

A Better Future

A consultation on a future
strategy for adults with autistic
spectrum conditions



Plain English Version

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A Better Future

A consultation on a future strategy for adults with autistic spectrum conditions

Plain English Version

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Ministerial foreword

I am delighted to open this consultation on the first government **strategy** to support adults with autistic spectrum conditions (ASC) to live life as full and equal citizens. The strategy is our plan for how we will run services in the future.

The consultation is a vital part of a government project to improve the lives of adults with an ASC, their families and carers and the professionals who work with them.

At the end of 2009, we will produce our final strategy for delivering:

- better support for commissioners and other professionals who work with and support adults with an ASC
- research into how many people have an ASC
- research into how people with an ASC cope with the transition from adolescence to becoming an adult, and
- clear links with other parts of government that affect adults with an ASC.

I will make sure that the final strategy has the power to make sure that change really does happen.

Adults with an ASC, and their families, face a great many barriers in their everyday lives and in getting the services and support that they need.

ASCs are often overlooked or misunderstood by professionals and by society. For instance, we know that:

- adults with an ASC can struggle to access health and social care services
- very few adults with an ASC have long-term jobs that they enjoy, and
- adults with an ASC find it hard to access community services such as transport and housing.

We know that many things must change to make life better for adults with an ASC. We want this consultation to help us to have a better understanding of what the challenges are and what can be done to make change happen.

Adults with an ASC do not always get the right support. But there are lots of examples of where the right advice and support has really improved a person's quality of life and well-being.

Support is not just about health and social care; it's also about identifying **all** the things that a person may want or need to live their life to the full. This is why our consultation is looking at employment, education and social inclusion, as well as at health and social care.

Thanks

I would like to thank the **external reference group** for their help.

The group chairman was Mark Lever, Chief Executive of the National Autistic Society.

The group also included

- people with an ASC
- parents and carers of adults with an ASC
- representatives of organisations that support people with an ASC
- health and social care professionals
- employers and others who support people with an ASC to find and keep a job, and
- education professionals.

A handwritten signature in black ink that reads "Phil Hope". The signature is written in a cursive style with a period at the end.

Phil Hope MP
Minister of State for Care Services

Executive summary

This consultation will help us find out what we should be doing to deliver the greatest change for the largest number of adults with an ASC.

The external reference group of people whose lives are affected by ASCs, either in their work or personally, have helped us to identify **5 key themes** for the consultation.

The 5 themes are:

1. social inclusion
2. health
3. choice and control
4. awareness raising and training
5. access to training and employment.

We chose these themes because they cover the main concerns that adults with an ASC have told us they have. They are also the areas where we believe we can deliver the greatest change.

However, we know that the themes do not cover all the issues. So we want to use the consultation:

- to find out whether these 5 themes are the most important ones to look at, and
- to find out whether what we say about the themes is correct.

Both the external reference group and the government departments involved in developing our strategy for adults with an ASC have ideas about what we could do to make changes. Some of their ideas are in this booklet, but we also want to hear the ideas of as many other people as possible to help us decide exactly what to put in the final strategy.

To help us understand how we can deliver services in the best possible way, we want you to tell us about what has worked or not worked with services that you are involved with.

We would also like to know about the costs, benefits and risks involved in delivering the services you are involved with.

There is a list of questions we would like you to answer on pages 34 to 54. Please send us your answers before **Tuesday 15 September 2009**.

Terminology

We know that there are a number of terms that different people and groups prefer, including **autistic spectrum disorder**, **autistic spectrum condition**, **autistic spectrum difference** and **neuro-diversity**. This consultation booklet uses **autistic spectrum condition (ASC)**.

An ASC is a lifelong condition that affects how a person communicates with and relates to other people. It also affects how a person makes sense of the world around them. We use the word 'spectrum' because it shows that ASCs vary a lot from one person to another.

The 3 main areas of difficulty, which all people with an ASC share, are difficulties with:

1. **social communication**

(e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice)

2. **social interaction**

(e.g. problems recognising and understanding other people's feelings and managing their own feelings)

3. **social imagination**

(e.g. problems understanding and predicting other people's intentions and behaviour and imagining situations outside of their own routine).

Many people with an ASC are particularly sensitive to, or lack sensitivity to things like:

- sounds
- touch
- tastes
- smells
- light, or
- colours.

This is called **sensory sensitivity**.

People with an ASC often prefer to have a fixed routine and may not like change.

Many people with an ASC may also have other conditions such as **attention deficit hyperactivity disorder (ADHD)** or **dyspraxia**.

Asperger syndrome is a type of ASC. People with Asperger syndrome have fewer problems with speaking than some other people with autism. They are also often of average or above average intelligence.

People with an ASC often have no obvious disability, so it can be hard to make other people aware of their condition. For this reason, many adults with an ASC find that they are misunderstood.

Some people do not want other people to know about their condition, but may still need a lot of support. This means that parents and other relatives often provide care and support which can cause stress for everyone.

Approach to the consultation

We have not recommended what changes we think should be made in this consultation booklet. This is because we want to find out first what adults with an ASC and people who work with and support them think.

This consultation will help us decide what we should recommend and what results we should concentrate on when we publish the final strategy later this year.

Statistics

We need to make sure that we consult the right people and have reliable evidence to support our recommendations and achieve the results we want.

Estimates of how many people have an ASC vary depending how the condition is diagnosed and defined. Earlier studies estimated around 5–10 people per 10,000 of the population have an ASC, but more recent reports estimate up to 116 per 10,000.

The Department of Health is working to understand these figures better.

It is important before we develop our final strategy to understand more about what has already worked in delivering change and how new ways of working have improved the lives of adults with an ASC.

We want to collect as much evidence as possible to help us develop our final strategy. This is why we want people to tell us about examples of good and bad practice and about their own local knowledge and experiences.

Impact assessments

As this consultation booklet does not make proposals or recommendations, we have not done an impact assessment of costs, risks and benefits. However, the final strategy will be accompanied by an impact assessment of these issues.

