

What do you think?

A Better Future for adults with autism

Easy read

This is an Easy Read version of a booklet called **A Better Future – a consultation on a future strategy for adults with autistic spectrum conditions.**



If you want to read the full-length booklet, you can find it at:
www.dh.gov.uk/en/Consultations/Liveconsultations/DH_098587



When we say **we** in this booklet we mean the **Department of Health.**



Different people use different words to describe autism.

Some people say autistic spectrum disorder, autistic spectrum condition or neuro-diversity. This booklet uses **people with autism** or **adults with autism** and includes people with Asperger syndrome.



You may like to have someone to support you when you look at this booklet.



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What is this booklet about?

We want to find out how we can make life better for adults with autism, their families and people who work with them.



We have already asked one group of people how they think we might do this.

This group included:

- adults with autism
- parents and people who look after adults with autism
- people whose job it is to help adults with autism



They said there are 5 areas where they think we should make changes to make things better for adults with autism. These areas are:

1. Helping adults with autism where they live.



2. Making healthcare better for adults with autism.



3. Adults with autism choosing the services and support they need.



4. Helping people like doctors, social workers, teachers, the police and housing officers to understand more about autism.



5. Helping adults with autism get jobs and training.



This booklet tells you what the group has already told us about these areas.



At the end of each section there are some questions for you to answer.



Your answers will help us decide what we should do to make services better in the future.



This is important because adults with autism have the same rights as everyone else. This means that adults with autism should be treated fairly.



Please send us your answers before **Tuesday 15 September 2009.**



What is autism?

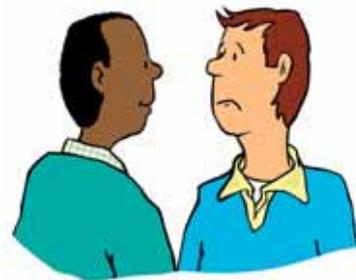
Autism is a disability. It affects how people deal with other people.

People with autism:

- may find it hard to make people understand what they mean and what other people mean



- sometimes don't understand other people's feelings and find it hard to control their own feelings



- find it hard to understand why other people do things in a different way to them.



People who have autism have it for their whole life.

Some people with autism have **sensory sensitivity**. This means that they are very sensitive to:

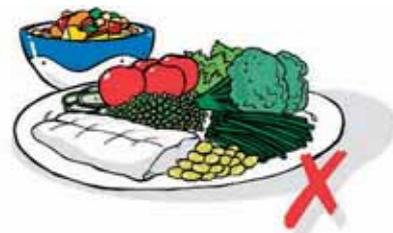
- loud noise



- being touched



- different tastes



- some smells



- bright light



- some colour.



People who don't have autism can find it hard to understand what needs people with autism have because:



- often you can't see that someone has autism just by looking at them



- people don't always want other people to know they have autism



- different people with autism need different levels of support.



We think that about 1 out of every 100 people have autism.

Anybody can have autism.





Questions

You can answer all or just some of the questions. Please write your answers in the spaces below the questions. If you need more space, please use extra pieces of paper.

There are 5 areas where we think we need to make changes to make life better for adults with autism. These are:

1. Helping adults with autism where they live. This may mean help with things like finding somewhere to live, help with travelling where they need to go and help to do things in their free time.
2. Making healthcare better for adults with autism.
3. Adults with autism choosing the services and support they need.
4. Helping people like doctors, social workers, teachers, the police and housing officers to understand more about autism.
5. Helping adults with autism get jobs and training.

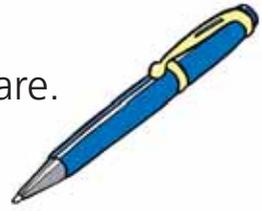
0.A Are there any other areas that you think we need to include?

Yes

No



0.B If you answered yes, please tell us what the other areas are.



