



Overarching report of findings from the *Adult
Autism Strategy* consultation activities

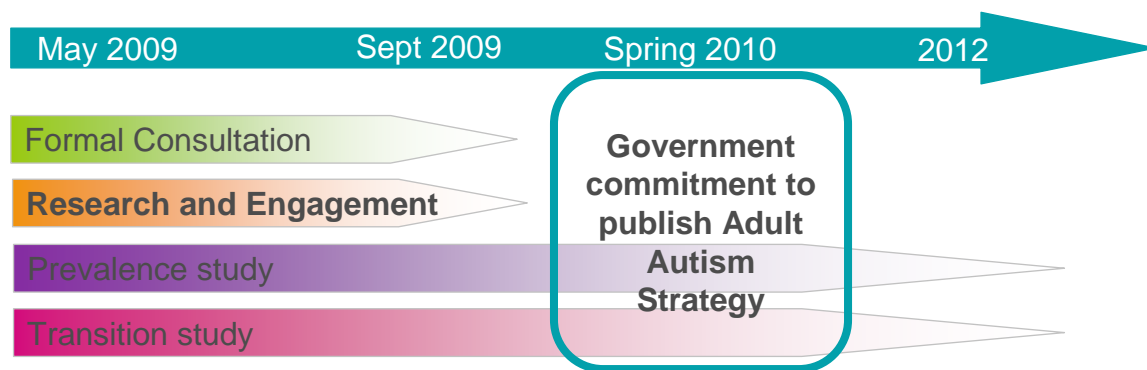
Prepared for COI and the Department of Health by Opinion Leader

18th December 2009

1. Brief introduction to the consultation: aims and methods

Background

The Department of Health (DH) has been working to developing a cross government strategy for adults with autistic spectrum conditions (ASC) since October 2008. In order to inform the consultation document, the work has been undertaken in collaboration with an external reference group (ERG) made up of service providers and practitioners across health, social care and employment sectors, as well as adults with autism and parents and carers of adults with autism. The consultation was launched on April 29th 2009. The planned activity is illustrated in the diagram below.



The consultation document states that the overall aim of the strategy is to support adults with an ASC to live life as full and equal citizens.

Objectives

The objectives of the consultation

The Department of Health (DH) is planning to publish a strategy on ASC. The strategy is due to be published by Spring 2010. The purpose of the online consultation and the wider engagement process was to seek views on what actions, in which areas, can deliver the greatest change for the largest number of adults with an ASC.

With support and advice from the ERG, DH identified five key themes for the consultation. The themes were chosen as representative of the main concerns that are of concern to adults with an ASC and, as such, are the areas that they 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, it was recognised that the themes may not cover all the issues, and the consultation was an opportunity to find out if the themes were the right ones to be the top priority for action.

The objectives of the research and engagement programme were to:

- Provide INSIGHT on the needs, expectations, views and experiences of people with Autistic Spectrum Conditions (ASC), their family, carers and professionals who work directly, or indirectly with people with ASC
 - EXPLORE reactions of all audiences to the themes, issues and actions stated in the consultation document
 - GENERATE SOLUTIONS to the barriers presented which prevent adults with an ASC living life as full and equal citizens
 - IDENTIFY PROMISING PRACTICE where awareness levels have been raised and where barriers have been addressed – and an understanding of the costs and benefits, including with regards to equality, associated with such initiatives
 - ENGAGE STAKEHOLDERS IN MEANINGFUL DEBATE
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2. Method and sample

Consultation approach

The consultation document was available as a printed document and available electronically on the DH website. A consultation website (hosted at <http://adultautismstrategy.dialoguebydesign.net>) was designed to enable people to read the document and respond to the corresponding questions. The questions and supporting text were made available in two formats, a standard version and an easier to read version. The standard consultation was open from the 29th April to 15th September; the easy read version opened later on the 2nd July and ran to the 15th September.

Online responses

The online consultation process was designed to be easy for people to use. Respondents could log on to the website and register their details. Once on the consultation pages of the website respondents could choose whether they would like to participate in the standard or the easy read version.

Paper, fax and e-mail submissions

Responses on the paper or emailed response forms, or those broadly following the question structure were entered into the same collation database used to group the online responses.