To help us develop the final strategy and to prepare an assessment of costs and benefits, we would like people who respond to the consultation to tell us about:

- examples of services that are already working well for them, and
- what the costs, benefits and risks have been for delivering these services in their local area.

Human rights

Equality and human rights are an important part of this project. People with an ASC have the same rights as everyone else.

As part of the consultation, we would also like people to think about and comment on our initial impact assessment on equality. You can find the assessment on our website at:

www.dh.gov.uk/en/Consultations/Liveconsultations/DH_098587

Question 3 asks you to tell us what you think the barriers might be to achieving equal access to services and good-quality outcomes for everyone with an ASC from the point of view of their:

- ethnicity
- gender
- disability
- age
- sexual orientation, and
- religion or belief.

Key themes

The next 5 chapters are about the 5 key themes already identified by the external reference group. There is a list of who was in this group on page 4.

Social inclusion

This chapter is about access to support, including social support, that adults with an ASC need to help them play as full a role as possible as included and active citizens. This includes housing needs and access to activities such as leisure, cultural activities, a social life and relationships. It also looks at making the environment more accessible to adults with an ASC.

(Employment is an important area of social inclusion. We look at this separately in the chapter called **Access to training and employment** (page 30).)

A vision for the future

All adults with an ASC will:

- be treated as equal citizens
- have the right support to help them meet their potential
- have access to a range of suitable support services that recognise that ASCs are complex conditions and encourage including people with an ASC in society
- have their social needs met through support to develop and maintain their family life and relationships
- be able to access meaningful activities during the day and evening. This could include employment or voluntary work, and non-work activities that are important to the person
- receive an ongoing person-centred approach to their needs, and
- have their range of needs, including physical, sensory, environmental and health needs, considered as they access support and the wider community.



All local authorities will:

- take a strategic approach to housing in their area
- assess and plan for the current and future housing needs of all local people, including vulnerable people such as those with an ASC
- work with partners to plan and commission relevant housing and related support needs, and
- make plans to meet the needs identified in their housing strategies.

Outcomes for adults with an ASC

We want to make sure that the changes made as a result of this consultation and our final strategy lead to the following results for adults with an ASC:

- **Improved quality of life**
This includes access to leisure, social activities and lifelong learning, and to public and commercial services. It also includes security at home, access to transport and feeling confident about their safety outside the home.
- **Making a positive contribution**
This includes taking an active part in community life.
- **Freedom from discrimination or harassment**
This means having equal access to services and not being picked on or abused.
- **Personal dignity**
This includes keeping clean and comfortable, enjoying a clean and orderly environment and access to the right sort of personal care.

Concerns raised by stakeholders

The people we have already spoken to have told us about the following 7 areas where people with an ASC are being socially included or excluded.

1 Local leadership

- In many areas there is no lead person or team responsible for making sure that assessments of need are done, or for developing services and support for people with an ASC and their families. This lack of leadership can mean that people with an ASC fall into the gap between mental health services and learning disability services. This is against government policy. This is a particular problem for people with high-functioning autism or Asperger syndrome.
- To solve this problem, it has been suggested that more local authorities could follow the Department of Health guidance that says that the Director of Adult Social Services should make sure that it is clear which of their teams or managers is responsible for assessing and meeting the needs of people with an ASC.
- Other suggestions include setting up a specialist ASC team in every local area, such as those set up in Liverpool, Oldham, Surrey and Northamptonshire.

GOOD PRACTICE EXAMPLE (LED BY THE PRIMARY CARE TRUST (PCT)):

Liverpool Asperger Team

The Liverpool Asperger Team is often used as an example of good practice. It is a multi-skilled team for adults with Asperger syndrome.

The team was set up in 2003 on the recommendation of a steering group which found that people with Asperger syndrome were most likely to be overlooked by some services.

The team is funded by the Central Liverpool PCT and the local authority. At the moment it has a team manager (who is also a head speech and language therapist), 2 community nurses, 2 clinical psychologists, an assistant psychologist, a social worker, 2 support workers, an assistant clinician and an administrator.

The team:

- has a person-centred approach
- provides assessment and diagnosis of Asperger syndrome
- gives direct support, and
- refers people on to other services.

The team works with other local services, including:

- schools and colleges
- mental health services, and
- specialist services, such as those for people involved in the criminal justice system and those receiving support from mental health or alcohol and substance misuse services.

The team also gives training and advice to professionals about Asperger syndrome. This includes regular awareness sessions, to help spread good practice across the local area.

GOOD PRACTICE EXAMPLE (LED BY THE LOCAL AUTHORITY): Oldham Metropolitan Borough Council

Oldham uses a range of different approaches to meet the needs of adults with an ASC.

Oldham is very committed to meeting the needs of people with ASCs. Veronica Jackson, Executive Director of People, Communities and Society in Oldham, chaired the Greater Manchester Autism Consortium. The group is now chaired by Oldham's Service Director for Adult Social Care, Paul Davies.

The Way Forward Group is made up of a range of agencies and services that concentrate on developing and maintaining services for children and adults with an ASC. The group includes employment, housing and education services and families affected by ASCs.

The group supports the Consortium. It has helped to bring about a range of new ideas to support people with an ASC, including:

- appointing a manager responsible for developing and providing services for ASCs, and
- creating a Vulnerable Adults Service, which works with people eligible for support following a Fair Access to Care Services (FACS) assessment but who are not the responsibility of other local authority teams. A lot of the people it supports have Asperger syndrome or high-functioning autism.

All Oldham's learning disability housing support, day service and respite provision is recognised by the National Autistic Society.

Oldham has also done a lot of work to develop a training strategy that provides

a range of levels from basic awareness to specialised training. This training is for people who provide direct support and carry out assessments of need, and also for other professionals such as police, housing providers and probation services.

Oldham is also testing a course on stress and anxiety for people with an ASC.

Oldham children's services have worked hard to make sure that there is enough support in ASC units in schools for before- and after-school clubs and activities for children with an ASC. This has led to developing training for people who work in leisure and youth services.

Oldham has also invested in services that help stop people with an ASC from suffering from deteriorating health or sense of well-being. This includes social groups. These low-cost services give people the social support they need, and have helped people to find jobs.