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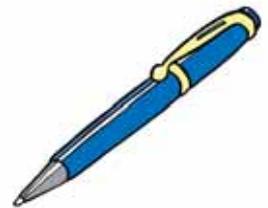
.....

0.C If you answered yes, do you think the other areas you have included are **more** or **less** important than the five main areas?

More important

Less important

About the same



Why do you think this?

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0.D Are you involved in giving or buying services for adults with autism? .

Yes

No



0.E If you answered yes, please tell us what these services are and how they have helped adults with autism.

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0.F Do you think that some adults with autism get better services because of who they are? For example, because they are a man or a woman, because of how old they are, because of their religion or their race, because they are gay or lesbian or because they have other disabilities as well as autism.

Yes

No



If you answered yes, how do think we could make services better for all adults with autism and not just for some adults with autism?

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1. Helping adults with autism where they live

We want to know how we can make sure adults with autism get the help they need to be part of the community, or where they live. This is called **social inclusion**.



This could be:

- help with housing
- help with looking after yourself at home, such as getting dressed and making a meal
- help for people to do things in their free time



- help with making friends



- help with travelling to where they want to go.



We want to make sure that people are not treated badly because they have autism.



What have people told us?

The people we have already asked said that:

- often no one is in charge of making sure adults with autism get the help they need
- people in charge of planning services need to know more about adults with autism, like how many people have autism locally



- there is not enough help for adults with autism to live a normal life.

This could be:

- help with talking to other people



- help with meeting people and making friends



- help with doing everyday things



- a lot of adults with autism live with their family. Some adults with autism could live by themselves, if they had more help



- some people who have a sensory sensitivity find it hard to use public transport like buses and trains because it can be very busy



- some adults with autism find it hard to go to new places. They might need someone to help them



- some people were also worried about whether we would do what we say we will.





Questions

You can answer all or just some of the questions. Please write your answers in the spaces below the questions. If you need more space, please use extra pieces of paper.

The [Helping adults with autism where they live](#) chapter (page 13) looks at the problems adults with autism may have at home and in their day-to-day activities.

People have told us that we need to do 4 things so that there is better help for adults with autism where they live. These are:

1. Make sure that the people who provide help for adults with autism understand what help adults with autism need.
2. Make sure that the people who provide help for adults with autism give the help that adults with autism need.
3. Make sure that adults with autism can get the help they need where they live both in their home and with their day-to-day activities.
4. Make it easier for adults with autism to get help with finding a house or flat and looking after it, get help with travelling where they need to go, and get help so they can do the things they like to do in their free time.

1.A Do you agree that these are the main things that we need to do so that there is better help for adults with autism where they live?

Yes

No

Not sure



1.B Please tell us why.

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1.C Do you need help with any of these things?

- a. help with finding a house or flat and looking after it
- b. help to look after yourself in your own home
- c. help with travelling to where you need to go
- d. help to make friends
- e. help so you can do the things you like to do in your free time.

Yes

No



1.D If you answered **yes**, please tell us why you need help with any of these things:



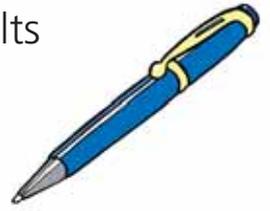
- a. help with finding a house or flat and looking after it
- b. help to look after yourself in your own home
- c. help with travelling to where you need to go
- d. help to make friends
- e. help so you can do the things you like to do in your free time.

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1.E What do you think would be the best ways to help adults with autism to do these things?



- a. to find a house or flat and look after it
- b. to look after themselves in their own home
- c. to travel to where they need to go
- d. to make friends
- e. to do the things they like to do in their free time.

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1.F Do you know of any help that adults with autism can get with these things where you live?

- a. help with finding a house or flat and looking after it
- b. help to look after themselves in their own home
- c. help with travelling to where they need to go
- d. help to make friends
- e. help so they can do the things they like to do in their free time.

Yes

No



1.G If you answered yes, please tell us about this help. Please tell us what you like or don't like about it.

