

Implementing “Fulfilling and rewarding lives”

*Statutory guidance for local authorities and NHS
organisations to support implementation of the
autism strategy*



Implementing Fulfilling and Rewarding Lives

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Implementing “Fulfilling and rewarding lives”

Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy

Foreword from the Minister for Care Services

Adults with autism should be able to enjoy an improved quality of life, increased personal autonomy and greater inclusion in every aspect of society. This guidance is the next step on a journey towards transforming the way public services support adults with autism. That journey, which began with the private member's bill brought by the Rt Hon Cheryl Gillan MP, the Autism Act 2009 and the autism strategy, *Fulfilling and Rewarding Lives*, provided the framework: now we are focusing specifically on how health and social care services can support adults with autism more effectively.

This document is a significant step forward. It focuses on four areas where health and social care bodies can practically change the way they support adults with autism – increasing understanding of autism amongst staff, strengthening diagnosis and assessment of needs, continuing to improve transition support for young people with autism and ensuring adults with autism are included within local service planning. The actions outlined draw on best practice that has emerged across the UK, and follow logically from the strategy. They also reflect the wider outcomes that the Coalition Government has identified as being the foundations for change in the NHS, social care and public health. More local, more joined up, more personal. And a determination to make a reality of 'No decision about me, without me.'

This guidance aims to empower local areas to develop services and support in ways that truly reflect the assessed needs and priorities of their community. It aims too to enable and encourage innovation in the way services are delivered.

That is why, although this guidance is issued only to local authorities and NHS bodies (as required in the Autism Act), I want to reiterate that change must come across all public services, and indeed through the impact and input of the Big Society too. The families of adults with autism, autism representative groups and adults with autism themselves have all contributed to developing this guidance and the preceding strategy: it is our intention that they continue to contribute to improving services, using this guidance to hold those who commission and provide health and social care services to account.

Only by such a transparent and mutual approach can we achieve the vision the Government has set out for adults with autism: fulfilling and rewarding lives within a society that accepts and understands them.



Paul Burstow
Minister of State for Care Services
Department of Health

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Status of this guidance

This guidance is issued under section 2 of the Autism Act 2009 (the Act). It is issued to local authorities, NHS bodies and NHS Foundation Trusts.

As set out in section 3 of the Autism Act 2009, it is to be treated as though it were guidance issued under section 7 of the Local Authority Social Service Act 1970 (LASS Act). This means that local authorities must “follow the path charted by the guidance, with liberty to deviate from it where the authority judges on admissible grounds that there is good reason to do so, but without freedom to take a substantially different course.”

Though the LASS Act does not directly apply to NHS bodies, section 3(2) of the Autism Act 2009 makes it clear that for the purposes of this guidance “an NHS body is to be treated as if it were a local authority within the meaning of the LASS Act”. The Act also specifies that the functions of an NHS body concerned with the provision of relevant services are to be treated as if they were social services functions within the meaning of the LASS Act.

Local authorities and NHS bodies must not only take account of this guidance, but also follow the relevant sections or provide a good reason why they are not doing so (one example might be because they can prove they are providing an equivalent or better alternative). If they do not follow the guidance and cannot provide a good reason, they may be liable to judicial review or default action by the Secretary of State.

An NHS body is a Strategic Health Authority, a Primary Care Trust, an NHS trust all or most of whose hospitals, establishments and facilities are in England and a Special Health Authority performing functions only or mainly in respect of England.

The definition of NHS body in the Autism Act does not include NHS Foundation Trusts. However, this guidance **does** include Foundation Trusts, and throughout, it is stated clearly what the responsibilities of local authorities, NHS bodies and NHS Foundation Trusts are. NHS Foundation Trusts will be expected to take the guidance into account in planning and providing services for adults with autism.

Introduction

Purpose of this guidance

The purpose of this guidance is to secure the implementation of *Fulfilling and Rewarding Lives: The strategy for adults with autism in England* by giving guidance to local authorities, NHS bodies and NHS Foundation Trusts around training of staff, the diagnosis of autism and the leadership and planning of services. This guidance will help these bodies to develop services that support and meet the locally identified needs of people with autism and their families and carers.

The strategy seeks to make existing policies and public services work better for adults with autism. This guidance therefore reminds local authorities, NHS bodies and NHS Foundation Trusts of what some of the relevant policies are and their existing duties and responsibilities. It refers to existing guidance to support adults with autism¹, and sets out some additional guidance to help these bodies implement the strategy.

Background

As required by the Autism Act 2009 (the Act)², on 3 March 2010 the then government published *Fulfilling and Rewarding lives: the strategy for adults with autism in England*.

Section 2(1) of the Autism Act further requires that:

“For the purpose of securing the implementation of the autism strategy, the Secretary of State must issue guidance—

(a) to local authorities about the exercise of their social services functions within the meaning of the Local Authority Social Services Act 1970 (c. 42) (see section 1A of that Act), and
(b) to NHS bodies and NHS foundation trusts about the exercise of their functions concerned with the provision of relevant services.”

As set out at the start of this document, because the guidance is required by law, it is known as “statutory” guidance. It is to be treated as if it were guidance issued under section 7 of the Local Authority Social Services Act 1970. This means that local authorities and NHS bodies³ must follow the relevant sections or provide a good reason why they are not (one example might be because they can prove they are providing an equivalent or better alternative)⁴. If they do not follow the guidance and cannot provide a good reason, they may be liable to judicial review⁵. Lack of sufficient resource would not necessarily constitute a good reason.