Research and engagement activity

A two stage research and engagement programme was adopted to ensure that it covered the exploration of needs and experiences of people with, or who are affected by, ASC as well as reactions to the issues raised in the consultation. A range of methodologies was used in the research and engagement programme. This was to enable adults with an ASC to take part in a way which was accessible for them. The research and engagement activity was conducted in 9 locations across England.

The research and engagement programme was divided into two stages.

The first was to:

- Explore the issues relevant to adults with an ASC, their carers and professionals
- Highlight at an early stage any clear gaps in the consultation document
- Identify good practice in supporting adults with autism
- Identify the changes that would make the most positive difference to adults with autism

The second stage built on the first stage of research and was set up to:

- Provide an opportunity for stakeholders to discuss the key issues arising from the previous stage and the issues raised in the consultation
 - Provide a forum to develop solutions
 - Prioritise and identify the impact proposed solutions might have on people with an ASC
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Sample

Consultation responses

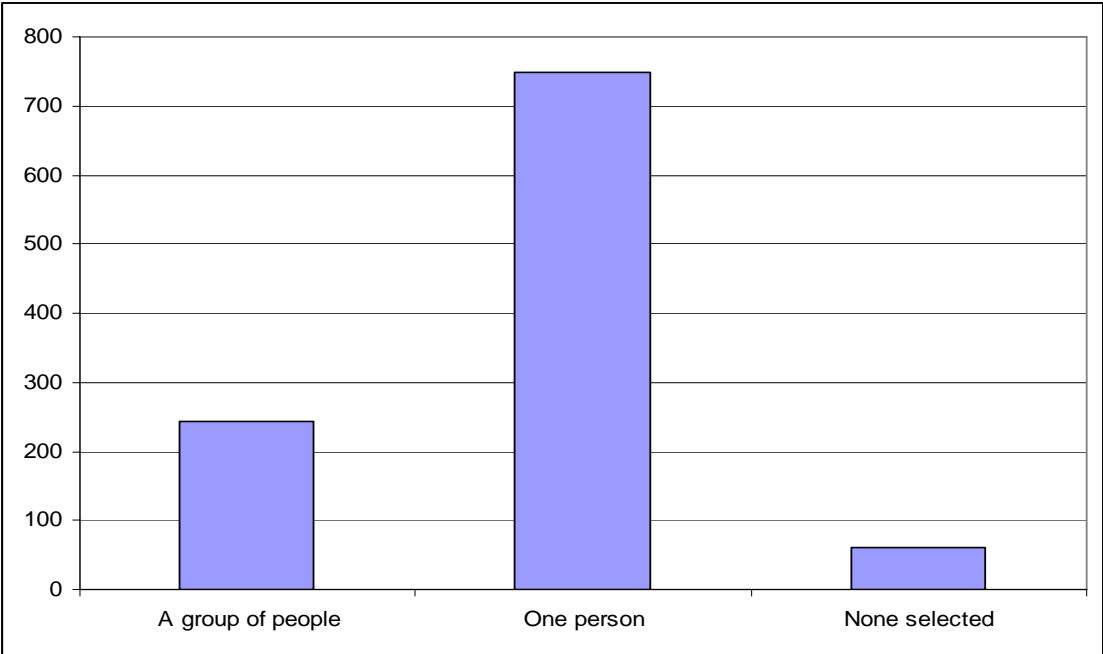
Responses

A total of 1025 people registered on the site during the submission phase, and 643 of these took part in the consultation. 490 offline submissions were received, 190 of these by email and 300 by post. Therefore a total of 1133 submissions were received. Submissions received after the closing date were logged and forwarded to DH to be read in full but are not included in this analysis.

