

# Think Autism



An update on our plans to help you make the most of what you can do



**An EasyRead version of:**

Fulfilling and rewarding Lives, the strategy for adults with autism in England: an update (April 2014)





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## About this paper

The Department of Health worked with other Government Departments to write this paper. We are part of the government in charge of healthcare and social care.



In 2009 a new law called the Autism Act gave adults with autism the right to get services they need.



In 2010 we wrote a plan for adults with autism in England. It was called **Fulfilling and Rewarding Lives**. The plan told everyone how to follow the new law.



We said we would check the plan in 2014 to see what has changed for adults with autism.

This paper is about what we found out and what will happen next.

# What is Autism?



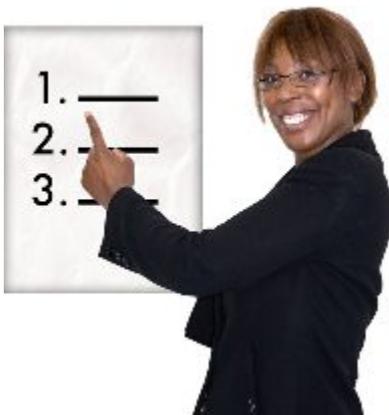
Autism is a condition. It affects how you deal with other people and how you understand the world around you.



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



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 3 main 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.

## A word from the Ministers



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



Local areas should have a person who is responsible for the services you need.



People with autism are involved in saying what services you need.



There are some good stories about people with autism who go to college or have jobs.



Things are better for some people with autism when they move from children's services to adult services.



This is just the start.

Different parts of the government must now work together to support people with autism.



Local services should help people with autism to:

- get the right support;



- get jobs;



- have a better life and be part of society.



People with autism, groups, families and carers told us what should be better.



This paper is about the 15 things that will help everyone think about autism.

## Part 1 - What needs to change?



The most important thing is still for people with autism to:

- live life to the full;



- make the most of the things they can do;



- live in a society that understands and accepts them;



- be told quickly that they have autism and get support if they need it;



- have services treat them fairly as individuals.



We needed to update our plan to:

- include what people with autism told us when we checked what has changed;



- look at what has been done so far and decide what happens next;



- include new services and organisations that can help people with autism have better lives.



Lots of things have changed since 2010:

- GPs now plan and pay for local health services;



- more people use **personal budgets** to have choice and control over their support;



- there are new ways for children with disabilities and their families to get support;



- services have to work together to give support to people;



- services need to make sure that they do not waste public money;

- local plans must think about how these things can help adults with autism get the lives they want.



## Part 2 - How we will check our plans

The Autism Act says we must check if our plan makes things better for people with autism.

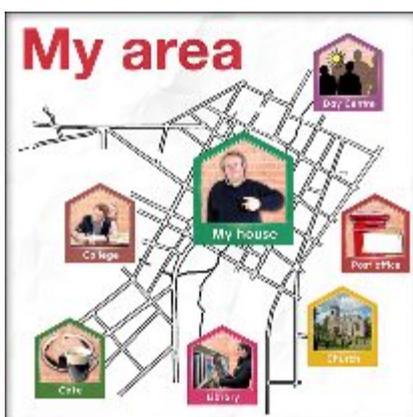


We checked last year and:

- nearly 2 thousand people came to meetings to talk about the Act;



- over 1 thousand people answered questions on the internet;



- local councils asked people with autism and their families about services in their area.



We will check again in the next 5 years.



The Minister for Care and Support services and a group called the **Autism Programme Board** will keep checking the plan is working.



You can see all the papers they write on the website: [www.gov.uk](http://www.gov.uk)



The Department of Health and other parts of the government say it is important that:

- staff are trained about what autism is;



- young people with autism have better support;



- local areas are helped to check if they are following the law about autism and our plan;



- different areas can show what they are doing and let you say what you think about your services;



- the police, courts and other law organisations understand autism and how it can affect people;



- services treat people with autism fairly;



- new ideas about supporting people with autism are shared;



- older people with autism are better supported.



Local areas must involve people with autism and their families because they live with autism.



## Part 3 - Making sure more people understand and know about Autism

3 things need to happen for people with autism.



People with autism live in a society that really understands and accepts them:



- be involved in your community, not just services for people with autism;



- have **champions** who can make sure everyone knows and understands about autism.



New ideas, services or projects to help you in your community:

- different types of support, especially if you do not meet the rules for getting services;



- support that helps you before things go wrong;



- support to be more independent or get a job.



## Better advice and information:

- services that work together to make it easier for people with autism and their families to get the information and support they need.



The **Autism Innovation Fund** is money to try new ideas to help people with autism.



These ideas help people with:

- advice and information;



- skills to be more independent;



- early support before things go wrong;



- employment and apprenticeships.



These ideas must:

- involve people with autism;



- use technology or new ways of planning or running a service;



- show how services will work together or involve other services, businesses or employers.



We will look for ideas that also use money from organisations, services or groups that are not part of the government.



