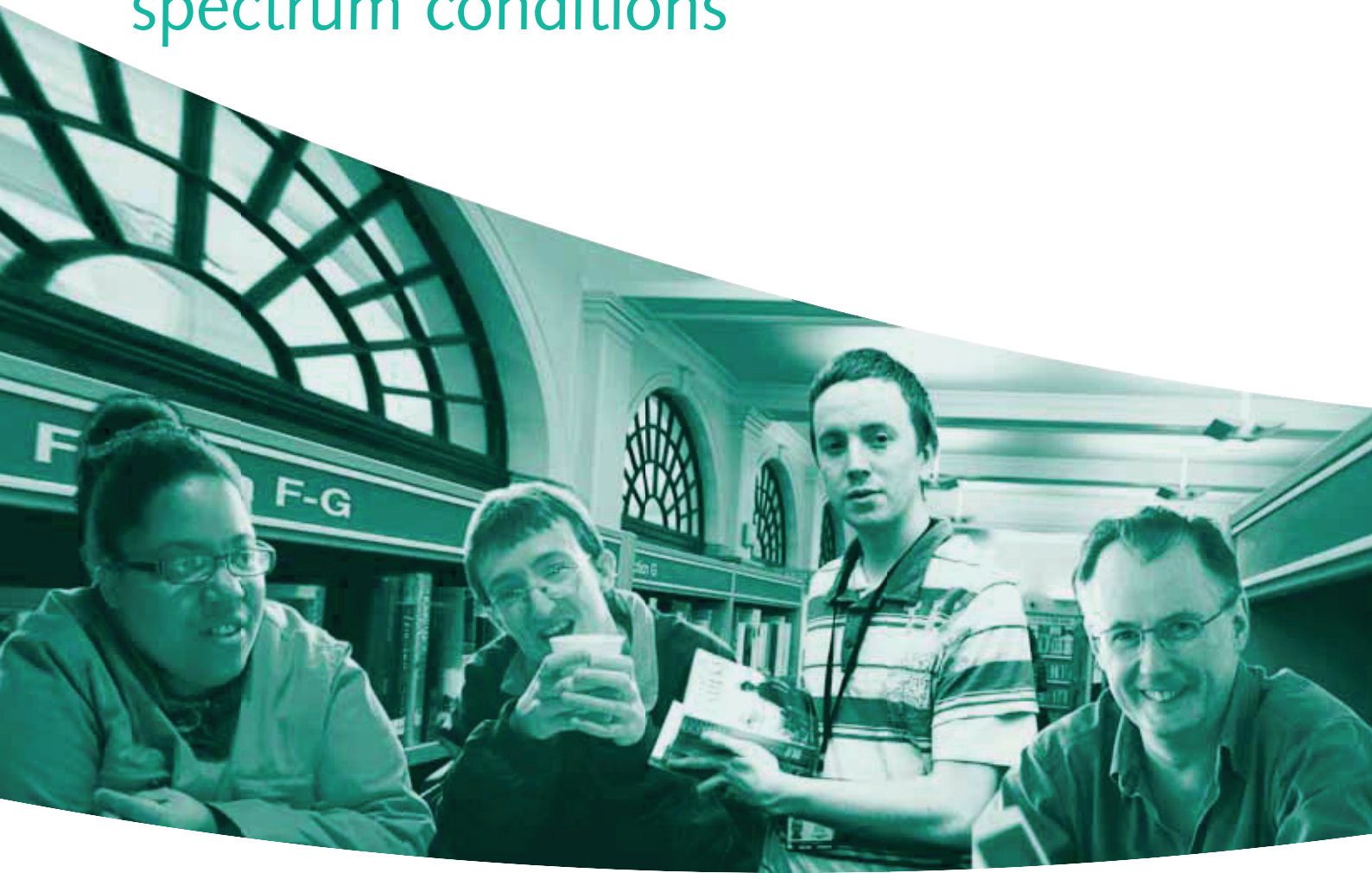


# A Better Future

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



**DH INFORMATION READER BOX**

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# A Better Future

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

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# Ministerial foreword

I am delighted to be launching this consultation process for the first government strategy to support adults with autistic spectrum conditions (ASC) to live life as full and equal citizens. I am grateful for the contribution that has been made by members of the external reference group chaired by Mark Lever, Chief Executive of the National Autistic Society, and including individuals with an ASC, parents and carers of adults with an ASC, representatives of organisations which support people with an ASC, health and social care professionals, employers and those with experience of supporting people with an ASC to find and keep a job, as well as education professionals.

This consultation is central to the overall programme of work that the Government is taking forward, and the development of the final strategy at the end of the year will pull together the range of outcomes that I have committed to delivering – better support for commissioners and other professionals working with, and supporting, adults with an ASC; research into prevalence and transition; and clear links with other areas of work across government that impact on adults with an ASC. I also remain committed to ensuring that the final strategy has the necessary power behind it to ensure change is delivered.

Adults with an ASC, and their families, face a great many barriers both in their everyday lives and in accessing the services and support that they need. Their condition is often overlooked or misunderstood by professionals and by society – we know that adults with an ASC can struggle to access health and social care services; we know that very few adults with an ASC are successfully employed in long-term, meaningful jobs; we know that adults with an ASC find it difficult to access community services such as transport and housing; we know that this and many other things must change for adults with an ASC.

I have seen and heard of many examples where adults with an ASC are failing to get the right support. However, I have also seen and heard of examples where, with the right advice, support and engagement, there has been a complete transformation in a person's quality of life and well-being. Personalised 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. That is why this consultation is looking beyond health and social care to employment, education and social inclusion.

This consultation seeks to achieve a better understanding of what the challenges are and what can be done to make change happen.

We have deliberately structured the debate around five core themes to ensure we hear your views on specific outcomes about what needs to change and how. I want the adult ASC strategy to be a co-production between government and people whose lives are affected by ASCs, either professionally or personally, every day.

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

The purpose of this consultation document and the related consultation process is to seek views on what actions, in which areas, can deliver the greatest change for the largest number of adults with an ASC.

With input from an external reference group of people whose lives are affected by ASCs, either professionally or personally, we have identified five key themes for this consultation. The themes were chosen as representative of the main concerns that we hear from adults with an ASC and, as such, are the areas that we believe can deliver the greatest change. These are social inclusion, health, choice and control, awareness raising and training, and access to training and employment. However, we recognise that the themes do not cover all the issues, and want to take this opportunity to find out if the themes and what we say about them are the right ones to be the top priority for action.

