DH Department of Health

Implementing "Fulfilling and rewarding lives"

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

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Implementing “Fulfilling and rewarding lives”

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

Foreword from the Minister for Care Services

This Government is committed to supporting people with autism to live independently as equal and included citizens. The Autism Act 2009, spearheaded in a Private Members Bill by Rt Hon Cheryl Gillan MP, was a hugely significant milestone on the road to achieving that goal. It was followed in March 2010 by the autism strategy, *Fulfilling and Rewarding Lives*, which set a clear agenda for how public services in particular must transform to better address the needs of adults with autism.

Now we are taking the next step with the development of this draft statutory guidance, which sets out how health and social services bodies should support the implementation of the strategy. Much of this builds on existing requirements and duties, reiterated and reinforced in the strategy: other aspects focus on raising awareness of autism amongst frontline staff, which has been identified as the key to delivering real change for all adults with autism.

We know that adults with autism, their families, carers and representative organisations all want to see the ambitions of the strategy translated into tangible advances in services and positive outcomes. We know that those health and social care staff involved in caring for and supporting adults with autism want to have their say in how services can and should be improved in all areas.

In response, I would like to invite you to take part in the consultation around this draft guidance. This is an important opportunity to influence the direction in which the autism programme progresses, particularly given the current financial constraints in which we must operate, and further proof of our commitment, set out in *The Coalition: our programme for government*[1] to enabling people to call the shots over the decisions that affect their lives. Your views will help define and refine our priorities as we seek to enable adults with autism to live fulfilling and rewarding lives as equal and included citizens in a free, fair and responsible society.

Paul Burstow MP, Minister of State for Care Services

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[1] Cabinet Office (2010) – *The Coalition: our programme for government*

Contents

Executive summary

This draft guidance is for health and social services bodies to support the implementation of *Fulfilling and Rewarding Lives: the strategy for adults with autism in England*[2]. It is currently provided as a draft for consultation, and will not be finalised until after the conclusion of the Spending Review, which is due to be completed in October 2010.

The guidance focuses on the seven areas required by the Autism Act 2009[3], in each case identifying what health and social services bodies are already expected to do, and then setting out any additional elements introduced by the strategy. The additional elements are focused on achieving two key outcomes:

- improving the way health and social care services identify the needs of adults with autism, and
- ensuring identified needs are met more effectively to improve the health and well-being of adults with autism.

These are both important steps towards the long-term vision set out in the strategy.

Throughout, the guidance underlines the importance of using existing processes and resources to achieve these outcomes. For example, the guidance stresses the importance of the provision of autism awareness training for staff, but emphasises that this can be delivered as part of existing equality and diversity training, or similar programmes. This is particularly important given the financial constraints that all public sector organisations are currently working under, and the need to demonstrate value for money. The guidance also places a clear emphasis on local areas finding the best ways to meet the needs of adults with autism in their area.

It is also essential to underline that all government departments are currently undergoing a spending review that is due to complete in October 2010. This consultation does not seek to pre-empt the outcomes of that spending review. This means that any statement within this draft guidance which relies on, or implies, additional resources is subject to review.

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[2] **DH (2010) – *Fulfilling and rewarding lives***
[3] **Autism Act 2009 section 2(5)**

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 Trusts, and NHS trust all or most of whose hospitals, establishments and facilities are in England and Special Health Authorities 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.

About this consultation

The purpose of this consultation is to seek views on the following draft guidance to health and social services bodies. This guidance has been drafted to support the implementation of the Autism Strategy *Fulfilling and Rewarding Lives* under the terms of the Autism Act 2009.

The draft guidance is set out in the body of this document, together with specific questions on which we want to obtain views from:

- adults with autism, their families and carers
- health and social care bodies responsible for the planning, commissioning and provision of services for adults with autism and their families and carers
- representative local and national organisations
- health and social care professionals, and
- any other party with an interest in improving the health and social care provided to adults with autism and their families and carers.

We want the consultation to reach as many people as possible, in line with our goal (set out in *The Coalition: our programme for government*) of giving people more say in the decisions that affect their lives.