Oldham believes that transition is another important area to look at. It is developing a 'transition house', which helps people to move back into the area from which they came after they have been living in another area. This happens before they move to living more independently.

Oldham has also started a new transition project, called *Get a Life*, which includes people with autism and Asperger syndrome. This project makes sure that there are good transition and person-centred plans. A pilot project is working with a group of 30 young people who have a mixture of conditions from ASCs to learning disability, and mental health needs combined with drug or alcohol abuse. The pilot project should be completed and a new system put in place by March 2011.

2 Data collection and strategic planning

- There is a lack of understanding at local level about the needs of people with an ASC. This is a major problem.
- A report for the Government's Social Exclusion Task Force highlighted the lack of information about the number of adults with an ASC. The report stressed the important effect that lack of information has on policy and service design.

The report said that there is not enough information to make a reliable estimate of how many people there are in the UK with an ASC. This lack of information makes it very hard to estimate how many people are unable to play their part in society and how best to meet their needs.

- The report was backed up by evidence from the Commission for Social Care

GOOD PRACTICE EXAMPLE: Data collection and local assessment of need in Lewisham

Local and national campaigning, and Lewisham's adult social care modernisation programme, led Lewisham to carry out a detailed analysis of the needs of people with an ASC.

They looked particularly at people with high-functioning autism and Asperger syndrome who may fall between learning disability and mental health services.

Lewisham used a number of different ways to collect statistics and opinions, using different methods tailored to each person.

They collected figures (quantitative data) from public bodies and voluntary partners and compared them with the national estimate to work out the number of people with an ASC in their local area. They also used the figures to work out how many adults with high-functioning autism there would be in the future. They used the figures along with what people told them (qualitative data) to predict what services they would need in the future and to help them understand the kind of support resources they would need to provide.

Face-to-face interviews with learning disability services, mental health teams and the

voluntary sector showed that there was a need to make it easier to get a diagnosis of ASC, and to get information and assessment for social care services.

Lewisham found that in their area 58% of people with an ASC were of non-white ethnic origin, and that most were male between the ages of 25 and 35. This information has helped them to plan services that meet needs better.

The research looked at the local social and economic effects on this group of people. A specialist interviewer encouraged people to speak freely on a range of topics appropriate to them. They were then able to identify key needs, including:

- practical life skills
- social and emotional skills
- education and employment
- housing, and
- support for family and carers.

Lewisham's final report will be made public before summer 2009.

This analysis will feed into the Joint Strategic Needs Assessments (JSNA), the development of transition services, and other commissioning strategies such as Supporting People – a government housing scheme.

Inspection (CSCI) self-assessment survey of local authorities, which showed that most local authorities:

- do not know how many adults with an ASC there are in their area, and
- do not include adults with an ASC in their JSNA.

This means that the needs of adults with an ASC are not being considered when planning and commissioning local services.

GOOD PRACTICE EXAMPLE: Regional strategic planning in Greater Manchester and the North East

Regional autism groups have been set up in both Greater Manchester and North East England. In both areas, local authorities come together to share their knowledge of what works strategically in ASC services, and to support each other in developing services.

Greater Manchester Autism Consortium

The Greater Manchester Autism Consortium has been running for over 10 years.

Every local authority in the group has set up an Autism Services Development Group. The group has representatives from all public agencies, parents and carers, and, in some cases, adults with an ASC.

The chair of each group is on the consortium steering group.

The groups look at what the local area can achieve by improving current services

using existing resources, and by better commissioning.

The consortium also funds the National Autistic Society's Family Services Development Project, which gives information, advice and support to families across Greater Manchester.

Data from this project is then fed back to help improve commissioning services.

North East Autism Consortium

The North East Autism Consortium was set up in 2006 to develop a regional approach to the planning needs and service needs of people with an ASC.

It is working towards developing a regional commissioning strategy. It is also looking at the lack of integrated services in health and social care.

Four ASC services development groups have been set up in the region to share good practice and development.

3 Community care and support

- Evidence from the CSCI review of who is eligible for social care showed that adults with an ASC are at risk of not being able to get community care because their needs are not always properly understood.
- Community care assessors and FACS assessors often do not have training in, or a proper understanding of, ASCs, so adults with an ASC are not properly supported to communicate their needs.

It has been suggested that assessors should be:

- trained, and
- supported in the assessment by people with expertise (such as a third sector organisation), if they have not finished their training.
- In many areas there is not enough support for adults with an ASC. This includes:
 - social skills training
 - social groups
 - independent living skills training, and
 - befriending.

We have been told that these types of services, which can make a big difference, are not available for many people.

- It was also suggested that key workers could be available to support adults with an ASC to find and use the services they need.

4 Housing

- Many adults with an ASC rely on their families and continue to live in the family home because they cannot get the support they need to live independently.

- It has been suggested that this is because:
 - many local authorities do not consider the needs of adults with an ASC in their housing plans
 - the specific support that adults with an ASC need is not always understood or available, and
 - the design of housing can be unsuitable for adults with an ASC (e.g. poor soundproofing may cause stress to people with sensory sensitivities).

5 Transport

- Transport is often not very accessible to people with sensory sensitivities or who find it difficult to manage in crowds.
- It has been suggested that more needs to be done to make sure that local transport plans include the needs of adults with an ASC.
- Training people with an ASC to use public transport with confidence could make a big difference.

6 Physical and sensory issues

- Some public spaces can be inaccessible for adults with an ASC. This is mainly due to sensory issues, but is also due to a lack of support workers to help adults with an ASC find their way around new places.

7 Other

- Some people have told us that they are worried that not enough will be done to make sure that change really will happen when carrying out our strategy.

GOOD PRACTICE EXAMPLE:

Social groups in Newham

There are a number of social groups across the country. These can be a great help to adults with an ASC and can help reduce **social exclusion**.

The Newham Asperger Service runs 2 social groups.

One is a monthly daytime outing chosen by the service users. The other is a monthly social group to support people to attend the DANDA (Developmental Adult Neuro-Diversity Association) evening.

