many members of our society.
- 8 The first and fundamental step of our strategy is to increase awareness and understanding of autism across all public services. If frontline staff know more about autism, they will be better able to recognise the condition and respond to it. This is essential to making existing policies work for adults with autism – across the entire autistic spectrum.
- 9 Chapter 2 of the strategy focuses on ways to increase awareness in health and social care, employment advice and other frontline public services. It includes recommendations to improve the autism awareness training given to staff across government, working with relevant bodies in each sector – as well as drawing on the input of adults with autism themselves – to build awareness of autism across frontline staff. The goal is to develop and deliver training and information resources that enable staff to adapt the way they provide services to an adult with autism – from their behaviour and communication to more fundamental changes, such as the treatments recommended in healthcare and the choices offered in social care or employment support.
- 10 The chapter also recognises the opportunities that come from putting autism awareness on the agenda with employers, as part of the Department for Work and Pensions' (DWP) programme of engagement with employers around recruitment and retention of disabled people.
- 11 The second strand of our strategy focuses on diagnosis and our goal of increasing capacity around diagnosis of autism in every area of the country. Chapter 3 explains how we are working with the National Institute for Health and Clinical Excellence (NICE), which is producing a clinical guideline that will include diagnostic processes. This can then be used by local National Health Service (NHS) bodies to

- develop a clear and consistent pathway for diagnosis.
- 12 Local commissioning of specialist autism teams can be an important way to build capacity locally, particularly around diagnosis. Across the country, there are a number of successful models of such teams and some examples are included in chapter 3.
  - 13 Crucially, we will also ensure that diagnosis is not an end in itself, but rather the beginning of improved support for an adult who has been diagnosed with autism. In particular, we underline the duty under the NHS and Community Care Act 1990 for local authorities to assess a person who may be in need of community care services. Diagnosis of autism is already a reason for such an assessment – and needs to be recognised as such.
  - 14 An assessment of need is only valuable if effective services are available to support adults with autism. That is why chapter 4 sets out recommendations for improving access for adults with autism to the services and support they need. Like other changes, this is not something that can happen overnight, but the strategy creates a strong platform for beginning and driving forward the process of reform. In particular, it reiterates the requirement under the Disability Discrimination Act 2005 (DDA) for services to make reasonable adjustments for disabled adults: this includes adults with autism.
  - 15 The chapter then examines how we can make personalisation of social care work for adults with autism – giving them greater choice and control over the services and support they receive. A key part of this is ensuring a smooth and successful transition to adult services for those people who have been diagnosed with autism as children.
  - 16 Over the last few years, the Government has made it clear that work is the best form of welfare, the most effective route out of poverty and a vital part of social inclusion. However, adults with autism are currently significantly under-represented in the labour market. That is why chapter 5 looks at how we will help adults with autism into work. It explains changes underway to the welfare system to better support adults with autism, through effective work preparation programmes and through improvements to our benefits and tax credit systems.
  - 17 While these chapters explain our overall direction, it is clear that the key to change lies at the local level. In chapter 6, therefore, we focus on building capacity and capability at local level to enable local partners to develop relevant services for adults with autism to meet identified needs and priorities. We set out some key recommendations, rooted in effective practice around the country, that local partners should consider in planning and commissioning services. In particular, we make it clear that we expect each local area to develop its own commissioning plan for

services for adults with autism – building on the outcomes of the Joint Strategic Needs Assessment (JSNA). Such plans help make it clear to all local partners, and local representative groups, how change will be delivered in each area.

- 18 The strategy is designed to set overall direction. It will be followed by a first-year delivery plan by 31 March 2010, and the publication of statutory guidance for health and social care and a full delivery plan by the end of 2010. It will be formally reviewed in 2013. Progress on delivering the strategy will be led nationally by a new autism programme board, which will be co-chaired by the Minister for Care Services and the Director-General of Social Care at the Department of Health (DH).

# TERMINOLOGY

In producing this strategy, we recognise that there are a number of terms that different individuals and groups prefer to use, including autistic spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity. In this strategy, we use the term “autism” as an umbrella term for all such conditions, including Asperger syndrome. This is in line with the approach to terminology adopted by key autism representative organisations, including the National Autistic Society (NAS), as well as the NAO and the Public Accounts Committee (PAC) in their recent reports, and will help ensure the strategy is understood by and accessible to the widest possible audience.

For the purposes of this strategy, autism is defined as a lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. The three main areas of difficulty, which all people with autism share, are known as the ‘triad of impairments’. They are difficulties with:

- social communication (e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice)
- social interaction (e.g. problems in recognising and understanding other people’s feelings and managing their own)

- social imagination (e.g. problems in understanding and predicting other people’s intentions and behaviour and imagining situations outside their own routine).

Many people with autism may experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours. People with autism often prefer to have a fixed routine and can find change incredibly difficult to cope with. Many people with autism may also have other conditions such as attention deficit hyperactivity disorder (ADHD), a learning disability or dyspraxia.

Autism is known as a spectrum condition, both because of the range of difficulties that affect adults with autism, and the way that these present in different people. For example, Asperger syndrome is a form of autism. People with Asperger syndrome typically have fewer problems with speaking than others on the autism spectrum, but they do still have significant difficulties with communication that can be masked by their ability to speak fluently. They are also often of average or above average intelligence.





# 1. 'FULFILLING AND REWARDING LIVES': THE STRATEGY FOR ADULTS WITH AUTISM IN ENGLAND

## Our vision for adults with autistic spectrum conditions

1.1 The Government's vision for transforming the lives of and outcomes for adults with autism is:

**'All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.'**

1.2 For adults with autism, this means:

- having a right to receive an assessment of need from social services
- getting the same opportunities for education and further education as everyone else
- being supported to get a job and stay in work
- being able to choose where to live – just like anyone else

- having relationships and social networks
- having their health needs properly met in a way which is appropriate for someone with autism
- being safe from hate crime and discrimination
- living in a society where people understand, respect and accommodate difference, and
- receiving support to live independently, as appropriate.

1.3 This vision is grounded firmly within an equality and human rights approach. It is based on the fundamental principle that adults with autism have the same rights as everyone else, and that they should be able to access services and participate in society on an equal basis.

1.4 We know that – despite the significant strides made over the last decade to increase equality and tackle exclusion – adults with autism are currently not treated fairly. They, and the people who care for them, have often been badly let down by public services which have failed

to recognise or respond to their needs. This must change.

## Realising our vision

1.5 The vision set out above is a long-term goal. Achieving it requires a cultural shift, where the complexities and challenges of autism are understood not only by public services but also more widely within society. It also requires many of the changes currently underway within public services to be embedded: approaches such as personalisation in care provision, *Work Choice* and integrated local commissioning are essential to giving adults with autism the right support in the right way.

1.6 But the benefits of achieving this vision are huge. While we know that some adults with autism do live fulfilling lives, making successful and important contributions to their communities, the economy and their own families, currently too many adults with autism are not able to do this. Too many are dependent on benefits for their income and on the care and support of their families, not only for housing but simply to cope with their everyday lives. For those without this support, the outlook is worse: the risk of severe health and mental health problems, homelessness, and descent into crime or addiction. The costs in financial terms to public services are enormous: the costs in emotional terms for both adults with autism and their families more devastating still. By improving the lives of adults with autism, by enabling them to live independently, supporting

them into work and while at work, and by identifying their health needs earlier, the impact will be immense.

1.7 This strategy is an essential step towards realising our vision. It builds on the work that is already underway to transform the services and support available to adults with autism, in particular the Autism Act 2009. While the strategy sets the direction for this long-term change, its focus is on the shorter term – specifically, the next three years – after which **we commit to formally reviewing progress and revising the strategy as necessary**. During these three years, our strategy focuses on:

- 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.



- 1.8 **To oversee progress against the strategy, and provide overall direction and governance, DH is now setting up a national autism programme board, which will be co-chaired by the Minister for Care Services and the Director-General of Social Care. The board will include representatives from other government departments as well as stakeholder groups.**

to address the unmet needs of so many members of our society.

- 1.10 *Valuing People Now*,<sup>3</sup> the Government's strategy for people with learning disabilities, recognised that adults with autism are some of the most excluded and least heard people in society – and that service providers, commissioners and policy makers were not specifically addressing their needs. While action being taken forward under *Valuing People Now* will benefit those adults with autism who also have learning disabilities – approximately half of them – the Government is clear that more must be done to support all adults across the whole autistic spectrum.

- 1.11 Building on the evidence set out in a series of important and telling reports, including *I Exist* (published by NAS),<sup>4</sup> the Autism Act 2009 sets out the Government's commitment to improve inclusion and ensure adults with autism are able to participate fully in society.

## The Autism Act 2009: a legislative landmark

- 1.9 The Autism Act was created in response to increasing evidence that a significant proportion of adults with autism, across the whole autistic spectrum, are excluded both socially and economically. For example, estimates suggest that only 15% of adults diagnosed with autism are in employment,<sup>2</sup> health outcomes are worse than for the population at large, and a large number of adults with autism continue to live with their families rather than independently in their own homes. This is not acceptable, and it is clear that action needs to be taken locally, regionally and nationally to lead change. While we recognise that the economic climate, and particularly the budgetary constraints on all public services, which are compelled to do more with less, make it a difficult time for public services to respond to a new strategy, we can no longer ignore the moral imperative

## The immediate impact of the Autism Act

- 1.12 The Autism Act 2009 was the first ever piece of legislation designed to address the needs of one specific impairment group: adults with autism. The publication of this unique and groundbreaking Act has brought the challenges faced by adults with autism to the fore as never before.

2. NAS (2008) *Think Differently – Act Positively: Public perceptions of autism*, p. 19 ([www.autism.org.uk/content/1/c6/01/47/21/think%20diff%20act%20pos.pdf](http://www.autism.org.uk/content/1/c6/01/47/21/think%20diff%20act%20pos.pdf))

3. DH (2009) *Valuing People Now: A new three-year strategy for people with learning disabilities*

4. NAS (2008) *I Exist: The message from adults with autism in England*

It has already helped raise awareness of autism, generating widespread media and public discussion. It demonstrates that the Government recognises autism as a lifelong condition that has a major impact on the lives of both those people with the condition, and those who care for and support them.

1.13 The development of the Act, meanwhile, highlighted a range of issues and challenges around support for adults with autism which government bodies have already begun to address.

- To further increase knowledge on the prevalence of autism in adults, DH is funding a study to explore rates of autism in a representative sample of adults in England. This will report its findings in 2011.
- This comes in addition to the DH commitment, set out in *Valuing People Now* (2009), to establishing a new three-year Public Health Observatory (PHO) in relation to people with learning disabilities. The work of this new PHO will include the collation of existing data on the prevalence of people with autism who also have a learning disability, what services they access, and the quality of those services.
- To improve processes around diagnosis, referral and management of autism, NICE is developing two new clinical guidelines – one covering adults,

and one covering children and young people.

- To help put the needs of adults with autism on the map in every area, estimates of numbers of adults with autism will be included in the revised core data set for JSNAs, due to be published in spring 2010.
- To reinforce the requirement under the DDA that services should make reasonable adjustments for adults with autism, the 2010/11 NHS Standard Contract for Mental Health and Learning Disability Services includes, for the first time, specific reference to adults with autism.
- To help drive forward the personalisation agenda in social care for adults with autism, the Social Care Institute for Excellence (SCIE) is working with NAS to produce an *At a Glance Personalisation Briefing on Autism* – one of a series of such briefings for different groups.
- To accelerate the development of effective local services for adults with autism, DH is planning to extend its programme of Payment by Results for Mental Health to include adults with autism more effectively. The recently published care clusters which act as a national currency (common contracting and payment unit) will be available for use in 2010/11, but do not adequately capture the care requirements of adults with autism. Therefore DH will work with

autism experts during 2010 to consider how this can be addressed.

- As part of ongoing measures to inform good practice in services at transition, it will be important to explore through research the specific experiences of young people with autism and their families of multi-agency transition services. That is why DH and the Department for Children, Schools and Families (DCSF) are funding a study, which will report in January 2012.
- In response to a PAC comment that "university students with autism may need to use Disabled Students' Allowances (DSAs) to fund social, rather than course-related, support",<sup>5</sup> the Department for Business, Innovation and Skills (BIS) will take steps to clarify the types of support that students with autism can pay for with their DSA.

1.14 There are also emerging indications that the needs of adults with autism are becoming recognised more widely, and that local services are beginning to evolve to meet those needs. The Care Quality Commission report *The State of Health Care and Adult Social Care in England 2009* found that 83% of local authorities surveyed were now considering the needs of adults with autism in JSNAs, commissioning strategies and plans.<sup>6</sup> We now need to build on this momentum.

1.15 In developing the Act, Parliament recognised that much had already been done to improve the lives of children and young people with autism. It also acknowledged that actions now underway would continue to support children and young people more effectively. As a result, the focus of the Act is on adults, and it specifically requires the development of "a strategy for meeting the needs of adults in England with autistic spectrum conditions by improving the provision of relevant services to such adults by local authorities, NHS bodies and NHS foundation trusts".<sup>7</sup> This document provides that strategy.

1.16 The Act also mandates the development of statutory guidance for health and social care to support the implementation of the strategy. This will be published no later than 31 December 2010 and must include guidance about:

- “(a) the provision of relevant services for the purpose of diagnosing autistic spectrum conditions in adults;
- (b) the identification of adults with such conditions;
- (c) the assessment of the needs of adults with such conditions for relevant services;
- (d) planning in relation to the provision of relevant services to persons with autistic spectrum conditions as they move from being children to adults;

5. House of Commons PAC (2009) *Supporting people with autism through adulthood*

6. Care Quality Commission (2009) *The State of Health Care and Adult Social Care in England: Key themes and quality of services in 2009*

7. Autism Act 2009, section 1 (1)

- (e) other planning in relation to the provision of relevant services to adults with autistic spectrum conditions;
- (f) the training of staff who provide relevant services to adults with such conditions;
- (g) local arrangements for leadership in relation to the provision of relevant services to adults with such conditions.”<sup>8</sup>

The statutory guidance will build on the core areas of activity set out in this strategy.