Both the external reference group and the government departments involved in developing the strategy had ideas about what actions could make change happen. Some of those ideas are reflected in this document, but we want to hear the ideas of as many people as possible to help decide and inform the right approach for the final strategy. To help us understand how services can be delivered in the best possible way, we are also interested in what you can tell us about what has worked or not worked with services that you are involved with. We also want to know about the costs, benefits and risks involved in delivering the services that you are involved with.

# Terminology

In producing this consultation document we recognise that there are a number of terms that different individuals and groups prefer to use, including autistic spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity. This consultation document uses the term 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. The word 'spectrum' is used because the characteristics of the condition vary from one person to another.

The three main areas of difficulty, which all people with an ASC share, are known as the 'triad of impairments'. They are difficulties with:

- social communication (e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice)
- social interaction (e.g. problems in recognising and understanding other people's feelings and managing their own)
- social imagination (e.g. problems in understanding and predicting other people's intentions and behaviour and imagining situations outside of their own routine).

Many people with an ASC may experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours.

People with an ASC often prefer to have a fixed routine and can be averse to change. Many people with an ASC may also have a co-morbid condition such as attention deficit hyperactivity disorder (ADHD) or dyspraxia.

Asperger syndrome is a form of ASCs. People with Asperger syndrome have fewer problems with speaking than others on the autism spectrum and are often of average or above average intelligence.

It can be hard to create awareness of ASCs as people with the condition often have no obvious disability – many adults find that they are misunderstood. Some individuals will not want to have their condition recognised, but their need for support may be great. In such cases, parents and other relatives often provide the care and support needed and this can lead to further stresses within the home and for all concerned.

# Approach to the consultation

This consultation document deliberately does not set out recommendations about what needs to change and how those changes can be achieved. It does, however, seek to focus the debate on the types of outcomes that we aim to identify in the development of the final strategy for publication later this year.

Our aim is to consult openly and widely, deciding upon the recommendations and outcomes in the final strategy in co-production with adults with an ASC and all those involved in working with and supporting them.

One of the challenges for developing the final strategy is ensuring that we have the right evidence base to support the proposals and recommended outcomes. The existing estimates of the prevalence rate for ASCs vary dependent upon how it is diagnosed and defined. Earlier studies estimated prevalence to be around 5–10 per 10,000 of the general population<sup>1</sup>, but more recent reports<sup>2</sup> have estimated prevalence rates up to 116 per 10,000. The Department of Health recognises the need for a better understanding of prevalence and is commissioning work in this area.

In addition to understanding more about the number of people affected by ASCs, it is also important for the development of the final strategy to understand more about what type of approaches have been effective in delivering change and how new ways of working and local system reform have improved outcomes for adults with an ASC.

As part of the consultation process the Department of Health wants to gather as much evidence as possible to inform its thinking. In responding to the consultation, we would encourage people to contribute examples of and information about their local knowledge and experiences to help inform the debate.

As this consultation document does not set out proposals or recommendations, it is not accompanied by an impact assessment of costs, risks and benefits; the final strategy to be published at the end of the year will be accompanied by an impact assessment considering those issues. To help inform the final strategy and our assessment of costs and benefits, we are asking stakeholders to use this consultation process to share with us examples of current service delivery that is working well and what the costs, benefits and risks have been of taking that approach in your local area.

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1 Lotter V (1966). Epidemiology of autistic conditions in young children, I. Prevalence. *Social Psychiatry* 1: 124–37.

2 Baird G et al. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *The Lancet* 368 (9531): 210–15.

Finally, it is important to recognise that this programme of work is set within an equality and human rights approach – that people with an ASC have, and should be able to enjoy on an equal basis, the same rights as everyone else. The Department of Health also recognises the need to understand the impact of this work in relation to issues of equality and human rights.

To that end, as part of the consultation process, we would encourage people to consider, and comment on, the accompanying initial impact assessment on equality. We would welcome specific feedback on what the barriers might be to achieving equitable access to services and good quality outcomes for everyone with an ASC from the perspective of ethnicity, gender, disability, age, sexual orientation and religion or belief.

## Key themes

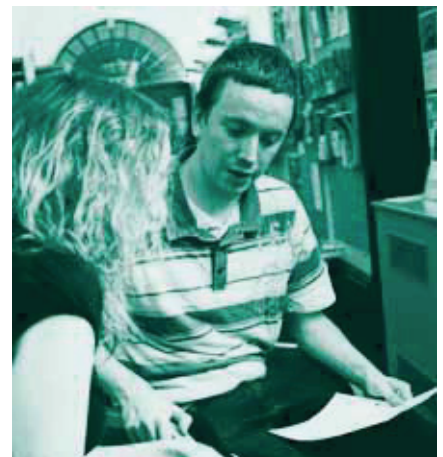
# Social inclusion

This chapter deals with access to appropriate support, including social support, that adults with an ASC need to enable them to play as full a role as possible as included and active citizens. This includes housing needs and access to meaningful activities, including leisure, cultural activities, a social life and relationships, as well as making the physical and sensory environment accessible to adults with an ASC.

Employment – a key aspect of social inclusion – is looked at separately in the access to training and employment chapter.

### A vision for the future

All adults with an ASC are treated as equal citizens and are fully and appropriately supported to fulfil their potential. They can access a range of appropriate and timely support, reflecting the complexity of ASCs, that promotes inclusion. Their social needs are met through support to develop and maintain their family life and relationships. They can also access meaningful activities during the day and evening, which could include employment or voluntary work, but also non-work related activities that are important to the individual and established through an ongoing person-centred approach. It also means the range of needs of people with an ASC, including physical, sensory, environmental and health needs, are taken into account as they access support and the wider community.



All local authorities will take a strategic approach to housing in their area, assessing and planning for the current and future housing needs of all local people, including vulnerable people such as those with an ASC. As part of the role, authorities will also be expected to work with partners to plan and commission relevant housing and related support needs and to set out their plans for addressing the needs identified in their housing strategies.

### Outcomes for adults with ASCs

In relation to social inclusion, we want to ensure that the changes made as a result of this consultation and subsequent strategy lead to the following outcomes for adults with an ASC:

- **improved quality of life**, which includes access to leisure, social activities and life-long learning and to universal, public and commercial services. It also includes security at home, access to transport and confidence in safety outside the home
- **making a positive contribution**, which includes active participation in the community
- **freedom from discrimination or harassment**, which means equality of access to services and not being subject to abuse
- **personal dignity**, which includes keeping clean and comfortable, enjoying a clean and orderly environment and availability of appropriate personal care.

### Concerns raised by stakeholders

The following points summarise some of the concerns raised by stakeholders about the experiences of people with ASCs of being socially included or excluded.