One of the key challenges in producing guidance around this subject is that there is currently well-documented variation in services and approach through the country. Our aim is to support all local areas to deliver the best outcomes for people with autism and their families and carers, but this has to be set within local circumstances and priorities. Further, although there are many different models of service in use in different areas, several of these are quite new, and there is not yet sufficient evidence to assess which models are most effective.

For this reason, *Fulfilling and Rewarding Lives* did not mandate any one approach or model: the draft guidance does not either. However, the published version of this guidance, post-consultation, will be accompanied by some well-evidenced examples of good practice. We would, therefore, welcome any further examples of models of support or innovative approaches – as well as the costs, benefits and risks of these – to include in the accompanying good practice guidance.

This draft guidance should also be seen in the wider economic and public spending context. It is important we understand the full costs and benefits of proposals which would require additional investment or redistribution of funding. These will be assessed as part of the spending review. In addition, the government has made clear its commitment to promoting the radical devolution of power and greater financial autonomy to local government – offering increased flexibility for local authorities and services to make decisions that best serve their communities.

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This means that in some cases the guidance may not place as many expectations on health and social care bodies as some respondents may wish. **It is important to underline therefore that this guidance – though having legal force as explained below – is not set in stone. It will be reviewed regularly and revised as appropriate, as the evidence base develops on how best to support the needs of adults with autism to live independently as equal and included citizens.**

Background

As required by the Autism Act 2009 (the Act)[4], 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 bodies[5] 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)[6]. If they do not follow the guidance and cannot provide a good reason, they may be liable to judicial review[7]. Lack of sufficient resource would not necessarily constitute a good reason.

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.

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[4] **"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)**

[5] **For a definition of "NHS body", see page 7"*Status of this guidance*"**

[6] **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.**

7 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. A judicial review is a challenge to the way in which a decision has been made, rather than the rights and wrongs of the conclusion reached. For further details, see *www.judiciary.gov.uk/judgment_guidance/judicial_review*.

Structure of the guidance

In line with the Act, this draft guidance is divided into sections on:

1. the provision of services 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 services to adults with autism
6. the training of staff who provide services to adults with autism
7. local arrangements for leadership in relation to the provision of services to adults with autism.

Each section includes specific questions for consultation. These are also included in the questionnaire booklet. Please fill in your answers in the questionnaire booklet. Full details of the consultation process are set out at the end of the document.

To help staff working in local authorities and NHS bodies and NHS Foundation Trusts, the published version of this guidance will be supported by some best practice examples of services for adults with autism. These are not statutory, but should prove useful for anyone planning or delivering services for adults with autism.

Fulfilling and Rewarding Lives highlighted 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. These are not set out in any detail in this consultation document, not least because we are still seeking to gather more examples and invite any reader to share good practice examples with us in responding to this consultation.

Our intention is that good practice examples should be published as an accompanying document to the statutory guidance, and 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.

The outcomes we seek

While some adults with autism enjoy fulfilling lives, currently too many do not. The autism strategy, *Fulfilling and Rewarding Lives*, set out a clear vision for transforming the lives of adults with autism:

‘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. However, the policies and practices outlined in this draft statutory guidance provide the next important step towards that goal. In particular, the guidance seeks to:

- improve the way health and social care services identify the needs of adults with autism, and
- ensure identified needs are met more effectively.

By achieving these outcomes, we will deliver tangible improvements in services and support for people with autism, enabling them to live fulfilled and rewarding lives in a free, fair and responsible society. This in turn will drive progress towards the long-term goal of improving the lives of adults with autism, their families and carers – which will also ultimately benefit the wider community.

DRAFT GUIDANCE

Introduction

The purpose of this guidance is to help local authorities, NHS bodies and NHS Foundation Trusts implement *Fulfilling and Rewarding Lives: The strategy for adults with autism in England*, and develop services and support to meet the locally identified needs of people with autism and their families and carers. It aims to help these authorities understand their duties in relation to adults with autism and to provide them with clear information on how they can fulfil those duties.

There is already a wealth of policy and guidance to support adults with autism[8]: this guidance seeks to clarify this existing policy so that local authorities, NHS bodies and NHS Foundation trusts and the health and social care staff who work for them are better able to meet their existing duties. This will in turn deliver better support for adults with autism and their families.