The aim of these groups is to give adults with Asperger syndrome or high-functioning autism the chance to meet other people, develop friendships and share experiences and advice.

The groups also aim to reduce isolation and build people's confidence in accessing community activities.

The Newham Asperger Service has also arranged training sessions on subjects such as keeping safe in the community and coping with anger.

Health

This chapter looks at specialist healthcare for adults with an ASC, including multi-disciplinary assessments and diagnosis, and support after diagnosis. It also looks at access to general healthcare and to mental health care where appropriate.

A vision for the future

- All adults with an ASC will be able to access an assessment based on their needs and skills, including diagnosis, from qualified local professionals. These professionals will be part of a multi-agency team, which works together with other services.
- The assessment will be part of an ongoing package of care specially designed for each person.
- Support for adults with an ASC and their families will be widely available after diagnosis.
- All adults with an ASC will get the health services and support they need from a healthcare system that makes reasonable adjustments and has a good understanding of ASCs. Services will also understand the sensory issues and other conditions that affect people with an ASC.

Outcomes for adults with an ASC

We want to make sure that the changes made as a result of this consultation and final strategy lead to the following results for adults with an ASC:

- **Improved health**
This includes having good physical and mental health (including being protected from abuse and exploitation).
- **Freedom from discrimination or harassment**
This means having equal access to services and not being picked on or abused.



GOOD PRACTICE EXAMPLE: Integrating diagnosis with other services and support in Northamptonshire

The Transition and Liaison Team (TLT) in Northamptonshire gives diagnosis and short-term support services after diagnosis to adults with Asperger syndrome (and other conditions, such as attention deficit hyperactivity disorder and Tourette's syndrome).

It also supports people who have already had a diagnosis, especially during the transition from adolescence to adulthood.

Northamptonshire Healthcare NHS Trust has modernised its services, which has helped the TLT to reduce health inequalities. They have done this by providing services that respond to need and focus on the skills of key professionals to reach people and groups that access services late or not at all.

The team receives referrals and works with a wide range of other services and agencies. These include:

- learning disability
- mental health (including inpatient services)
- accommodation and commissioning
- social care and health

- employment
- Connexions and further education services, and
- voluntary sector organisations.

The service concentrates on:

- ways to reduce social isolation and mental health difficulties
- developing independent living skills and relationships
- a range of suitable supported housing options
- better social and academic support and learning opportunities during transition and in continued education
- carers' needs
- improving employment opportunities and support
- better access to services for people who have been in contact with the criminal justice system, and
- better emotional support.

The TLT has involved service users throughout its development, and is using a local training and awareness programme to look at unmet needs. This will help early detection, intervention and treatment of ASCs.

Concerns raised by stakeholders

The people we have already spoken to have told us we need to consider the following 5 areas of healthcare.

1 Diagnosis and support after diagnosis

- There is a lack of NHS services in England that can offer diagnosis of ASCs, particularly for adults.
- Some GPs are not able to identify ASCs in order to refer people on for diagnosis.
- There are worries about the ability of adult mental health professionals to recognise ASCs. In some cases assessments may only be made where there is also a clear psychiatric problem.
- There is not a clear pathway to diagnosis in adults.
- Diagnosis is often isolated from other services. It should be integrated.
- People who cannot get a diagnosis often find it hard to get the support they need.

- There is not enough counselling or information to support the person and their family.

2 Data collection and strategic planning

- There is not enough information at PCT and local authority level about the number of adults with an ASC and their support needs. This makes it difficult to plan and commission services.
- There is a lack of clear systems in many areas for sharing information between services. This means that details about a person's diagnosis and needs can be lost if they move or transfer between services. This is a particular problem when someone moves from children's to adult services.
- It has been suggested that clearer guidance for health and local authority commissioners on commissioning ASC services could help.

GOOD PRACTICE EXAMPLE:

Accessible healthcare

Making reasonable adjustments to healthcare services can be very easy.

A mother of 2 sons, both of whom have an ASC, tells us that her GP is the only person who gives them support.

She told us that her GP knows that both her sons function better in the afternoon so they always have afternoon appointments. If possible, they have the last appointment of the day. This means that the GP can spend longer with her sons if he needs to. It is also quieter.

The GP lets the elder son, who is 21, read books about his treatment. He also lets the son read his medical notes on the screen to

make sure he is happy with what has been written about him.

The GP knows that the elder son would rather see some doctors than others, and this is not a problem.

If there are no appointments available the mother can ask the receptionist to fit them in anyway and they always get to see someone within 24 hours. This arrangement works for all the practice services. Although the asthma clinic is in the morning, it will arrange to see the sons in the afternoon.

The mother says: "I have no doubt that we would sink were it not for the understanding and adjustments made by our GP and his practice. A little understanding really can go a very long way."

3 Accessible healthcare

- Reasonable adjustments in healthcare are not always made for adults with an ASC. For instance, some people need longer appointments to build a good relationship with their GP, or easy ways to book an appointment. It has been suggested that this is partly because there is a lack of training and awareness about ASCs in the healthcare system.
- There is a lack of understanding of the other health conditions that many people with an ASC have. There is also a lack of understanding of the sensory difficulties that many people with an ASC have.
- Other health problems in adults with an ASC may not be recognised.
- It has been suggested that PCTs and NHS trusts could do more to make sure that the needs of adults with an ASC are considered when planning equality schemes and new services.
- It has also been suggested that annual health checks could be helpful for adults with an ASC.

4 Mental health

- People have told us about cases of wrong diagnosis of mental health issues and about inappropriate treatments.
- Help with things such as social skills training could reduce the risk of adults with an ASC becoming socially isolated. It could also help with their mental health.
- There are not enough specialist adult ASC services to look after difficult cases – including services for people who have come into contact with the criminal justice system.
- There is a need for specialist services to be better co-ordinated with other commissioners and service providers.

5 Other

- Continuing care assessors (the people who decide whether someone can have their care paid for by the NHS) do not usually know enough about ASCs.
- There is not enough research and evidence in some areas about what works for adults with an ASC.
- There needs to be more checking of existing ASC services to make sure that they work well.