#### 1 Local leadership

- Concerns were raised over the lack in many areas of a local lead individual or team to take responsibility for ensuring that assessments of need were carried out, and for developing services and support for people with an ASC and their families. This lack of leadership can result in people with an ASC, and particularly those with high functioning autism or Asperger syndrome, falling into the gap between mental health and learning disability services. This is contrary to the intention of government policy<sup>3</sup>.
- To resolve this issue, stakeholders have suggested that more local authorities could implement the Department of Health guidance that states that the Director of Adult Social Services (DASS) should ensure that it is clear which team, or manager, within his or her staff has responsibility for assessing and meeting the eligible needs of people with an ASC<sup>4</sup>.
- Other suggestions include establishing a specialist local ASC team in every local area, such as those already in place in Liverpool, Oldham, Surrey and Northamptonshire.

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3 Department of Health (2006). *Better services for people with an autistic spectrum disorder: A note clarifying current Government policy and describing good practice*: 7. London: Department of Health.

4 Department of Health (2006). *Best Practice Guidance on the role of the Director of Adult Social Services*: 21. London: Department of Health.

**GOOD PRACTICE EXAMPLE (PRIMARY CARE TRUST (PCT) LED): Liverpool Asperger Team**

Regularly held up as an example of good practice, the Liverpool Asperger Team is a multi-disciplinary team for adults with Asperger syndrome. It was established in 2003, following recommendations from a steering group which identified that people with Asperger syndrome were most likely to fall through the gaps in service provision. Funded by the Central Liverpool PCT and the local authority, it currently consists of a team manager (who is also a head speech and language therapist), two community nurses, two clinical psychologists, an assistant psychologist, a social worker, two support workers, an assistant clinician and an administrator.

The team has a person-centred approach and provides assessment and diagnosis of Asperger syndrome, offers direct support through its managed care pathway approach, and makes referrals on to other services. The team also works with 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 and alcohol and substance misuse services.

The team also offers training and advice to professionals about Asperger syndrome; this includes regular awareness sessions, enabling good practice to cascade through the local area.

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

Oldham is a leading authority for ASC provision and uses a range of different approaches to meeting the needs of adults with an ASC. There is high level commitment to ASCs in the authority. Veronica Jackson, Executive Director of People, Communities and Society played an integral part when she chaired the Greater Manchester Autism Consortium; this is now chaired by Oldham's Service Director for Adult Social Care, Paul Davies.

The Way Forward Group is a multi-agency group, made up of services that have a focus on developing and maintaining services for children and adults with an ASC, including employment, housing and education, and includes families affected by ASCs; the group feeds into the Consortium. This group has been instrumental in helping to bring about a range of initiatives to support people with an ASC, including a specific development and implementation manager for ASCs providing a central point of focus, and a Vulnerable Adults Service which works with people eligible for support following a Fair Access to Care Services (FACS) assessment but who do not fit the remit of other teams. A significant number of the people it supports have Asperger syndrome or high functioning autism.

All Oldham's learning disability supported tenancy, day service and respite provision are accredited by the National Autistic Society's accreditation scheme. There has also been significant investment in a training strategy

which includes a graded approach from basic awareness to specialised training. This training is provided not only to those who provide direct support and carry out assessments of need, but to other professionals including police, housing providers and probation services. Oldham is presently piloting a course on stress and anxiety for people with an ASC. Oldham children's services have allocated some significant resources towards identifying gaps in extended school provision for children in the ASC resource bases, and this has led to investment in training for leisure and youth providers.

Oldham has also invested in preventative services including social groups. These low-cost interventions provide not only the social support people need, but have acted as a springboard into employment by helping people to realise their ambitions and goals.

Transition is another significant area of attention in Oldham. The authority is in the process of developing a 'transition house' enabling people to be relocated back into the area from out of area placements, before more independent provision is found. It has also initiated a new transition project, *Get a Life*, which is partly focused on autism and Asperger syndrome, ensuring that good transition and person-centred plans are in place. The pilot has a cohort of 30 young people identified who have a mixture of diagnosis from ASCs to learning disability, and mental health needs combined with dual diagnosis. The process should be completed and a system in place by March 2011.

## 2 Data collection and strategic planning

- A lack of understanding at local level about the needs of the ASC population has been raised as a key concern.
- A report undertaken for the Government's Social Exclusion Task Force highlighted the lack of information about the number of adults with an ASC and emphasised the impact this has upon policy and service design: "We have insufficient epidemiological information reliably to estimate the prevalence of adult neuro-developmental disorders in the UK population... This is a major gap in the evidence needed to estimate

the prevalence of chronic exclusion and the most effective responses to the needs of the people affected."<sup>5</sup>

This was backed by evidence from the Commission for Social Care Inspection (CSCI) self assessment survey of local authorities, which showed that few local authorities knew how many adults with an ASC there were in their area and that few were including adults with ASCs in their Joint Strategic Needs Assessments (JSNA)<sup>6</sup>. This means that the needs of adults with an ASC cannot be taken into account in the planning and commissioning of local services.

### GOOD PRACTICE EXAMPLE: Data collection and local assessment of need

Local and national campaigning, along with the authority's adult social care modernisation programme, have been drivers for Lewisham to conduct a detailed needs analysis for people with an ASC, with a specific focus on those with high functioning autism and Asperger syndrome who may fall between learning disability and mental health services. Lewisham used a mixed method, in-depth approach in gathering quantitative and qualitative data, matching the methods to the individuals and using specialist input.

The quantitative analysis pulled together data from statutory and voluntary partners and compared this to the national prevalence estimate to establish local prevalence and profile the future adult population with high functioning autism. This was used alongside qualitative data to predict future service capacity and understand the kind of support resources needed.

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

voluntary sector also revealed the need for a clearer pathway to diagnosis, information and assessment for social care services.

The authority profiled the gender, age and ethnicity of those identified, 58% being of non-white ethnic origin, most being male between the ages of 25 and 35, which will inform a service response.

The aim of the qualitative research was to explore the particular local impacts on this group of people within the social and economic context of Lewisham. A specialist conducted semi-structured in-depth interviews which encouraged people to speak freely on a range of topics using themes where they were appropriate to the participant. A thematic analysis identified 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 in spring 2009.

This analysis will feed into the JSNA, the development of transition services, and other commissioning strategies such as Supporting People.

5 Schneider J (2007). *Better outcomes for the most excluded*: 69. Nottingham: The Institute of Mental Health, The University of Nottingham and Nottinghamshire Healthcare NHS Trust.

6 Answers to the ASC specific questions from the CSCI self-assessment survey 2007/08 made available from CSCI on request.