## Implementing the strategy

- 1.17 **We will also publish a first year delivery plan by 31 March 2010**, setting out our priority actions to make change happen, including the development of regional delivery plans. This will be followed by a further delivery plan, giving more detailed plans for the longer term.
- 1.18 This strategy, along with the statutory guidance and delivery plans, is also an integral part of the Government’s response to the NAO report and the PAC report. The Government agrees with the conclusions set out in both of these important reports; the core themes of the NAO report – better strategy and planning, based on good information and raising levels of knowledge and awareness of the nature of autism and the potential needs of autistic people – are at the heart of this strategy.

1.19 We have examined the recommendations made by both the NAO and PAC in depth, particularly in the light of the responses to the consultation conducted during summer 2009, and these are reflected in this strategy. Where we believe that existing measures and approaches will better meet the objectives which NAO and PAC set out, we will make this clear. Further details on the actions we propose to take will be included in the first-year delivery plan, and some specific recommendations will be taken forward in that delivery plan and the statutory guidance that will follow.

1.20 Officials have also met NAO representatives to discuss ways to work together to build on the data modelling and analysis the NAO set out in its report, to improve our shared understanding of the costs and benefits of interventions to improve the lives of adults with autism.

## The focus of the strategy

- 1.21 The strategy focuses 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 to the services and support which adults with autism

8. Autism Act 2009, section 1 (5)

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.

These are important in themselves, but more significantly they are the foundations for the further change needed to achieve our long-term goal.

- 1.22 The approach in this strategy is to identify how to make existing policies work better for adults with autism. It does not depend on new investment – vital in the current economic context, where every public sector organisation is facing budget restrictions and is required to do more with less. It avoids putting increased burdens on frontline staff delivering public services, on businesses or on local planners with additional statutory requirements. It relies instead on the more substantial approach of ensuring mainstream services actively identify and respond to the needs of adults with autism.

## Building on existing policy

- 1.23 This approach reflects the fact that there is already a wealth of government policy and initiatives that should support adults with autism. These together embody the

agenda to personalise public services and include *Valuing People Now* and *Valuing Employment Now*, *New Horizons*, *Putting People First*, *High Quality Care for All*, *World Class Commissioning*, *Creating Strong, Safe and Prosperous Communities*, *Transforming Adult Social Care*, *Access to Work*, *Work Choice*, *Improving Health*, *Supporting Justice*, Lord Bradley's review of people with mental health problems or learning difficulties in the criminal justice system and *Roadmap 2025*.<sup>9</sup>

- 1.24 These programmes are about wholly transforming the way public services are planned, commissioned and delivered. In many areas, the changes introduced through these initiatives are beginning to have an impact on people's lives, including the lives of adults with autism. Public services are adapting the way they work and building their skills and capacity. We believe it is important that these changes form the basis of the improved services and support available to adults with autism. We have heard the message that people are missing out because they don't fall into either the learning disability or mental health 'box'. This is unacceptable.

- 1.25 Personalisation is about assessing the particular needs of each individual and giving them choice and control to build the right package of care based on those needs. The goal of this strategy is to move from fitting people into services to fitting services to meet people's needs.

9. See the list of policies that apply to adults with autism at the end of this document (p. 72).

## The core of our strategy

1.26 The first, and fundamental, step towards this is to **increase awareness and understanding of autism** across all public services – one of the NAO’s core themes. If frontline staff know more about autism they will be better able to recognise the condition and respond effectively when they are working with adults with autism. This is essential to making the existing policies work for adults with autism. As a minimum, autism awareness should be included as part of general equality and diversity training across the public sector. In certain professions – particularly health and social care – more specific training is required, both for those entering the profession and those already working. **We therefore commit to working with Skills for Health, Skills for Care, professional bodies and the Royal Colleges to ensure that effective training is developed.**

1.27 Increased awareness goes hand in hand with improving access to diagnosis. Many individuals and families have found that getting a diagnosis can be a difficult, time-consuming and frustrating process. Diagnosis can be important not only to individuals and families but also to those working with adults with autism. It is likely that staff will find it easier to help someone with autism if they know that this is their diagnosis.

1.28 That’s why the second strand of our strategy is to **develop a clear, consistent**

## pathway for diagnosis of autism

across the country. To support this, NICE is developing a clinical guideline which will include diagnostic processes. Our aim is to increase capacity around diagnosis so that in every area of the country people have easier access to diagnosis if they want it.

1.29 Crucially, we will also ensure that diagnosis is not an end in itself. The NHS and Community Care Act 1990 places a duty on local authorities to assess a person who may be in need of community care services. Diagnosis of autism is a reason for such an assessment – and needs to be recognised as such.

1.30 An assessment of needs is a vital step towards the third strand of our strategy: to **improve access for adults with autism to the services and support they need** to live independently within the community. For many, this simply means being able to access mainstream services more easily – creating parity of access to services across the whole public sector. Such services are designed to be available to all: people with autism must be able to benefit from them.

1.31 Equality and human rights legislation, including the DDA, makes it clear that services are required to make reasonable adjustments for disabled adults: this includes adults with autism. **We commit to delivering guidance to indicate the kinds of adjustments that might usefully be made, from physical adjustments to premises to improving**

**the ways those delivering services communicate with adults with autism.**

1.32 Personalisation of social care aims to increase individuals' involvement in assessing their own care needs, and give them greater choice and control in planning the kind of care available. This can include provision of direct payments and personal social care budgets. It is essential that, despite the many challenges involved, this approach is made to work for adults with autism that need social care, enabling them to exercise choice and control over the care they receive.

1.33 To succeed in the emerging world economy, we must use the skills, talents and aspirations of all our people. The ability to get, and keep, a job and then to progress in work is the best route out of poverty. That is why a key principle of welfare reform is a focus on retention and progression, not just job entry. Enhancing skills is vital to achieve this. In recognition of the fact that adults with autism are significantly under-represented in the labour market, we believe it is essential that we focus on **helping adults with autism into work**. As part of this, and following feedback from adults with autism and their families that the benefits system can be difficult to understand, we are also continuing to clarify the system and the help people are entitled to. The forthcoming delivery plan will provide more details on some of the actions we will take.

1.34 Above all, the key to enabling adults with autism to play a fuller part in their communities lies in effective local services and support. Therefore the fifth strand of our strategy is to build capacity and capability at local level **to enable local partners to develop relevant services for adults with autism to meet identified needs and priorities**, learning from what already works and involving adults with autism in developing those services where appropriate. This should include consideration of the approach embodied in *Total Place* initiatives in breaking down the barriers between different services and increasing the use of pooled budgets to better meet the needs of the whole community.

1.35 DH has already provided guidance<sup>10</sup> for Directors of Adult Social Services (DASS) that recommends the appointment of a joint commissioner/senior manager who has in his/her portfolio a clear commissioning responsibility for adults with autism. Now we set out our expectation that each local area should develop its own commissioning plan for adults with autism. This, along with the inclusion of estimated numbers of adults with autism within the core data set for JSNAs (see 1.13 above), will help ensure the needs of adults with autism are not overlooked.

10. DH (2008) *Services for adults with autistic spectrum conditions (ASC): Good practice advice for primary care trust and local authority commissioners*

## Understanding the parameters of the strategy

1.36 The strategy seeks to represent the needs of those across the entire autistic spectrum, and those who care for and support them. It has been developed using the core principles of inclusivity and co-production, with extensive public consultation<sup>11</sup> and the involvement of an External Reference Group on autism. We have sought the views of adults with autism themselves, and also their families and informal carers, representative organisations and professionals working in any field who come into contact with adults with autism.

1.37 The consultation process also highlighted examples from around the country of effective ways to adjust and develop services to support adults with autism. The strategy – and particularly the forthcoming guidance – will share these examples, to help local commissioners and planners learn from what works.

1.38 We believe that, over the next three years, many of these approaches will become more commonplace. Through this, we will gain a better understanding of best practice. Other ongoing activities, including the implementation of the autism strategy in Wales, as well as drawing on the evidence that we have and continue to gather about rates of autism, will also inform our future direction when the strategy is reviewed in 2013. This

review will naturally involve the views of stakeholders, and in particular the views of adults with autism and their families.

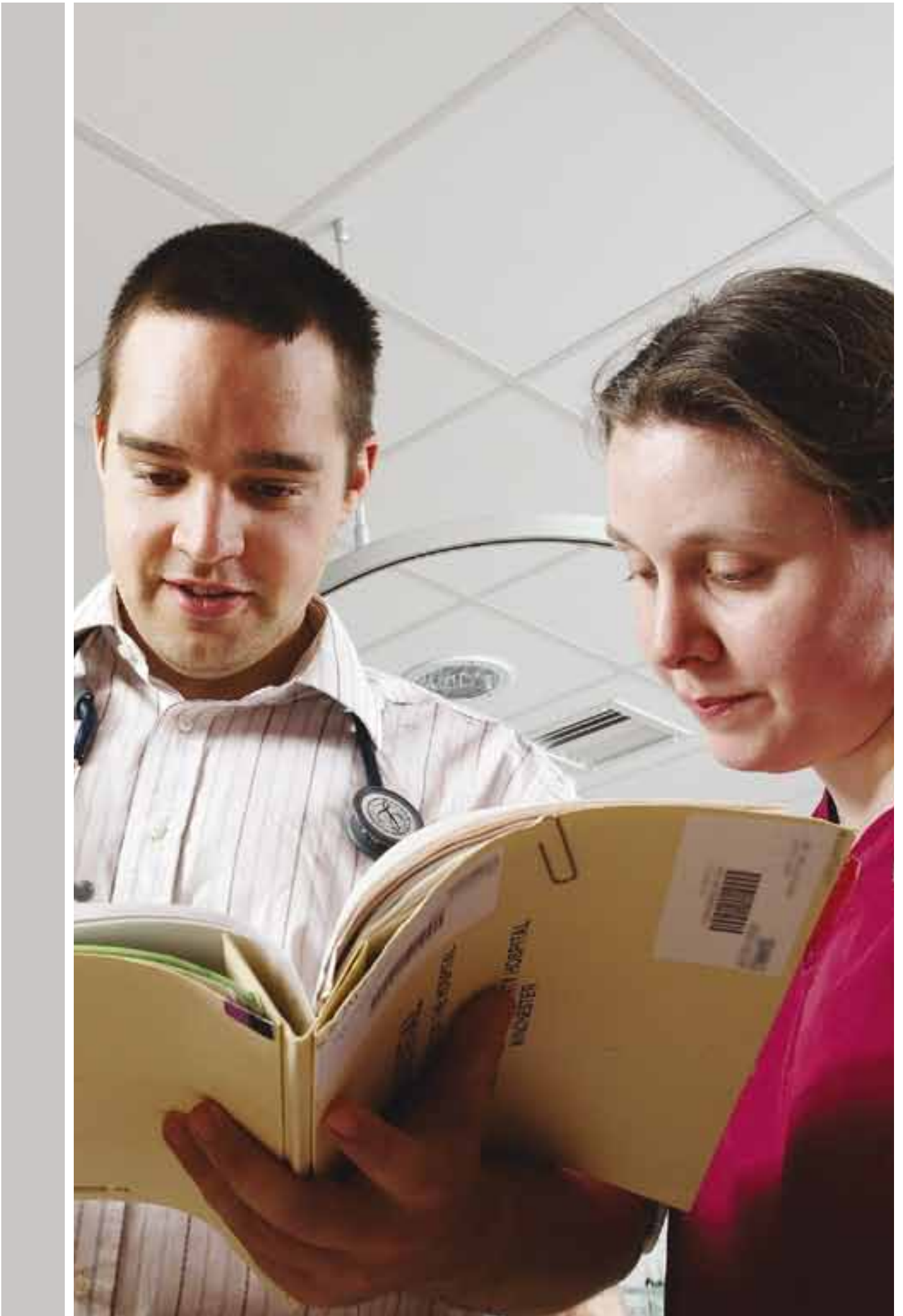
1.39 This strategy is a strong start to a long journey. Fundamental to delivering real inclusion and equality for people with autism is a change in culture, attitudes and behaviours across the public sector. That cannot be achieved overnight. That is why **we commit to keeping progress under review so that we can take further action if the improvements we seek are not delivered.**

1.40 Change will be a long-term process. But the actions and approach described below will deliver a real impetus and set a clear framework for development of local partnerships and services to transform the lives of people with autism.

11. The *Overarching report of findings from the Adult Autism Strategy consultation activities* is available at [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_110923](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_110923)  
A summary of submissions received can be found at [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_111278](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111278)







## 2. INCREASING AWARENESS AND UNDERSTANDING OF AUTISM

Frontline staff, from GPs to benefits advisers, acknowledge that their understanding of autism is limited. While most professionals know something about autism, they do not necessarily understand how autism affects people. This makes it hard for them to recognise autism and communicate appropriately. It also means they may have little idea of how to adapt their behaviour and their services.

In this chapter, we set out our strategy to increase understanding of autism by:

- improving autism awareness training for all frontline public service staff, in line with the needs of their job, and
- developing specialist training for staff in health and social care.

### Awareness of autism today

2.1 *“Although most people have heard of autism, they do not actually understand the whole spectrum and how it affects people differently. Most will cite ‘Rain Man’ and assume that all autistic people are the same as the character in the film.”<sup>12</sup>*

- 2.2 As adults with autism, or their family and carers would testify, this is simply not the case – and this stereotyping is one of the biggest sources of frustration and causes of isolation.
- 2.3 While causing problems in all aspects of everyday life, a lack of understanding is most damaging in public services.
- It can mean adults with autism do not trust public services, and creates a barrier to their wanting to use them.
  - A lack of understanding that autism is a spectrum condition can lead to inappropriate, stereotypical or narrow responses. Adults with autism have told us about employment advisers who had recommended only certain types of jobs to them, social workers who had assumed that all people with autism have a learning disability, and others who had simply directed all adults with autism to Asperger syndrome support groups.
  - If staff do not know about autism and how it affects behaviour and responses, then they can have no idea of how to adjust the way they deliver services, their

12. This quotation comes from a consultation response. Throughout this strategy, we make frequent use of such responses, unedited. Any quotation in italics is a consultation response.

approach to communication or their expectations.