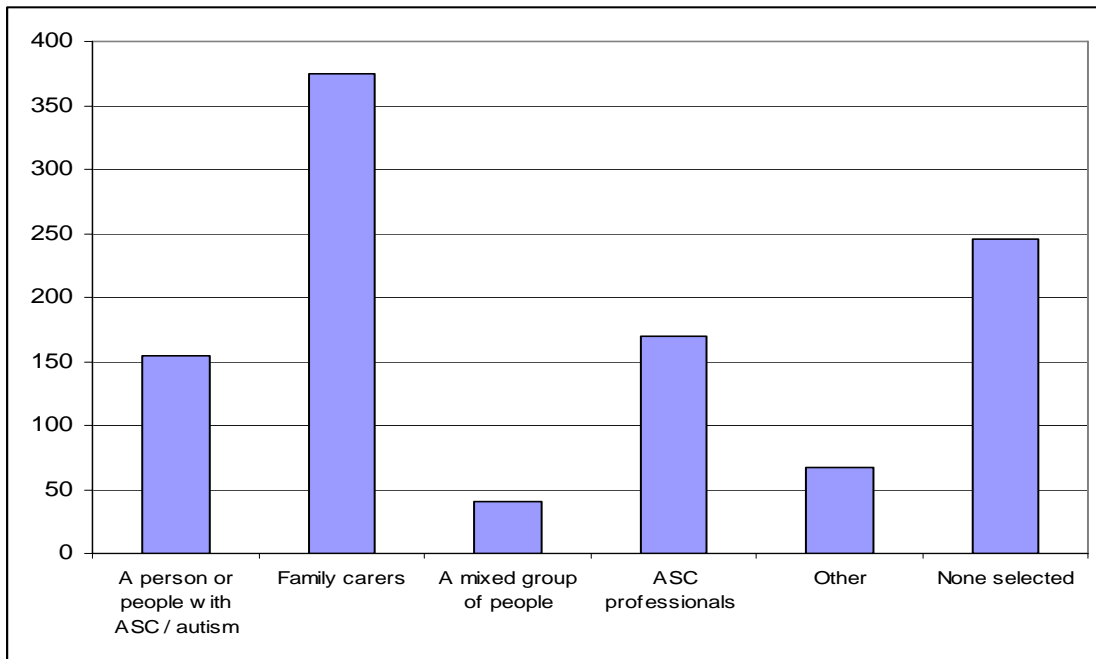
Participation statistics

A series of personal and organisational questions were asked when people registered to take part in the consultation and on the paper forms. This section displays the results of these questions for those that responded to the consultation. Participants who submitted responses by email have been counted as 'none selected' in the participation statistics, unless it clearly stated otherwise in their submission.

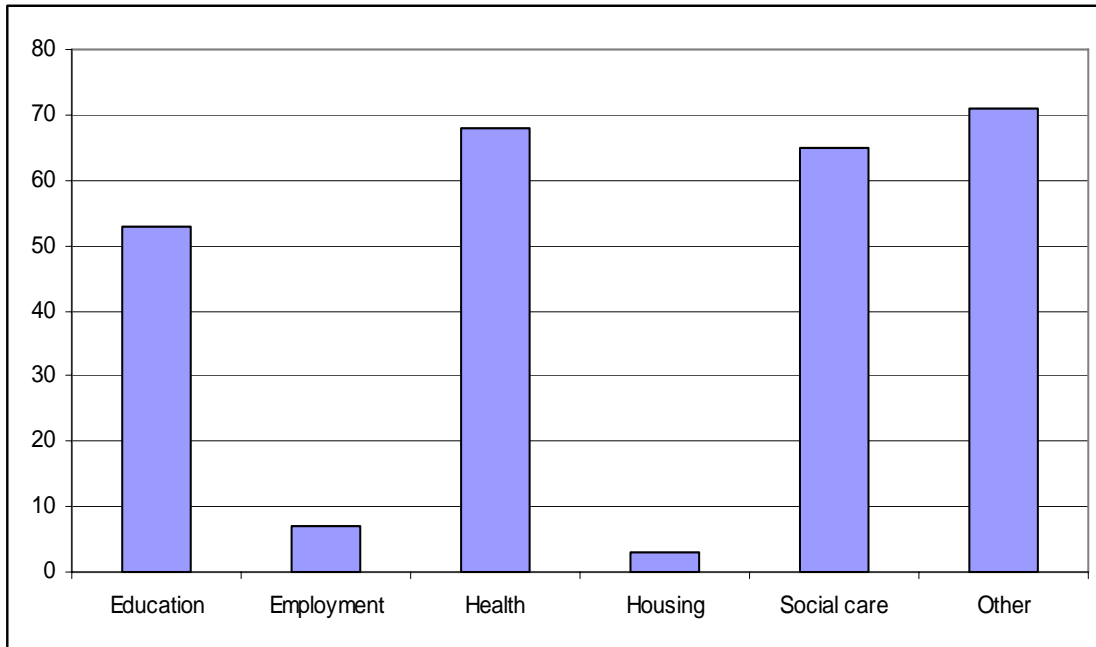
1. Are these comments from:



2. Are you (or the group of people):



3. If you are a professional involved with people with an ASC, in which area do you work?
(267 people responded to this question)



Research and engagement activity

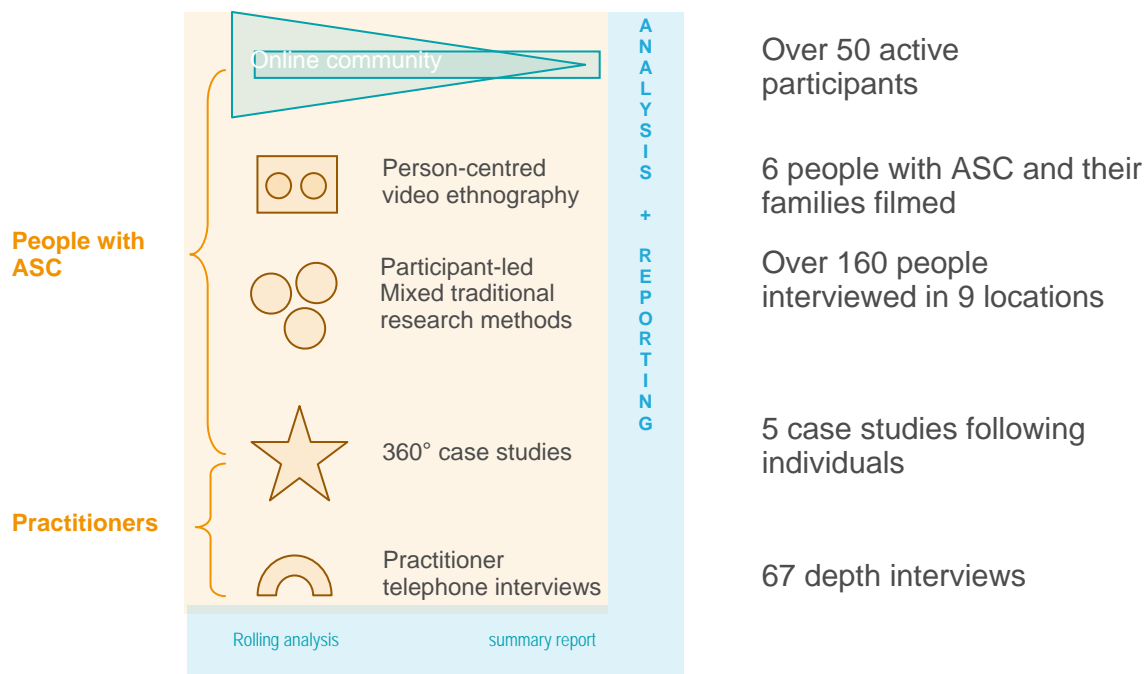
A range of methodologies was used in the research and engagement programme. This was to enable adults with ASC to take part in a way which was accessible for them. The research and engagement activity was conducted in 9 locations across England and the locations were the same for stages 1 and 2. The locations were chosen to reflect a range of urban and rural areas, have representation in each of the 9 government regions and include some locations which had greater and lesser service provision for adults with ASC.

The locations in which the research was conducted were:

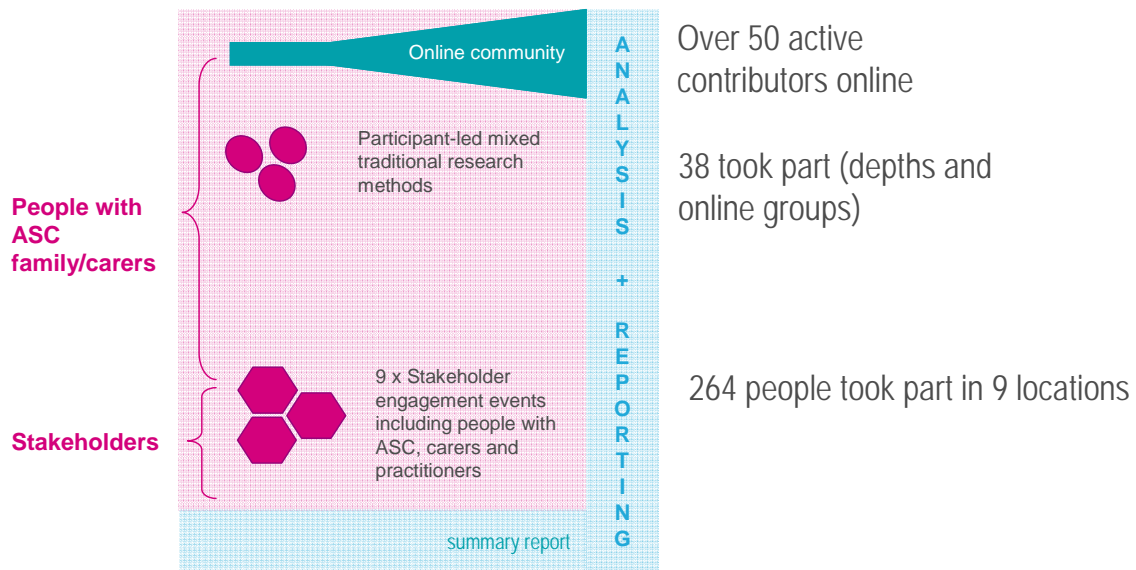
- Plymouth
- Newcastle
- Sheffield
- Leicester
- Manchester
- Reading
- London
- Ipswich
- Birmingham

The research and engagement was based on the following activity in stages 1 and 2:

Stage 1



Stage 2



Toolkit responses

A toolkit was available on the consultation website for people to download and use to conduct local discussions about the issues raised by the consultation. A total of 16 different responses were received. Five of these local discussions were attended by professionals and providers of services for people with an ASC; another five involved just adults with an ASC. A further four events had a range of participants including professionals and adults with an ASC. Organisations which held these discussion events ranged from voluntary sector groups such as the National Autistic Society, to County and Borough councils, Learning Difficulties Partnership Boards and Learning Disability Teams within Acute Trusts. The events were held in a wide range of locations in England including London, Gloucestershire, Telford, Shropshire, Worcestershire, Stockton, Wirral, Lancaster, Essex and Surrey. At least 270 people took part in these events. A further 26 individual responses were received from adults with an ASC.

3. Summary of key actions

The combined consultation activities have uncovered a very large amount of information about what is working well and less well for adults with an ASC. However, there is consensus around many of the issues highlighted. The key areas for improvement are therefore as follows:

- **Raising public awareness and acceptance of ASC.** Raising the level of understanding and acceptance amongst the general public would improve many aspects of life for adults with an ASC. This includes understanding of the condition and how to adapt behaviour to meet the needs of adults with an ASC.
 - **Improving key professionals' level of training.** Key professionals who work directly with adults with an ASC lack awareness of what ASC is and how to work with adults with an ASC.
 - Training levels should be improved amongst frontline health, social care, criminal justice, housing, transport, education and benefits and employment professionals.
 - Training levels could be tiered so that all practitioners have a basic understanding but they have local experts who provide advice and information as well as a point for referral.
 - **Improving access to local services.** Adults with an ASC in many areas are not receiving the help and support they need. If adults with an ASC have an IQ higher than 70 and do not have clinical mental health problems they are generally not eligible to receive support from either learning disabilities or mental health services: frequently, there are no other services to support them.
 - **Improving local leadership.** An identified individual or a team must take responsibility for responding to the needs of adults with an ASC to help them to live their lives to the full, make the most useful contribution to society and avoid crises.
 - **Personalising services.** ASC's present a unique set of challenges for each individual. Designing support or care around the individual is therefore essential to provide support that truly meets the individual's needs. This requires full appreciation of the individual's circumstances, skills and abilities as well as flexibility in the way that services are delivered.
 - **Taking account of sensory issues.** Many adults with an ASC are highly sensitive to stimuli such as noise, light and touch. Adaptations to a range of settings where appropriate including housing, employment situations and healthcare would improve accessibility.
 - **Improving the diagnosis pathway.** Adults with an ASC often receive a late diagnosis or are misdiagnosed. This prevents them from receiving appropriate care and support. There is also a lack of post-diagnosis support. As such there is a need to improve the diagnosis pathway and standardise diagnosis tools to improve rates of recognition and diagnosis.
 - **Ensuring adults with an ASC can access the healthcare they need.** Adults with an ASC can struggle to access the healthcare they need. This can be due to a wide range of issues such as practitioners not identifying the condition, other conditions being overlooked because of ASC 'masking' other conditions. This may be across a range of healthcare settings including Accident and Emergency, outpatient clinics, primary care and mental health services etc. These services must adapt services to ensure adults with an ASC have parity of access.
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4. Cross-cutting themes