We will tell you more about this fund at the end of June 2014.



## Part 4 – The 15 important things to do

1. **Make sure my community understands about autism and accepts and includes me.**



Health and social care services can support people to be part of their local community. But everyone needs to **Think Autism** so you really belong.



Businesses must make changes so people with autism can enjoy the same things as everyone else. For example, Autism Friendly times at cinemas or theatres.



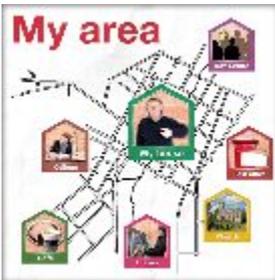
People with autism, carers and groups will help people in their area understand autism better.



There could be an award for organisations that show they really understand autism.



**Autism champions** or experts will help change things. We will tell you more about this by the end of June 2014.



**2. My local area thinks about what is important to me. I know if they are doing as well as other places.**



Local councils must have an Autism Partnership Board or other ways to involve people with autism in planning.



The National Autistic Society have written a guide about involving people with autism in Partnership Boards. There is information on their website: [www.autism.org.uk](http://www.autism.org.uk)



New laws will say adults must be involved in their support plans. If you cannot do this, your family or an advocate must make sure you are involved.



Local councils must say what services people can expect for children and young people. They must think about the services young people with autism need.



Local councils must involve people with autism and their families when they check how they are using these plans. They must make it easy for you to see how well your council is doing.

### 3. I want to link to other people and groups.



Adults with autism can find it difficult to make friends. Voluntary groups can help you meet other people who can give support or advice.



It will be easier to know who can get services from your local council. If people with autism do not get services, they can still get information and help from local groups.



Local councils must make sure they have the right services for people with autism and their families. Services that give a little bit of support when you need it can stop things going wrong.



The Autism Innovation Fund will help with ideas for services like this.



#### 4. I want everyday services to understand autism and help me do things other people do.

People with autism can find it hard to use services that are noisy, busy or difficult to understand.



The law says services must change things if they can so people with a disability (including autism) have the same chance to use them.



These changes are called **reasonable adjustments**. They mean thinking about things like buildings, training staff, information and planning.



Autism Passports can include information about you that show people what help or support you need.

They are not the same as passports you use when you travel outside the UK.



Other parts of the government will look at changes to make it easier for people with autism to claim benefits or go to school or college.



Training about treating people equally will help our staff understand what things are like for people with autism.



## 5. I want to be safe in my community.

The new **Victims Code** says the police and other law organisations must support people who are **victims** (affected by crime).



People with autism can get extra support. There is also support for **witnesses** (people who see a crime).



Many people with autism can be bullied or treated badly on public transport.



Drivers and other staff will be trained about disabilities (including autism).

Services will have to show how they keep disabled passengers safe.



The **Journey Assistance Card** tells transport staff that you need help to travel.



People can also be bullied on their phones or computers. From September 2014 all young people will be taught how to stay safe on the internet.



## 6. See me as a person, not just a person with Autism.

Adults with autism said many people only think about their autism.



They have ideas about what people with autism are like and do not expect you to be different.



This can make it very difficult if you need different types of support because of your religion, sexuality or race.



We will work with groups and organisations in 2014 – 2015 to find out more about this.

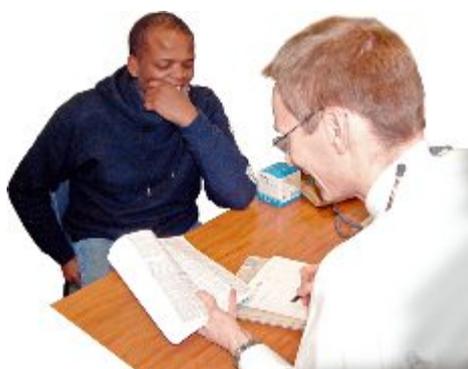


## 7. I want the right support at the right time in my life.

More children are told they have autism now.



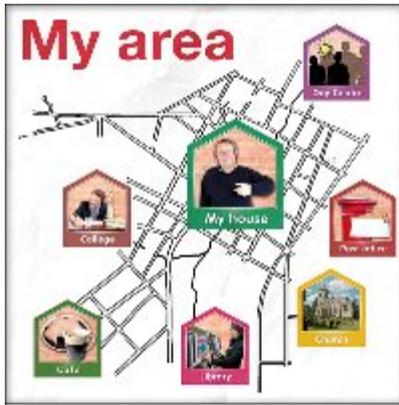
In the past we did not know as much about autism so many adults did not find out until they were older.



A doctor can help arrange for you to have a test so see if you have autism and this can help you get the right support and help.



This is important for adults who might have lots of problems but miss out on support or services.



Each local area should have clear information about how to check if someone has autism.



They should use information about people with autism to plan the right services.



The Care Quality Commission (CQC) and NHS England will tell us how each area is doing with this.