*“Professionals have a habit of asking the person with an ASC [autism] for insight into their own problems e.g. why do you think you are feeling like this? The person struggles to find a reason and comes up with whatever they can think of at the time.”*

*“Service users [adults with autism] are often treated under general anaesthetic in hospital just to treat simple conditions because the person won’t keep still and alternative solutions for treatment have not been explored.”*

- In the criminal justice system, police officers, probation services and courts may all be unaware of the communication challenges posed – leading to overly heavy-handed responses to incidents.

*“People think that autistic people are being rude or arrogant and ban them from cafes, pubs, cinemas etc. They call the police who also believe the autistic person to be arrogant, rude etc and then arrest them for a public order offence.”*

- 2.4 Many professionals recognise that this lack of understanding is a problem. The NAO report found that “eighty per cent of GPs feel they need additional guidance and training to manage patients with autism

more effectively”.<sup>13</sup> This refers not only to knowing more about how to communicate with individual patients, but also to having the understanding to tailor treatment programmes or interventions to reflect the needs of patients with autism.

### **Improved understanding makes a big difference**

- 2.5 Where professionals do understand autism, however, the impact on services – and on the lives of adults with autism – is immense. The consultation received several examples of this, with respondents citing GPs and dentists, colleges and universities, who have sought to understand autism and used that understanding to improve services. Our goal is to ensure that such understanding is more widespread. This is wholly in line with the NAO report and recommendations. However, increasing awareness and understanding of autism should be considered as a starting point and not a solution in itself.

- 2.6 Equally, there are many examples from within the community, of individuals who have informed themselves about autism to help them better respond to an adult they know or work with.

*“My son’s cleaners are the most valuable of all his supporters. They have been on the internet, looking up Aspergers and are able to talk with him effectively. They clean his house well and he knows what they are*

13. NAO (2009) *Supporting people with autism through adulthood*, p. 19, para 2.3

*there for. They do not patronise, placate or criticise.”*

## Increasing awareness and understanding of autism

### Improving autism awareness training for all frontline public service staff, in line with the needs of their job

2.7 When adults with autism use public services, all too often the onus is on them (or their carers) to explain to staff what having autism means. In some cases, this can affect their eligibility for financial support; in others, it can make a major difference to the advice they receive. When it comes to the criminal justice services, it can change the way that police officers or courts view a situation.

2.8 To tackle this and increase understanding of autism among frontline staff, **we recommend that autism awareness training should be included within general equality and diversity training programmes across all public services.** For example, autism awareness could be included as an integral part of the training strategy outlined in *Improving Health, Supporting Justice*.<sup>14</sup> Extending equality and diversity training programmes in this way is not just good practice: it reflects the duty under the DDA to make reasonable adjustments for disabled adults – including adults with autism.

2.9 While it will be up to individual organisations to decide how to provide

such training, **the forthcoming statutory guidance will provide examples of best practice for health and social care, and emphasise the importance of involving adults with autism and their carers in developing and delivering training.**

2.10 This training should focus less on the theory of autism and more on giving staff an insight into how autism can affect people, drawing directly on the experiences and input of adults with autism and their families. This will better enable staff to understand the potential behaviours of adults with autism in different settings, so they can respond appropriately and make reasonable adjustments to better accommodate adults with autism.

2.11 A particular area where adults with autism have highlighted the need for increased awareness is among employment and benefits advisers. This reinforced the findings of the NAO report. Since November 2005, Jobcentre Plus has included autism-specific content as part of its training for new Disability Employment Advisers (DEAs). To enable existing DEAs to acquire and maintain their knowledge of autism, Jobcentre Plus has supported two autism tutorials held by the Employers' Forum on Disability. Events such as these help advisers, including DEAs, to develop an even greater understanding of autism and the issues related to employment. It will now build on this by **ensuring that autism awareness training is provided to all DEAs who have not yet received**

14. DH (2009) *Improving Health, Supporting Justice: The National Delivery Plan of the Health and Criminal Justice Programme Board*

**it**, and reviewing ongoing learning processes to make sure DEAs maintain and update their knowledge.

2.12 Jobcentre Plus has also focused on ways to improve the autism awareness of Personal Advisers and make sure they become aware of autism and the issues related to employment earlier in the training process than before. It has done this by specifically directing advisers, during their initial training, to guidance on autism, developed in consultation with individuals and organisations who understand autism and have expertise in responding to those with the condition.

2.13 Personal Advisers continue to have access to online training modules covering autism, as well as the advice of DEAs on specific disabilities.

2.14 **We believe it is therefore essential that autism awareness training is available to all staff in the criminal justice sector.** Currently, there is a programme of awareness training for prison staff which aims to raise awareness of the needs of prisoners who have learning disabilities. This programme, which is supported by the DH National Learning Disability Offender Steering Group, includes autism awareness.

### **Developing specialist training for staff in health and social care**

2.15 Health and social care are sectors where the need for training is perhaps even greater. Staff here come into contact with adults with autism most frequently, and can

be highly influential in determining the kind of support adults with autism receive, both through needs assessment processes and in terms of the actual care and treatment prescribed or provided.

2.16 **We believe it is therefore essential that autism awareness training is available to everyone working in health or social care** – from specialist consultants to GP receptionists, whose response to an adult with autism in the waiting area or trying to book an appointment may influence their willingness to visit their doctor.

2.17 That training must lead not only to improved knowledge and understanding but also to changing the behaviour and attitudes of health and social care staff. To do this, training should reflect the actual situations staff work in.

2.18 **We will therefore work with partners to develop effective training modules and approaches which can be used by local authorities and primary care trusts (PCTs) to create training programmes locally.** The statutory guidance to be published in 2010 will provide examples of effective approaches, drawing on the experience of previous programmes – such as the training provided around learning disabilities – to improve the knowledge of frontline practitioners. This may include e-training modules and half-day or full-day training courses from experts in the diagnosis and management of autism.

**2.19 DH has also recently commissioned the development of new online resources and information about autism for those working in the health and social care sectors.**

These will provide an instantly accessible resource for professionals and practitioners to refresh their knowledge and improve their ability to understand and respond appropriately to people with autism.

2.20 Clearly, training the millions of people who work in the health and social care sectors is an enormous challenge and cannot happen overnight. **We will work with PCTs and local authorities to identify priority groups for training** – many of whom will be staff directly involved in providing residential or day care or supported living services.

2.21 The end goal is that all NHS practitioners will be able to identify potential signs of autism, so they can refer for clinical diagnosis if necessary (see chapter 3), but more importantly so they can understand how to adapt their behaviour, and particularly their communication, when a patient either has been diagnosed with autism or displays these signs. This in turn will mean that adults with autism feel more comfortable seeking healthcare – not only reducing the likelihood of challenging behaviour in healthcare settings, but more significantly meaning their health needs will be identified and addressed earlier.

2.22 We also want to see the development of specialist training in health and social

care so that staff – from consultants to community nurses – who wish to specialise in autism or develop further knowledge can do so, supported by their local health and social care community. The end goal here is that, within each area, there are some staff who have clear expertise in autism. They can then be consulted as required by colleagues.

2.23 While in-house training and continuous professional development (CPD) will raise awareness of staff already working in the healthcare sector, it is equally important that autism awareness is part of the training for those coming into healthcare professions. **We believe that autism awareness should be part of the core training curricula for doctors, nurses and other clinicians**, and we commit to working with the General Medical Council, which sets expected outcomes and standards for medical schools, and the Postgraduate Medical Education and Training Board to determine how we can deliver this goal. We are also working with the Royal College of General Practitioners, the Royal College of Nursing, the British Psychological Society and the Royal College of Psychiatrists to improve the quality of autism awareness training in their curricula. Finally, and crucially, we are also working with the sector skills councils (SSCs), Skills for Health and Skills for Care to develop the training materials, drawing on their expertise in how to build knowledge most effectively.

2.24 In social care, **we recommend that autism awareness should be an essential part of the training given to staff carrying out community care assessments**, and all local authorities are expected to ensure that their staff have had such training. Again, this is an approach that the NAO report endorsed. The statutory guidance will provide useful examples on how to do this, while emphasising that assessment itself should be conducted in line with the processes and principles adopted in the development of *Working to Put People First: The Strategy for the Adult Social Care Workforce in England*.<sup>15</sup>

2.25 There should also be more advanced training for those wishing to follow career pathways that will focus on working with adults with autism – such as becoming personal assistants, occupational therapists or residential care workers. This would help increase the capacity of the social care workforce to understand and meet the needs of adults with autism.

### **Raising awareness among and through employers**

2.26 Engaging with employers has been a highly successful strand of DWP's work to support disabled people into employment. DWP is continuing to work with key employers at a national level to better engage them with the recruitment and retention of disabled people, including adults with autism. While this approach does not specifically

target any one disability, its aim is to increase opportunities for disabled people and overcome the barriers they face in finding work.

2.27 During 2007–2009, the *Employ Ability* campaign, with support from Jobcentre Plus, developed successful workshops to educate employers about the potential benefits and obligations of employing staff with all kinds of difficulties and disabilities. Jobcentre Plus is continuing to use the knowledge gained from this event to educate and positively influence employers.

2.28 This has the potential to deliver a number of benefits for adults with autism. As well as leading to more adults with autism being in work, it also provides a key means of changing attitudes about autism across the rest of the workforce. The knowledge that comes from working in close contact with adults with autism on a day-to-day basis is invaluable.

2.29 In line with this approach, the PAC recommended that DWP “work with employer organisations to raise awareness of the benefits of employing people with autism, and the adjustments needed to support them”.<sup>16</sup>

2.30 In response to this recommendation, **DWP is investigating whether existing campaigns and programmes such as *Employ Ability* can be extended**

15. DH (2009) *Working to Put People First: The Strategy for the Adult Social Care Workforce in England*

16. House of Commons PAC (2009) *Supporting people with autism through adulthood*



**to include more examples of adults with autism.**

2.31 Under the DDA, employers are required to make reasonable adjustments to workplace conditions and organisational processes to better support adults with autism. But as well as promoting the employment of adults with autism, another vital aspect is to help build an understanding among the wider workforce of what working with an adult with autism might mean. This need not be limited to those who directly work with an adult with autism, or the HR staff. Instead, as a family care group recommended, *“For large organisations the general staff training guidance should include autism awareness training to a level where staff know the potentially difficult situations which could arise and feel confident enough to manage them successfully”*.

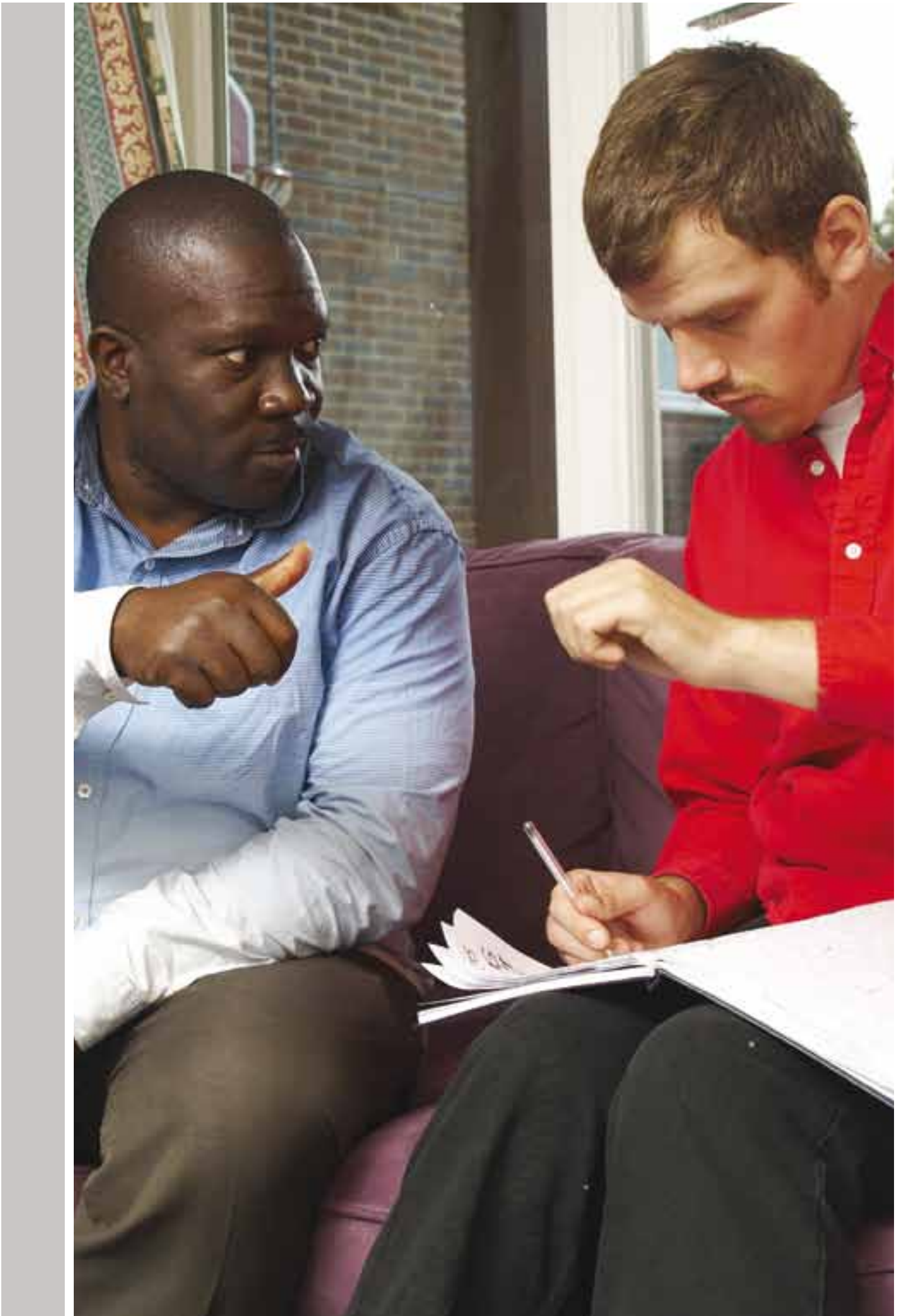
2.32 This can be easily integrated into diversity awareness training and – like other aspects of such training – helps build understanding, reduce conflict and above all improve working performance and culture. Government organisations can lead the way in this, and in future **it will be expected that autism awareness training is included in the equality and diversity planning and single equality schemes of all central government departments.**

**Raising public awareness**

2.33 One of the benefits of this approach to raising awareness of autism through

public services and employers is that it will also begin the process of raising public awareness more generally, reducing stereotypes and misconceptions.