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2. Making healthcare better for adults with autism

We want to make sure adults with autism have the healthcare they need.



This means help from doctors and hospitals.



We want to make sure that people with autism can find out that they have autism and are given help to understand what this means.



We want to help adults with autism and their families so that the people with autism have better, healthier lives.



What have people told us?

When we asked people, they said that we need to be better at:

- finding out when someone has autism, so that they can get the help they need



- helping adults with autism as they grow up. Children with autism use different services to adults with autism, so the people in charge of those services must work well together



- making sure that adults with autism get any extra help they need when they go to see a doctor or go to the hospital



- helping adults who have other problems as well as autism. Like all adults, sometimes adults with autism get mental health problems. They may need different help with these problems than other adults with mental health problems. Mental health problems are to do with your mind and not your body.





Questions

You can answer all or just some of the questions. Please write your answers in the spaces below the questions. If you need more space, please use extra pieces of paper.

The [Making healthcare better for adults with autism](#) chapter (page 23) looks at the problems for adults with autism getting the healthcare they need.

People have told us that there are 4 main ways we can improve healthcare for adults with autism. These are:

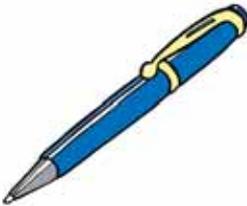
1. Make it easier for adults to find out if they have got autism and get the healthcare they need.
2. Make sure that people working in the health service have information about the adults with autism who live in their area, so that they can make sure that help is available for them.
3. Make places like doctors' surgeries and hospitals easier to get to for adults with autism and make sure these places are easy for adults with autism to use.
4. Help doctors, nurses and social workers who work with people who have mental health problems to understand more about autism. This will mean they can better help people with autism who also have mental health problems.

2.A Do you agree that these are the most important ways to improve healthcare for people with autism?

Yes

No

Not sure



2.B Please tell us why.

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2.C How did you find out that you had autism?

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2.D What help did you get to understand what having autism means?



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2.E What do you think we should do to make health services better for adults with autism? For example, how could we make it easier for adults with autism to get the treatment they need, to visit a doctor's surgery or use a hospital?



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2.F Health services are things like doctors' surgeries and hospitals. What health services in your area are easiest for you to use? Why are they easiest?



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3. Adults with autism choosing the services and support they need

We want to make sure adults with autism can choose the services or help they need, so that they can live how they like.



We also want to make sure adults with autism have a say in the services on offer.



We need to make all information about local services easy to understand.



This will make it easier for adults with autism to choose the services they need.



Often adults with autism need someone to speak for them. We need to make it easier for adults with autism to find someone to speak up for them.



If an adult with autism needs support to speak for themselves, we want to help them to do this.



What have people told us?

When we asked people, they said that we need to give adults with autism more choice:



- All adults with autism are different and need different sorts of help. Adults with autism should be able to make plans about the support they need. This will help make sure they get the right help to live how they want to live.



- Children with autism need different help to adults with autism. When a person is growing up, they need a plan to say how the help they get will change.





Questions

You can answer all or just some of the questions. Please write your answers in the spaces below the questions. If you need more space, please use extra pieces of paper.

The [Adults with autism choosing the services and support they need](#) chapter (page 29) looks at how adults with autism can make choices about the help they get and about what they do in their lives.

People have told us that there are 4 ways we can make sure that adults with autism can make choices about the help they get and about what they do in their lives. These are:

1. Make sure that adults with autism can get person-centred plans and are in control of their lives. Person-centred plans are documents that say what things people want to do and what help they need to do this.
2. Provide better help for people with autism as they leave school and start doing new things.
3. Make it easier for adults with autism to find someone to speak up for them or help them to speak for themselves.
4. Make sure that adults with autism are asked how they think the services they use could be improved.

3.A Do you think that these are the most important ways to make sure that adults with autism can make choices about the help they get?