**8. I want my local area to think about autism and understand the services I need.**

Local councils need to know how many people have autism so they can plan the services they need.



This is difficult because many people do not know they have autism, do not tell services about it or do not ask for help.



Local councils and GPs will get better at writing down if someone has autism.



GPs will be better at working with other services to support patients with autism and their families.



Advocacy services and other groups will help councils find out how many people have autism.



## 9. Staff in health and social care services understand how autism can affect me.

All staff in health and social care services should be trained about autism.



Staff like social workers who find out what support you need must also understand autism or involve someone who does.



It is helpful if staff in other services like swimming pools or leisure centres are trained about autism.



We are looking at how well the autism training on the internet works.



People need the right support as soon as possible. We are looking at training about autism for social workers and GPs so they can send you to the right services.



## 10. I want my family to get the help and support they need

When you find out you have autism, your carer should get an **assessment** to see what support they need.



Local councils must make sure their plans for carers include people with autism.



Carers will get information about the Carers' Allowance and other benefits they can get.



## 11. Services understand how to support me when there are big changes in my life.

### Thinking about younger people

If you are under 25 years old you may have just 1 plan for your education, health and care based on your needs.



Schools must plan early before you move to adult services. Councils can find out what support you need before you are 18 years old.



Young people with autism have new rights in colleges and training.



Councils will also have to plan for young people who do not go to college or have jobs.



There is support for young people to learn through college, apprenticeships or work experience.



Staff in colleges should get training about autism.



## Thinking about older people

Many older people with autism do not have families to help them get services. A new law would give them advocacy support if they need help with this.



Local councils must think about older people with autism when they plan services.



The Government will look at National Autistic Society information about how to support older people with autism in taking this work forward.



### Thinking about other changes

Getting married, having children or losing a job are all big changes in your life.



You need good support when something like this happens. If you do not get it, you might need support for your mental health or other problems.



Local councils can plan services to support you before things go wrong.



## 12. I want people to understand my autism and know how to support my other needs.

Care services must understand the extra support people with autism need for other problems.



Up to half of all people with a learning disability also have autism.



More people with autism can have more mental health problems than other people and they need the right support for this.



Some people with autism use behaviour to communicate they are angry or upset.



Other people might need extra healthcare.



People were treated really badly at a hospital called Winterbourne View. Many of them had autism.

The government has written a plan to try to stop this happening again.



The plan includes:

- people living in homes in the community and not hospitals;



- better planning for each person's needs;



- better support if the person is very angry or upset;



- new rules about holding people to stop them hurting themselves or other people.



### **13. I need the police, courts and other law services to understand about autism.**

You need the right support if you are a victim, a witness or the police think you were involved in a crime.



Police, prison staff and other law services should be trained about disabilities like autism.



They need to understand you might have problems talking or understanding what they say.



If the police or courts know you have autism they can make adjustments in how they treat you.



They can decide to send you to health or care services instead of going to court. This is called Liaison and Diversion.



Prisons will get better at finding out who has autism and giving them the right support.



## 14. I want to be independent and make the most of my skills and abilities.

If you meet the rules to get services you should have more control over your support.



One way to do this is to have a personal budget to pay for the services or support you choose.



We are paying the National Autistic Society to help more people with autism have a personal budget.



Schools and colleges can also help you learn to be as independent as possible.



## 15. I want support to get and keep a job.

Working is important for everyone. It helps you pay for the things you want and be part of society.

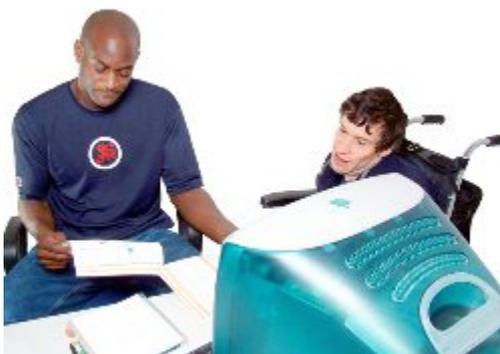


Not many adults with autism have jobs but we hope our plan will change things.



The plan includes:

- training about autism for employers and organisations that help people get jobs;
- training for staff in benefits offices about autism and other disabilities you cannot see;





- special employment advisors to support disabled people before they get a job and when they are working.

**DWP** Department for Work and Pensions

The Department for Work and Pensions is helping employers who are not sure how to employ people with disabilities (including autism).



We asked people with autism about getting a job and how different services could support them better.



We will write a report about this for the Autism Programme Board.



Local councils must think about work when they plan services for people with autism.



The Autism Innovation Fund could help with this.



There may be local schemes to help people with autism get a job.

## Part 5 - What happens next



This paper tells you about the changes to our plans to help people follow the law on autism.



The actions it includes will help local councils, health services and other organisations in what they need to do.



We want everyone to think about how to make things easier for people with autism.



This will help you do the same things as everyone else because services understand your needs.



We will ask what people think about these ideas and then write new rules for services later in 2014.

## Credits



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