2.34 This kind of increased public awareness is essential to achieving our long-term vision of a society that accepts and understands adults with autism.



## 3. DEVELOPING A CLEAR, CONSISTENT PATHWAY FOR DIAGNOSIS OF AUTISM

For many adults, receiving a clinical diagnosis of autism is an important step towards a fulfilling life. It can not only help them and their families understand their behaviour and responses, but should also help with access to services and support, if they need them.

Currently, diagnosis can be a complex and lengthy process. Adults with autism talk of having to battle hard – sometimes for years – to get a diagnosis, and then finding that diagnosis is being challenged when they try to access services.

This strategy makes recommendations for changing that process to develop a clear and consistent pathway for diagnosis in every area, and:

- increasing capacity around diagnosis
- ensuring a diagnosis is recognised as a reason for a community care assessment or reassessment, and
- providing relevant information to adults with autism and their family or carers *at the point of diagnosis* to help them understand the condition and access local support.

### Diagnosis today

- 3.1 As with any condition, identification of possible autism is the essential first step to effective support. But for many adults with autism, there is a need and a desire for a formal clinical diagnosis – something that they can then refer to when seeking to access services. This can be as important a step for parents or carers as for the individual with autism.
- 3.2 Diagnosis is particularly important for adults who have not previously had their condition recognised: their life to date may have been greatly affected by a sense of not fitting in, of not understanding the way they respond to situations or why social settings, for example, are difficult. It is equally important for their families or those who care for and support them: in line with the Think Family agenda, it can be an important step in ensuring that support takes account of how autism can affect the whole family.
- 3.3 This is the case even for those who are already receiving support for a learning disability or mental ill-health: diagnosis of autism can change the way they are treated and supported.

3.4 The majority of those diagnosed with autism received their diagnosis as children. DCSF and DH have worked closely over a number of years to encourage early identification of potential autism and seek to link this with relevant support in schools. As these processes continue to strengthen, and are backed by improvements to the transition process into adulthood, we should see a reduction in the numbers of adults with autism who have not yet received a diagnosis.

3.5 However, throughout the consultation process, respondents have repeatedly described their problems in accessing diagnostic services – and in gaining relevant support if they are diagnosed.

*“Diagnosis in our case it took 46 years. I had tried and tried to get a diagnosis because we suspected Autism – no one would listen. One psychiatrist even said to me ‘How could a diagnosis help? It wouldn’t alter your situation.’”*

*“I don’t want other parents receiving an ASC [autism] diagnosis for their child being told to go away and find out about it, nor do I want people to be continually told that they won’t get an assessment or that ‘you don’t want to label them’.”*

### **Local areas taking the initiative**

3.6 While these kinds of problems are widespread, many local areas have taken the initiative and developed diagnosis and assessment services, linked directly to initial support.

- To increase access to diagnosis, the Tees, Esk and Wear NHS Foundation Trust has piloted a multi-disciplinary team consisting of a consultant clinical psychologist, a consultant psychiatrist and a speech and language therapist. The team takes referrals from across the Trust area of over-18s who are thought to have autism, irrespective of their cognitive ability. Anyone referred will have already been assessed for mental health needs: the focus here is on identifying autism. In just over a year, the team received over 100 referrals.
- In Glasgow, an autism resource centre provides a range of services for adults with autism and their families or carers, starting with diagnosis. From there, it offers support and information about education, training, housing, employment, leisure and social opportunities and what support is available from health and social care.
- In the London Borough of Newham the approach is built around providing training to partners in the area, including colleges, voluntary groups and community groups, to help identify those who may benefit from an assessment. Assessment is made easier to access, with anyone meeting certain criteria entitled to individual assessment to understand their needs. While the assessment is carried out by healthcare practitioners, much of the signposting and support is provided by the partners.

- One of the most widely known services is the Liverpool Asperger Team, funded by the Liverpool PCT. It was established in 2003 in response to findings from a local steering group that people with Asperger syndrome were most likely to fall through the gaps in service provision. The multi-disciplinary team of ten staff provides diagnosis of Asperger syndrome, as well as direct support through its managed care pathway. It also works with other local services, providing direct advice and support as well as promoting awareness of Asperger syndrome.

3.7 We want to build on approaches such as these to ensure diagnosis is more easily accessible, no matter where an individual lives, and that it leads to valuable support for adults with autism.

## Developing a clear, consistent pathway for diagnosis

### Building on increased awareness to increase referrals

3.8 We believe the underlying issue around diagnosis is a lack of awareness of autism among health and social care staff in particular. The steps set out in chapter 2, covering training for all health and social care staff, will therefore make a significant difference to the likelihood of being referred for diagnosis: if staff are more aware of autism, they will be more likely to identify potential cases and feel better equipped to refer.

3.9 However, there also needs to be a cost-effective referral pathway for autism available in every area, which GPs, mental health practitioners and those working in the voluntary sector are aware of and can follow. **The forthcoming NICE guideline will set out a model care pathway(s), which will form the foundation for local commissioners to develop referral and care pathways in their areas, supported by their strategic health authority where necessary.**

3.10 Best practice shows that in areas where an autism lead is appointed, the profile of the condition is raised and services for adults with autism improve. Because of this, **we recommend that local areas appoint a lead professional to develop diagnostic and assessment services for adults with autism.** These professionals will need to work closely with the local specialised commissioning group, as specialised services for Asperger syndrome and autism are included in the definition set for specialised commissioning.

### Increasing capacity around diagnosis

3.11 By 2013, when this strategy will be reviewed, we expect there to be a clear pathway to diagnosis in every area. While we recognise that specialist diagnostic services have proved a highly effective way of making diagnosis more accessible in many areas, it is not expected that a diagnostic team or service will be located in all areas. Instead, the most important step for now is that a diagnostic service should be easily accessible for all areas.

3.12 To achieve this, we also need to examine ways to increase capacity around the process. We recognise that diagnosis of autism in adults is often highly complex, particularly where there is little or no information regarding early development. However, in other cases, diagnosis may be more clear-cut: in such cases, a swifter, less resource-intensive diagnostic process would be of real value. Through the consultation process, a number of different models were suggested, ranging from specialist services to GP diagnosis to online toolkits to enabling dedicated nurse practitioners – such as those who already work with adults with autism on a daily basis – to diagnose. Future developments could also see the introduction of a ‘triage’ arrangement to identify people who need access to a diagnostic service.

3.13 The feasibility of these different methods is being examined by NICE, with the help and involvement of NAS. **While developing the forthcoming clinical guideline, NICE will consider how to make the diagnostic process more accessible and consistent.**

### **Linking diagnosis to a rigorous assessment of individual need**

3.14 Diagnosis alone is not enough: the fundamental change we want to see is that diagnosis leads to a person-centred assessment of need, in line with the NHS and Community Care Act 1990. Under this Act, local authorities have a duty to assess a person who may be in need of community care services – either at the

individual’s request, or in certain situations where the local authority believes care services may be necessary. **Diagnosis of autism should be recognised as a reason for assessment.**

3.15 Such an assessment, carried out by trained practitioners and taking account of the communication needs of adults with autism, will be the key to unlocking care services throughout a person’s lifetime. It will provide a comprehensive view of the person’s condition and how it affects them – drawing on the experiences and views of the person themselves, their family and carers. This will then be an important part of their records in the future, and can be referred to when necessary to inform care decisions or support applications for additional services.

3.16 Where the needs assessment shows that there is a greater requirement for immediate support – ranging from health or social care to advocacy or skills training – there will be a clear description of such needs, making it easier for the person or their carers to access that support. For example, those with additional mental health needs may require further support from local mental health services: the assessment can act as a trigger for this.

3.17 Where the person’s needs are low-level, it may lead to no extra support or services at that time. But because the assessment has been completed, if the person’s circumstances change – for example, if they become unemployed, experience

bereavement or come into contact with the criminal justice system – they will be able to seek a reassessment and be better able to access support when they need it.

mental health problem, physical illness, homelessness or coming into contact with the criminal justice system. By recognising their needs earlier, and responding to them, we hope to prevent adults with autism reaching such crises – something that is beneficial not only to them and their families but also to wider society.

3.18 Equally, where someone has previously had a needs assessment, and is then diagnosed as having autism, this should be recognised as a potential reason for reassessment.

3.19 **It is best practice that diagnosis of autism is recognised as a catalyst for a carer's assessment.** Though anyone who provides a regular and substantial amount of care for someone aged 18 or over is entitled to request a carer's assessment, it should be offered to them specifically after diagnosis. This is in line with the duty on local authorities under the Carers (Equal Opportunities) Act 2004 to inform carers, in certain circumstances, of their right to an assessment of their needs.

3.22 It must be reiterated that adults with suspected autism do not need to wait for diagnosis to request and receive a community care assessment: they or their carers are already entitled to request one if they believe they require support. Similarly, local authorities are able to offer an assessment to adults with suspected autism without needing formal diagnosis.

#### **Reviewing eligibility criteria for social care**

3.20 Linking diagnosis so clearly with assessment of needs is an important cultural change, reducing the emphasis on diagnosis itself. This should help professionals to feel confident in referring someone for diagnosis, as instead of pathologising the condition, the focus is on diagnosis as a step towards needs assessment and providing the right level of help to the adult with autism.

3.23 In response to concerns about the way in which Fair Access to Care Services (FACS) guidance, issued by DH in 2003, has been implemented in some local authorities, and in recognition of the vital new policy context articulated in *Putting People First*, the Commission for Social Care Inspection (CSCI) was asked to review the application of eligibility criteria for social care and its impact on people.

3.21 Diagnosis and early assessment can also play a vital role in preventative approaches. Currently, too many adults with autism only come to the attention of services when they reach crisis point: a severe

3.24 Following their recommendations, FACS guidance has been revised and will be published in February 2010. This aims to support fair and transparent implementation of eligibility criteria, within the new policy context of personalisation and prevention, and will act as a bridge towards wider social care reform. It also

reiterates that people who do not meet the eligibility threshold should still be able to expect adequate signposting to alternative sources of support.

3.25 Alongside the revised FACS guidance, SCIE is in the process of developing an online training resource for social care staff to ensure that the criteria are applied more consistently across the country.

### **Providing relevant information to adults with autism and their family or carers at the point of diagnosis**

3.26 Diagnosis of autism can be a life-changing moment for both the person diagnosed and their family. Support for both, therefore, needs to start at that point: not some weeks after when they can next get an appointment. In many circumstances, the immediate needs are:

- information about autism – what it is and how it affects those who have the condition, and
- information about sources of help for the individual and their family – from telephone helplines to local voluntary groups.

3.27 While some adults diagnosed get this kind of information – particularly where diagnosis is made by a specialist service provider – too many do not, and have to search hard for support. We want to change this situation and increase the quality and consistency of information

provided to newly diagnosed adults with autism and their families.

3.28 **To help local authorities and PCTs develop the right kinds of information, the forthcoming statutory guidance will provide more details of what information adults with autism and their family or carers are likely to need after diagnosis.** Based on this, local organisations may wish to develop shared templates for information. Clearly, it is essential that any such information is provided in accessible ways, drawing on guidance such as the Office for Disability Issues (ODI) top tips for accessible communication.<sup>17</sup>

3.29 The NHS Choices website can also be a valuable resource of information for adults with autism and their families. Its section ‘Living with autism’ provides general information about autism and diagnosis, as well as links to sources of help: [www.nhs.uk/Livewell/Autism/Pages/Autismhome.aspx](http://www.nhs.uk/Livewell/Autism/Pages/Autismhome.aspx)

17. See [www.odi.gov.uk](http://www.odi.gov.uk) for more information







## 4. IMPROVING ACCESS FOR ADULTS WITH AUTISM TO THE SERVICES AND SUPPORT THEY NEED TO LIVE INDEPENDENTLY WITHIN THE COMMUNITY

Equality of access is a fundamental principle of UK public services. But it is clear that, too often, adults with autism are not currently able to access the services or support they need. This strategy sets out to change this and ensure that adults with autism are able to benefit fully from mainstream public services by:

- reiterating the DDA requirement for services to make reasonable adjustments for adults with autism
- enabling adults with autism to benefit from personalisation of social care, and
- improving transition planning to give people with autism the right start in their adult life.

### Accessing services and support today

4.1 For many adults with autism, mainstream public services can be largely – or completely – inaccessible. While some of this is due to a lack of understanding

among staff, there are also a number of other factors. Many people with autism are hypersensitive to light and noise; they have significant difficulties with communication; they struggle with the formats, language and instructions of forms or standard letters from organisations such as banks or GPs. Therefore when they seek to access mainstream services, from healthcare to employment advice and benefits to education, they struggle to cope with the way those services are offered.

*“Many people with autism experience problems with crowded and noisy environments such as doctors’ surgeries and hospital waiting rooms.”*

4.2 The consequences of this can be seen in a variety of different outcomes.

- In healthcare, it is clear that many adults with autism have become reluctant to see a GP or other professional. This can mean diagnosis and treatment of often minor conditions can be delayed to the point where they become far more damaging.

- Educational settings which do not make adjustments for people with autism can make it harder for adults with autism to complete courses and gain qualifications, as well as missing out on the social aspects of college life.
- Difficulties with transport can make it even harder for adults with autism to access other community services and activities, serving to increase their exclusion.

*“Our local college South Downs in Waterlooville has been excellent. They have a disability committee organised by the disability team, run by the students and even have an Asperger specialist. They have a quiet room for any disabled person to use when necessary. They have an excellent no bullying policy, and all the tutors my daughter has been taught by have been wonderfully understanding and supportive. A wonderful example for other colleges to follow.”*

4.3 While similar stories could be told of other disabilities, where people struggle to access services and support, it is clear that adults with autism face particular challenges with using mainstream public services.

