

## **Adult autism strategy research**

### **Participant summary**

#### **Introduction**

This is a summary of the research and engagement events which took place to help the Government develop their future strategy for adults with autistic spectrum conditions (ASC) alongside a formal consultation.

The research and events took place between June and September 2009. They were organised and run by Opinion Leader.

#### **Terms we will use in this summary**

There are lots of different terms for adults on the autistic spectrum. In this summary we will use the term 'adults with ASC' (autistic spectrum conditions) to describe people with autism and Asperger syndrome.

#### **Aims of the research and engagement events**

The aims of the research and engagement events were to:

- Find out about what currently works and what doesn't work for adults with ASC, their family members, carers and professional people who work with them
- Find out the changes that would make the biggest difference to adults with ASC
- Hear about examples of good services that are being offered to adults with ASC at the moment
- Understand what the main priority areas are for adults with ASC
- Hear about ideas for improving the priority areas
- Make sure that that adults with ASC, those indirectly affected by ASC and service providers have their opportunity to comment

#### **About the research**

The research was conducted in two stages. In the first stage we talked to 260 people and in the second stage we talked to 352 people.

These people included:

- Adults with ASC
- Family and carers of adults with ASC
- Professionals who work with adults with ASC

The research was done using the Internet (online focus groups and an online community), face to face individual interviews, focus groups and research events with around 30 people.

The people taking part in the research came from different places in England including: Birmingham, Ipswich, Leicester, London, Manchester, Newcastle, Reading, Plymouth and Sheffield.

## The priority areas

Lots of topics and points were raised over the course of the research. However the people taking part thought that there were five main areas which they thought would result in the biggest improvements to the lives of adults with ASC. These five main areas are:

1. Diagnosis and support - Helping people to find out when someone has an ASC so that they can get the help they need. After being diagnosed, people should be able to receive support.



2. Helping people in the community - Ensuring that adults with an ASC can get the help they need to be part of the community, do things in their free time and make friends if they want to.



3. Employment and other activities - Ensuring that adults with autism are able to do regular activities which they enjoy and make them feel good about themselves.



4. Housing and support - Ensuring that adults with an ASC are able to get the right housing and support to live as independently as they want to.



5. Health - Ensuring that adults with an ASC are able to get the healthcare they need.



This summary will now talk about each one of the five main areas and actions in turn.

## 1. Diagnosis and support



The people who took part in the research said that diagnosis was a very important area for many adults with ASC. Some adults with ASC said that being diagnosed had helped them understand themselves better.

People said that it was not always easy for adults with ASC to get a diagnosis and they sometimes had to wait a long time for it or pay for a private diagnosis.

They also said that there needed to be support available for adults once they have been diagnosed with ASC, to help them decide what to do next and how to get access to services they might need.

People felt that diagnosis and support for adults with ASC could be improved by:

- Increasing awareness and knowledge of ASC amongst professionals, like GPs
- Improving access to diagnosis for those who may have ASC
- Making the diagnosis process more standard across England
- Improving access to support services once an adult with ASC is diagnosed for example, help with paying bills or help in the home



## 2. Helping people in the community



People said that helping adults with ASC in the community was important so that they can live happy and fulfilling lives. If they need it they should be given help to look after themselves, do the things they like to in their spare time, be part of the community and socialise with others (if they want to).

People also said that adults with ASC can have different needs to each other. They thought that they should be given the chance to choose what services they need, or have their family, carers or professional people to help them choose. They may also need someone like an advocate to speak for them or help them speak up, to make sure their needs are being met.

The people who took part in the research believe that if adults with ASC are given more help in the community they will be less likely to have big problems or worry about things a lot.