This guidance is issued to local authorities, NHS bodies and NHS Foundation Trusts. These organisations are responsible for ensuring that the guidance is followed by their staff and 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.

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.

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[8] ***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.**

1. The provision of services for the purpose of diagnosing autistic spectrum conditions in adults

For many adults, receiving a clinical diagnosis of autism is an important step towards a fulfilling life. It can help them and their families and carers understand their behaviour and responses, and should also help with access to services and support, if they need them. Diagnostic services are therefore an important element in delivering the vision for adults with autism.

Current duties

There is currently no single diagnostic process for autism – partly because of the complexity of diagnosing autistic spectrum conditions. However, the National Institute for Health and Clinical Excellence (NICE) is developing a new clinical guideline for adults with autism. This is expected to be published in September 2011 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.[9]

What the strategy 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.[10]"

To accelerate this, the strategy recommends that "local areas appoint a lead professional to develop diagnostic and assessment services for adults with autism.[11]"

What this means for health and social care

- The NICE clinical guideline for adults with autism is expected to be published in September 2011. In order to be ready for the guidance, **NHS bodes and NHS Foundation Trusts that commission or provide diagnostic and assessment services need to review existing best practice[12] now with a view to establishing how it can be adopted in their area or**

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[9] NICE is also developing a separate clinical guideline for autism in children and young people. This is also expected to be published in September 2011

[10] *Fulfilling and rewarding lives*, paragraph 3.11

[11] *Fulfilling and rewarding lives*, paragraph 3.10

[12] 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*

organisation. In addition, they should **review the current pathway to diagnosis in their area or organisation**.

- **Each local authority should consider appointing 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.
- 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 diagnosis of autism should open up the opportunity for the adult diagnosed to receive an assessment of their needs. To enable this to happen, **healthcare professionals who make a diagnosis of autism should inform the adult diagnosed, and/or their carers, that under the NHS and Community Care Act 1990[13] local authorities have a duty to carry out an assessment of needs if the adult diagnosed asks for one (and it appears to the local authority that they may be in need of community care services).** This does not require healthcare professionals to conduct an assessment. Instead, it focuses on raising awareness that local authorities are under a duty to conduct an assessment if the adult diagnosed contacts them and appears to the local authority to need community care services. In this way, the emphasis is placed on joining up services, so that those diagnosed with autism are able to get the support they need – if they need it.

Providing information post-diagnosis

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 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.aspx**

Consultation

We would like your views on the following questions about the proposed guidance around diagnosis. Please write your answers in the questionnaire booklet provided.

1.1 Do you think that this guidance explains the responsibilities that local authorities, NHS bodies and NHS Foundation Trusts have for adults with autism around diagnosis?

1.2 If not, what changes would you propose?

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[13] **National Health Service and Community Care Act 1990, section 47**

1.3 Is there anything else to add that would make a difference?

1.4 Do you think this section of the guidance is clearly worded and will be understood by health and social care professionals, people with autism and parents/carers?

1.5 Do you have any other comments on diagnosis?

We will also explore the cost and benefits of issuing guidance to local authorities, NHS bodies and NHS Foundation Trusts to appoint a lead professional to develop diagnostic services for adults with autism in their area. **We would therefore welcome examples of how local authorities, NHS bodies and NHS Foundation Trusts currently deliver and manage diagnostic and assessment services for adults with autism** – for example, whether they provide a dedicated diagnostic service (perhaps shared between several areas) or rely on GPs across the area to diagnose, perhaps following additional training. We also want to examine how responsibility for diagnostic services is allocated – for example, whether it can be added as an additional responsibility of a lead professional in other areas, or whether a dedicated member of staff is required.

2. The identification of adults with autism

As with any condition, identification of possible autism is the essential first step to effective support – even before formal diagnosis. While some adults – and their families and carers – will want a formal diagnosis, for others identification is sufficient, particularly if this leads to changes in the way that public services support them.

Current duties

There is no specific duty to identify adults with autism – and the strategy could not, and does not, impose one. However, as in all areas of health and social care, staff are encouraged to be aware of potential signs of a condition and to adapt their behaviour as appropriate. Under the NHS and Community Care Act 1990, local authorities have a duty to assess people who may be in need of community care services: this includes people with autism who may be in need of such services.