4.6 The challenge ahead is to ensure that examples like these become the norm.

## **Ensuring that adults with autism can access the services and support they need**

### **How some services have responded**

4.4 There are excellent examples of how services have responded to the needs of adults, making small adjustments to become far more accessible. For example, a dentist in Easington in County Durham schedules appointments for adults with autism at either the beginning or very end of the day, depending on when it is best for them, and they don’t have to wait in the waiting room. Some adults with autism go for a preliminary visit to be shown what a dental surgery is like and what noises they will hear. Individual doctors – both GPs and in hospitals – have come in for praise, as have some DEAs.

### **Requiring services to make reasonable adjustments for adults with autism**

4.7 Since December 2006, under the disability equality duty, all public sector organisations are required to make reasonable adjustments to services to ensure they are accessible for disabled people. This duty includes making adjustments for people with autism. Too often, this aspect of the duty has been overlooked, with the focus mostly on physical and sensory impairments.

4.5 Many parents told the consultation of how colleges had taken account of the needs of students with autism:

4.8 The Standard Contract for Mental Health and Learning Disabilities explicitly requires service specifications, and therefore service providers, to demonstrate how reasonable adjustments for adults with autism are made.

4.9 While it will remain up to individual organisations to decide on the adjustments that they can make, potential areas include:

- premises – for example, taking account of hypersensitivities and providing quiet or lower-light areas within educational or healthcare settings, prisons and police cells
- processes – such as scheduling appointments at less busy times, allocating extra time to adults with autism and being flexible about communication methods (i.e. less reliance on telephone-based services)
- communications – including avoiding ambiguous questions, not pressurising adults with autism in conversation and being aware of sensitivity to touch, ensuring essential documents and forms are available in accessible formats – in particular, easy read and formats that take account of sensory issues in their choice of colours, and
- planning and preparation – for example, offering opportunities for adults with autism to visit settings in advance to familiarise themselves with what to expect, such as visiting a court prior to giving evidence.

4.10 **DH has already committed to delivering guidance for mental health and learning disability services to indicate some of the kinds of adjustments that might usefully be made, from physical**

**adjustments to premises to improving the ways those delivering services communicate with adults with autism.**

This guidance will be available to all public services, and will draw on examples of the kinds of adjustments that have been made in health and social care settings, as well as on guidance such as the ODI's top tips for accessible communication. We will also work with adults with autism and autism representative groups in developing this guidance.

4.11 DWP has also underlined its commitment to making adjustments for adults with autism using Jobcentre Plus services. As well as making any *required* reasonable adjustments – such as making use of the most suitable environment or premises for conducting work focused interviews – **DWP will also 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.**

4.12 Within the justice sector, one of the most important steps is to make sure that adults with autism have access to the support they need – whether as victims, witnesses or perpetrators of crimes. Teams that work within criminal justice agencies, such as the Criminal Justice Liaison Teams, should ensure that they have access to the expertise to support adults with autism. Developing pathways through the criminal justice system for adults with autism will help identify key players locally who may

be required to work alongside criminal justice staff.

over the care services they receive, in line with their assessed needs.

### **Enabling adults with autism to benefit from personalisation of social care**

4.13 The goal of social care today is to deliver personalised services that give each individual the right support to live a more fulfilling life. We are committed to making this approach work for adults with autism.

4.14 As well as giving people more choice over the care and support services they access, personalisation also encourages a culture of innovation in terms of service development and delivery. It acts as a catalyst for local partners to work together to respond to individual needs, creating innovative packages of care and support that often go beyond traditional care services to include different forms of support that make a real difference.

4.15 We recognise that adults with autism will need additional support to make choices about their care, and that having choice is only of value when there are suitable services and support available to choose from within the local area. Therefore it will take some time for personalisation to be of benefit to all adults with autism that are eligible for social care. However, in many areas the process is underway, and statutory guidance will give examples of how this is working.

4.16 Personal budgets are an integral part of personalisation, giving adults more control

4.17 Adults with autism are eligible for personal budgets and direct payments, but indications suggest that, in some areas, they are not being offered them. We therefore reiterate their eligibility, and recommend that for those that need and want them, **adults with autism are able to access personal budgets and direct payments, in line with the assessment of their needs.**

4.18 This already happens in some areas, and some of the most commonly selected services are low level interpersonal support, such as personal assistants to help with administrative and domestic activities, advocacy and buddying services, to enable adults with autism to participate in different social and leisure activities.

4.19 Services such as these are vital for enabling adults with autism to live independently and access mainstream services. For example, consultation responses highlighted that adults with autism use such services to:

- help them budget and manage financial issues, from benefit applications to paying rent
- give them the support they need when talking to advisers, doctors or other professionals

- help them learn to cope with difficult and unfamiliar situations, from travelling on public transport to getting used to attending college or a new job, and
- open up mainstream social and leisure activities.

4.20 Importantly, they also help reduce the burden on family carers.

4.21 We recognise that access to services like these is inconsistent, and that there are not yet enough advocates available to support all those who would want one. This is true for all vulnerable people, not only adults with autism.

4.22 For adults with autism, many of the most effective advocacy and buddy schemes are delivered through the third sector and volunteer groups, who have a real insight into the challenges faced by adults with autism. However, funding is often a significant issue for such groups which makes it hard for them to increase their capacity. Given how valuable these services can be for individuals, we believe that more should be done to support volunteer and third sector groups to deliver these kinds of services. **We therefore encourage local authorities to explore how to support volunteer and third sector groups in planning and commissioning services locally.** One key route to do this may be through working with user-

led organisations<sup>18</sup> for disabled people or Centres for Independent Living.

4.23 The ODI is currently working to develop the Right to Control,<sup>19</sup> a new approach to giving disabled adults more choice and control over the support they receive. The Right to Control draws together a number of funding streams to ensure a streamlined provision of self-directed support for eligible disabled adults. Pilot schemes will be launched later in 2010. The programme implicitly supports increased choice for adults with autism, whether or not they also have a learning disability.

### Supporting travel training

4.24 Public transport can be hugely daunting for many adults with autism – making them reluctant to use it, and so unable to participate fully in the community.

4.25 Travel training, developed under *Valuing People Now*, for adults with learning disabilities, has proved invaluable in helping build confidence in using public transport – including for those adults with autism who also have a learning disability.

4.26 **We recommend that travel training is made available nationwide for all adults with autism that would benefit from it.** While the delivery models will need to be adjusted to reflect the different needs of adults with autism, we believe it will be a vital enabler of improved participation in the community and of

18. HM Government (2005) *Improving the life chances of disabled people*. Recommendation 4.3

19. See the ODI website for more information: [www.odi.gov.uk/working/right-to-control.php](http://www.odi.gov.uk/working/right-to-control.php)

greater independence – particularly when backed by more accessible information about transport, which is something the Department for Transport is working to deliver.

### **Ensuring transition planning gives people with autism the right start in their adult life**

4.27 Through school, children with autism and their families will usually have access to support that helps them achieve and be included. It also provides a focal point of activity in the day. Therefore one way of improving access to services for adults with autism is by focusing on managing the transition to adulthood so that young people have access to the services they need from the start of their adult life.

4.28 For young people with statements of special educational needs (SEN) – which includes the majority of children and young people identified with autism in schools – there is a statutory transition planning process which begins in Year 9 and plans for the remainder of their school careers (often up to their 19th birthday) and their transition to adulthood. Young people with autism who do not have a statement of SEN may instead have a Health Action Plan that covers not only medical management of their condition, but also can look at social skills and strategies to enable self-care and independent living. In particular, this can help act as a route to access support in further or higher education.

4.29 However, as several reports have highlighted,<sup>20</sup> transition planning arrangements do not always work well for young people with autism.

4.30 DCSF has continually sought to review the transition planning process in partnership with DH, to help drive improvements in its effectiveness. **Under *Aiming High for Disabled Children*, DCSF is investing £19 million in a Transition Support Programme to improve transition planning.** The programme aims to ensure that all local authorities have strategic arrangements in place to meet their statutory duties and follow existing guidance effectively. The Transition Support Programme provides funding and local adviser support to every local authority area to improve the transition experience for young people from age 14 as they plan for life after school. Every local area should be meeting minimum standards in transition or better by 2011.

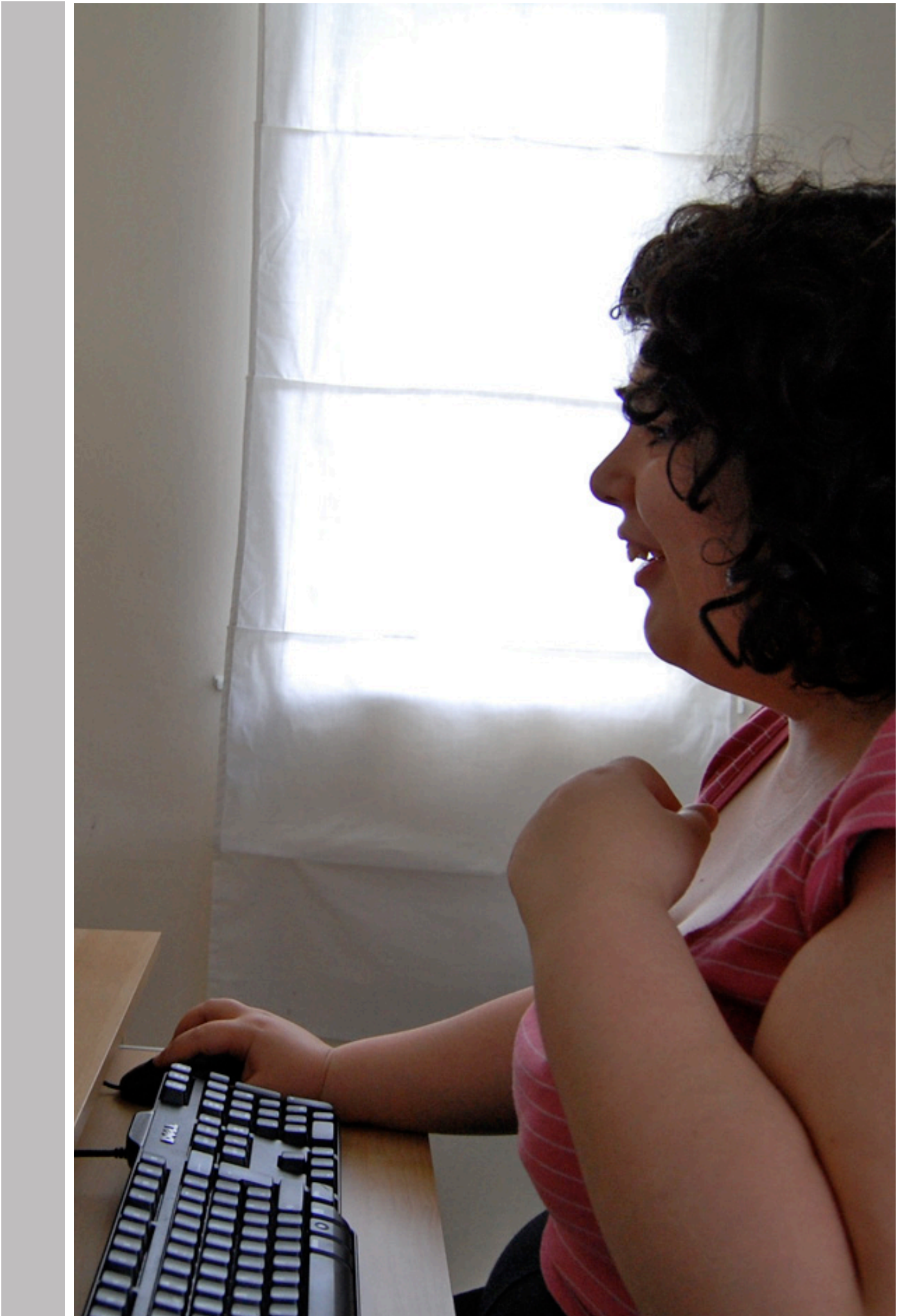
4.31 The National Transition Support Team (NTST), based at the Council for Disabled Children, is contracted to deliver the Transition Support Programme. It is using its local self-assessment work to identify good practice in transition planning for disabled young people, including those with autism, and is promoting this through its website [www.transitionsupportprogramme.org.uk](http://www.transitionsupportprogramme.org.uk).

4.32 While the Transition Support Programme will bring benefits to young people with

20. Transitions were considered in the House of Commons PAC report *Supporting people with autism through adulthood* and the NAO report of the same name. They were also the theme of the All-Party Parliamentary Group on Autism (2009) *Transition to adulthood: Inquiry into transition to adulthood for young people with autism*



all types of SEN, more needs to be known about the experiences that young people with autism and their families have of multi-agency transition services. That is why DH and DCSF are funding a study, which will report in January 2012.



## 5. HELPING ADULTS WITH AUTISM INTO WORK

The ability to get, and keep, a job and then to progress in work is the best route out of poverty, and a central part of social inclusion. We know that adults with autism are significantly under-represented in the labour market and we are committed to doing more to help adults with autism into work. This strategy focuses on four aspects of our activity to support adults with autism:

- ensuring adults with autism benefit from wider employment initiatives
- personalising welfare and engaging employers
- improving existing provision, and
- developing new approaches that will better support adults with autism.

This has not only financial consequences on adults with autism and their families, but also means that adults with autism miss out on the social inclusion and personal fulfilment that comes through work.

5.2 The impact is equally significant for the UK economy. Not only does it mean that many adults with autism are dependent on benefits, this under-representation also indicates that UK employers are not benefiting from the skills and talents adults with autism can offer in the workplace. As the recent NAO report<sup>22</sup> emphasised, this is a major missed opportunity which – in the emerging world economy – must be addressed.