### REGIONAL STRATEGIC PLANNING:

#### Greater Manchester Autism Consortium and the North East Autism Consortium

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

The Greater Manchester Autism Consortium has been running for over ten years. Every local authority in the consortium has set up a multi-agency Autism Services Development Group (ASDG). Representatives from all statutory agencies, parents and carers, and, in some cases, adults with an ASC sit on the group. The chair of each group is on the consortium steering group. The groups look at what can be achieved in the local area by improving current provision within resources, and by better informing the commissioning process.

The consortium also funds the National Autistic Society's Family Services Development Project, which provides information, advice and support to families across Greater Manchester. Data from this project is then fed back to inform the commissioning process.

The North East Autism Consortium was established in 2006 to develop a regional approach to addressing the planning and service needs of people with an ASC. In particular, it is working towards the development of a regional commissioning strategy and addresses the lack of integration with service provision across health and social care.

Four ASC services development groups have been established in the region, offering the opportunity to share good practice and development.

### 3 Community care and support

- Evidence from the CSCI review of eligibility criteria showed that adults with an ASC are at risk of being excluded from accessing community care under the current system created by the FACS guidance, because their needs are not always properly understood<sup>7</sup>.
- This means that often community care assessors and FACS assessors do not have training in or a proper understanding of ASCs, so adults with an ASC are not properly supported to communicate their needs. Stakeholders suggest training for assessors and support in the assessment from those with expertise (such as a third sector organisation), where training has not been completed.
- Stakeholders have said there is insufficient support for adults with an ASC in many localities. This includes social skills training, social groups, independent living skills training and befriending. Concerns were raised that these types of low-intensity services which can make a big difference were not available for many people.
- It was also suggested that key workers could be assigned to support adults with an ASC to navigate the services they need.

<sup>7</sup> Commission for Social Care Inspection (2008). *Cutting the Cake Fairly. CSCI review of eligibility criteria: 37*. London: CSCI.

#### 4 Housing

- Concerns were raised that many adults with an ASC are dependent on their families and continue to live in the family home, unable to access the support they need to live independently.
- Stakeholders suggested that this was because:
  - many local authorities do not reflect consideration of the needs of adults with ASCs in their housing plans
  - the specific support that adults with ASCs need is not always understood or available
  - the design of housing can be inappropriate for adults with ASCs (e.g. poor sound insulation may cause stress to those with sensory sensitivities).

#### 5 Transport

- Transport can often be inaccessible for people with sensory sensitivities or who find it difficult to manage in crowds. Stakeholders suggested that more needed to be done to ensure that local transport plans included the needs of adults with ASCs. Support through travel training could make a substantial difference.

#### 6 Physical and sensory issues

- Some public spaces can be inaccessible for adults with ASCs, largely due to sensory issues, but also as a result of a lack of support workers to help adults with ASCs navigate new places.

#### 7 Other

- Stakeholders also had concerns about making sure that change actually happened in the implementation of the strategy.

#### GOOD PRACTICE EXAMPLE:

##### Social groups can help reduce social isolation and exclusion

There are a number of social groups across the country. They can be a vital lifeline for adults with an ASC and can help reduce social exclusion.

The Newham Asperger Service, for example, runs two monthly social groups.

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

The purpose of these groups is to give adults with Asperger syndrome or high functioning autism an opportunity to meet other people, develop friendships and share experiences and advice. It also aims to reduce isolation and build people's confidence in accessing community activities. The Asperger Service has also arranged training sessions, 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, as well as post-diagnostic support. It also addresses access to general healthcare and to mental healthcare where appropriate.

## A vision for the future

Adults with an ASC are able to access a needs (and skills) based assessment (including diagnosis) from suitably qualified local professionals from a multi-agency team, who are well integrated with other services. This assessment informs an ongoing personalised package of care. Post-diagnostic support for adults with an ASC and their families is widely available. All adults with ASCs get the health services and support they need from a healthcare system that makes reasonable adjustments and has an appropriate understanding of ASCs, including associated sensory issues and co-morbidities.

## Outcomes for adults with an ASC

In relation to health, we want to ensure that the changes made as a result of this consultation and subsequent strategy lead to the following outcomes for adults with an ASC:

- **improved health**, which includes enjoying good physical and mental health (including protection from abuse and exploitation)
- **freedom from discrimination or harassment**, which means equality of access to services and not being subject to abuse.



## Concerns raised by stakeholders

The following points summarise some of the concerns raised by stakeholders about the experiences of adults with an ASC in accessing specialist healthcare and diagnosis, and general healthcare, including reasonable adjustments.

### 1 Diagnosis and post-diagnostic support

- Concerns were raised about the lack of NHS services in England that can offer diagnosis of ASCs, particularly for adults.
- Concerns were also raised among stakeholders about the ability of GPs to identify ASCs in order to refer on for diagnosis.
- There were further worries about the ability of adult mental health professionals to recognise ASCs and that in some cases assessments may only be made where there was a significant psychiatric co-morbidity.
- A lack of a clear pathway to diagnosis in adulthood was also raised as an issue by stakeholders.
- There were concerns that diagnosis was often isolated from other services rather than integrated and multi-disciplinary.
- For those unable to access diagnosis, accessing the support they need can be difficult<sup>8</sup>.
- Stakeholders highlighted insufficient counselling and supportive information for the individual and their family as a challenge.

### GOOD PRACTICE EXAMPLE: Diagnosis integrated with other services and support: Northamptonshire Healthcare NHS Trust – Transition and Liaison Team

The Transition and Liaison Team (TLT) provides a diagnostic service and short-term post-diagnostic support service to adults with Asperger syndrome (and other developmental conditions, e.g. ADHD and Tourette's Syndrome), but also supports those with an existing diagnosis, especially during the period of transition to adulthood.

Through service modernisation, Northamptonshire Healthcare NHS Trust has enabled the TLT to narrow health inequalities by providing responsive services, focusing on the skills of key professionals on reaching groups and individuals that access services late or not at all. The team receives referrals and works jointly with a vast range of services and agencies, including specialist forensic, learning disability, mental health (including inpatient), accommodation and commissioning, social care and health, employment, connexions and further education services, as well as with organisations in the voluntary sector. The service focuses on interventions to reduce social isolation and mental health difficulties; development of independent living skills and relationships; a range of appropriate supported housing options; better social and academic support and learning opportunities during transition and in continued education; carers' needs; improvement in employment opportunities and support; better access to forensic services, and better post-diagnosis emotional support.

The TLT has involved service users throughout its development, and through a comprehensive local training and awareness programme is addressing unmet need to enable early detection, intervention and treatment.