¹ *Fulfilling and Rewarding Lives* includes a list of policies that apply to adults with autism. Though some of the specific programmes described there may be subject to change, it provides a useful policy context for how the strategy was developed.

² “The Secretary of State must prepare and publish a document setting out 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,” Autism Act 2009 section 1(1)

³ For the definition of “NHS body”, see page 6 “Status of this guidance”

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NHS Foundation Trusts are treated differently under the Autism Act. They are expected to take this guidance into account in planning and providing services for adults with autism.

The outcomes we seek

This Government has made clear its intention that health and social care are run from the bottom up, with ownership and decision-making in the hands of professionals, patients, service users and carers. Our focus is on outcomes, not process targets, and the ultimate outcome we seek for adults with autism is the vision set out in *Fulfilling and Rewarding Lives*:

‘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.’

As the strategy acknowledged, this vision is a long-term goal, and one that requires change across all public services. We are therefore publishing – alongside this statutory guidance – a set of key outcomes and service ambitions, which will help, evaluate progress across public services towards the overall vision.

However, as required by the Act, this guidance focuses only on health and social care, and provides the next step towards delivering a system that provides personalised care for all adults with autism that reflects their health and care needs, supports carers and encourages strong joint arrangements and local partnerships.

In particular, this guidance sets out how health and social care services can:

- improve the way they identify the needs of adults with autism, and
- incorporate those identified needs more effectively into local service planning and commissioning, so that adults with autism and their carers are better able to make relevant choices about their care.

Though the guidance provides direction, the ultimate aim is that local areas apply it to reflect local needs, existing strengths in service provision and the landscape they work in. If a service is successfully delivering for adults with autism, it should not be changed simply to reflect this guidance: instead, it should be seen as a model for other services to learn from.

⁴ Case law has established that complying with section 7 guidance involves more than simply taking account of the guidance. Rather, local authorities must “follow the path charted by the guidance, with liberty to deviate from it where the authority judges on admissible grounds that there is good reason to do so, but without freedom to take a substantially different course” (R v Islington Borough Council, ex parte Rixon (1998 ICCLR 119)). A local authority which failed to comply with section 7 guidance without a compelling reason for doing so would be acting unlawfully and could find itself subject to judicial review or default action by the Secretary of State.

⁵ Judicial review is a type of court proceeding in which a judge reviews the lawfulness of a decision or action made by a public body.

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Similarly, one of the underlying principles of the guidance is to avoid new burdens or extra requirements that health and social care professionals must meet. Instead, the emphasis is on making sure existing policies are followed: that is why throughout the guidance, there is a clear reminder of what existing policies, responsibilities and duties are.

However, though we do not seek change for change's sake, the guidance – like the Autism Act 2009 and the strategy – exists because we know that services must improve to better meet the needs of adults with autism: it is not sufficient to simply carry on with the status quo, and local areas should be accountable for the way they respond to this guidance.

As well as the specific outcome for adults with autism – the vision set out in *Fulfilling and Rewarding Lives* – this guidance works towards the broader outcome for the NHS, social care and public health, as set out in the relevant outcomes frameworks.

Changing landscape

The NHS White Paper *Equity and Excellence: Liberating the NHS* sets out proposed changes for the NHS including the establishment of a new NHS Commissioning Board, and a transfer of responsibility for health improvement to local government. It is envisaged that local authorities and GP consortia will work together on planning and commissioning services for local populations. The plan set out in *Liberating the NHS* provides the opportunity for a much greater degree of local co-ordination and integrated working to shift the balance of power towards local communities and individuals. This guidance reflects as far as possible the changes already announced.

The Secretary of State already has a duty, under the Autism Act, to keep the strategy under review: as part of this, the guidance will also remain under review and will be updated as required to align with the new structures.

Scope of this guidance

As required by the Autism Act, this guidance is issued to local authorities, NHS bodies and NHS Foundation Trusts. These organisations will also want to ensure that the guidance is followed by other organisations that deliver services under contract for them such as organisations contracted to provide residential or day care on behalf of a local authority.

Other providers of public services – such as employment services, police and probation – are not legally required to have regard to it. However, by following the guidance, these bodies could help improve the delivery of the services they provide: for example, ensuring that staff who provide services to adults with autism have received autism awareness training would clearly be of value across all public services.

This guidance relates to England only. Services for adults with autism in Scotland, Wales and Northern Ireland are the responsibility of the devolved administrations.

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The Welsh Assembly Government has its own *Strategic Action Plan for Autistic Spectrum Disorders (ASD)*, which was published in April 2008. An ASD Strategic Action Plan is being finalised for publication in Northern Ireland, while in Scotland the ASD Reference Group completed its work by publishing guidance to local agencies on commissioning services for people with autism⁶.

Structure of the guidance

The Autism Act required that guidance covers the following:

1. the provision of relevant services⁷ for the purpose of diagnosing autistic spectrum conditions in adults
2. the identification of adults with autism
3. the assessment of the needs of adults with autism for relevant services
4. planning in relation to the provision of relevant services to people with autism as they move from being children to adults
5. other planning in relation to the provision of relevant services to adults with autism
6. the training of staff who provide relevant services to adults with autism
7. local arrangements for leadership in relation to the provision of relevant services to adults with autism.