What the strategy says

The strategy recognises that the biggest barrier to identification of autism is a lack of awareness amongst frontline staff. That's 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:

"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 how to adapt their behaviour, and particularly their communication, when a patient either has been diagnosed with autism or displays these signs[14]"

and that:

"it is … essential that autism awareness training is available to everyone working in health or social care."[15]

What this means for health and social care

- **Local authorities, NHS bodies and NHS Foundation Trusts should consider what autism awareness training is made available to all staff working in health and social care and how training can be prioritised.**
- **For this training to have maximum impact on identification of autism, it should focus on helping staff identify potential signs of autism and giving them an insight into**

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[14] *Fulfilling and rewarding lives*, paragraph 2.21

[15] *Fulfilling and rewarding lives*, paragraph 2.15

how to make reasonable adjustments in their behaviour and communication for people who have a diagnosis of autism or who display these signs. This is vital to achieving the key outcome of improving the way health and social care services identify the needs of adults with autism.

- The impact of training will be accelerated by local authorities, NHS bodies and NHS Foundation Trusts prioritising training for staff who are most likely to have initial contact with individuals who have or may display potential signs of autism. Prioritisation of training will need to reflect the way services are delivered locally.

Consultation

We would like your views on the following questions about the proposed guidance around the identification of adults with autism. Please write your answers in the questionnaire booklet provided.

2.1 Do you think that this guidance explains the responsibilities that local authorities, NHS bodies and NHS Foundation Trusts have around identification of adults with autism?

2.2 If not what changes would you propose?

2.3 Is there anything else to add that would make a difference?

2.4 Do you think that this section of the guidance is clearly worded and will be understood by health and social care professionals, people with autism and parents/carers?

2.5 Do you have any other comments on identification of adults with autism?

We will also explore the cost and benefits of issuing guidance that training be available to all staff – whilst leaving local authorities, NHS bodies and NHS Foundation Trusts to decide how such training would be delivered. **We would therefore welcome examples of innovative best practice locally and how training can be delivered in the most cost effective way** (for example, by including autism awareness in existing training packages or programmes, or provision of appropriate information through other available means, such as e-learning packages or DVDs).

3. The assessment of the needs of adults with autism for relevant services

Diagnosis or identification of autism alone is not enough: the most important outcome is that diagnosis always leads to a person-centred assessment of need for care and support.

Current duties

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 care services may be necessary. **This duty applies to people with autism.**

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.

What the strategy says

The strategy makes it clear that "diagnosis of autism should be recognised as a reason for assessment[16]." In addition, where someone has previously had a needs assessment, and is subsequently diagnosed as having autism, this should be recognised as a potential reason for reassessment. This will help ensure care resources are targeted at those with the greatest need.

The strategy also says that: "It is best practice that diagnosis of autism is recognised as a catalyst for a carer's assessment."[17]

What this means for health and social care

This introduces no new requirements in terms of assessment. 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. To enable local authorities to fulfil these duties, local authorities, NHS bodies and NHS Foundation Trusts are encouraged to take the following steps:

- Each local authority should consider allocating responsibility to a named joint commissioner/senior manager to lead commissioning of community care services for adults with autism in the area.

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[16] ***Fulfilling and rewarding lives***, paragraph 3.14

[17] ***Fulfilling and rewarding lives***, paragraph 3.19

- **When an adult is diagnosed with autism, the NHS body or NHS Foundation Trust providing healthcare services to the adult should inform 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 and with the individual's consent.
- **The healthcare professional that diagnoses autism should inform the person who is diagnosed that local authorities have a duty to carry out a community care assessment if the person requests it and it appears to the local authority that the person may be in need of community care services.**
- **The social services department should contact the adult with autism – and any registered carers – to inform them of their entitlement to an assessment and inform carers of the right to a carer's assessment.**
- **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*.**
- **Local authorities are encouraged to ensure that staff carrying out an assessment have had appropriate autism awareness training.**
- **The Director of Adult Services 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.

Consultation

We would like your views on the following questions about the proposed guidance around assessment of needs. Please write your answers in the questionnaire booklet provided.