Yes

No

Not sure



3.B Please tell us why.

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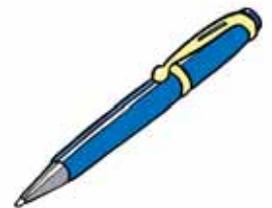
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3.C Have you been able to make choices about the help you get? This might be help at home, help with your day-to-day activities, help with getting a house or flat, help with meeting new people, or help travelling where you need to go.

Yes

No



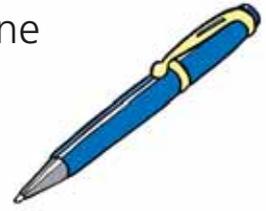
3.D If you answered yes, please tell us about the choices you made and how you made them.

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3.E What do you think are the best ways to help adults with autism choose the help they need? For example, having more information about what help is available or having someone like a social worker to explain what help you could get.



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3.F Did you get any help with making choices about the services you use and other help you need?

Yes

No



3.G If you answered yes, please tell us what help you got to make these choices and how it helped you.

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4. Helping people like doctors, social workers, teachers, the police and housing officers to understand more about autism

So people can help people with autism they need to know more about how it affects people.



We want to give everyone more information, so that they can understand adults with autism better.



We want to help people who work with adults with autism to understand them, so that they can help them more.



We want to help by giving people training. These people include carers, teachers, social workers and people at work.



We also want people who help you find a job and give advice about benefits to understand autism.



What have people told us?

When we asked people, they said:

- we need to give more information about autism and how adults with autism behave. It is harder for people with autism if people don't understand them
- people like carers, teachers, benefits and housing staff need training on the needs of adults with autism



- social workers need to know more about adults with autism, so that they can give them the help they need



- doctors and people who give healthcare to adults with autism need to know more about autism, so that they can know when someone has autism, and give them the help they need.





Questions

You can answer all or just some of the questions. Please write your answers in the spaces below the questions. If you need more space, please use extra pieces of paper.

The [Helping people like doctors, social workers, teachers, the police and housing officers to understand more about autism](#) chapter (page 35) looks at how to make sure that people working with adults with autism understand autism better.

Many people who work with adults with autism do not understand autism very well. We think there are 3 things that would help these people understand autism better. These are:

1. Give people like employers and the police more information about autism.
2. Teach people like social workers and people who work in places like colleges, housing offices and Jobcentre Plus about autism.
3. Make sure that new social workers, doctors and nurses are taught about autism as part of the training they have to do before they can start their new job.

4.A Do you agree that these are the best ways to help people understand autism better?

Yes

No

Not sure



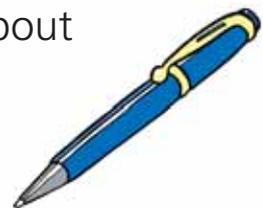
4.B Please tell us why.

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4.C Please tell us which people you think most need to have extra training about autism and why. For example, doctors and nurses, social workers, people who work in housing and Jobcentre Plus, people who work in colleges, people who give advice about benefits.

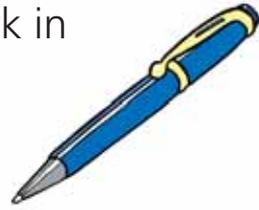


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4.D Please tell us the kinds of things you would like people such as doctors and nurses, social workers and people who work in housing to know about autism.



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5. Helping adults with autism get jobs and training

We want to help adults with autism at work, at school and with training.



We want to:

- help adults with autism get a job they like
- make sure adults with autism get the help they need to keep their jobs
- make sure adults with autism get benefits and tax credits while they look for work
- make sure adults with autism will be able to get the same education as everyone else.



What have people told us?

The people we have already spoken to have said:

- not many adults with autism have a full-time job



- most bosses do not know much about autism so they do not help adults with autism enough at work



- it is hard for many adults with autism to understand and get money from benefits and tax credits they need



- there is not enough help for adults with autism to get the education and training they need.