However, there is no requirement under the Act that these seven areas are covered separately. Therefore, in recognition of the fact that there are important links between some of these areas, this guidance is structured as follows:

- A. Training of staff who provide services to adults with autism – covering item 6 above
- B. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services – covering items 2, 1 and 3 above
- C. Planning in relation to the provision of services to people with autism as they move from being children to adults – covering item 4 above.
- D. Local planning and leadership in relation to the provision of services for adults with autism – covering items 5 and 7 above

This structure helps clarify the links between these areas and simplifies the guidance. It also ensures the guidance is more clearly focused on the outcomes we seek.

Good practice examples

Fulfilling and Rewarding Lives stated that the statutory guidance would include examples of good practice in areas such as provision of training to health and social care staff, or the information which people should have following a diagnosis of autism.

⁶ The Scottish Government (2008) – Commissioning Services for People on the Autism Spectrum: Policy and Practice Guidance

⁷ Relevant services are defined in section 4(1) of the Act and mean in relation to NHS bodies health services provided under the NHS Act 2006 and in relation to local authorities means services provided in exercise of the authority's social services functions (within the meaning of section 1A of the LASS Act 1970)

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Instead of including these as part of the formal guidance, these examples will be available online soon via the DH website, and will be refreshed and added to as new models are developed and tested out in practice. This way, we can create a living and growing resource not just for health and social care bodies but also for adults with autism and their families and carers.

Terminology

Throughout the guidance, as in the strategy, we use the term “autism” as an umbrella term for all autistic spectrum conditions, including Asperger syndrome.

A. Training of staff who provide services to adults with autism

Fulfilling and Rewarding Lives makes it clear that the most fundamental step towards improving services for adults with autism is to increase awareness and understanding of autism across all public services. Increased awareness and understanding of autism will provide the foundations for the broader changes sought to the way services are provided, planned and delivered.

Improving training around autism, and increasing its availability, is therefore at the heart of the strategy for all public service staff. This guidance focuses on what this means for local authorities and NHS bodies, while recognising that the forthcoming changes to the NHS will affect the way training is delivered for the NHS workforce.

The guidance covers two distinct areas:

- general autism awareness training, which should ultimately be available for everyone working in health and social care
- specialised training for staff working in key roles – such as GPs, those responsible for conducting community care assessments, and those in leadership roles locally.

Current policies, duties and responsibilities

Health and social care commissioners and providers are expected to ensure that each member of their workforce has the relevant professional qualifications and competencies to fulfil their role and function. They are also expected to ensure that all members of their workforce have access to relevant training to enable them to deliver those roles in line with the Department of Health (DH)'s workforce strategies for health and social care.

What *Fulfilling and Rewarding Lives* says

Fulfilling and Rewarding Lives states that:

“it is ... essential that autism awareness training is available to everyone working in health or social care.”⁸

It also sets out the desired outcome:

“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.”⁹

⁸ Fulfilling and rewarding lives, paragraph 2.16

⁹ Fulfilling and rewarding lives, paragraph 2.17

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Further, it makes it clear that:

“training should reflect the actual situations staff work in.”¹⁰

In addition to autism awareness training for frontline staff, the strategy recommends the development of specialist training in health and social care so that staff who wish to specialise in autism or develop further knowledge can do so.

The strategy commits DH to working with key partners such as the General Medical Council, the Postgraduate Medical Education and Training Board, 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. These organisations have been engaged throughout the development of the strategy and stated their commitment to reviewing their curricula. As a result, this requires no additional investment from government.

What this means for health and social care

- Local authorities, NHS bodies and NHS Foundation Trusts should seek ways to make autism awareness training available to all staff working in health and social care. In line with the principles set out in *Fulfilling and Rewarding Lives*, as a minimum autism awareness training should be included within general equality and diversity training programmes¹¹.
- The core aims of this training are that staff are able to identify potential signs of autism and understand how to make reasonable adjustments in their behaviour, communication and services for people who have a diagnosis of autism or who display these characteristics.
- Those staff who are most likely to have contact with adults with autism are the priority groups for training.
- In addition to general autism awareness training for staff, local areas should develop or provide specialist training for those in key roles that have a direct impact on access to services for adults with autism – such as GPs¹² or community care assessors – and those whose career pathways focus on working with adults with autism, such as personal assistants, occupational therapists or residential care workers. The end goal of this specialist training is that, within each area, there are some staff who have clear expertise in autism.

Delivering training effectively

In recognition of the potential benefits of combining training programmes in each local area, the lead professional in the area should be involved in the commissioning of training. However, in local authorities or NHS bodies/Foundation Trusts, there is likely to be a training manager responsible for ensuring the delivery of autism awareness training.

¹⁰ Fulfilling and rewarding lives, paragraph 2.17

¹¹ Fulfilling and Rewarding Lives, paragraph 1.26

¹² According to the 2009 National Audit Office report *Supporting people with autism through adulthood* “eighty per cent of GPs feel they need additional guidance and training to manage patients with autism more effectively.” (p.19 para 2.3)

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The following points aim to help those responsible for training make best use of their budgets and time.