3.1 Do you think that this guidance explains the responsibilities that local authorities. NHS bodies and NHS Foundation Trusts have around needs assessments for adults with autism?

3.2 If not, what changes would you propose?

3.3 Is there anything else to add that would make a difference?

3.4 Do you think that this section of the guidance is clearly worded and will be understood by health and social care professionals, people with autism and parents/carers?

3.5 Do you have any other comments on assessment of needs for relevant services?

4. Planning in relation to the provision of relevant services to young people with autism as they become 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.

Current duties

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.

Where a young person with autism has no statement of SEN or Health Action Plan, local authorities can arrange an assessment of needs and the provision that will be required to meet those needs where young people are thinking of going on to further education or training. These assessments should 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 need and wishes of the individual young person and reviewed and updated each year.

What the strategy 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. It 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 are expected to follow 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*[18]. Guidance, including legislative requirements and case study examples, are set out in *A transition guide for all services*[19].**
- **The Director of Adult Services 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 duties apply to young people with autism. They are all existing requirements.

Consultation

We would like your view on the following questions about the proposed guidance around transitions. Please write your answers in the questionnaire booklet provided.

4.1 Do you think that this guidance explains the responsibilities that local authorities have around transition from child to adult services for young people with autism?

4.2 If not, what changes would you propose?

4.3 Is there anything else to add that would make a difference?

4.4 Do you think that this section of the guidance is clearly worded and will be understood by health and social care professionals, people with autism and parents/carers?

4.5 Do you have any other comments on transition?

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[18] ***Special Educational Needs Code of Practice* (reference DfES 51/2001)**
[19] ***A transition guide for all services* (DCSF & DH reference 00776-2007DOM-EN)**

5. Planning in relation to the provision of services to adults with autism

This includes the provision of specialist or dedicated autism services in line with locally identified needs and priorities, and access to universal services for adults with autism.

Current duties

The Disability Discrimination Act 2005 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 Disabilities[20] explicitly requires service specifications, and therefore service providers, to demonstrate how reasonable adjustments for adults with autism are made.

Across social care generally, 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 power[21]. Local authorities should seek ways to 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.

Aside from core services offered in every area, service planning and provision locally is expected to reflect local needs and priorities, generally identified through the Joint Strategic Needs Assessment (JSNA). As part of completing the core data set for JSNA, local partners are now expected to include information about numbers of adults with autism in the area. This helps ensure the needs of adults with autism are considered as part of local service planning.

What the strategy says

To make mainstream services accessible to adults with autism, the strategy reiterates both the disability equality duty 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

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[20] **Available at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111203**

[21] **Cabinet Office (2010) – *The Coalition: our programme for government* section 28 "Social Care and Disability"**

usefully be made[22]" 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 strategy[23] 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 approach[24]."

To achieve this, the strategy makes it clear that each local area should "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[25]." The key here is that this should reflect local needs.

In terms of what services should be considered and how they should be offered, the strategy highlights best practice which shows that "where outcomes for adults with ASC have improved this has been as a result of the development of local teams[26]" 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 proved effective[27].

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 needs[28]." 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.

What this means for health and social care

- **It is best practice that all local authorities, NHS bodies and NHS Foundation Trusts develop local commissioning plans around services for adults with autism, and review them annually**. Any such plans should be based on effective needs analysis underpinned by good information about adults with autism in the area.
- **To develop such plans, it will typically be necessary to gather information** about:
    - The number of adults with autism in the area
    - The range of need for support to live independently

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[22] ***Fulfilling and rewarding lives*, paragraph 4.10**
[23] ***Fulfilling and rewarding lives*, paragraph 6.1**
[24] ***Fulfilling and rewarding lives*, paragraph 6.9**
[25] ***Fulfilling and rewarding lives*, paragraph 6.9**
[26] ***Fulfilling and rewarding lives*, paragraph 6.22**
[27] ***Fulfilling and rewarding lives*, paragraph 6.20**
[28] ***Fulfilling and rewarding lives*, paragraph 4.17**

  - 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.[29] Also, under the disability equality duty (section 49A of the Disability Discrimination Act 1995), local authorities are required to monitor the impact of their policies and to develop policies having regard to the impact of them on disabled people. They are under a duty in carrying out their functions to have due regard to promote equality of opportunity. The ability to fulfil that duty depends on gathering information about adults with disabilities in the area. This means that local authorities should already by gathering some or all of the information set out above as part of fulfilling the equality duty.