<sup>8</sup> Of the 53 local authorities who responded to a National Autistic Society survey of local authority services, over half believed that those with a diagnosis of ASC would find it easier to access services than those without.

## 2 Data collection and strategic planning

- Stakeholders raised concerns about insufficient data at PCT and local authority level on the numbers of adults with an ASC and their support needs to inform local planning and commissioning.
- There were also concerns about an absence of clear protocols in many areas for sharing information between services, meaning that details about an individual's diagnosis and needs can be lost if they move or transfer between services, particularly from children's to adult services.
- It was suggested that clearer guidance for health and local authority commissioners on commissioning ASC services could be useful.

## 3 Accessible healthcare

- Stakeholders argued that reasonable adjustments are not always made for adults with an ASC in healthcare settings

(e.g. longer appointment times in order to build a good relationship with their GP, simple appointment booking procedures). It was suggested that this was partly because there is a lack of training/awareness in relation to ASCs in the healthcare system.

- Concerns were raised about a lack of understanding of co-morbidities experienced by many people with an ASC and about a lack of understanding of the sensory difficulties experienced by many people with an ASC.
- There were concerns that additional health problems in adults with an ASC can go unrecognised in what may be described as diagnostic overshadowing.
- It was suggested that PCT and NHS trusts could do more to ensure that the needs of adults with an ASC were taken into account when they develop equality schemes and when they develop new services.

### GOOD PRACTICE EXAMPLE:

#### Accessible healthcare

Making reasonable adjustments in a healthcare setting can be very easy. A mother of two sons, both of whom have an ASC, tells us that her GP is the only means of support that they have.

She says:

"He is aware that both function better in the afternoon and so we are always given afternoon appointments. If possible we are given his last appointment so that he can spend longer with our sons if he needs to. It is also quieter then. He is quite happy to let my eldest son who is 21 read any books with information regarding treatment and also his notes on the screen to make sure that he is happy with what has been written.

He is also aware that our eldest is more comfortable speaking to some of the doctors within the practice than others and this has been noted without it becoming an issue. If there are no appointments available we can speak to any receptionist and state that we have an arrangement with the practice and we have always been able to see someone within 24 hours. This goes right across the board within the practice. The asthma clinic, which usually runs on a morning, will also see our son in the afternoons. 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."

- There were suggestions that adults with an ASC could benefit from annual health checks.

#### **4 Mental health**

- Stakeholders highlighted a number of cases of misdiagnosis or inappropriate treatment (i.e. medication or therapy).
- There is evidence that preventative measures such as social skills training could reduce the risk of adults with an ASC becoming socially isolated and experiencing deteriorating mental health.
- Stakeholders said there were not enough specialist adult ASC services – including forensic services to manage complex cases.
- Stakeholders further highlighted the need for better co-ordination between specialist services (and with other commissioners and providers).

#### **5 Other**

- Continuing care assessors do not generally have sufficient knowledge of ASCs.
- There is a lack of research and evidence base in a number of areas around what works for adults with ASCs.
- Stakeholders said that there needed to be more evaluation and accountability of existing ASC services.

# Choice and control

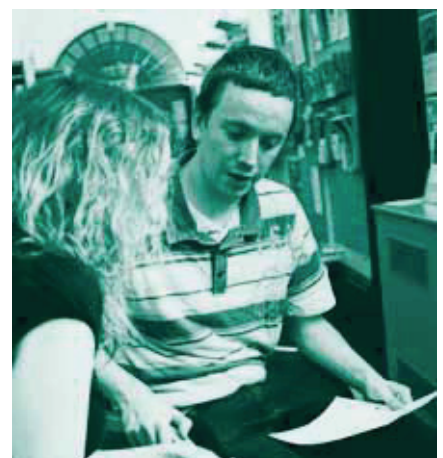
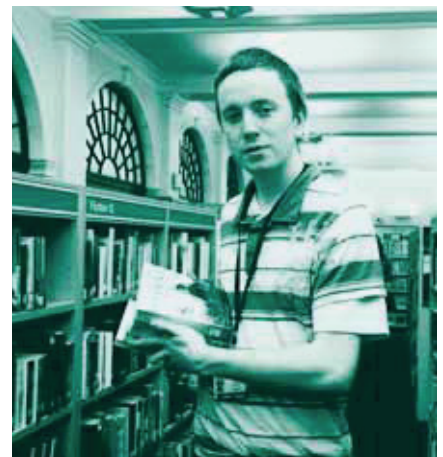
This chapter covers person-centred planning, advocacy, transition planning and involvement in service development.

## A vision for the future

Adults with an ASC are given the support they need to be empowered to take control of their lives, participate as much as they are able in society and pursue the lifestyle and relationships they choose. Adults with support needs will have a person-centred plan which is regularly reviewed to enable the individuals to meet their personal goals and objectives.

Having choice and control also means:

- making personal/individual budgets accessible to adults with an ASC
- ensuring access to a proper and ongoing transition plan for all young people with an ASC
- providing support for adults with an ASC so that they can communicate effectively
- making advocacy available for those who would benefit
- ensuring that adults with an ASC, their families and user-led organisations play a central role in relevant policy development and in local service development.



## Outcomes for adults with an ASC

In relation to choice and control, we want to ensure that the changes made as a result of this consultation and subsequent strategy lead to the following outcomes for adults with an ASC:

- **exercise of choice and control** through maximum independence and access to information and being able to choose and control services, as well as managing risk in personal life
- **making a positive contribution**, which includes maintaining involvement in local activities and being involved in policy development and decision making
- **freedom from discrimination or harassment**, which means equality of access to services and not being subject to abuse.

## Concerns raised by stakeholders

The following issues have been raised by stakeholders as central to achieving real choice and control for people with an ASC.

### 1 Making personalisation work for adults with an ASC

- The personalisation agenda is integral to achieving choice and control for individuals with an ASC. However, stakeholders have said that adults with an ASC often do not have support plans that are holistic and meet their unique needs. Stakeholders have told us that they want support to develop and maintain person-centred plans that identify the support they need to achieve choice and control.

### GOOD PRACTICE EXAMPLE:

#### Person-centred planning

Lisa, who has an ASC, was until recently living in a residential setting for six adults with ASCs. She had lived in the residential house for 12 years and regularly used the service day provision down the same road.

In recent times, her behaviour in the house had deteriorated to such an extent that extra staffing was being put in to support her 'challenging' behaviour. There was initially talk of her sponsoring authority taking her 'back to county' even though she had stated she wanted to stay in the town she knew and had links in.