- As the strategy made clear, initial autism awareness training can be delivered as part of existing equality and diversity training or similar programmes. Local areas may also want to consider online training, DVDs etc, as well as using the DH-commissioned online resources and information about autism for those working in the health and social care sectors, which will be available from March 2011.
- Clearly, there is considerable scope to share resources with other organisations locally – for example, co-commissioning a training programme or course.
- Autism awareness training should not be seen as a one-off.
- The most effective training will help staff put what they are learning in context, by reflecting the situations they work in – for example, in terms of the kinds of reasonable adjustments that can be made to their working environment.
- When identifying who requires training within an organisation, it is important to consider all staff – not just those in frontline service delivery. For example, a practice manager may have a key role to play in making adjustments to the setting to make it accessible for adults with autism; the response of a receptionist can make a big difference to whether an adult with autism makes and keeps an appointment.
- As well as budgeting for core awareness training, it may be necessary to allocate funding for more specialist autism training for certain staff – including those who wish to specialise in autism. It is not expected that each local authority, NHS body or NHS Foundation Trust develops its own specialist training programme, but rather that applications for specialist training are considered within the training budget.
- When planning or commissioning training, organisations should where possible involve adults with autism, their families and carers and autism representative groups. This may be in terms of inviting them to comment on or contribute to training materials, or asking them to talk to staff about autism and how it affects them, or to provide the training.

B. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services

A central part of the Government's vision for adults with autism is that "they can get a diagnosis and access support if they need it." This will require a significant shift from the current situation, where many adults find it difficult to get a diagnosis, and those that have been formally diagnosed do not necessarily receive an assessment of what support and care they need.

For many adults, receiving a clinical diagnosis of autism is an important step towards a fulfilling life. Currently, guidance is unclear about how diagnosis should be offered – partly due to the complexity of diagnosing autism (as a spectrum condition). This results in inconsistent practice across the country.

However, as *Fulfilling and rewarding lives* made clear, diagnosis is not a goal in itself. Instead, it is one part of an integrated process which should lead to adults with autism being able to access the services and support they need. This guidance aims to clarify how that process should operate from initial identification of possible autism through referral to diagnosis to assessment of needs for care services.

Current policies, duties and responsibilities

Currently, there are no specific duties around identification and diagnosis of autism beyond core professional standards within health and social care. There is also no single diagnostic process for autism.

However, the National Institute for Health and Clinical Excellence (NICE) is developing a new clinical guideline for adults with autism. This is scheduled to be published in July 2012 and will set out a model care pathway (or pathways), which will form the foundation for local commissioners to develop referral and care pathways in their areas. As part of this, NICE will consider how to make the diagnostic process more accessible and consistent.¹³

Under section 47(1) of the NHS and Community Care Act 1990, local authorities have a duty to assess a person who may be in need of community care services. This assessment may be triggered either by the individual requesting it or if the local authority believes community care services may be necessary. **This duty applies to people with autism.**

¹³ NICE is also developing a separate clinical guideline for autism in children and young people. This is scheduled to be published in September 2011

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Such an assessment should be carried out by trained practitioners, and where there are potential signs of autism, the assessment should take account of the communication needs of adults with autism. **Assessment of eligibility for care services cannot be denied on the grounds of the person's IQ.**

What *Fulfilling and rewarding lives* says

“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.”¹⁴

To accelerate this, *Fulfilling and rewarding lives* recommends that:

“local areas appoint a lead professional to develop diagnostic and assessment services for adults with autism.”¹⁵

However, as the strategy also states:

“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.”¹⁶

and reinforces that by saying:

“diagnosis of autism should be recognised as a reason for assessment.”¹⁷

The strategy also says that:

“It is best practice that diagnosis of autism is recognised as a catalyst for a carer's assessment.”¹⁸

However, as with any condition, identification of possible autism is the essential first step to effective support – even before formal diagnosis. *Fulfilling and rewarding lives* recognises the role that frontline staff can play in this, and acknowledges that the biggest barrier to identification of autism is a lack of awareness amongst frontline staff. That is why the strategy emphasises the importance of appropriate information and training so that staff can identify and respond to the needs of adults with autism. In particular the strategy says that:

“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, but more importantly so they can understand

¹⁴ Fulfilling and rewarding lives, paragraph 3.11

¹⁵ Fulfilling and rewarding lives, paragraph 3.10

¹⁶ Fulfilling and rewarding lives, paragraph 3.14

¹⁷ Fulfilling and rewarding lives, paragraph 3.14

¹⁸ Fulfilling and rewarding lives, paragraph 3.19

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how to adapt their behaviour, and particularly their communication, when a patient either has been diagnosed with autism or displays these signs”¹⁹

The strategy also reiterates the duties around the provision of a person-centred assessment of need, and in particular emphasises that:

“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”²⁰.

What this means for health and social care

From identification to diagnosis

- As set out in section A above, it is important that staff across health and social care receive autism awareness training so that they are better able to identify potential signs of autism. The aim of this training is that staff can:
 - inform the person who may have autism, or their families or carers, about the availability of diagnosis, and direct them appropriately if they want to access diagnosis – for example, explaining how they can get formally referred for diagnosis
 - make reasonable adjustments to the way they provide services to the person who may have autism.
- Each area should put in place a clear pathway for diagnosis of autism, from initial referral through to assessment of needs. An important starting point will be to review the current pathway to diagnosis in their area or organisation. Where there is an effective pathway locally, which has the support of clinicians and adults with autism, their families and carers, this should form the foundation of any further changes.
- The NICE clinical guideline for adults with autism is scheduled to be published in July 2012. In order to be ready for the guidance, NHS bodies and NHS Foundation Trusts that commission or provide diagnostic and assessment services need to review existing best practice²¹ now with a view to establishing how it can be adopted in their area or organisation. Once the NICE clinical guideline is published, NHS bodies and NHS Foundation Trusts that commission or provide diagnostic and assessment services should review their diagnostic processes and services against NICE’s best practice guidance. The aim of this is to make the diagnostic process more accessible and consistent.
- It is important that all relevant local organisations such as social care teams understand what the pathway to diagnosis is.