Choice and control

This chapter covers person-centred planning, advocacy, transition planning and involving people in developing services.

A vision for the future

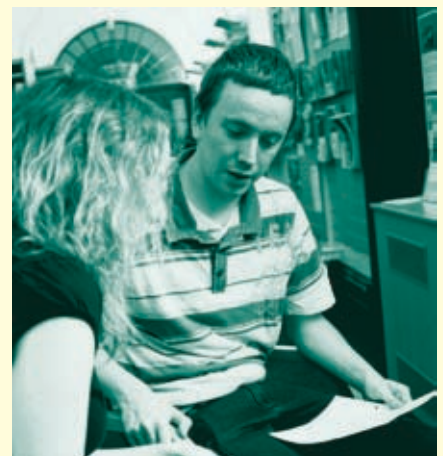
Adults with an ASC will get the support they need to:

- take control of their own lives
- take part as much as they can in society, and
- have the lifestyle and relationships they choose.

Adults with support needs will have a person-centred plan which is regularly reviewed to help them to meet their personal goals and objectives.

Having choice and control also means:

- making personal or individual budgets accessible to adults with an ASC
- making sure that all young people with an ASC have a proper ongoing transition plan
- supporting adults with an ASC to communicate effectively
- providing advocacy for people who need it, and
- making sure that adults with an ASC, their families and user-led organisations play a central role in developing relevant policy and local services.



Outcomes for adults with an ASC

We want to make sure that the changes made as a result of this consultation and final strategy have the following results for adults with an ASC:

- **Exercise of choice and control**
This means having maximum independence and access to information. It also means being able to choose and control services, as well as manage risk in personal life.
- **Making a positive contribution**
This includes being involved in local activities and in developing policy and making decisions.
- **Freedom from discrimination or harassment**
This means having equal access to services and not being picked on or abused.

Concerns raised by stakeholders

The people we have already spoken to have told us we need to consider the following 4 areas to achieve real choice and control for people with an ASC.

- 1 **Making personalisation work for adults with an ASC**
 - Having a personal plan is very important to make sure that people with an ASC have choice and control over their own lives. However, adults with an ASC often do not have support plans that consider all their needs. People want support to develop and maintain person-centred plans that identify the support they need to give them choice and control.

GOOD PRACTICE EXAMPLE:

Person-centred planning

Lisa has an ASC. Until recently, she lived in a residential house for 6 adults with an ASC. She had lived in the house for 12 years and regularly used the service day provision in the same road.

However, her behaviour in the house became worse and extra staff were needed to support her 'challenging' behaviour. At first it was thought that her sponsoring authority should take her back into their area, even though she had said she wanted to stay in the town where she lived now and which she knew well.

Then Lisa herself led a series of meetings with a person-centred planning facilitator. She was able to communicate where and how she wanted to live, and a plan for the support that she would need was developed. She moved into her own rented house and now has one-to-one support at all times. She also played an important part in choosing the staff that support her.

Since then there have been no problems and her stress and anxiety levels have got much better. She is clearly a different and happier person.

- Assessment for personal budgets can be too inflexible to meet the needs of adults with an ASC. So people may get a personal budget that is not enough to buy the right services to meet their individual needs.
- Adults with an ASC want brokerage services. These are services which help people decide which services they should buy. They also want advice on using personal budgets. These needs should be considered when working out individual or personal budgets.
- People with an ASC have also said that they need more support centrally and locally to help them communicate in the way they want to. This includes having access to alternative and augmentative communication devices, which they can use instead of speech or to supplement it.
- Adults with an ASC need more support to develop and maintain personal relationships.

2 Transition

- There are major problems with transition from children's to adult services. How transition happens varies in different areas and there is a need for more person-centred planning. Also, the transition process is often last-minute, leaving little time for people with an ASC and their families to think about their choices. Transition planning needs to start when a person with an ASC is 14 years old.

- Young people who do not have a statement of special educational needs can also miss out on transition planning.
- For a successful transition, children's and adult services need to share information well.
- People want transition planning to identify future need in all areas, including work, education, social care, health and housing.

3 Advocacy

- Many adults with an ASC need advocacy to help them have meaningful communication with other people. Adults with an ASC can find it difficult to get the right sort of advocacy to have their say.
- There is also not enough skills training in self-advocacy for adults with an ASC.
- It has been suggested that there could be an advocacy service in every local authority which is able to support adults with an ASC in the right way, and to train them as self-advocates.
- There is a need for better information for adults with an ASC to help them make decisions.

4 Involvement in making policy and planning services

- It has been suggested that local and national forums should be set up so that adults with an ASC and their families could become involved in consultations on policies that affect them.
- Local projects such as Local Involvement Networks (LINKs) could involve people with an ASC more.
- Consultation documents and other information about local services should be in accessible formats.

GOOD PRACTICE EXAMPLE:

Involving people

The National Autistic Society is setting up 'consultative groups' throughout the UK. One has already been set up in the south of England and has met 3 times. Groups are also being set up in the north of England, Scotland and Wales. All groups will meet 3 to 4 times a year.

The groups will help the National Autistic Society to respond to consultations about government policies which affect people with an ASC.

Members of all the groups have quite complex needs and most of them will attend the meetings with their support worker.

The meetings are carefully designed to make sure that everyone can take part. Papers in easy read format are sent to the members with a clear agenda before the meetings. Members can then discuss the information with their support worker before the meeting.

The meetings are held in ASC-friendly places and there are rooms where people can go if they need to take a break.

Members of the group and their support workers say that group members:

- enjoy the meetings
- like the flexibility of the meetings because they are encouraged to speak to the group themselves but can ask their support worker to speak for them if they prefer
- respond well to having the questions in an easy read format and working through them with their support worker before saying what they think at the meetings
- respond well to using visual aids to answer questions and to encourage discussion (e.g. symbols and photographs), and
- like having the chance to stay the night before. This means they do not have to worry about getting to the meeting early in the morning. It also gives them the chance to socialise with other members in a friendly setting.