A person-centred planning facilitator was brought in and after a series of meetings that Lisa herself led, she was able to communicate where and how she wanted to live and a plan outlining the support that she would need to achieve this was developed. She moved into her own (rented) house and is supported 1:1 at all times. She played a key role in the recruitment of the staff that support her.

To date there have been no incidents, her stress and anxiety have diminished significantly. She is visibly a different person and has blossomed in her new environment.

- There are also concerns that the assessment process for the allocation of personal budgets can be too inflexible to accurately reflect the unique needs of adults with an ASC. This can result in the provision of an inadequate personal budget and ultimately an inadequate service to meet those needs.
- Stakeholders have told us they want brokerage and advice services on the use of personal budgets to be available to adults with an ASC, and that the need for brokerage should be taken into account when allocating resources for an individual/personal budget.
- People with an ASC have also said that more support is needed centrally and locally to ensure people have access to the support they need to communicate in the way they want to (including access to alternative and augmentative communication (AAC) devices).
- Stakeholders have also said that more support is needed to help adults on the spectrum to develop and maintain personal relationships.

## 2 Transition

- There are substantial concerns about transition from children's to adult services and concerns that delivery and cultures are patchy, with a greater need for person-centred planning. Furthermore, the transition process is often 'last-minute', leaving little time for people with an ASC and their families to consider their options. There needs to be an emphasis on transition planning commencing from the age of 14 years.

Stakeholders also expressed concerns that young people who do not have a statement of special educational needs can miss out on transition planning.

- Best practice shows that successful transition comes through effective information sharing between children's and adult services<sup>9</sup>.
- Stakeholders have told us that they want transition planning to identify future need in all areas including employment, education, social care, health and housing.

## 3 Advocacy

- Advocacy is necessary for many adults with an ASC to be able to engage in meaningful communication with others. Adults with an ASC can find it difficult to gain access to appropriate advocacy.
- There is also a shortage of skills training in self-advocacy for adults with an ASC.
- Stakeholders have suggested that there could be an advocacy service in every local authority which is able to appropriately support adults with an ASC and to train adults with an ASC as self-advocates.
- There are also calls from stakeholders for better information to be available for adults with an ASC to inform their decision making.

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<sup>9</sup> See, for example, Department of Health/Department for Children, Schools and Families (2008). *Transition: moving on well. A good practice guide*. DH/DCSF.

#### 4 Involvement in policy making and service planning

- Stakeholders suggested establishing local and national forums for adults with an ASC and their families who could be involved in consultations on relevant policies.
- Local initiatives such as Local Involvement Networks (LINKs) could be more inclusive of people with an ASC.
- The need to make consultation documents and other information about local services available in accessible formats was noted.

#### **GOOD PRACTICE EXAMPLE: Involving people: National Autistic Society – consultative groups**

The National Autistic Society is establishing 'consultative groups' throughout the UK. One has already been set up in the south of England and has met three times. Groups are also being set up in the north of England, Scotland and Wales. All groups will meet three to four times a year and will be consulted on government policy issues to help inform consultation responses of the National Autistic Society's policy and campaigns team.

Members of all groups have relatively complex needs and the majority will attend the meetings with support workers.

The meetings are clearly structured and run in order to make sure that everyone can participate in the most meaningful way. Papers for the meetings are provided in easy read format and sent to the members along with a clear agenda, in advance, so that they can discuss them with their support worker before the meeting.

The meetings are held in ASC-friendly venues and there are break-out rooms available if people need to take a break from the meeting at any point.

Feedback from the members of the group and the support workers is that group members:

- enjoy attending
- respond well to the flexibility of the meetings where they are encouraged to feed back to the group themselves but are able to ask their support workers to feed back for them if they prefer not to speak in front of the group
- respond positively to being given questions in an easy read format and then working through them with their support worker before feeding back
- respond positively to using visual support to answer questions and stimulate discussion (e.g. symbols and photographs)
- appreciate being given the opportunity to stay the night before, both to reduce the anxiety of getting to a venue early in the morning and to have the opportunity to socialise with other members in an informal setting.

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

# Awareness raising and training

This chapter looks at public awareness raising programmes and workforce issues, including training. Each of the key themes has highlighted the issue of a lack of awareness of ASCs and of training in ASCs among professionals, front-line staff and others who work with people with an ASC. This chapter will look in more detail at what that training means.

## A vision for the future

There is broad awareness and understanding of ASCs. The contribution that adults with an ASC can make to society is recognised. People working in health, social care, employment, criminal justice and other agencies have relevant training or awareness to enable an understanding of the nature of the range of autism spectrum conditions and the ability to respond appropriately to the needs of adults with an ASC and their families. The vulnerability of some adults with an ASC is recognised, particularly among those working in safeguarding and in the criminal justice system. The training that is delivered supports best practice, is also competently delivered, monitored and evaluated.

## Outcomes for adults with ASC

In relation to awareness and training, we want to ensure that, in line with the transformation agenda, the changes made as a result of this strategy lead to greater general awareness of ASCs as well as a more informed workforce – both of which will support the achievement of the following outcomes for adults with an ASC:

- **improved health**, which includes enjoying good physical and mental health (including protection from abuse and exploitation).



- **improved quality of life**, which includes access to leisure, social activities and life-long learning and to universal, public and commercial services. It also includes security at home, access to transport and confidence in safety outside the home
- **making a positive contribution**, which includes active participation in the community
- **exercise of choice and control** through maximum independence, access to information and being able to choose and control services, as well as managing risk in personal life
- **freedom from discrimination or harassment**, which means equality of access to services and not being subject to abuse
- **economic well-being**, which includes access to sufficient income and resources as well as the ability to meet costs arising from specific individual needs
- **personal dignity**, which includes keeping clean and comfortable, enjoying a clean and orderly environment and availability of appropriate personal care.

### Concerns raised by stakeholders

The following points summarise some of the concerns raised by stakeholders about how adults with an ASC are affected by a lack of awareness and understanding of their condition.

#### 1 Awareness of ASCs

- Key concerns were that understanding among the wider population of the characteristics of ASCs and how this can affect behaviour is low, leading to intolerance, discrimination and

#### 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 credit card size and has the card holder's name and space for the details of two emergency contacts on the back. The card alerts people to the fact that the holder has autism or Asperger syndrome.

Autism Anglia has provided the police with training on autism and Asperger syndrome and has also begun training with Essex Fire Service, at individual fire stations.

Autism Anglia has had positive feedback from parents of card holders: "In a music gig my son got distressed and confused, his friend took him to the front and showed the organiser the card – they helped him out!"