5.3 *Building Britain's Recovery: Achieving Full Employment*<sup>23</sup> reiterates the Government's aspiration of getting eight out of every ten people of working age into employment and creating a society in which everyone who wants to work is doing so. To reach an 80% employment rate, DWP will need to help many more people over 50, people with caring responsibilities, parents and disabled people into work – and give them the individually tailored support they need to do so. Adults with autism should benefit

### The labour market and adults with autism

5.1 It is widely accepted that adults with autism are under-represented in the labour market. Research from NAS puts the employment level of adults with autism as low as 15%.<sup>21</sup>

21. NAS (2008) *Think Differently – Act Positively: Public perceptions of autism*, p. 19 ([www.autism.org.uk/content/1/c6/01/47/21/think%20diff%20act%20pos.pdf](http://www.autism.org.uk/content/1/c6/01/47/21/think%20diff%20act%20pos.pdf))

22. NAO (2009) *Supporting people with autism through adulthood*

23. DWP (2009) *Building Britain's Recovery: Achieving Full Employment* ([www.dwp.gov.uk/policy/welfare-reform/legislation-and-key-documents/building-britains-recovery/](http://www.dwp.gov.uk/policy/welfare-reform/legislation-and-key-documents/building-britains-recovery/))

from this – and so should those who currently care for them.

5.4 The Government recognises that achieving this level of inclusion in the labour market is a long-term goal and that, within these groups, there are many individuals who are currently a long way from having the skills and capabilities required by employers. Some adults with autism fall into this category and require specialist support.

5.5 In *Valuing Employment Now*, our strategy to radically increase employment for people with learning disabilities, we set out a number of important changes to employment support for this group. Many people with learning disabilities also have autism, but many of the changes set out in *Valuing Employment Now* are designed to benefit adults with autism even if they do not have a learning disability.

- The commitment to improving the quality standards and workforce development for supported employment and increasing the quality, capacity and availability of job coaching will help improve the support offered to adults with autism.
- Project Search, the new internships programme for people with learning disabilities, is based on a US model which has proven to work well for adults with autism. It is designed to help them gain employment skills in a stable

environment and is being piloted in fourteen large employers across England. Young people with autism will be among the participants at some pilot sites.

- The insights and good practices identified through Getting A Life, the programme to understand how to improve support into work for young people with learning disabilities, will inform delivery of the autism strategy and initiatives to support people with autism into work over the coming years.

### **Ensuring adults with autism benefit from wider employment initiatives**

5.6 Young people are a particular area of focus for the Government during this period of economic downturn. *Building Britain's Recovery: Achieving Full Employment* therefore announced over 100,000 new opportunities for young people, meaning that from January 2010 all 18-24 year olds, including those with autism, will be guaranteed a job, work placement or work related skills training from the six-month point of their claim to Jobseeker's Allowance (JSA). This will be delivered through:

- a new job created through the Future Jobs Fund<sup>24</sup>
- help with getting an existing job in a key employment sector

24. The Future Jobs Fund, which is part of the Young Person's Guarantee, is worth around £1 billion and will create 170,000 new jobs – at least 120,000 for young people and a significant proportion in areas of high unemployment

- new work-focused training opportunities, and/or
- a place on a Community Task Force, delivering real help within local communities.

5.7 DWP will also increase the number of non-graduate internships from 10,000 to 20,000. As the economy recovers, the Government will continue to provide employment support so that people can find – and stay in – work. There are still uncertainties to confront and the Government will continue to provide support as the recovery continues.

5.8 **DWP is committed to ensuring that these programmes work for young people with autism, and that the choices and support they are offered reflect their specific needs.** The training for advisers outlined in chapter 2 of this strategy is essential to ensuring that this happens, as is the fact that this support will be available to young people with disabilities earlier. So, they will, for example, be able to access Future Jobs Fund opportunities at the thirteen-week point of their claim to JSA rather than after six months.

## Personalising welfare and work support

5.9 The Government will continue to take forward welfare reform to personalise the support given to people seeking work. At the core of this process is the principle that

the ability to get and keep a job, and then to progress in work, is the best route out of welfare dependency. But the personal needs of individuals can differ vastly. Some require intensive support to build skills and overcome barriers to work, while others need little more than access to job opportunities.

5.10 This spectrum of needs in society as a whole is mirrored – if not intensified – when it comes to adults with autism. At one end of the autistic spectrum, many adults are highly skilled and often highly qualified. The support they need is very different from those who have struggled to get qualifications, or who have learning disabilities or mental ill-health.

5.11 At the higher functioning end of the autistic spectrum, the focus needs to be on enabling people to take the next step into work – perhaps giving them the extra support they need through the application process so they can demonstrate their skills, or helping them develop the social skills that are such a fundamental part of the workplace. While some of this involves working with the individuals themselves, it also demands our working with employers to change their perspectives and approaches.

5.12 Chapter 2 highlighted some of the ways DWP is already seeking to engage employers. There are also many examples of employers across the UK who have taken steps to better include adults with autism – from formal schemes such as

the successful mentoring programme at Goldman Sachs (which was highlighted in the autism strategy consultation document *A Better Future*) to individual employers and managers making a difference themselves.

*“Our son has worked for an outdoor clothing firm (Saturday job) for at least 3 years, mainly because the team leader was prepared to take him on after he had completed 3 weeks of work experience and was prepared to learn about autism and make the necessary adjustments. This has been a very positive experience for our son and has given him the confidence to take on another part time job.”*

to increase opportunities for work are accessible for adults with autism.

5.13 Changing employer perspectives is a long-term process, but an important one. Employer organisations have an important role to play in highlighting the benefits of employing adults with autism, and organisations such as Prospects, NAS’s employment and training service, also work closely with employers to identify how they can best use the skills of their autistic staff.

5.14 But for those who need more help, we need to do more. We need to ensure that adults with autism get the information, advice and guidance they need to improve their skills and prepare for work. We need to ensure they receive the financial support they are entitled to. And we need to ensure that government-led programmes

5.15 Our current approach to welfare reform aims to overcome these barriers and give all adults the personalised employment support and benefits advice they need to get them into work. In our Delivery Plan we will explain how Jobcentre Plus customer services and benefits processes address the needs of autistic people, and the issues and concerns identified during our consultation exercise and within NAS’s *Don’t Write Me Off*<sup>25</sup> report.

## Reforming existing provision

5.16 DWP is committed to building pan-disability services for its customers, where provision is flexible and based on individual need, rather than a ‘one size fits all’ approach.

5.17 Following recommendations for improvement made by the NAO, the Prime Minister’s Strategy Unit report *Improving the life chances of disabled people*, the PAC and the views of many disabled people, employers, external delivery partners and Jobcentre Plus staff, DWP undertook a major review of its existing specialist disability employment provision (i.e. WORKSTEP, Work Preparation and the Job Introduction Scheme).

5.18 As a result, **this provision will be replaced by a new programme – Work Choice – from October 2010.** Work

25. NAS (2009) *Don’t Write Me Off*

Choice will be a pan-disability programme, designed to help customers who face complex disability-related barriers and have the highest support needs to find and keep a paid job, or progress in work. The new programme will provide specialist support for adults with autism where DWP mainstream provision may not be appropriate or does not meet the particular needs of the individual.

5.19 Work Choice customers will be encouraged to progress in their careers while they are on the programme and a new funding model will encourage increased progressions from Work Choice into unsupported employment, where this is appropriate for the individual customer.

5.20 Access to Work is a DWP programme that helps disabled people overcome work-related obstacles. It can provide support with such things as special equipment or software, support workers, and travel to and within work that many adults with autism will find helpful in getting and keeping employment. It is flexible, easy to access and shows high levels of satisfaction from disabled people and their employers. It has also been recognised by the NAO as highly cost-effective. In recognition of the high levels of demand for the programme and its success in helping disabled people get and keep jobs the Government committed in December 2008 to doubling the Access to Work budget to £138 million by 2013/14.

#### 5.21 **Jobcentre Plus has now changed Access to Work to improve support services for customers with autism.**

The programme now offers customers the option of an Access to Work funded Job Coach as and when they require one – for example, when there are changes in a customer’s job at a later stage within the same employment. Previously, this support was only available in the first six months of the customer’s job.

5.22 DWP also recently announced its commitment to review Pathways to Work, its back-to-work programme available to all customers claiming incapacity benefits and Employment and Support Allowance (ESA) in Great Britain – which includes a large number of adults with autism. This review builds on the recently published statistics on the operation of the new medical assessment for ESA.

5.23 Pathways to Work was the first programme of tailored support for this customer group. It gives customers a flexible menu of different support options that can be tailored to their needs, including:

- Work-Focused Interviews (WFIs)
- help finding and applying for jobs
- help to manage a health condition or disability (Condition Management Programmes)
- training, and

- extra money to boost in-work income (the Return to Work Credit).

ensuring that back-to-work support is as personalised and co-ordinated as possible.

5.24 *Building Britain's Recovery: Achieving Full Employment* set out the underpinning principles for reform to Pathways: clarity of process and customer journey; flexibility, and tailoring of support to the needs of the individual; and placing rights and responsibilities at the heart of the relationship between customer and personal adviser. DWP is currently working with stakeholders to develop detailed proposals for reform, which will be published in spring 2010.

5.27 In December 2009, we published the results of an independent review led by Rachel Perkins that looked at how the Government could better help people with a mental health condition back to work. *Realising ambitions: Better employment support for people with a mental health condition*<sup>26</sup> made a number of recommendations which focused on ensuring that employment services better understand the needs of people with a mental health condition, and that health/social services see employment as part of a recovery approach and a health outcome.

5.25 The review will also look at how we can strengthen support for customers no matter what benefit they receive, including support for disabled people and those with a health condition on JSA. The Personalised Employment Programme, for example, which tests a more personalised system of support for a combined customer group of JSA and ESA claimants, including adults with autism, will provide important evidence to inform the future delivery model.

5.28 At the same time, we also published our response to the review *Work, Recovery and Inclusion*,<sup>27</sup> and *Working our way to better mental health: a framework for action*.<sup>28</sup>

5.29 *Work, Recovery and Inclusion* listed a number of actions that DWP will take, including:

- doubling the capacity of mental health co-ordinators and using them to build networks at a local level between work and health/social services
- adapting Access to Work to ensure it is better targeted at people with mental health and fluctuating conditions,

## Developing new approaches that will better support adults with autism

5.26 We know that adults with autism and mental health conditions can be at a double disadvantage in the labour market. This is why DWP is committed to

26. *Realising ambitions: Better employment support for people with a mental health condition* is a review commissioned by DWP and led by Rachel Perkins of South West London and St George's Mental Health Trust, supported by Paul Farmer of Mind and Paul Litchfield of BT

27. HM Government (2009) *Work, Recovery and Inclusion* ([www.cabinetoffice.gov.uk/social\\_exclusion\\_task\\_force/psa/supporting\\_delivery/work-recovery-inclusion.aspx](http://www.cabinetoffice.gov.uk/social_exclusion_task_force/psa/supporting_delivery/work-recovery-inclusion.aspx))

28. DWP and DH (2009) *Working our way to better mental health: a framework for action* ([www.workingforhealth.gov.uk/initiatives/Mental-health-and-employment-strategy/default.aspx](http://www.workingforhealth.gov.uk/initiatives/Mental-health-and-employment-strategy/default.aspx))



making it more flexible and piloting cover for small businesses for episodic absences

- piloting internships for people with mental ill-health and those who have been away from the labour market for a considerable period of time, and
- through the Equalities Bill, seeking to outlaw the inappropriate use of pre-employment questionnaires.

5.30 While we recognise that not all adults with autism also have mental ill-health, **we will make it clear that the actions and initiatives we are introducing – such as internships and cover for episodic absences – should be available to support adults with autism.**

5.31 *Working our way to better mental health: a framework for action* is the first cross-government strategy to focus on mental health and employment. It provides a high-level framework to influence and inform policy development and sets out expectations of employers, healthcare professionals, organisations and individuals. Building on it, DWP will:

- encourage employers, particularly those in the public sector, to offer more employment opportunities to people who have mental ill-health
- launch an occupational health adviceline for smaller businesses in nine pilot sites across Great Britain

- test a range of early intervention job retention approaches, including the Fit for Work Service pilots and embedding Employment Advisers in Improving Access to Psychological Therapies (IAPT), and
- introduce a new network of mental health co-ordinators in each Jobcentre Plus district to improve access to co-ordinated health and employment support for jobseekers.

Again, these initiatives should be seen as supporting and including adults with autism.

5.32 Many of the initiatives recognise the importance of co-ordinated health and employment support for jobseekers. They build on the strong partnerships already created with GPs through the Pathways Advisory Services pilots, which tested placing Jobcentre Plus advisers in GP surgeries. **These pilots are now being expanded to treble the capacity.**

5.33 As part of the ongoing goal to personalise support for disabled people – including adults with autism – the ODI has worked with disabled people to develop the Right to Control. This will give disabled people greater choice and control over the support and services they receive, and shift the balance of power from the state to the individual. Disabled people taking part in the Right to Control trailblazers will have a legal right to:

- be told how much support they are eligible to receive
- decide and agree, with the public body, the outcomes they want to achieve, based on the objectives of the funding streams they access
- have choice and control over the support they receive, and
- be able to choose how they receive the support.

#### 5.34 The Right to Control will include:

- Access to Work (DWP)
- Independent Living Fund (DWP)
- Specialist Disability Work Programmes, for example WORKSTEP (DWP)
- Disabled Facilities Grants (CLG)
- Non-statutory housing-related support (also known as Supporting People) (CLG).

5.35 From late 2010, around eight local authority areas in England will become trailblazer sites. The aim is to build on the approaches used by DH in piloting individual budgets for adults in receipt of social care with a greater focus on employment. Adult social care will be aligned with the Right to Control during the trailblazers.





## 6. ENABLING LOCAL PARTNERS TO DEVELOP RELEVANT SERVICES FOR ADULTS WITH AUTISM TO MEET IDENTIFIED NEEDS AND PRIORITIES

While central government can set the framework for improving the lives of adults with autism – removing barriers, working to increase awareness – much of the responsibility for delivery of this strategy sits locally. It is here that partners can come together to develop relevant services – and extend existing ones – that enable adults with autism to be included in society, reflecting the needs and priorities of the local area.

Increasingly, government is moving towards a model of area-based funding and service delivery. This in itself will help agencies and services come together to share resources to support adults with autism. To build on this, the strategy focuses on:

- putting the needs of adults with autism on the map in every area
- identifying and promoting service models that are proven to make a positive difference for adults with autism, and

- enabling adults with autism and their families to have greater choice and control over where and how they live.