One of the groups was filmed as part of a new guide on how to include people with an ASC in consultation events and focus groups.

Awareness raising and training

This chapter looks at projects to raise public awareness and workforce issues, including training. Each of the 5 key themes has shown up a lack of awareness of ASCs and a lack of training in ASCs among people who work with people with an ASC. This chapter looks in more detail at what training is needed.

A vision for the future

- There will be good awareness and understanding of ASCs.
- The contribution that adults with an ASC can make to society will be recognised.
- People working in health, social care, employment, criminal justice and other areas will have the right training or awareness to be able to understand the range of ASCs.
- People working in these services will have the skills to respond in the right way to the needs of adults with an ASC and their families.
- The vulnerability of some adults with an ASC will be recognised, particularly by people responsible for preventing abuse, and in the criminal justice system.
- Training will support best practice. Training will also be of high quality, and checked to make sure it is effective.



Outcomes for adults with an ASC

We want to make sure that the changes made as a result of this strategy lead to greater awareness of ASCs among the general public and at work. This will help achieve the following results for adults with an ASC:

- **Improved health**
This includes having good physical and mental health (including being protected from abuse and exploitation).
- **Improved quality of life**
This includes access to leisure, social activities and lifelong learning, and to public and commercial services. It also includes security at home, access to transport and feeling confident about their safety outside the home.
- **Making a positive contribution**
This includes taking an active part in community life.
- **Exercise of choice and control**
This means having maximum independence and access to information. It also means being able to choose and control services, as well as manage risk in personal life.
- **Freedom from discrimination or harassment**
This means having equal access to services and not being picked on or abused.
- **Economic well-being**
This includes having enough money and resources to meet the costs of a person's specific needs.
- **Personal dignity**
This includes keeping clean and comfortable, enjoying a clean and orderly environment and access to the right sort of personal care.

GOOD PRACTICE EXAMPLE: Autism Anglia's ASC alert card

The ASC alert card was introduced in October 2007. It is supported by Essex Police and Suffolk and Norfolk Constabularies.

The card is the size of a credit card and has the card holder's name and space on the back for the details of 2 people to contact in an emergency. The card says that the holder has autism or Asperger syndrome.

Autism Anglia has trained the police on autism and Asperger syndrome and has also begun training Essex County Fire and Rescue Service.

Autism Anglia has had good feedback from parents of card holders. One person told us that her son got upset and confused at a music gig. His friend took him to the front and showed the organiser the card and they helped him out.

Cambridgeshire, Hertfordshire and Bedfordshire police forces have now asked Autism Anglia to issue a version of the alert card for their areas.

Concerns raised by stakeholders

The people we have already spoken to have told us we need to consider the following 5 areas where adults with an ASC are affected by a lack of awareness and understanding of their condition.

1 Awareness of ASCs

- Not many people recognise or understand ASCs or how they can affect people's behaviour. This leads to intolerance, discrimination and isolation.
- In a survey by the National Autistic Society, 83% of people with Asperger syndrome felt strongly that many of their problems were due to other people not understanding them.
- It has been suggested that adults with an ASC and their families should help develop national projects and awareness campaigns. The campaigns should show positive images of adults with an ASC. Local awareness campaigns and events could also be helpful.
- Awareness campaigns could be aimed at different groups, including the general population, employers, the criminal justice system, people working in public transport, and leisure services.

2 Training

- A number of key groups need better training in ASCs. They include people working in healthcare, social care, employment support (e.g. disability employment advisors), housing, criminal justice, adult education and benefits.
- Different levels of training are needed for different people. Training will depend on a person's level of responsibility, their role and how much they are likely to be involved with adults with an ASC.

- It has been suggested that adults with an ASC and their families should be involved in the design and delivery of training.
- Some local authorities have developed ways to spread awareness training across the public sector in their local area – see the 'Good practice example' box below.

3 Social care

- There can be a low level of knowledge and understanding of ASCs among social workers. It has been suggested that ASCs should be included in undergraduate and postgraduate training programmes for social workers.
- People who do assessments, including FACS and NHS continuing care, do not always get training in ASCs.
- Personal assistants have training needs that are not always met.

GOOD PRACTICE EXAMPLE:

Awareness training in Surrey

The County Autism Group and the person in charge of services for people with autism have developed a network of 80 ASC champions across all services in Surrey. These champions have 6 months' training and advice from a mentor before they help share their training with their team. Champions get support to meet one another and share good practice across services.

Assessment of this process showed that it had led to positive results for people with an ASC.

The team have also supported Surrey County Council and Surrey and Borders Partnership NHS Foundation Trust to develop ASC training, with different levels of training for staff in different services.

- It has been suggested that the new training in ASCs which is being developed by Skills for Care could be used as part of the introductory training for staff working with people with an ASC.
- We need to make sure that anybody who delivers local services especially for people with an ASC, such as social skills training, can get the right training to help them deliver their service well.

4 Healthcare

- There is low awareness of ASCs among mental health professionals. This can lead to the wrong diagnosis or treatment.
- More needs to be done to make sure that ASCs are included in undergraduate and postgraduate medical training.
- It has also been suggested that non-medical staff in healthcare should have some awareness training in ASCs.

5 Other

- Training is needed for people who support people with an ASC to find and keep a job (e.g. disability employment advisors).
- There is also a need to train benefits advisors, work capability assessors, disability support officers in further and higher education, and people in the criminal justice system.

Access to training and employment

This chapter looks at employment support, including both support to get a job (paid or unpaid) and support in the workplace. It covers raising awareness of ASCs among employers and employees, and access to adult education and skills. It also looks at access to benefits.

A vision for the future

- All adults with an ASC will have the chance to have work that suits their skills and interests.
- All adults with an ASC will have access to the right level of support to meet their needs at work.
- There will be skills and education courses that match the needs of adults with an ASC preparing for work, and to develop their skills when they have a job. This will mean that they can progress and have the chance to achieve their full potential.
- The benefits and tax credit systems will support people while they look for work. They will also recognise the additional costs for people with an ASC.
- Further, higher and lifelong learning will be accessible to adults with an ASC.