Questions

You can answer all or just some of the questions. Please write your answers in the spaces below the questions. If you need more space, please use extra pieces of paper.

The [Helping adults with autism get jobs and training](#) chapter (page 41) looks at the problems adults with autism have when they try to get a job and training. It also looks at benefits.

People have told us that we need to do 4 main things to make it easier for adults with autism to get jobs and training. These are:

1. Make sure that adults with autism can get the help they need to find and keep a job.
2. Make sure employers know about autism.
3. Make sure that adults with autism can get the benefits and tax credits they need.
4. Help adults with autism to get the training and education they need.

5.A Do you agree that these are the most important ways to make it easier for adults with autism to get jobs, training and benefits?

Yes

No

Not sure



5.B Please tell us why.



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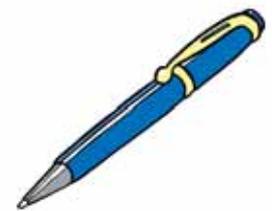
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5.C Have you had any problems trying to get a job, training or benefits?

Yes

No



5.D If you answered yes, please tell us about the problems you have had trying to get a job.

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5.E If you answered yes, please also tell us about the problems you have had trying to get training.



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5.F If you answered yes, please also tell us about the problems you have had trying to get benefits.

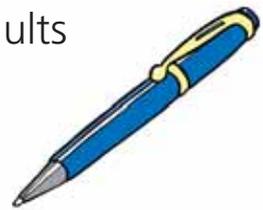


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5.G What do you think we should do to make it easier for adults with autism to get training or a job? For example, we could make sure that people like employers and people who help adults with autism to find a job know more about autism.



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5.H What help have you had to help you get a job or training?



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5.I How has it helped you?



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Further comments

6.A Please tell us anything else you think we need to do to make life better for adults with autism.



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About your response

6.B Please tell us whether your answers to these questions are from:

one person

a group of people



6.C If it is a group, how many people helped answer the questions?

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6.D Are you or the group (please only mark one):

a person or people with autism?

family carers?

professionals involved with people with autism?

other – please say what:

.....



6.E If you are a professional, in which area do you work?

health

social care

employment

housing

transport

education

other – please say what:

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6.F If the answers are from a group, please tell us how many people from each of the types of people listed above were involved.



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What is your ethnic group?

6.G Choose one section from A to D. Tick one box to tell us which ethnic group you are from.

A White

British

Irish

any other white background. Please say which:



.....

B Mixed

white and black Caribbean

white and black African

white and Asian

any other mixed background. Please say which:

.....



C Asian or Asian British

Indian

Pakistani

Bangladeshi

any other Asian background. Please say which:

.....



D Black or black British

Caribbean

African

any other black background. Please say which:



.....

6.H It would help us if you put your name and where you are from. If this is a group response, then this is particularly important.

Name of individual or group:

.....

Town or city or county:

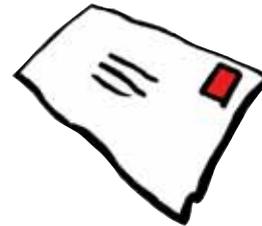
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What to do next

Please answer the questions and send them **before 15 September 2009** to:



Adult ASC Strategy Consultation
Department of Health
Room 124
Wellington House
133–155 Waterloo Road
London SE1 8UG



Or you can tell us what you think online at www.dh.gov.uk/en/Consultations/Liveconsultations/index.htm

Or email us at autism@dh.gsi.gov.uk



The Department of Health will hold a number of events for people who work with adults with autism and for adults with autism and their families around the country.

You can find out more about events and information on our website: www.dh.gov.uk/en/Consultations/Liveconsultations/index.htm

Freedom of information

We may share the information you give us with other people.

If you want us to keep the information private, it would be helpful if you could tell us why you think we should do this.

If we are asked about the information you have given us, we will consider your explanation, but we cannot promise to keep your information private.



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