

# **Making 'Think Autism' Work**



# How local councils and the NHS should use our plans for people with autism



Please tell us what you think before the **19th December 2014**.



Easy Read version of: Consultation on new statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy for England

## What is in this paper?



NHS

Guide

# About this paper 1 What is Autism? 3 A word from the Minister, Norman Lamb 5 Asking what you think 10 About the guide 13 Our ideas for the guide 16 1. Training staff 16 2. Finding out if someone has autism 20



3. Making transition easier for 23 people with autism

page

What is i	n this paper?	page
	4. Local leaders who understand people with autism	25
	5. Keeping people safe	29
Fquality Act	6. Making changes	31
	7. Supporting people with lots of needs	33
NHS Contractions	8. Work and jobs	35
Court	9. Working with the Criminal Justice System	37
B	How to tell us what you think	40
Policy	How we are finding out what people think	42
Policy	Keeping information safe	43



## About this paper

The Department of Health wrote this paper. We are part of the government in charge of healthcare and social care and we are responsible for the Autism Strategy.



Think Autism

e most of what you can a

In 2010 we wrote our plan for adults with autism in England. It was called **Fulfilling and Rewarding Lives**.







We wrote a guide in 2010 to go with the plan for local councils and NHS organisations.

Now we are updating the guide for local councils and NHS organisations because some things have changed since 2010.



This paper tells you about our ideas on updating the guide and asks what you think about them. It is called a consultation.



There is also an answer booklet you might like to use to tell us what you think.



**How to tell us what you think** on page 40 tells you how to send us your answers.



## What is Autism?

Autism is a condition. It affects how you deal with other people and how you understand the world around you.



If you have autism, you have it for your whole life.



People with autism are all different but usually have problems in 3 main areas.



These areas are:

1. Talking to other people to say what you need and how you feel.



2. Meeting new people and making new friends.



**3.** Understanding what other people are thinking.



When we say **autism** we also mean people with Asperger Syndrome and people who have autism with other conditions which are mostly **hidden**.



This means conditions like dyslexia, dyspraxia, dyscalculia or other mental health issues which can't be seen by just looking at someone.



## A few words from the Minister

#### Norman Lamb, Minister for Care and Support



Our plan is starting to make things better for adults with autism in England.



Some local areas have a team of autism experts to make sure you have the services you need.



People with autism are becoming more involved in saying what services are needed.



There are over half a million people with autism in England who will use lots of different services.



Councils and NHS organisations must help other services understand how to:

 understand and support people with autism



 make changes to help them use services



• involve people with autism in planning services.



2 new laws will help local services support people with autism and their families better:



The Children and Families Act will help young people with autism get ready to be adults





The Care Act says services health and social care services must work together to keep people safe and well so they need less care and support.





We want people with autism to have the same opportunities and chances as everyone else.



We can only make sure people with autism get the support they need if they:

can understand and access
services, and are understood by
people who work in these services



• feel safe in their local communities



 can find out that they have autism and get the care and support they need



 are involved in decisions about local services.



This paper says how health and social care services can make sure all services help people with autism have better lives.



Please tell us what you think about our ideas.



## Asking what you think

In this paper, we say what we expect councils and the NHS to do now.

We then say what else we think they should do.



These extra things will help health and social care services:

 get better at finding out what support adults with autism need



 meet these needs so adults with autism have good, healthy lives and feel valued and respected.



We also tell you how changes to laws might affect people with autism.



#### Who we are asking

We would like to hear from:

• adults with autism



their families and carers

 health and social care organisations that plan, buy or run services for adults with autism



 local and national organisations that speak for people with autism





 people who work in health or social care services



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#### How to answer the questions

There are questions for you to think about at the end of each part of the guide.

These questions are in the answer booklet. This is a separate paper you can use to tell us what you think.



You can write your answers in the answer booklet or fill them in online.



See **How to tell us what you think** on page 40 for more details.



## **About the guide**

#### Who the guide is for

The guide is for local councils and NHS organisations in England. It is also for any organisations that they pay to run services for them.



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Council

Other organisations such as police or employment services should make sure their staff know how to support adults with autism.