Outcomes for adults with an ASC

We want to make sure that the changes made as a result of this consultation and final strategy lead to the following results for adults with an ASC:

- **Economic well-being**
This includes having enough money and resources to meet the costs of a person's specific needs.



- **Making a positive contribution**

This includes taking an active part in the community through paid work or voluntary work.

Concerns raised by stakeholders

The people we have already spoken to have told us we need to consider the following 4 areas which affect adults with an ASC who are trying to find a job and which affect their experiences at work.

1 Work

- Only 15% of adults with an ASC have full-time jobs.
- Some adults with an ASC have difficulties accessing the support and funding they need to find and keep a job.
- Jobcentre Plus staff (including disability employment advisors) do not always know how to meet the needs of adults with an ASC.
- The organisations that support people with an ASC to look for work should be paid for helping people to improve their skills, and not just when the person gets a job.
- It has been suggested that more specialist services are needed for adults with an ASC as they look for paid or voluntary work, including social skills training.
- There is a need to develop more voluntary work for adults with an ASC.
- Other suggestions include providing advice for employment advisors who support adults who have had an ASC diagnosis while at work.



GOOD PRACTICE EXAMPLE:

From voluntary work to paid employment

David has an ASC. He went on the National Autistic Society's employment service (Prospects) Brighter Horizons course. The course is designed to develop skills for work and to support people to find and do a long-term voluntary job in order to improve their job skills.

David went to group workshops once a week on subjects such as:

- coping at work
- facing the future
- relationships at work, and
- healthy living.

He also had one-to-one sessions every week to help him in areas where he felt he needed to improve. For example, David has always struggled to make friends. He finds it very hard to start and end conversations, or to know what to say when he first meets someone.

He spent a lot of time on conversation skills and how to interpret body language. He learnt about suitable and unsuitable topics of conversation at work and began to look for a voluntary job.

David was keen to work in a supermarket and his employment support worker found him a job as a grocery assistant at a local store for 8 weeks. The work involved filling the shelves, collecting stock from the warehouse and helping customers with their shopping. He worked 3 days a week for 5 hours a day.

David's employment support worker visited him weekly to discuss how everything was going and to talk about any problems. He also met with David's boss to talk about any issues that had come up. David's colleagues were very helpful and friendly, and he got very positive feedback on the work he was doing.

As David got more confident, he made it clear that he enjoyed his new job very much. He said that he liked working in the supermarket because he liked being busy and it gave him a sense of responsibility.

On his last day, David's employment support worker met with David's boss. The boss said that David had worked harder than most of the full-time staff. He said that he would like David to join as a paid member of staff when a job came up.

2 Employers

- Employers can have a low awareness of ASCs, which means that they fail to make reasonable adjustments to the workplace and to their recruitment processes. This can lead to discrimination.
- It has been suggested that employers may need to ask for advice about how to make reasonable adjustments for people with an ASC.
- It has also been suggested that things could be improved if the Department for Work and Pensions (DWP) worked to raise awareness of ASCs. This could include awarding a mark of approval (a sort of kite mark) to good employers of people with an ASC to recognise their achievements.
- Some employers support people with an ASC well using buddying schemes or ASC 'passports', which record a person's access needs.

GOOD PRACTICE EXAMPLE:

Goldman Sachs' mentoring scheme

The company Goldman Sachs has been involved with the National Autistic Society's Prospects service for 6 years. It has given work experience to 23 people during this time.

Nearly everyone who has had work experience has gone on to a full-time job after leaving Goldman Sachs. Five people have also stayed with the company as full-time permanent staff.

Part of the secret of the success of the programme has been the use of mentors or buddies who sit with the person to encourage and support them, be their friend and help them to become part of the team.

Often the person on work experience does not need a lot of support, but the mentoring scheme means that they have someone to talk to if they need to, about things like how people usually behave at work, or if they need some extra support.

3 Benefits and tax credits

- It is difficult for many people with an ASC to access and understand the benefits and tax credits that they can get.
- People have told us that DWP and HM Revenue and Customs could make sure that all information about benefits, tax credits and pensions is available in accessible formats (including plain English and easy read).
- It has been suggested that it would be helpful to have an awareness campaign aimed at adults with an ASC about the benefits they can get.

- It has also been suggested that DWP should check the decisions made about applications for benefits from people with an ASC. They should look at sample cases to make sure that the right decisions are being made, and to identify any gaps in the knowledge of the people who make the decisions.
- Training for people involved in the benefits system in the support needs of people with an ASC is also important.

4 Education and training

- There is not enough support for adults with an ASC to help them access education and training. It is important to help people to develop the skills they need for work during the transition to becoming an adult.
- It has been suggested that transition planning could include agreeing with the young person what they want to achieve in education and work, and making a plan on how achieve this.
- It has also been suggested that local authorities should make sure that Connexions makes reasonable adjustments for people with an ASC, including adjustments for sensory issues.
- Other suggestions include the Department for Children, Schools and Families making sure that all children with an ASC have the chance to do work experience, and for the Department for Innovation, Universities and Skills to make it clear that Disabled Students' Allowances can be used for social support as well as for academic support.

Consultation questions*

1a. The following themes have been identified as areas where action needs to be taken to improve the lives of adults with an ASC:

- social inclusion
- health
- choice and control
- professional training
- employment

Are there other themes that need to be included?
Yes/No/Unsure

1b. If yes, please tell us what they are.

1c. If yes, are your suggested themes more or less important than the five key themes in improving the lives of adults with an ASC?

- more important
- less important
- of equal importance

* If you need more space for your answers please attach more pages.

3. In your experience, do ethnicity, gender, disability, age, sexual orientation and religion or belief have an impact on how adults with an ASC access and experience services and the quality of outcomes? Please highlight any measures we can take to reduce adverse impact and promote positive impact.

You can email us at autism@dh.gsi.gov.uk to share your examples of good practice or to tell us more about the impact and benefits of providing services in certain ways.

Social inclusion

The social inclusion chapter looks at the problems adults with an ASC can face when trying to access the support they need to live more independent lives and access the community in which they live.