### Services for adults with autism today

- 6.1 The focus of this strategy is rightly to make it easier for adults with autism to access mainstream public services and to be fully included within society. However, specific services and support dedicated to adults with autism can play a pivotal role in enabling them to use mainstream services effectively.
- 6.2 These kinds of services help adults with autism to live more fulfilling lives within society – as do many user-led and voluntary support groups, which help adults with autism build friendships and share experiences. They also enable more adults with autism to live independently.
- 6.3 In its report *The State of Health Care and Adult Social Care in England 2009*, the Care Quality Commission cited examples of councils and PCTs working together in a number of ways to support adults with autism, including developing pathways

and protocols for people with Asperger syndrome and working with the third sector to develop a multi-agency strategy for people on the autistic spectrum.<sup>29</sup>

### **Services are not available consistently**

- 6.4 But while there are examples from across England and Wales of effective and relevant services for adults with autism, such services are not available consistently.
- 6.5 This is not just a 'postcode lottery': even within the same area, different adults with autism will have very different experiences, depending on factors as varied as their position on the autistic spectrum – sometimes services are available only to those with Asperger syndrome, for example – the professionals they have dealt with and even the way they came into the system. There remains a lack of co-ordination locally, particularly as, until now, adults with autism have not been seen as a priority in processes like the JSNA.

## **Enabling local partners to develop relevant services for adults with autism to meet identified needs and priorities**

### **Putting the needs of adults with autism on the map in every area**

- 6.6 Over the last few years, there has been a clear move in government policy towards area-based funding, which is designed to encourage a more collaborative approach to public services in each local area. Instead of each organisation developing its own

services within its own budget, local partners are better able to join up resources – both financial and human – to provide a more coherent response to the needs of the community.

- 6.7 The Total Place Pilots are adding to our experience and understanding of how local agencies can better work together for their communities. Over the coming months, key learning points from different models of integration will be reviewed and shared to make improved joint working more systematic across the NHS and local authorities.
- 6.8 Perhaps the most important tool locally, however, remains the JSNA, which requires all local partners to come together and identify priorities for services. **The JSNA core data set is currently being reviewed and estimates of numbers of adults with autism will be included when the revisions are published in spring 2010.** These estimates can be compared with the numbers of adults with autism known to services (such as learning disability or mental health services) to give an indication of possible unmet need. This can then inform the relevant single agency or joint strategic commissioning mechanisms required both to identify and meet the full health and wellbeing needs of all adults with autism.
- 6.9 Building on this, **we expect each local area to develop its own commissioning plan around services for adults with**

29. Care Quality Commission (2009) *The State of Health Care and Adult Social Care in England: Key themes and quality of services in 2009*

**autism that reflects the output of the JSNA and all other relevant data around prevalence.** This will need to be developed within the scope of existing resources and budgets, but, as many areas have shown, there is a clear business case to be made for improving the services available for adults with autism locally, and adopting a more preventative, supportive approach. For example, several areas have been able to reallocate resources from inappropriate placements of adults with autism in full-time psychiatric care; instead, they are able to provide day-to-day support that is more cost-effective and typically gives adults with autism greater independence.

6.10 To lead on this, **local authorities should follow the DH guidance which states that the Director of Adult Social Services (DASS) should ensure there is a joint commissioner/senior manager who has in his/her portfolio a clear commissioning responsibility for adults with autism.**<sup>30</sup> Experience suggests the best results come when this commissioner or senior manager is an integral part of mainstream commissioning processes. It is also important to reiterate that any professional leading on commissioning services for adults with autism will need to work closely with the local specialised commissioning group, as set out in paragraph 3.10.

6.11 As well as leading on the development of services for adults with autism in the

local area, this commissioner/manager should also participate in relevant local and regional strategic planning groups and partnership boards. For example, they could work closely with Valuing People Regional Leads and Deputy Regional Directors and others to ensure that personalisation is addressing the needs of adults with autism.

6.12 To support the work of this local commissioner/manager, local partners may also want to consider establishing a local autism partnership board that brings together different organisations, services and stakeholders locally and sets a clear direction for improved services. **The first-year delivery plan will provide examples of possible structures for such boards, drawing on best practice that already exists around the country.**

6.13 The key is that local partners come together in one place to discuss priorities and challenges together: how that might be done will need to be determined locally. We recognise that, in some areas, existing structures may fulfil the same purpose – such as Learning Disability Partnership Boards and Mental Health Local Implementation Teams (LITs) which have a separate sub-group reporting to them around the needs of people with autism. This may be an effective model to follow. Learning disability partnership boards have been successful in improving local planning of services for adults with learning disabilities. In a number of areas similar boards have been set up for autism.

30. DH (2008) *Services for adults with autistic spectrum conditions (ASC): Good practice advice for primary care trust and local authority commissioners*

Local services should build on this and support the development of local autism partnership boards.

services for adults with autism, and improve their access to mainstream services.

6.14 To help set direction at a regional level, **DH will work with the Association of Directors of Adult Social Services (ADASS), strategic health authorities, local government offices, deputy regional directors and other key partners to support the development of a regional delivery plan for adults with autism in each government region.** This should set out the key regional priorities – such as better access to mainstream services, increased availability of housing, better relationships with employers – and also help map existing services across the region, identifying in particular voluntary sector services that would benefit from additional support and ways to build their capacity. The national autism programme board will provide the overall governance to support and oversee these regional plans.

6.17 Service planning and the JSNA also require clear evidence about rates of autism. Building on the evidence we already have about the prevalence of autism,<sup>32</sup> DH is funding a study to explore rates of autism in a representative sample of adults in England. The study will report its findings in 2011 and builds on a small-scale study which began in 2008 to help develop a suitable methodology for estimating prevalence accurately.

6.18 In addition, to aid information sharing about adults with autism in the future, **DH will lead the development of an agreed protocol for what information should be recorded and how it should be shared with other services. This protocol will also look at how information about numbers of adults with autism locally should be compiled and fed into centrally collated data about rates of autism.**

6.15 **It is essential that the views of adults with autism and their carers are sought and taken into account in the development and delivery of services locally, in line with the duty to involve set out in *Creating Strong, Safe and Prosperous Communities*.**<sup>31</sup>

**Identifying and promoting service models that are proven to make a positive difference for adults with autism**

6.16 Together, the combination of clear local responsibility and shared regional direction will help strengthen the development of

6.19 In most areas, services for adults with autism are typically provided through either mental health or learning disability services. While these offer valuable support to many of the adults with autism eligible for them, it is clear that, under this model, a large

31. Communities and Local Government (CLG) (2008) *Creating Strong, Safe and Prosperous Communities*

32. Autism rates were shown in the Alternative Provider Medical Services (APMS) 2007 study to be 1.0% of the adult population living in private households (or one in every 100 adults).



number of adults with autism will receive no specific help as they have neither mental ill-health nor a learning disability. Equally, some of those who use these services find that their needs are not fully met by them.

6.20 The consultation highlighted a number of models adopted in different areas of the country which provide dedicated services for adults with autism.

- In the Royal Borough of Windsor and Maidenhead (RBWM), a prevalence study led to the establishment of a full-time team of three (a team manager, a care manager and an assistant care manager) to support adults with autism. This team has a number of responsibilities, including being the key point of contact for issues relating to adults with autism, identifying best practice, and highlighting gaps in provision. The team will also be responsible for leading work with commissioners to ensure that appropriate services are established. So far, the team has developed a fortnightly social group, a health and wellbeing group and training for professionals. All team members also hold a caseload of work with individuals and they expect to support 50 individuals at any one time. The team works closely with local voluntary organisations and NAS to create an invaluable service that deals with every area relating to the lives of adults with autism who have previously not been eligible for services.
- The Somerset Asperger Syndrome Consultancy Team was founded in January 2005 and takes referrals from local community mental health teams. The team consists of a team manager, another social worker, a community nurse, two clinical psychologists (equivalent to one full-time team member) and, for the equivalent of one day a week, an occupational therapist. It is able to offer a variety of interventions to support professionals working directly with people with Asperger syndrome, including diagnosis, consultancy, training and preventative support. Since its creation in January 2005, the team has received approximately 300 referrals.
- The Nottinghamshire Adults with Asperger team was set up in 2007 and is funded by Nottinghamshire County Council to meet the needs of adults with Asperger syndrome and high functioning autism. A team of five social care staff works across the county, in close partnership with health services, to provide a range of support, from advice and assistance in getting a diagnosis (although it does not offer diagnosis) to community care assessments to advice and assistance in getting the correct benefits. It also focuses on important quality of life issues, such as help with finding suitable accommodation and related support, advice and help with using leisure facilities and information about self-help groups, social groups and groups for carers.

6.21 We believe such models can be of real value in giving adults with autism the support they need. However, while there are already many good examples of specialist services such as these, no particular model has become common practice across the NHS and social care. Instead, services have been developed to reflect local needs and priorities, with a clear business case.

6.22 Best practice shows that where outcomes for adults with ASC have improved this has been as a result of the development of local teams. Local services should look to build on this practice and consider developing teams in their local area.

6.23 Therefore **to enable local partners to develop relevant services in every area, DH will continue to identify best practice and promote effective service models** in the forthcoming statutory guidance. As suggested in the NAO report, this guidance will seek to highlight examples of cost-effective ways to develop higher quality appropriate services locally, rather than relying on expensive out-of-area placements. Our experiences around *Valuing People Now* will be invaluable in this.

6.24 As well as examining models for joint commissioning and service delivery, we will also seek to identify examples of community services that have had a positive impact. For example, a number of colleges have now developed programmes

for adults with autism that focus on social and living skills.

- West London Community College offers adults with autism courses in emotional health, sexual relationships and living in the community.
- In Weston-super-Mare, Weston College worked with NAS to develop a specialist inclusion programme for learners with autism, helping them succeed in mainstream education. Learners are able to access dedicated support and tutoring as well as additional courses to help build their confidence in independent living and social integration.

6.25 There are also many support groups, run by third sector organisations, people with autism and their families. These play an important role in giving adults with autism a social life, supporting them to build relationships and enabling them to meet others with autism without worrying about how they will be judged or viewed. They can also provide an invaluable setting for training in life skills, as well as social skills, for example in cooking, dealing with money and bills and relationship advice. **In line with the Government's response to the consultation on implementing the *Independent Living Strategy*,<sup>33</sup> ODI is looking at ways to build the capacity of disabled people's organisations, including those that support adults with autism.**

33. ODI (2008) *Involving disabled people: Government response to the consultation on implementation and monitoring of the Independent Living Strategy*

## Enabling adults with autism and their families to have greater choice and control over where and how they live

6.26 The Government has stated that it aims “to enable people with learning disabilities and their families to have greater choice and control over where and how they live”.<sup>34</sup>

This includes adults with autism, and, as underlined in *Putting People First* and the *Independent Living Strategy*, means that:

- the needs of adults with autism should be taken into account in local housing planning, design and allocation, in line with local priorities
- support should be available for adults with autism who want to, or have to, live independently – both on an ongoing basis and during the transition period into a new home, and
- adults with autism and their carers should be given help to understand the options available to them, including the financial help they may be entitled to.

6.27 Local authorities are already required under the DDA to take account of the needs of disabled adults when considering housing provision. This includes taking account of the needs of adults with autism and means that in allocating homes to adults with autism, housing services should take account of individuals’ needs, as identified through the needs assessment process – as they should for any other vulnerable adult.

6.28 This could involve a number of factors, such as:

- considering the location of any home allocated – and, particularly, proximity to established sources of support, including family carers
- recognising any sensitivities the adult has. While every individual has different needs, many adults with autism can find certain housing conditions distressing. A common example is hypersensitivity to harsh lighting; other issues exist around layout of a home and furniture and fittings. These can be addressed both in designing new homes and in making alterations to existing housing stock.

6.29 Housing design increasingly takes account of the needs of residents – such as older people and disabled people. The Homes and Communities Agency is responsible for housing design standards and, following the recent report *Housing our Ageing Population: Panel for Innovation*,<sup>35</sup> is set to revise best practice design criteria. This provides an ideal opportunity to look at housing provision for adults with autism.

**Drawing on the expertise and input of specialist suppliers, the Homes and Communities Agency will incorporate, take account of and give reference to best practice on housing design for adults with autism in their forthcoming design and quality criteria standards.**

34. DH (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*

35. The Housing Our Aging Population Panel for Innovation (HAPPI), CLG and DH (2009) *Housing our Ageing Population* ([www.homesandcommunities.co.uk/Housing-Ageing-Population-Panel-Innovation](http://www.homesandcommunities.co.uk/Housing-Ageing-Population-Panel-Innovation))

6.30 As well as looking at housing design, local authorities are also required to make reasonable adjustments to processes such as choice-based lettings procedures to ensure they are accessible.

6.31 Valuing People Now partnership boards are already overseeing improvements to housing for adults with learning disabilities: their responsibilities also extend to adults with autism.

6.32 For adults with autism who want to, or have to, live independently, a support programme is almost as important as the availability of housing itself. This will build on the assessment of needs: levels of support might range from assistance with personal care and safety, to managing money, to help with decision-making. As indicated in chapter 4, many responses to the consultation indicated the benefits of low-level support, such as with administrative or domestic tasks, that can make a real difference to the levels of choice and control adults with autism have over where and how they live.

6.33 Though the Government's overall goal – as set out in the Independent Living Strategy – is to give disabled people who need support to go about their daily lives greater choice and control over how support is provided, we recognise that some adults with autism will continue to choose, and rely on, some form of residential care. This is particularly the case for older people,

who may not have family carers able to support them, and those with the most severe or complex needs.

### **Reforming Housing Benefit**

6.34 Housing Benefit is an important source of income for many adults with autism and their families. DWP reforms to the administration of Housing Benefit have already cut both fraud and error. The challenge now is to reform Housing Benefit further so that it can help people into work. A lot of people are unaware that they can claim Housing Benefit when in work. DWP is therefore promoting a Housing Benefit awareness campaign with help from key stakeholders.

6.35 In December 2009, DWP launched a public consultation on the next stage of housing benefit reform.<sup>35</sup> The consultation, which closed on 22 February 2010, includes proposals for work incentives to remove some of the uncertainty that comes with moving into work.