#### What is in the guide?

We need to update the guide to make sure it thinks about:

how to make Think Autism work

 how adults with autism can live as an equal part of their communities



 new laws and changes to health and social care services.

The guide tells local councils and NHS organisations how to make our plans work for adults with autism in England.



The Autism Act is a law which says local councils and the NHS should aim to do what the guide says unless they can show there is a really good reason for not doing it.

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We will write a final version of the guide after December 2014 when we have asked people what they think.

# How we will check what is happening







Each area has to check how well they are doing with their autism plans each year and tell us about good ways of working.



Adults with autism, families and carers will be involved in these checks and say what they think about services.



## Our ideas for the guide

## **1. Training staff**

#### What the guide says now

Councils and the NHS must give autism training to everyone who works in health and social care.

This training will help them:



 understand how to talk to and support people with autism and their families



 think about any changes that would make it easier for people with autism to use their service.





Councils and the NHS must also give staff any extra training they need to help them work with adults with autism.



- They must have a plan for training to make sure:
  - they always have enough staff who understand autism



 new staff have training and all staff have the chance to learn more about autism



 adults with autism and their families and carers are involved in planning training.



# Extra information for the new guide

Training about autism can be part of training about treating everyone fairly and equally.



Services can use DVDs or internet training. The guide will have links to websites with information or materials for autism training.



We also want councils and the NHS to think about:

ways to share training



 how to help staff link the training to their work



make sure **all** staff have basic autism training (not just those who meet the people in their job)



planning extra training for staff who need special skills.





## 2. Finding out if someone has autism and what support they will need.

#### What the guide says now

Some people do not find out they have autism until they are adults. This means life can be difficult because they do not get the information or support they need.



Your local council and health services should make sure there are good ways to find out:

if someone has autism



what support they need

 how to get the right health support quickly.



If you have autism, someone from your local council should meet you to find out what support you need.



Your council cannot say you are too clever to need support. Some people with autism or Asperger Syndrome might be very clever but find everyday things difficult to do.



Your carer can have a meeting like this as well to find out what support they need.



You should get good information about autism and the support you can get.



# Extra information for the new guide

Information to help local areas check they give good support to adults with autism.



Clinical Commissioning Groups (**CCGs**) plan and pay for local health services and are responsible for making sure services are available to support people.



There will be some more information for **CCGs** soon to help understand the health support adults with autism might need.



# 3. Making transition easier for people with autism.

Transition means going from using children's services to using adult services.



#### What the guide says now

Local councils must help young people with autism plan for being adults. They must say which young people have special educational needs.

# Extra information for the new guide

The **Children and Families Act** gives young people up to 25 years old more rights to support with their education, health and care. This gives them more time to find the right care and support.



Local councils must say what services there are for children and young people with special educational needs.



Health organisations must work with local councils to write Education, Health and Care plans for young people with autism who need support.



Services must work together to help young people do the things that are important to them and move into adult life.



The guide will say how to support young people who do not meet the rules for getting adult services from the council.



4. Local leaders who understand what people with autism need.

#### What the guide says now







They should also make sure other services have plans for supporting people with autism and their families.



**Health and Wellbeing Boards** are a good way to bring everyone together to plan and check things.



Health and social care services must work with other services to collect good information about:

 the number of local people with autism



• the support they need.



This should include information about their age, race and religion and where people live.



This will help plan the services people need.



# Extra information for the new guide

Health and social care services should listen to people with autism, their families and carers.



They should have a plan about the support people with autism need to live the lives they want.



Services need to collect better information so they know about:

 people who do not know they have autism



people who have autism but do not use any special services.



They should use national information to understand how many people in their area might need support with autism.



The **Care Act** says health and social care services must work with housing services so people with autism get the housing they need.



## 5. Keeping people safe

If adults with autism do not have the support they need, things can go wrong and they might need more support.



#### What the guide says now

Councils and NHS organisations should include people with autism in their plans and make sure their staff understand autism.



# Extra information for the new guide

Councils must have services that stop things going wrong for people. This includes information, advice and community and voluntary groups.



Health staff must understand things that are difficult for adults with autism and when they might need more support.



Information about a toolkit that can help adults with autism who use mental health services.



Councils, health organisations and the police must work together to keep adults with autism safe and check what is happening if they think someone is at risk.