¹⁹ Fulfilling and rewarding lives, paragraph 2.21

²⁰ Fulfilling and rewarding lives, paragraph 3.18

²¹ See in particular Services for adults with autistic spectrum conditions (ASC): Good practice advice for primary care trust and local authority commissioners (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_097418) and good practice examples cited in Fulfilling and Rewarding Lives

From diagnosis to assessment of needs

- It is vital that local authorities fulfil their duties under the 1990 Act by ensuring that adults diagnosed with autism who may have community care needs are offered an assessment. This is not a new requirement. To enable local authorities to fulfil these duties, local authorities, NHS bodies and NHS Foundation Trusts should take the following steps:
 - When an adult is diagnosed with autism, the NHS body or NHS Foundation Trust providing healthcare services to the adult informs, with the individual's consent, the relevant local authority adult services department promptly to ensure that a community care assessment can be carried out within a reasonable time period if the individual wants such an assessment.
 - The social services department then contacts the adult with autism – and any registered carers – to inform them of their entitlement to an assessment and inform carers of their right to a carer's assessment.
 - In addition, healthcare professionals who make a diagnosis of autism inform the adult diagnosed, and/or their carers, that they also have the right to request such an assessment. This will help ensure that if adults diagnosed with autism are not offered an assessment by the local authority following diagnosis within a reasonable time period, they can still access one.
- All assessments 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*.
- As *Prioritising Need*²² says: “Staff undertaking assessments or supporting self-assessments should be sufficiently skilled in understanding people with a range of needs so that specific groups are not marginalised”. It is therefore recommended that as far as possible assessment of needs be carried out by a professional who has a good knowledge of autism, and reasonable adjustments made to the assessment process to enable the adult with autism to take part fully.
- If an adult who has previously received an assessment of need for care services is subsequently diagnosed as having autism, this is a potential reason for reassessment. If an adult who has previously been refused an assessment of need is subsequently diagnosed as having autism, this is a reason for assessment.
- Assessment of eligible needs for services should not be influenced by availability of services: for example, if the assessing professional identifies that the adult with autism would benefit from an advocate, the report should reflect that whether or not advocacy services are available. This will not only help the adult with autism access the right services in the future, or benefit from relevant support when in employment or education, but also will feed into the overall picture of the needs of adults with autism in the area, and local Joint Strategic Needs Assessment (JSNA).

²² DH (2010) *Prioritising need in the context of Putting People First: a whole system approach to eligibility for social care - guidance on eligibility criteria for adult social care, England 2010*

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Responsibilities

- Each local authority should appoint a lead professional to develop diagnostic and assessment services for adults with autism in their area. This should be done in conjunction with the Local Strategic Partnership.
- The Director of Adult Social Services (DASS) is responsible for ensuring that the correct processes are in place within the local area for:
 - conducting assessments of needs
 - the prompt sharing of information between diagnostic services and adult services about adults diagnosed
 - timely formal notification of the entitlement to an assessment of needs and, where relevant, a carer's assessment.

Delivering diagnosis and assessment effectively

While some areas already have effective pathways for diagnosis, most do not. The following points will help guide planning diagnostic pathways and subsequent services.

- Diagnosis of autism is **not** a guarantee of support or services. It is a reason for assessment of needs and an important piece of information to be stored on an individual's health record to support future care. Access to publicly funded care services is based on meeting the criteria set out in *Prioritising Need*.
- Diagnosis is not compulsory: not all adults who exhibit the characteristics of autistic spectrum conditions will want to be referred for formal diagnosis. Therefore, adults who may not have a formal diagnosis of autism are still entitled to a needs assessment in line with the principles of the 1990 Act.
- Diagnosis of autism can be a life-changing moment for both the individual and their family. Therefore, it is important that adults diagnosed with autism are given access to information about autism and about sources of support – even if they do not qualify for publicly funded care services following an assessment of needs. These should include:
 - Contact details for local autism support services and voluntary groups
 - Contact details for national autism representative groups
 - Signposting to the “Living with Autism” section of the NHS Choices website, www.nhs.uk/Livewell/Autism/Pages/Autismhome.asp.
- It is important to underline that an individual's needs change during their lives: an adult with autism who has been assessed as not needing care services when first diagnosed may later require services. This is particularly the case for older adults with autism living with family carers: while the family carers are able to support them, they may not require additional social care. However, when those family carers are no longer able to support them, adults with autism may need to be reassessed.
- While the focus of assessment of needs under the 1990 Act is on need for care services, there may also be a need for autism-specific health services following diagnosis. It is important that these are not overlooked.

C. Planning in relation to the provision of services to people with autism as they move from being children to adults

Through school, children with autism and their families and carers will usually have had access to support that helps them achieve and be included. Without effective transition planning, this support will disappear once people with autism reach adulthood – leaving them isolated at this critical point.

This has been identified as a problem for some years, and there has been substantial investment in recent years in improving the transition support offered to young people with autism. As a result, more young people with autism now receive transition planning and support, and the majority of local areas have put in place multi-agency transition protocols.