6.36 In particular, DWP is considering further reforms to the size criteria, which might help people whose circumstances do not fit with current rules. For example, adults with autism (like other disabled adults) who receive help from a non-resident carer may miss out because the rules cannot provide them with an extra room where the carer is required to stay overnight. The consultation invited responses on ways of helping through Housing Benefit.

36. DWP (2009) *Supporting people into work: the next stage of Housing Benefit reform – Public Consultation* ([www.dwp.gov.uk/consultations/2009/supportingpeopleintowork.shtml](http://www.dwp.gov.uk/consultations/2009/supportingpeopleintowork.shtml))

## 7. OUR NEXT STEPS

- 7.1 As made clear from the start of this document, this strategy is an important step on the road to a long-term goal. It builds on the landmark Autism Act 2009, setting a direction for future change and focusing on some of the elements needed to drive that change. Increased awareness of autism across public services is the essential starting point; consistent diagnosis helps formally recognise the condition and encourage public services to respond; and improved access to public services begins an ongoing process to ensure adults with autism get the support they need.
- 7.2 Above all, though, change needs to be driven locally, through strong local leadership, as set out in chapter 6.
- 7.3 To help enable local partners to provide this impetus and direction, we are producing:
- a first-year delivery plan, to be published by 31 March 2010, which sets out our priority actions
  - a full delivery plan for this strategy, by the end of 2010.
- 7.4 In addition, during 2010, DH will consult on and publish guidance under S7 of the Local Authority and Social Services Act 1970 to support the delivery of the strategy in health and social care. The guidance will be published in December 2010.
- 7.5 The NICE clinical guideline for children and young people is scheduled to be published in September 2010. The guideline for adults will follow at a later date.
- 7.6 We will assess the impact of all these actions – as well as the other steps already taken to transform services for adults with autism in England and Wales – as part of our formal review, in 2013. This review will be an inclusive and co-operative process, conducted with the involvement of all stakeholders but in particular adults with autism and their families. From there, we will identify and clarify what our next steps will be.
- 7.7 We know that the change needed to realise our vision will be a long-term process. But the actions and approach we have set out are designed to deliver a real impetus and set a clear framework for development of local partnerships and services to transform the lives of people with autism.

# SUMMARY OF ACTIONS

## **'Fulfilling and rewarding lives': The strategy for adults with autism in England**

- We commit to formally reviewing progress in three years' time and revising the strategy as necessary. (1.7)
- To oversee progress against the strategy, and provide overall direction and governance, DH is now setting up a national autism programme board, which will be co-chaired by the Minister for Care Services and the Director-General of Social Care. The board will include representatives from other government departments as well as stakeholder groups. (1.8)
- We will also publish a first year delivery plan by 31 March 2010. (1.17)
- We commit to working with Skills for Health, Skills for Care, professional bodies and the Royal Colleges to ensure that effective autism awareness training for health and social care professionals is developed. (1.26)
- We commit to delivering guidance to indicate some of the kinds of adjustments that might usefully be made, from physical adjustments to premises to improving the ways those delivering services communicate with adults with autism. (1.31)

- We commit to keeping progress under review so that we can take further action if the improvements we seek are not delivered. (1.39)

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

- We recommend that autism awareness training should be included within general equality and diversity training programmes across all public services. (2.8)
- The forthcoming statutory guidance will provide examples of best practice for [providing training within] health and social care, and emphasise the importance of involving adults with autism and their carers in developing and delivering training. (2.9)
- [Jobcentre Plus will ensure] that autism awareness training is provided to all DEAs who have not yet received it. (2.11)
- We believe it is essential that autism awareness training is available to all staff in the criminal justice sector. (2.14)
- We believe it is essential that autism awareness training is available to everyone working in health or social care. (2.16)
- We will work with partners to develop effective training modules and approaches which can be used by local authorities

and PCTs to create training programmes locally. (2.18)

- DH has recently commissioned the development of new online resources and information about autism for those working in the health and social care sectors. (2.19)
- We will work with PCTs and local authorities to identify priority groups for training. (2.20)
- We believe that autism awareness should be part of the core training curricula for doctors, nurses and other clinicians. (2.23)
- We recommend that autism awareness should be an essential part of the training given to staff carrying out community care assessments. (2.24)
- DWP is investigating whether existing campaigns and programmes such as Employ Ability can be extended to include more examples of adults with autism. (2.30)
- It will be expected that autism awareness training is included in the equality and diversity planning and single equality schemes of all central government departments. (2.32)

### **Developing a clear, consistent pathway for diagnosis of autism**

- The forthcoming NICE guideline will set out a model care pathway(s), which will form the foundation for local commissioners to develop referral and care pathways in their areas, supported by their strategic health authority where necessary. (3.9)

- We recommend that local areas appoint a lead professional to develop diagnostic and assessment services for adults with autism. (3.10)
- While developing the forthcoming clinical guideline, NICE will consider how to make the diagnostic process more accessible and consistent. (3.13)
- Diagnosis of autism should be recognised as a reason for assessment [under the NHS and Community Care Act 1990]. (3.14)
- Diagnosis of autism should also be recognised as a catalyst for a carer's assessment. (3.19)
- To help local authorities and PCTs develop the right kinds of information, the forthcoming statutory guidance will provide more details of what information adults with autism and their family or carers are likely to need after diagnosis. (3.28)

### **Improving access for adults with autism to the services and support they need to live independently within the community**

- DH has already committed to delivering guidance for mental health and learning disability services to indicate some of the kinds of adjustments that might usefully be made, from physical adjustments to premises to improving the ways those delivering services communicate with adults with autism. (4.10)
- DWP will 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. (4.11)

- Adults with autism should be eligible for personal budgets and direct payments, in line with the assessment of their needs. (4.17)
- We encourage local authorities to explore how to support volunteer and third sector groups in planning and commissioning services locally. (4.22)
- We recommend that travel training is made available nationwide for all adults with autism that would benefit from it. (4.26)
- Under *Aiming High for Disabled Children*, DCSF is investing £19 million in a Transition Support Programme to improve transition planning. (4.30)

## Helping adults with autism into work

- DWP is committed to ensuring that these programmes [announced in *Building Britain's Recovery: Achieving Full Employment*] work for young people with autism, and that the choices and support they are offered reflect their specific needs. (5.8)
- [Existing specialist disability] provision will be replaced by a new programme – Work Choice – from October 2010. (5.18)
- Jobcentre Plus has now changed Access to Work to improve support services for customers with autism. (5.21)

- We will make it clear that the actions and initiatives we are introducing [as part of *Work, Recovery and Inclusion*] – such as internships and cover for episodic absences – should be available to support adults with autism. (5.30)
- These pilots [placing Jobcentre Plus advisers in GP surgeries] are now being expanded to treble the capacity. (5.32)

## Enabling local partners to develop relevant services for adults with autism to meet identified needs and priorities

- The JSNA core data set is currently being reviewed and estimates of numbers of adults with autism will be included when the revisions are published in spring 2010. (6.8)
- We expect each local area to develop its own commissioning plan around services for adults with autism that reflects the output of the JSNA and all other relevant data around prevalence. (6.9)
- Local authorities should follow the DH guidance which states that the Director of Adult Social Services (DASS) should ensure there is a joint commissioner/senior manager who has in his/her portfolio a clear commissioning responsibility for adults with autism. (6.10)
- The first-year delivery plan will provide examples of possible structures for [local autism partnership] boards, drawing on best practice that already exists around the country. (6.12)



- DH will work with the Association of Directors of Adult Social Services (ADASS), strategic health authorities, local government offices, deputy regional directors and other key partners to support the development of a regional delivery plan for adults with autism in each government region. (6.14)
- It is essential that the views of adults with autism and their carers are sought and taken into account in the development and delivery of services locally, in line with the duty to involve set out in *Creating Strong, Safe and Prosperous Communities*. (6.15)
- DH will lead the development of an agreed protocol for what information should be recorded and how it should be shared with other services. This protocol will also look at how information about numbers of adults with autism locally should be compiled and fed into centrally collated data about rates of autism. (6.18)
- To enable local partners to develop relevant services in every area, DH will continue to identify best practice and promote effective service models. (6.23)
- In line with the Government's response to the consultation on implementing the *Independent Living Strategy*, ODI is looking at ways to build the capacity of disabled people's organisations, including those that support adults with autism. (6.25)
- Drawing on the expertise and input of specialist suppliers, the Homes and Communities Agency will incorporate, take account of and give reference to best practice on housing design for adults with autism in their forthcoming design and quality criteria standards. (6.29)

# LIST OF POLICIES THAT APPLY TO ADULTS WITH AUTISM

The list below summarises some of the key government policies and publications from recent years that apply specifically to adults with autism and that form the policy background in which this strategy has been developed.

This list is alphabetical and is by no means exhaustive. The fact that a policy or document is not included here does not mean it does not apply to adults with autism.

- *Access to Work* – a specialist disability programme delivered by Jobcentre Plus, which provides practical advice and financial assistance towards the support needed by disabled people to help them overcome work-related obstacles resulting from disability.
- *Aiming High for Disabled Children (2007)* – the Transition Support Programme works to support local areas to improve transition arrangements across health and social care, including consolidating person centred approaches.
- *The Bradley Review (2009)* – examines the extent to which offenders with mental health or learning disabilities could, in appropriate cases, be diverted from prison to other services, and the barriers to such diversion. The review makes a series of recommendations to Government including the organisation of effective liaison and diversion arrangements and the services needed to support them.
- *Building Britain's Recovery: Achieving Full Employment (2009)* – sets out Government plans to combat the effects of the recession and to help young people into jobs and training more quickly, to support older workers, and to deliver a more flexible, personalised service.
- *Creating Strong, Safe and Prosperous Communities (2008)* – provides statutory guidance to local authorities and their partners on creating strong, safe and prosperous communities. It covers the duty to involve, and duties around Local Area Agreements in the Local Government and Public Involvement in Health Act 2007.
- *Disability Discrimination Act (2005)* – promotes civil rights for disabled people and protects disabled people from discrimination. The Act requires public bodies to promote equality of opportunity for disabled people. It also allows the Government to set minimum standards so that disabled people can use transport easily.
- *High Quality Care for All (2008)* – the final report of Lord Darzi's NHS Next Stage Review. It responds to the 10 SHA strategic visions and sets out a vision for an NHS with quality at its heart.
- *Improving Health, Supporting Justice (2009)* – this national delivery plan contributes to key Government initiatives around protecting the public, reducing health inequalities, reducing

reoffending, and health improvement and protection.

- *Improving the Life Chances of Disabled People* (2005) – disabled people in Britain should have full opportunities and choices to improve their quality of life, and should be respected and included as equal members of society. A key area is independent living.
- *Independence and Opportunity: Our Strategy for Supporting People* (2007) Department for Communities and Local Government – intends to improve housing opportunities.
- *Independent Living Strategy* (2008) – a commitment to shared understanding of the principles and practice of independent living. Disabled people who need support to go about their daily lives will have greater choice and control over how support is provided; and disabled people will have greater access to housing, health, education, employment, leisure and transport opportunities and to participation in family and community life.
- *Mental Capacity Act* (2005) – came into force in 2007 providing a clearer legal framework for people who lack capacity, for those caring for them and for the professionals who work with them by setting out key principles. It puts people who lack capacity at the heart of the decision-making process – this includes people with autism and those who may not find it easy to express their choice in words. The Act requires an assumption that people have capacity to make decisions for themselves unless there is evidence to the contrary.
- *National Service Framework on Long Term (Neurological) Conditions* (2005) – sets out quality requirements and the evidence base for services to people with long-term neurological conditions resulting from disease of, injury or damage to, the body's nervous system. It applies to health and social care services working with other key agencies, such as providers of transport, housing, employment, education, benefits and pensions.
- *National Service Framework for Mental Health – five years on* (2004) – key relevance is continued work to tackle social exclusion.
- *New Horizons: Working together for better mental health* (2009) – a cross-government programme of action with the twin aims to: improve the mental health and wellbeing of the population; improve the quality and accessibility of services for people with poor mental health.
- *Our Health, Our Care, Our Say: A New Direction for Community Services* (2006) – services should become more responsive, focusing on people with complex needs, and shifting care and support closer to home.
- *Putting the frontline first: smarter government* (2009) – sets out how the Government will improve public service outcomes while achieving the fiscal consolidation that is vital to help the economy grow. The plan has three central actions: to drive up standards by strengthening the role of citizens and civic society, to free up public services by recasting the relationship between the centre and the frontline, and to streamline the centre

of Government, saving money for sharper delivery.

- *Putting People First (2007)* – key relevance is the provision of information, advice and advocacy, early intervention and re-enablement, prevention and personalisation. Maintains that access to high quality support should be universal and available in every community. Local, statutory and voluntary and private sector organisations should be fully engaged in this transformation.
- *Roadmap 2025 (2009)* – sets out how government departments are working towards disability equality by 2025. The document lists achievements since 2005 and plots the next steps in improving services, access and opportunities in 14 broad areas such as employment, housing, travel and tackling discrimination.
- *Safeguarding Adults: A Consultation on the Review of the 'No Secrets' Guidance (2008)* – to safeguard and protect adults who may become vulnerable and enable them to live safely in their local communities and not be constrained by abuse.
- *Valuing Employment Now: real jobs for people with learning disabilities (2009)* – sets out an ambitious goal to increase radically the number of people with learning disabilities in employment by 2025.
- *Valuing People: A New Strategy for Learning Disability for the 21st Century (2001)* – focuses on achieving full lives for people with learning disabilities and aims to redress inequalities.
- *Valuing People Now (2009)* – restates the principles and priorities in the Valuing People White Paper, and is committed to achieve its aims within the next three years with a delivery plan.
- *Work Choice* – a new pan-disability programme will, from October 2010, help customers who face complex disability related barriers and have the highest support needs to find and keep a paid job or progress while in work. This will include adults with autism. The new programme will provide specialist support where DWP mainstream provision may not be appropriate or does not meet the particular needs of the individual.
- *World Class Commissioning (2007)* – the world class commissioning programme aims to transform dramatically the way health and care services are commissioned in England.



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