## 6. Making changes

A law called the **Equality Act** says services must make changes (**reasonable adjustments**) so disabled people can use them, including people with autism.



#### What the guide says now

Health and social care organisations must make sure people with autism can use their services and any services they pay people to run for them.



They must make sure they do not treat people with autism unfairly when they give services and information.



# Extra information for the new guide

There will be more information about the types of changes services can make to buildings, communication, planning or the way they give a service.



We will give examples of technology and equipment that can help people with autism communicate and live a fulfilling life.



We will put a link to the **Equality Act** website and information about how public services can check they have made these changes.



# 7. Supporting people with lots of needs

Winterbourne View was a hospital where people were treated badly by the staff. A lot of these people had autism.



People with autism who have difficult behaviour or lots of needs should live in their own homes and not in hospital.

#### What the guide says now

Councils and NHS organisations must:

 move people who should not be living in hospitals into the community



have good local plans to support people with difficult behaviour.

The Mental Capacity Act is a law to protect people who cannot make decisions for themselves.

Health and social care staff must understand how this law can help people make decisions and have as much freedom as possible.

## Extra information for the new guide Health and social care services mu

Health and social care services must understand how to keep people safe without taking away their freedom and choice.

Services should work together to care for people with lots of needs in the community where they can be with their family and friends.



LAW



All staff should understand the Mental Capacity Act and the law about taking away a person's freedom.



## 8. Work and jobs

#### What the guide says now

Councils and NHS organisations should help people plan to get skills and work.



They should also set a good example by helping more people with autism work for them.



# Extra information for the new guide

Ask people with autism what support they need to get work and include this in local autism plans.



Make sure employment services are involved in local **Autism Partnership Boards**.

Autism Partnership Boards bring together local organisations to help improve services for people with autism in their area.



Help young people with autism move into adult services and help them with their employment needs.



Think about all the different ways to support people with autism to get and keep jobs.



# 9. Working with the Criminal Justice System.

The criminal justice system (CJS) means the police, courts, prisons and probation services.



The guide is not for criminal justice services.



It tells councils and NHS organisations how to work with these services to support adults with autism.



#### What the guide says now

These services must work together in local areas to tackle crime:

• the council



- police
- probation service
- Clinical Commissioning Groups (CCGs)
- fire and rescue services.



Some areas are trying out **Liaison and Diversion** services. This means checking whether someone has autism and making sure they get the support they need at the police station or court.



Sometimes they send people to other services that can support them better.



Councils and health services must support people with autism in prison and help them plan for leaving prison.





# Extra information for the new guide

The guide will have a link to websites and other information about how the criminal justice system should work with people with autism.



Councils and NHS organisations must tell criminal justice services about autism training.



We will say that councils must make sure their services link with **Liaison and Diversion** services.



Councils must check what support people with autism need if they are in custody or in prison.



NHS organisations must give people with autism who commit crimes the support they need.



## How to tell us what you think

Telling us what you think will help us make sure the right thing happens for people with autism.



An answer booklet came with this booklet.



It has some questions to help you think about our ideas.



Please tell us what you think before the **19th December 2014**.



We are only asking about the guide for autism plans for England.

You can write your answers in the separate answers booklet and post it to:



Consultations Co-ordinator Adult Autism Statutory Guidance Consultation Department of Health 3rd Floor Area 313A Richmond House 79 Whitehall London SW1A 2NS



There is more information on our website: http://consultations.dh.gov.uk/

This site is not in EasyRead.



You can also email your answers to: autism@dh.gsi.gov.uk

We will put information about what people said and changes to the guide on our website at **www.gov.uk** after the consultation has finished.



# How we are finding out what people think

We have followed the government's rules for finding out what people think.

If you want to say something about the way we have done this, please contact:



Consultations Co-ordinator Department of Health 2E08 Quarry House Leeds. LS2 7UE



Email: consultation.co-ordinator@dh.gsi.gov.uk



Please do not send the answer booklet to this address.



## **Keeping information safe**

We will stick to the law and Department of Health rules about using information.



The **Freedom of Information Act** means people can ask to see public information.



You can tell us if you do not want us to share your information but we might still have to share it with other people.





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