There are several themes that were repeatedly mentioned in the engagement events and in the consultation responses as being relevant to many aspects of adults with autism and carers' lives. These are outlined below:

Choice and Control

There are two key aspects which are perceived to be essential to give adults with an ASC choice and control over the decisions which affect their lives. These are personalisation and communication support and advocacy.

Adults with an ASC are not empowered to exert a high degree of choice and control over the decisions which affect them. This is partly due to the lack of services available to adults with an ASC which makes choice difficult or impossible. It is also due to service providers not being able or willing to offer choice to adults with an ASC in a way which is meaningful for them. For example, trying to explain verbally the range of leisure activities available to an adult with an ASC may be meaningless to them, however if they visited the alternative activities in person they might be able to make an informed choice.

Many called for increased personalisation in the delivery of services for adults with an ASC. Person-centred plans and personal budgets were perceived by some to have the potential to make personalisation of services a reality for adults with an ASC. Person-centred plans, if they were widely used, respected and implemented, could help to ensure that the adult with an ASC's preferences and aspirations are taken into account when providing services to them. Personal budgets if adequately resourced could give adults with an ASC the ability to choose the services they need (subject to availability). However, whilst these are currently working well for some, others do not have access to suitable services, some do not have budgets which match their level of need and some find it difficult to appoint support staff and manage the services they are receiving. Participants in the consultation activities highlighted the difficulties faced by adults with an ASC during transitions such as the transition from children's services to adult services. Some called for person specific transition planning to be undertaken to ensure that transitions are well managed and to help ensure services are made available to adults with an ASC during and after transitions.

In addition to person-centred plans, communication support and advocacy were perceived to be important to help adults with an ASC to achieve a greater degree of choice and control over decisions which affect them. Access to advocacy and self advocacy was perceived to be important to support adults with an ASC to ensure that their views are listened too. Communication support was perceived to be important to help adults with an ASC to better interpret the world and communicate more fully with people who do not have an ASC. Currently access to advocacy and communication support is limited, however it is perceived to be working well where it is available.

Key priority actions

- Establishing person-centred approaches for identifying individual needs and providing personalised solutions. This can be achieved via person-centred plans and personal budgets.
- Greater access to advocacy services including self advocacy
- Improved signposting of information about the services available to support adults with an ASC

Awareness raising and training

General awareness raising amongst members of the public, in particular professionals who come into contact with adults with an ASC, is perceived to be fundamental to improving the lives of adults with an ASC. Improving awareness of ASC would enable people working with adults with an ASC to start making the necessary adjustments to their service and the way they communicate with adults with an ASC. However, in order to do this people working with adults with an ASC need to understand how to identify adults with an ASC; how to communicate with adults with an ASC; and the needs of adults with an ASC in different situations.

Participants in the consultation activities believe that targeted, tiered training is required for each of the key groups of professionals working with adults with an ASC. The most important professionals are listed below:

- Employers
- Benefits service workers
- Health professionals
- Social workers
- Police/Criminal Justice System
- Teachers / education
- Housing
- Mental health professionals

Public understanding and awareness of ASC is perceived to be important to enable members of the public to adapt their behaviour to interact more productively with adults with an ASC. Some of the adults with an ASC who took part in the consultation activities had experienced bullying or insensitive treatment from members of the public because of their condition.

Data collection

Within the Social Inclusion chapter there were more responses mentioning the importance of data collection than anything else (134 additional comments), the perception being that basic information about the prevalence of ASC is fundamental to planning and decisions about resource allocation.