However, work is continuing to improve the effectiveness of transition planning and the forthcoming Department for Education (DfE) Green Paper on improving the support available to children with Special Educational Needs (SEN) and disabilities, and their families, will consider further changes to transition planning. There is also research underway at the University of York into transitions for young people with autism. The research, funded by DH, will provide in-depth qualitative data on the support provided for young people with autism and their families in five case study areas and seeks to identify best practice.

In the interim, however, this guidance focuses on the existing transition planning process.

Current policies, duties and responsibilities

For young people with statements of 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 (when the young person is 13 or 14) and plans for the remainder of their school careers (often up to their 19th birthday) and their transition to adulthood.

While it is true that in general the number of statements of SEN has been falling, the number of statements for children with autism has risen from 24,000 in 2004 to 39,320 in 2010. Around 70% of children with autism identified through the SEN system have statements and therefore transition planning must take place for them.

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.

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Local authorities **must** arrange assessments of needs and the provision that will be required to meet those needs for all young people with statements who are thinking of going on to further education or training. They can also arrange these assessments for other young people with SEN. These are known as section 139A assessments. Best practice is that these assessments build on the information that is already known about the young person for example through school based interventions.

These processes require adult and children's services to work with schools, families and young people themselves to identify support needs during the transition to adulthood and enable positive outcomes.

Every local area has received funding and adviser support for 2007 to 2011 to improve their transition planning for disabled young people aged 14 -19 to address inconsistencies highlighted in a 2007 report on disabled children's services. Effective transition planning should include career preparation up to age 16 and plans for education, employment, training, transport, housing and leisure from 16 to 19 and beyond. **Crucially transition plans should be individually tailored to the needs and wishes of the individual young person and reviewed and updated each year.**

What *Fulfilling and rewarding lives* says

The strategy reiterates the work underway by DH and DfE to improve transitions for young people with autism. In particular, it highlights the Transition Support Programme under *Aiming High for Disabled Children*. This programme aims to ensure that all local authorities have strategic arrangements in place, including a clear multi-agency agreed protocol, to meet their statutory duties and follow existing guidance effectively. As at December 2009, 70% of local authorities had a multi-agency transition protocol and 90% had joint processes in place across agencies.²³

The Transition Support Programme also promotes a person-centred approach to transition planning, focusing on the desired outcomes for these young people.

What this means for health and social care

- Local authorities need to comply with their existing legal obligations under the statutory guidance around transition planning in relation to their social services responsibilities for children and young people set out in the *Special Educational Needs Code of Practice*²⁴. Guidance, including legislative requirements and case study examples, are set out in *A transition guide for all services*²⁵.
- The SEN Code of Practice states that Connexions services are responsible for overseeing the delivery of the transition plan. Where local authorities no longer use Connexions, the responsibility for overseeing delivery returns to the local authority itself.

²³ This is a significant improvement compared to the findings of the NAO in its June 2009 report *Supporting people with autism through adulthood*.

²⁴ Special Educational Needs Code of Practice (reference DfES 51/2001)

²⁵ *A transition guide for all services* (DCSF & DH reference 00776-2007DOM-EN)

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- Professionals working with a young person with autism approaching transition, including child and adolescent mental health services (CAMHS) professionals, special educational needs co-ordinators (SENCOs) and social workers should inform the parent and young person of their right to a community care assessment and inform carers of the right to a carer's assessment.
- Professionals working with a child with autism approaching transition should inform social services that this individual is approaching adulthood and may need a community care assessment. The social services department should then formally contact the young person with autism, and their family, before the young person reaches adulthood, to invite them to receive a community care assessment.
- NHS bodies and NHS Foundation Trusts should ensure that protocols are in place in every local area for the transition of clinical mental health care for children with autism in receipt of CAMHS. Where individuals do not fulfil referral criteria for adult mental health teams, it would be good practice for local authorities and NHS bodies to signpost on to other sources of support and information available locally and nationally. Commissioners should be informed of gaps identified in services in these instances to support future planning.
- The DASS is responsible for ensuring that the local area follows its statutory duties around transition planning and that the local area meets at least minimum standards in transition planning.

These policies apply to young people with autism. They are all existing responsibilities.

Delivering transition planning effectively

The significant improvements seen in transition planning over recent years have also helped highlight some best practices to support effective transitions. Some of these are set out here.

- Transition should not be seen as a single point of switch-over. The most effective transitions are carefully planned and managed over a number of years. Connexions Personal Advisers can support young people from age 13 up to 25; they can therefore provide the continuity that young people with autism may need.
- Young people with autism – and their families and carers – should always be involved in transition planning. This is in line with the principle set out in *Equity and Excellence: Liberating the NHS* of “no decision about me without me.” Where appropriate, young people could be offered the assistance of an advocate to speak on their behalf and ensure their views are heard.
- For transitions to be effective, it is essential that information is passed on between children's and adult services. This is not just in terms of information about individuals at the point of transition, but also reflects the need to share information about the needs and numbers of children with autism in a local area to help with longer-term service planning.
- Local authorities, NHS bodies and NHS Foundation Trusts should ensure that all professionals involved in transitions for young people with autism have received appropriate training about autism so that they may adjust their behaviour to reflect the needs of the young person concerned .