Stakeholders identified the following as key areas where action is needed to improve social inclusion:

- strengthening local leadership to help overcome the problem of adults with an ASC falling into the gap between learning disability and mental health
- improving data collection and the way local authorities plan and commission services to ensure that the needs of adults with an ASC are taken into account
- improving access to community care and ASC-specific support for adults with an ASC, and
- improving access to housing, transport and public spaces for adults with an ASC.

4a. Do you agree that these are key areas where action is needed to improve social inclusion for people with an ASC?

Yes/No/Unsure

4b. Please explain your answer.

Health

The health chapter looks at the challenges faced by adults with an ASC as they try to access diagnosis and post-diagnostic support. It also looks at accessing general and specialist healthcare services (including mental health).

Stakeholders identified the following as key areas where action is needed in relation to healthcare services:

- improving access to diagnosis and post-diagnostic support (e.g. through changes to local or regional structures)
- improving data collection and the way in which health authorities plan and commission diagnostic and specialist health services for adults with an ASC
- making healthcare settings such as GP surgeries more accessible for adults with an ASC, and
- improving the understanding of ASCs among mental health professionals and developing interventions to reduce the risk of people with an ASC developing additional mental health problems.

8a. Do you agree that these are key areas where action is needed?

Yes/No/Unsure

8b. Please explain your answer.

Choice and control

The choice and control chapter looks at the barriers that prevent adults with an ASC from having choices and taking control of their lives.

Stakeholders identified the following as key areas where action is needed to ensure that adults with an ASC have more choice and control over their lives:

- ensuring that personalisation (including access to person-centred plans and to personal/individual budgets) is made to work for people with an ASC
- improving transition planning
- improving access to advocates and self-advocacy support, and
- ensuring that adults with an ASC are better involved in service development and the development of policy that affects them, including making policy and consultation documents more accessible.

12a. Do you agree that these are key areas where action is needed?
Yes/No/Unsure

12b. Please explain your answer.

13. Please provide details of your experiences of the challenges faced by adults with an ASC as they try to make choices and take control of their lives.

A series of horizontal lines provided for writing an answer to the question above.

14. What actions do you think should be taken to address the concerns raised in the choice and control chapter (e.g. ensuring that person-centred plans are more widely available, development of brokerage, advice and advocacy services, including people with an ASC in the development of individual/personal budgets)?

15. If possible, please give examples where these concerns have been successfully addressed at a local level.

About your response

Are these comments from:

- one person
- a group of people

If in a group, how many people were involved in producing this response?

Are you/the group of people (please only mark one):

- a person/people with an ASC
- family carers
- professionals involved with people with an ASC
- other – please say what: _____

If you are a professional involved with people with an ASC, in which area do you work?

- health
- social care
- employment
- housing
- transport
- education
- other – please say what: _____

If the comments are from a group of people, and the group is mixed, please tell us here how many people from each of the types of people listed above were involved in producing the response:

What is your ethnic group?

Choose one section from A to E, then tick the appropriate box to indicate your cultural background.

A White

- British
- Irish
- any other white background, please specify: _____

B Mixed

- white and black Caribbean
- white and black African
- white and Asian
- any other mixed background, please specify: _____

C Asian or Asian British

- Indian
- Pakistani
- Bangladeshi
- any other Asian background, please specify: _____

D Black or black British

- Caribbean
- African
- any other black background, please specify: _____

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:

The consultation process

Timings

The consultation runs for 20 weeks from 29 April 2009 to 15 September 2009.

Process

Please answer the questions and send them before **15 September** 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 ASCs and for people with an ASC and their families around the country.

There is also a toolkit to support local organisations and groups to run their own events.

You can find out more about events and information on our website:

www.dh.gov.uk/en/Consultations/Liveconsultations/index.htm

You could also ask your local authority or local ASC organisation about events they may be holding in your area.

Remit

This consultation and the final strategy are for England only.

Services for adults with an ASC in Scotland, Wales and Northern Ireland are the responsibility of the administrations in these areas.

- The Welsh Assembly Government published its own Strategic Action Plan for Autistic Spectrum Disorders (ASD) in April 2008.
- An ASD Strategic Action Plan is being prepared for publication in Northern Ireland.
- The Scottish ASD Reference Group has published guidance for local agencies on commissioning services for people with autism.

Summary of consultation responses

A summary of the replies to this consultation will be made available before or at the same time as any further action, such as the development of statutory guidance. We will put it on our consultations website at: www.dh.gov.uk/en/Consultations/Responsestoconsultations/index.htm

Criteria for consultation

This consultation follows the Government's Code of Practice on Consultation.

We aim to:

- consult people when there is still time for them to influence policy
- consult for at least 12 weeks, or for longer if it is possible and sensible
- be clear about:
 - what we want the consultation to do
 - how much influence people will have
 - what the costs are likely to be, and
 - what we think the benefits of the proposals will be
- make sure that the consultation is accessible to, and clearly aimed at, the people it is meant to reach
- only consult people when it is necessary so that they are happy to support the consultation
- analyse carefully what people say and give clear feedback to them after the consultation, and
- make sure that the people who run consultations have good training in how to run a consultation and share what they learn from the experience.

The full Code of Practice on Consultation is on the Better Regulation website at: www.berr.gov.uk/whatwedo/bre/consultation-guidance/page44420.html

Comments on the consultation process itself

If you want to comment on 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 your answers to the consultation to this address.

Confidentiality of information

We manage the information you give us in your answers to this consultation in line with the Department of Health's Information Charter.

We may share or publish information you give us, including personal information, according to the access to information laws – especially the Freedom of Information Act 2000 (FOIA), the Data Protection Act 1998 (DPA) and the Environmental Information Regulations 2004.

Under the FOIA, there is a code of practice which public authorities must obey. If you want us to treat the information that you give us in confidence, it would be helpful if you could explain to us why you think the information you have given us should be confidential.

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

The Department of Health will use your personal data according to the DPA. This will usually mean that we will not share your personal data with other people or organisations.



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