- 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.
- **It will be best practice for local commissioning plans to set out how the local authority will ensure that adults with autism are able to access personal budgets and benefit from the personalisation of social care.**
- **In developing these plans, local authorities, NHS bodies and NHS Foundation Trusts should consider the role of local community and volunteer groups in delivering services to meet the needs of adults with autism.**

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[29] **The Department of Health (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 201 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***

- **All local authorities, NHS bodies and NHS Foundation Trusts who provide mental health and learning disability services are encouraged to review the DH guidance about the adjustments to service delivery to better include adults with autism.**
- **All local authorities, NHS bodies and NHS Foundation Trusts, their employees 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.**

The Director for Adult Social Care 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
- ensuring that the views of adults with autism and their carers are taken into account in the development of services locally.

Consultation

We would like your views on the following questions about the proposed guidance around planning the provision of services for adults with autism locally. Please write your answers in the questionnaire booklet provided.

5.1 Do you think that this guidance explains the responsibilities that local authorities, NHS bodies and NHS Foundation Trusts have around planning for the provision of services for of adults with autism?

5.2 If not what changes would you propose?

5.3 Is there anything else to add that would make a difference?

5.4 Do you think that this section of the guidance is clearly worded and will be understood by health and social care professionals, people with autism and parents/carers?

5.5 Do you have any other comments on service planning?

We will explore the cost and benefits of issuing guidance to local authorities and NHS bodies that they develop commissioning plans around services for adults with autism. **We would therefore welcome examples of how such plans have improved outcomes for adults with autism and whether planning for adults with autism can be integrated with other planning activities.** We would also be interested in examples of how local areas have successfully met the needs of adults with autism without developing specific commissioning plans.

6. The training of staff who provide services to adults with autism

Improving training around autism is at the heart of the strategy for all public service staff – but particularly for those working in health and social care. This includes not only general autism awareness training, but also highly specialised training for staff in a range of roles that wish to develop their knowledge of autism.

Current duties

Health and social care commissioners and providers are expected to ensure that each member of their workforce has the relevant professional qualifications 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's workforce strategies for health and social care.

What the strategy says

In addition to autism awareness training for frontline staff (see section 2, *The identification of adults with autism*), the strategy further 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

Training managers within the local authority, NHS body or NHS Foundation Trust are responsible for ensuring the delivery of autism awareness training. We recognise that they will have strict budgets to work with. It is important to reiterate therefore that autism awareness training can be delivered as part of existing equality and diversity training or similar programmes.

However, 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.

In terms of specialist training, it is not expected that each local authority, NHS body or NHS Foundation Trust develops its own training programme, but rather that applications for specialist training are considered within the training budget.

Consultation

We would like your views on the following questions about the proposed guidance around training for NHS and local authority staff. Please write your answers in the questionnaire booklet provided.

6.1 Do you think that this guidance explains the responsibilities that local authorities, NHS bodies and NHS Foundation Trusts have around training for staff?

6.2 If not, what changes would you propose?

6.3 Is there anything else to add that would make a difference?

6.4 Do you think that this section of the guidance is clearly worded and will be understood by health and social care professionals, people with autism and parents/carers?

6.5 Do you have any other comments on training?

7. Local arrangements for leadership in relation to the provision of services to adults with autism

Effective local leadership is essential to ensuring the needs of adults with autism are met in each area. Building on existing guidance, the strategy recommends a range of ways to ensure local leadership is inclusive and clear.

Current duties

DH guidance[30] states that the Director of Adult Social Services (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 follow it.

What the strategy says

The strategy 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.

In addition, 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 services[31]."