D. Local planning and leadership in relation to the provision of services for adults with autism

One of the fundamental goals of *Fulfilling and rewarding lives* is that public services better meet the needs of adults with autism. While in part that means the development and delivery of specialist or dedicated autism services in response to locally identified needs and priorities, it also reflects the need for public services to be more effective and more personalised for adults with autism – as was stated in the overall vision:

“they [adults with autism] can depend on mainstream public services to treat them fairly as individuals”.

This section of the guidance therefore focuses on how local areas can better identify needs, and what structures and processes can best enable those needs to be met. In particular, it looks at the leadership structures locally, which will help drive change. Importantly, it does not pre-empt any decisions about what services should be made available, or how.

Current policies, duties and responsibilities

All public service delivery is currently underpinned by the Equality Act 2010, which requires all organisations that provide a service to the public to make reasonable adjustments to those services to ensure they are accessible for disabled people. **This includes making reasonable adjustments for people with autism.** Potential areas for consideration include adjustments to premises to take account of hypersensitivities, adjustments to processes, such as scheduling appointments at less busy times, and adjustments to communications, for example by ensuring essential documents and forms are available in accessible formats.

The Standard Contract for Mental Health and Learning Disabilities²⁶ explicitly requires service specifications, and therefore service providers, to demonstrate how reasonable adjustments for adults with autism are made.

In addition to these underlying principles, in recent years there has also been a clear shift in the approach to social care. Today, the goal is to deliver personalised services that give each individual the right support to have more choice and control over their own lives. *The Coalition: our programme for government* sets out the Government’s commitment to extending the roll-out of personal budgets to give people and their carers more control and purchasing power²⁷.

²⁶ Available at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111203

²⁷ Cabinet Office (2010) – *The Coalition: our programme for government* section 28 “Social Care and Disability”

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This was reinforced with the publication of *Think Local, Act Personal*, a new concordat for the social care sector and in the Government's vision for adult social care²⁸, in November 2010.

In practice, this means that aside from core services offered in every area, service planning and provision locally should reflect local needs and priorities, generally identified through the JSNA.

To ensure transparency and accountability at a local level, we recommend that local partners should include information about numbers of adults with autism in the area as part of completing the core data set for JSNA. Based on this, they can then take account of the needs of adults with autism and their carers within local service planning, and so enable adults with autism to make choices about the services and support they receive, providing additional support where necessary to enable people to make choices.

DH guidance²⁹ states that the DASS in each local authority should ensure there is a joint commissioner/senior manager who has in his/her portfolio a clear commissioning responsibility for adults with autism. **This is the key leadership role locally and local authorities are expected to appoint someone.**

What Fulfilling and rewarding lives says

To make mainstream services accessible to adults with autism, the strategy reiterates both the disability equality duty³⁰ and an existing DH commitment to “delivering guidance for mental health and learning disability services to indicate some of the kinds of adjustments that might usefully be made³¹” to better include adults with autism. Enabling adults with autism to access these mainstream services is important in terms of social inclusion and ensures they have more choices.

However, the strategy³² also underlines that:

“specific services and support dedicated to adults with autism can play a pivotal role in enabling them to use mainstream services effectively”

and that :

“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 approach³³.”

To achieve this, the strategy makes it clear that each local area should:

²⁸ DH (2010) – A vision for social care: Capable communities and active citizens

²⁹ DH (2006) – Best Practice Guidance on the Role of the Director of Adult Social Services

³⁰ The Public Sector Equality Duty under section 149 of the Equality Act 2010 is due to be implemented in April 2011 and will replace the disability equality duty.

³¹ Fulfilling and rewarding lives, paragraph 4.10

³² Fulfilling and rewarding lives, paragraph 6.1

³³ Fulfilling and rewarding lives, paragraph 6.9

“develop its own commissioning plan around services for adults with autism that reflects the output of the JSNA and all other relevant data around prevalence³⁴.”

The key here is that this should reflect local needs.

The strategy also recommends that adults with autism should be “able to access personal budgets and direct payments, in line with the assessment of their needs³⁵.” It also points to the value of advocacy and buddy schemes, many of which are delivered through the voluntary and community sector and social enterprises. It therefore encourages local authorities to explore how to support volunteer and community groups, and social enterprises, in planning and commissioning services locally.

Fulfilling and rewarding lives recognises that effective local leadership is essential to ensuring the needs of adults with autism are met in each area. Building on existing guidance, it recommends a range of ways to ensure local leadership is inclusive and clear. In particular, it reinforces the guidance that the DASS should ensure there is a joint commissioner/senior manager with a clear commissioning responsibility for adults with autism, and sets out some specific means of ensuring that the joint commissioner/senior manager appointed is able to deliver the leadership required. These include:

- making them an integral part of mainstream commissioning processes
- ensuring that the commissioner/manager works closely with the local specialised commissioning group and other relevant organisations
- ensuring that the commissioner/manager participates in relevant local and regional strategic planning groups and partnership boards, such as Valuing People regional delivery boards and the proposed Health and Wellbeing Boards.

What this means for health and social care

- Local authorities should allocate responsibility to a named joint commissioner/senior manager to lead commissioning of community care services for adults with autism in the area. This named commissioner should participate in relevant local and regional strategic planning groups and partnership boards, to ensure that the needs of adults with autism are being addressed.
- Local authorities, NHS bodies and NHS Foundation Trusts should develop local commissioning plans for services for adults with autism, and review them annually. In future, this activity could be led by the local Health and Wellbeing Board under its proposed remit to lead the JSNA and support joint commissioning. Any such plans should be based on effective needs analysis (such as the JSNA) underpinned by good information about adults with autism in the area. They should include not only social care services but also – where relevant – health services and interventions, which help, improve the health outcomes of adults with autism. Some examples of these will be available online as part of the good practice examples.