At the invitation of Cambridgeshire, Hertfordshire and Bedfordshire police forces, Autism Anglia will soon be issuing a 'West Anglian' version of the alert card.

isolation. In a survey by the National Autistic Society, 83% of individuals with Asperger syndrome felt strongly or very strongly that many of the problems they faced were a direct result of others not understanding them.

- It was suggested that national actions and awareness campaigns, developed with support from adults with an ASC and their families and also showing positive images of adults with an ASC, could help to tackle this issue. Local awareness campaigns and events could also be helpful.
- Awareness could be targeted at a number of different groups, including the wider population, employers, the criminal justice system, those working in public transport, and leisure services.

## 2 Training

- Stakeholders identified a number of key groups that needed better training in ASCs. This included those working in healthcare, social care, employment support (e.g. disability employment advisors), housing, criminal justice, adult education and benefits.
- Within these groups, it was recognised that different levels of training would be required for different individuals dependent on their level of responsibility, their role and their likely degree of involvement with adults with an ASC.
- Stakeholders suggested that adults with an ASC and their families be involved in the design and delivery of training.
- It was also emphasised that some local authorities had developed ways to cascade awareness training across the public sector in their local area – see information box.

### GOOD PRACTICE EXAMPLE:

#### Surrey

The County Autism Group and autism lead have developed a network of 80 ASC champions across services in all sectors in Surrey. These champions have six months' training and mentoring and then help cascade this training to their team. Champions are supported to network and share good practice across services. Assessment of this process showed that it had led to positive outcomes for individuals with an ASC.

In addition, the county group and autism lead have supported Surrey County Council and Surrey and Borders Foundation Trust to jointly develop an ASC training pathway with different levels of training for staff in different services.

## 3 Social care

- Concerns were raised about the level of knowledge and understanding of ASCs among social workers and it was suggested that ASC be included in undergraduate and postgraduate training programmes for social workers.
- Particular concerns were raised about the training received by people undertaking assessments, including FACS and NHS continuing care.
- There were also concerns raised about the training needs of personal assistants.
- Stakeholders discussed the new knowledge set in ASCs currently under development by Skills for Care. It was suggested that it could be used as part of an induction for staff working with people with an ASC.

- There were also concerns about the need to ensure that anybody tasked with delivering local ASC-specific services, such as social skills training, could access appropriate training to deliver this service competently.

#### **4 Healthcare**

- Concern was expressed that low awareness of ASCs among mental health professionals can lead to misdiagnosis and inappropriate treatment.
- Calls were made for more to be done to ensure that ASC was included in undergraduate and postgraduate clinical training.
- Stakeholders also suggested that non-medical staff in the healthcare system have some awareness training in ASCs.

#### **5 Other**

- Stakeholders felt that training was needed for those involved in supporting people with an ASC to find and maintain a job (e.g. disability employment advisors).
- They also called for training of benefits advisors, work capability assessors, disability support officers in further and higher education settings 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 (whether paid or unpaid) and support within 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.

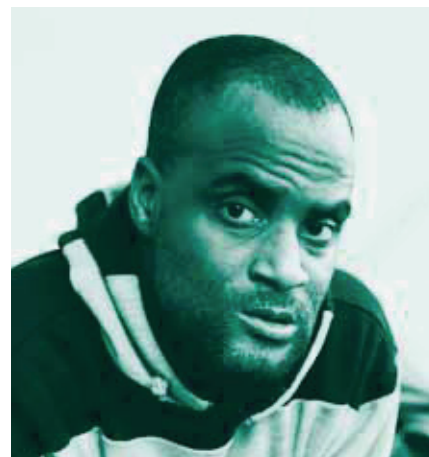
## A vision for the future

All adults with an ASC have the opportunity to work, appropriate to their skills and interest, and have access to the right level of support to meet their needs in the workplace. There are skills and education courses that match the needs of adults with an ASC preparing for work, and to develop their skills once in employment, so that they can progress and have opportunities to achieve their full potential. The benefits and tax credit systems support a journey into paid employment, while continuing to recognise the additional costs that people with ASCs can experience. Further, higher and lifelong learning opportunities are accessible to adults with an ASC.

## Outcomes for adults with an ASC

In relation to training and employment, we want to ensure that the changes made as a result of this consultation and subsequent strategy lead to the following outcomes for adults with an ASC:

- **economic well-being**, which includes access to sufficient income and resources as well as the ability to meet costs arising from specific individual needs
- **making a positive contribution**, which includes active participation in the community through employment or voluntary opportunities.



## Concerns raised by stakeholders

The following points summarise some of the concerns raised by stakeholders about the experiences of adults with an ASC trying to find a job and their experiences in the workplace.

### 1 Work

- Only 15% of adults with an ASC are in full-time employment<sup>10</sup>.
- Stakeholders have told us that some adults with an ASC have encountered difficulties accessing the support and funding they need to enter and retain employment. There are also concerns that Jobcentre Plus staff (including disability employment advisors) can be unaware of how to meet the needs of adults with an ASC.
- Stakeholders also noted the focus in Department for Work and Pensions (DWP) contracts for specialist employment support on job outcomes and the lack of consideration of achievements made in the progression towards work.
- They suggested that more specialist provision was needed for adults with an ASC as they seek work (whether paid and unpaid), including access to social skills training.
- The need to develop more voluntary work for adults with an ASC was also highlighted.
- Other suggestions included the development of advice for employment advisors who are supporting adults who received an ASC diagnosis while at work.



<sup>10</sup> Reid B (2006). *Moving on up? Negotiating the transition to adulthood for young people with ASC*. London: National Autistic Society.

### **GOOD PRACTICE EXAMPLE:**

#### **From voluntary work to paid employment**

David, who has an ASC, went on the National Autistic Society's employment service (Prospects) Brighter Horizons course. The course is designed to develop work-related skills and to support individuals to find and undertake an extended voluntary placement.

David attended weekly group workshops on various subjects such as coping at work, facing the future, workplace relationships, and healthy living. He also attended one-to-one sessions every week where he focused on areas in which he felt he needed to improve. For example, David has always struggled to make friends: something that he finds particularly difficult is starting and ending conversations, and knowing what to say when he first meets someone. In his one-to-one sessions he spent a lot of time discussing conversation skills and how to interpret body language. He also focused a lot on appropriate and inappropriate topics of conversation at work and began to search for a suitable voluntary placement.

David was keen to work in a supermarket and his employment support worker managed to find him an eight-week placement as a

grocery assistant at a local store. The work involved replenishing the stock in various departments, collecting stock from the warehouse and helping customers with their shopping. He worked three days per week for five hours per day. His employment support worker visited David weekly to discuss with him how everything was going and to talk about any problems that had occurred. His employment support worker would also meet with David's supervisor to discuss any issues that had arisen. His colleagues were very supportive and friendly, and David was receiving extremely positive feedback on the work that he was doing.