What this means for health and social care

- **As set out in existing best practice guidance, Directors of Adult Social Services in every local authority should ensure that there is a joint commissioner/senior manager who has in their portfolio a clear commissioning responsibility for adults with autism.**
- **Local authorities and NHS bodies should consider establishing local autism partnership boards, looking in particular at the example of learning disability partnership boards and the benefits they can deliver for individuals and services.**

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[30] **DH (2006) – *Best Practice Guidance on the Role of the Director of Adult Services***

[31] ***Fulfilling and rewarding lives*, paragraph 6.12**

Consultation

We would like your views on the following questions about the proposed guidance around local leadership in relation to the provision of services for adults with autism. Please fill in your answers using the questionnaire booklet provided.

7.1 Do you think that this guidance sets out sufficient information to support local leadership relating to the provision of services for adults with autism?

7.2 If not, what changes would you propose?

7.3 Is there anything else to add that would make a difference?

7.4 Do you think that this section of the guidance is clearly worded and will be understood by health and social care professionals, people with autism and parents/carers?

7.5 Do you have any other comments on local leadership?

We will also explore the cost and benefits of issuing guidance to local authorities and NHS bodies that they appoint a joint commissioner/senior manager who has in his/her portfolio a clear commissioning responsibility for adults with autism. **We would therefore welcome examples of how local areas currently ensure there is local leadership around commissioning services for adults with autism** – for example, whether it can be added as an additional responsibility of a lead professional in other areas, or whether a dedicated member of staff is required.

The consultation process

Timings

The consultation will run for a period of 12 weeks from 29 July 2010 to 22 October 2010.

Process

Respondents are invited to complete the questionnaire booklet and return it to:

Adults with Autism Statutory Guidance Consultation
Department of Health
Unit 124
Wellington House
135 -- 155 Waterloo Road
London SE1 8UG

Alternatively you can submit your views by emailing us at **autism@dh.gsi.gov.uk**. Printed copies of this document and the questionnaire are available on request by email or through this postal address.

The Department of Health will be making available a toolkit to support local organisations and groups to run their own events. Further details about events and information can be found on our website, **www.dh.gov.uk/en/consultations**.

You may also wish to contact your local authority or local autism organisation about events that they may be holding in your area.

Remit

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

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 autism[32].

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[32] **The Scottish Government (2008) – *Commissioning Services for People in the Autism Spectrum: Policy and Practice Guidance***

Summary of consultation responses

A summary of the responses to this consultation will be made available before or alongside any further action, such as the finalisation of this statutory guidance, and will be placed on the consultations website at **www.dh.gov.uk/en/consultations**.

Criteria for consultation

This consultation follows the Government's Code of Practice on Consultation. In particular, we aim to:

- formally consult at a stage where there is scope to influence the policy outcome
- consult for at least 12 weeks, with consideration given to longer timescales where feasible and sensible
- be clear about the consultation process in the consultation documents, what is being proposed, the scope to influence, and the expected costs and benefits of the proposals
- ensure the consultation exercise is designed to be accessible to, and clearly targeted at, those people it is intended to reach
- keep the burden of consultation to a minimum to ensure consultations are effective and to obtain consultees' 'buy-in' to the process
- analyse responses carefully and give clear feedback to participants following the consultation
- ensure officials running consultations are guided in how to run an effective consultation exercise and share what they learn from the experience.

The full text of the code of practice is on the Better Regulation website at: **www.bis.gov.uk/policies/better-regulation/consultation-guidance**.

Comments on the consultation process itself

If you have concerns or comments which you would like to make relating specifically to the consultation process itself please contact:

Consultations Co-ordinator
Department of Health
3E48 Quarry House
Leeds
LS2 7UE

email: **consultations.co-ordinator@dh.gsi.gov.uk**

Please do not send consultation responses to this address.

Confidentiality of information

We manage the information you provide in response to this consultation in accordance with the Department of Health's Information Charter.

Information we receive, including personal information, may be published or disclosed in accordance with access to information regimes (primarily the Freedom of Information Act 2000 (FOIA), the Data Protection Act (DPA) and the Environmental Information Regulations 2004).

If you want the information you provide to be treated as confidential, please be aware that under the FOIA, there is a statutory code of practice which public authorities must comply with and which deals, among other things, with obligations of confidence. In view of this, it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of information, we will take full account of your explanation, but we cannot give an assurance that confidentiality will be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department of Health.

The Department of Health will process your personal data in accordance with DPA and in most circumstances this will mean that your personal data will not be disclosed to third parties.