³⁴ Fulfilling and rewarding lives, paragraph 6.9

³⁵ Fulfilling and rewarding lives, paragraph 4.17

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- The commissioning of services should take account of the need for appropriate services such as care and support, travel training, etc.
- To develop such plans, it will typically be necessary to gather information locally about:
 - The number of adults known to have autism in the area
 - The range of need for support to live independently
 - The age profile of people with autism in the area – including those approaching 65 or above working age and the number of children approaching adulthood, to enable local partners to predict how need and numbers will change over time.

This does not necessarily require new information to be collected with associated resource implications. For example, it will be possible to use the national prevalence study DH has commissioned to make local estimates of need.³⁶ Also, local authorities should already be gathering some or all of the information set out above as part of helping to fulfil their requirements under the Disability Equality Duty (DED)³⁷. The DED requires local authorities to pay due regard to disability issues when carrying out their functions. Gathering information about adults with disabilities in the area would therefore be necessary to fully assess the equality impact of their policies and practices.

- In addition, it will also be valuable for local authorities to collect information about the numbers of adults with autism who are:
 - in employment in the area
 - likely to need employment support in order to work
 - placed in the area (and funded by) other local authorities
 - placed out of area by local authorities
 - in hospital or living in other NHS-funded accommodation
 - resettled from long-stay beds or NHS residential campuses to community provision
 - living at home on their own, or with family members, and not receiving health or social care services, or
 - living with older family carers.
- It will also be useful to gather information about the ethnicity, gender, religion or belief and sexual orientation of adults with autism so that local authorities, NHS bodies and NHS Foundation Trusts can understand the numbers of people from different backgrounds with autism.
- In developing these plans, local authorities, NHS bodies and NHS Foundation Trusts should consider the role of family carers and the support they need³⁸. Consideration should also be given to the role of the Big Society – in particular, local community and volunteer groups – in delivering services to meet the needs of adults with autism, their families and carers.
- Local commissioning plans should set out how the local authority will ensure that adults with autism are able to access personal budgets and benefit from the personalisation of

³⁶ DH is funding a study to explore rates of autism in a representative sample of adults in England. The contract was awarded by the NHS Information Centre on 26 March 2010 to a consortium led by the University of Leicester. The other members of the consortium are the University of Glasgow, Kings College London and the National Centre for Social Research (NatCen). Findings are expected in early 2011. See www.ic.nhs.uk/news-and-events/news/nhs-information-centre-awards-autism-study-contract-to-university-led-consortium

³⁷ As noted previously, the Public Sector Equality Duty is due to be implemented under the Equality Act in April 2011 and this will replace the DED.

³⁸ H M Government (2010) – Recognised, valued and supported: Next Steps for the Carers Strategy

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social care. As part of this, it will be important to consider the practical challenges involved in granting more choice to adults with autism, drawing on the principles set out in the Mental Capacity Act 2005³⁹.

- All local authorities, NHS bodies and NHS Foundation Trusts who provide mental health and learning disability services are recommended to review the DH guidance about the adjustments to service delivery to include adults with autism.
- All local authorities, NHS bodies and NHS Foundation Trusts and organisations with whom they have contracted to provide services are expected to take into account the views of adults with autism and their families and carers in developing and commissioning services for adults with autism. In some cases, this may require the use of advocates to speak on behalf of adults with autism.
- The DASS in each area is responsible for:
 - developing the area's commissioning plan around services for adults with autism, using the best available information about adults with autism in the area
 - appointing a joint commissioner/senior manager who has in their portfolio a clear commissioning responsibility for adults with autism
 - ensuring that the views of adults with autism and their carers are taken into account in the development of services locally.

Supporting improved local planning and leadership

The strategy highlighted several best practice approaches to support service planning and ensure an inclusive approach to leadership. These are reiterated here.

- The strategy suggests that “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 services⁴⁰.” In some areas, existing structures may fulfil the same purpose – such as Learning Disability Partnership Boards and Mental Health Local Implementation Teams (LITs). Local Health and Wellbeing Boards will also have a related function.
- In addition, the strategy refers to best practice that shows that “where outcomes for adults with ASC have improved this has been as a result of the development of local teams⁴¹” dedicated to supporting adults with autism, from diagnosis through to health management and help with day-to-day living. It includes examples of several different team structures that have been adopted⁴². In particular, these approaches have proved to be cost-effective, as the NAO report *Supporting people with autism in adulthood* underlined, because they provide the integrated support needed to help adults with autism be economically included and reduce the likelihood of them falling into crisis – requiring costly and complex mental health interventions or coming into contact with the criminal justice system.
- Such approaches also help reduce the risk of adults with autism ‘falling through the gap’ between mental health or learning disability support. The experiences of adults with autism

³⁹ See www.legislation.gov.uk/ukpga/2005/9/section/1

⁴⁰ Fulfilling and rewarding lives, paragraph 6.12

⁴¹ Fulfilling and rewarding lives, paragraph 6.22

⁴² Fulfilling and rewarding lives, paragraph 6.20

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indicate that receiving such support inappropriately – simply because that is all that is available locally – can ultimately create further problems.

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