As the placement progressed, David's confidence increased and he made it clear that he was thoroughly enjoying his new role. David said that he liked working there because it felt good keeping busy and gave him a sense of responsibility.

On the last day of David's placement his employment support worker met with David's supervisor. He said that David had actually been working harder than most of the full-time employees and asked David if he would like to join the team as a paid employee when a role became available.

## **2 Employers**

- Employers can have a low awareness of ASCs, which means that they fail to make reasonable adjustments to their workplace and their recruitment process. This can result in workplace discrimination. It was suggested that employers may need to seek advice about how to make reasonable adjustments for people with an ASC.
- Stakeholders felt that the situation could be improved by the DWP working to raise awareness of ASCs, including the development of a quality standard to indicate exemplary employers of people with an ASC.
- It was noted that some employers did well in supporting people with an ASC through buddying schemes or ASC 'passports', which record a person's access needs.

**GOOD PRACTICE EXAMPLE:**

**Goldman Sachs – mentoring scheme**

Goldman Sachs has been involved with Prospects for the past six years and has assisted 23 people with work experience during this time.

In nearly all cases, those that have gone through the work experience programme have gone on to full-time employment after leaving Goldman Sachs. Five people have also remained 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 alongside the individual not only to provide encouragement but to befriend the individual at the same time, offer support and help integration into the team. Often the individuals coming into the firm do not need great levels of support, but the mentoring scheme means that they can have someone to talk to when they have particular concerns, such as about the social norms at the workplace, or if they need additional support.

**3 Benefits and tax credits**

- Stakeholders felt that many people with an ASC have difficulty accessing and understanding the benefits and tax credits to which they are entitled.
- It was felt that this could be addressed by the DWP and HM Revenue & Customs (HMRC) working to ensure that all information about benefits, tax credits and pensions is available in accessible formats (including plain English and easy read).
- Stakeholders also commented that an awareness campaign targeted at adults with an ASC about the benefits available to them could be helpful.

- Stakeholders also proposed that the DWP monitors decisions made in applications from people with an ASC for benefits, taking sample cases to ensure that the right decisions are being made and to identify any knowledge gaps on the part of decision makers.
- Training of those involved in the benefits system in the support needs of people with an ASC was highlighted as an issue.

**4 Education and training**

- Stakeholders felt that there is insufficient support for adults with an ASC in accessing education and training, and also a lack of emphasis on work during the transition process to support the development of skills necessary for the workplace.
- Stakeholders proposed that transition planning could include agreeing educational achievement and work goals with the young person and a plan on how these are to be achieved.
- It was also suggested that local authorities should ensure that Connexions makes reasonable adjustments for people with an ASC, including adjustments for sensory considerations.
- Other suggestions included the Department for Children, Schools and Families making sure that all children with an ASC have the opportunity to undertake work experience placements, and for the Department for Innovation, Universities and Skills to issue guidance clarifying that Disabled Students' Allowances can be used for social support as well as more traditional 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? Please tell us what they are.

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1b. 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

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\* If you need more space for your response you may attach additional pages as necessary.





































## 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 (or the group of people): (please only mark one)

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

If you are a professional involved with people with 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:

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## 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:

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Town or city or county:

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# The consultation process

## Timings

The consultation will run for a period of 20 weeks from 29 April 2009 to 15 September 2009.

## Process

Respondents are invited to complete the attached questionnaire and return it to:

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

Alternatively you can submit your views online at [www.dh.gov.uk/en/Consultations/Liveconsultations/index.htm](http://www.dh.gov.uk/en/Consultations/Liveconsultations/index.htm) or email us at [autism@dh.gsi.gov.uk](mailto:autism@dh.gsi.gov.uk)

The Department of Health will be running a number of events for stakeholders and for people with an ASC and their families around the country. We will also be making available a toolkit to support local organisations and groups to run their own events. Further details about events and information can be found on our website above.

You may also wish to contact your local authority or local ASC organisation about events that they may be holding in your area.

## Remit

This consultation and the final strategy relate to England only. Services for adults with an ASC in Scotland, Wales and Northern Ireland are the responsibility of the devolved administrations.

The Welsh Assembly Government has its own Strategic Action Plan for Autistic Spectrum Disorders (ASD), which was published in April 2008. An ASD Strategic Action Plan is being finalised for publication in Northern Ireland, while in Scotland the ASD Reference Group completed its work by publishing guidance to local agencies on commissioning services for people with autism.

## Summary of consultation responses

A summary of the responses to this consultation will be made available before or alongside any further action, such as the development of statutory guidance, and will be placed on the consultations website at [www.dh.gov.uk/en/Consultations/Responsestoconsultations/index.htm](http://www.dh.gov.uk/en/Consultations/Responsestoconsultations/index.htm)

## Criteria for consultation

This consultation follows the Government's Code of Practice on Consultation. In particular, we aim to:

- formally consult at a stage where there is scope to influence the policy outcome
- consult for at least 12 weeks, with consideration given to longer timescales where feasible and sensible
- be clear about the consultation process in the consultation documents, what is being proposed, the scope to influence, and the expected costs and benefits of the proposals
- ensure the consultation exercise is designed to be accessible to, and clearly targeted at, those people it is intended to reach
- keep the burden of consultation to a minimum to ensure consultations are effective and to obtain consultees' 'buy-in' to the process
- analyse responses carefully and give clear feedback to participants following the consultation
- ensure officials running consultations are guided in how to run an effective consultation exercise and share what they learn from the experience.

The full text of the code of practice is on the Better Regulation website at: [www.berr.gov.uk/whatwedo/bre/consultation-guidance/page44420.html](http://www.berr.gov.uk/whatwedo/bre/consultation-guidance/page44420.html)

## Comments on the consultation process itself

If you have concerns or comments which you would like to make relating specifically to 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](mailto:consultations.co-ordinator@dh.gsi.gov.uk)

Please do not send consultation responses to this address.

## Confidentiality of information

We manage the information you provide in response to this consultation in accordance with the Department of Health's Information Charter.

Information we receive, including personal information, may be published or disclosed in accordance with the access to information regimes (primarily the Freedom of Information Act 2000 (FOIA), the Data Protection Act 1998 (DPA) and the Environmental Information Regulations 2004).

If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory code of practice with which public authorities must comply and which deals, among other things, with obligations of confidence. In view of this, it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information, we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department of Health.

The Department of Health will process your personal data in accordance with the DPA and in most circumstances this will mean that your personal data will not be disclosed to third parties.



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