People felt that adults with ASC could be helped more in the community by:

- Making sure adults with ASC can get support which is right for them. Some people think they should have a personal budget which they can decide how to spend or a person-centred plan



- Helping adults with ASC to find an advocate (to speak up for them)



- Making sure people that work in the community have training on the needs of adults with ASC. This includes a range of people like GPs, social workers, people who work for jobcentre plus and other employment agencies, people who work for the police and prison service and transport services



- Helping adults with ASC meet and communicate with other people, if they want to



### 3. Employment and other activities



In the research people said that both employment and other regular activities are important to adults with ASC. Having something to do in the day can help them feel good about themselves and help them to contribute to society. This might include paid work, voluntary work, education, training and regular daytime activities.

People think that both paid employment and other types of activities should be available for those who want to and are able to do them. They

should be made as easy for adults with ASC to do as possible, by making sure the places where they happen are suitable and the other people who work their understand ASC.

Adults with ASC who want to do paid employment said that companies need to be more willing to employ people with ASC. Traditional job interviews might not be suitable for all adults with ASC, so other options should be offered.

People felt that employment and other activities for adults with ASC could be improved by:

- Making it easier to access the activities that adults with ASC want to do
- More help to find work or activities, such as having a list of activities available in the local area
- Making sure that adults with ASC get the support they need to stay in work or education. This might include a buddy or mentor to support them
- Training for people who will be around adults with ASC



#### 4. Housing and support



The people taking part in the research thought that having appropriate housing is very important for adults with ASC. They need to live somewhere where they feel comfortable and happy. They also need the right level of support in their home to ensure they can live there safely and as independently as possible.

Adults with ASC have a range of needs and different people need different types of housing. Some people need lots of support, and to have someone helpful with them all of the time others need at crisis points and some people only need help occasionally. Some adults with ASC are very sensitive to light and noises. If the environment is not right for them it can cause stress and anxiety. Lots of adults with ASC also say that having to move houses a lot can cause them problems.

Some adults with ASC want to live by themselves and people think they should be able to do this if they want to. However, they may still need some support with day-to-day living to be able to do this.

People felt that housing and support for adults with ASC could be improved by:

- Making sure that adults with ASC are able to get housing which meets their individual needs. They should be able to live as independently as possible
- Making sure that support workers are trained to work with adults with ASC
- Help for adults with ASC if there is a problem at where they live
- Having support which is flexible enough to meet people's needs. For example some people only need help for 1 or 2 hours a week.



## 5. Health



People said that health was an important issue because, just like everybody in England, adults with ASC can have health problems during their life. Some adults with ASC have particular health issues that are connected to the condition, such as sensory issues e.g. sensitive to light and sound.

Some adults with ASC are not very good at explaining if they are ill or in pain, or may not realise that they should go to the doctor. When they do go to see the doctor, the doctor does not always know a lot about ASC and how it may affect other illnesses.

Many people also talked about doctor's surgeries and hospitals. They said these are not always suitable for adults with ASC, as the lighting may be too bright and waiting areas can be crowded. Some adults with ASC said they found it hard to attend an appointment with a doctor.

People felt that healthcare for adults with ASC could be improved by:

- Making sure that healthcare professionals are trained about the needs of adults with ASC



- Providing treatment for the adult with ASC's entire health needs, including physical and mental health



- Making it easier for adults with ASC to receive treatment, for example changes to waiting rooms and appointment times



- Having more specialists in ASC working in healthcare



## General points

Across the five areas they talked about, people also had some good points that applied to all of them. These are some more general things that people believe would improve the lives of adults with ASC:

- Making the public more aware of ASC and increasing the acceptance and understanding of ASC



- Developing policy and services with the help of adults with ASC



- Making sure that somebody in every local area takes responsibility for providing services which meet the needs of adults with ASC



- Training professional people, such as doctors, about ASC and how to adapt their services for adults with ASC



- Ensuring that adults with ASC have personalised support



- Making sure that adults with ASC get help to communicate with other people if they need it



There were lots of other things that the people who took part in the research told us. All the ideas discussed in the research have been recorded and will be used in the final report which will go to the Department of Health. This report will be published on the Department of Health website [www.dh.gov.uk](http://www.dh.gov.uk) at the end of November 2009.