Exclusion and discrimination

Many people felt that adults with an ASC are subject to widespread discrimination. This is system-wide, e.g. being excluded from services for disabled people, but also arises because of ignorance on the part of others. This results in adults with an ASC being socially excluded and economically disadvantaged. Women in particular mention feeling discriminated against when trying to get a diagnosis and when revealing their autism to other people because of erroneous stereotyping.

Funding and resource issues

Many participants believe that there is a lack of funding and resource available to cater for the needs of adults with an ASC. This is both on an individual level, e.g. funding support for residential care which could be taken away, and on a wider scale e.g. resources for services would have to be diverted from another client group to cater for adults with an ASC. This raises real dilemmas for practitioners who may wish to help adults with an ASC but cannot resource the changes necessary to meet their needs.

5. Priority areas

The first stage of the research and engagement activity identified a number of priority areas which participants suggested required changes in order to improve the lives of adults with an ASC. These are:

- Diagnosis and support
- Support in the community
- Employment and other meaningful activities
- Housing and support
- Health.

There is a considerable degree of similarity between the areas which were presented in the consultation document to those identified in this report. People responding to the consultation strongly agreed that the five themes in the consultation document (social inclusion, health, choice and control, employment and training, and awareness raising and training) were actions that needed to be taken to improve the lives of adults with an ASC. However, terminology used in the consultation was not perceived by adults with an ASC, carers and some practitioners taking part in the research and engagement activity to be in line with the way they think about the priorities for adults with an ASC.

Diagnosis and support was perceived to be such an important aspect of health that it required separate consideration. The health theme in this report therefore covers the other aspects of health that were perceived to be important to adults with an ASC. Housing and support was perceived to be a very important issue for adults with an ASC and as such has been discussed within a separate section of this report. Social inclusion was not a term that was widely understood by adults with an ASC and carers/family members, however, issues surrounding social inclusion have been included within the 'support in the community' section of this report. The employment and education theme was perceived to be too narrow to encompass the range of activities which are important to adults with an ASC.

Therefore, in this document we have included the theme employment and meaningful activities which includes training, education and other activities which people enjoy and provide structure.

Training and awareness was an issue which was perceived to be important across all of the themes in this report and we have therefore included it as a cross-cutting theme. Choice and control was also an issue which was important across several themes, however, participants felt better able to relate to the terms personalisation and user led services and policy.

Diagnosis and support

Adults with an ASC often struggle to obtain a diagnosis which results in them receiving a late diagnosis or not receiving a diagnosis at all. This can be due to the lack of professionals available to make diagnosis as well as professionals' lack of awareness of the signs of ASC. Some adults with an ASC receive misdiagnosis which can result in them getting inappropriate treatment or support.

There is also a lack of support for adults with an ASC post-diagnosis. This can lead to adults with an ASC experiencing problems such as isolation and mental health issues. Adults with an ASC wanted better access to support post-diagnosis. Many suggested that support should be linked to diagnosis to ensure that adults with an ASC receive support.

Key priority actions

- Improving identification of ASC through better training for frontline workers such as GPs, mental health, learning disability teams, teachers, social workers, housing officers and police.
- Interlinking diagnosis and support to help ensure that people receive support following diagnosis. This is essential since adults with an ASC often need support after being diagnosed and there is often a gap between receiving a diagnosis and receiving support which is difficult for adults with ASC.
- Local teams of ASC specialists to develop and coordinate a range of services. These teams could ensure that services are available to support adults with ASC and ensure that they can access them.

Support in the community

Across the consultation activities it was clear that many adults with an ASC, who had support needs, were not catered for. For some this was because they did not fit the eligibility criteria for learning disabilities teams nor do they have a mental health condition. For others, services were not able to meet their needs because of inflexibility or because services did not have access to the data needed to tailor services to meet needs.

This lack of support means that many adults with an ASC do not currently have access to community care and housing support. They also find it difficult to socialise and use public transport and leisure facilities. This can result in adults with an ASC becoming socially isolated and/or reliant on family

members. In some circumstances, long term lack of support can lead to crises including serious mental health problems, getting into trouble with the police and entering the criminal justice system.

A recurring overall theme relating to support in the community is the need for professionals and services working with adults in the community to recognise their individual needs and tailor their behaviour and services to meet these needs.

Many suggest that public sector partners must commission services and work in a far more joined up fashion than they currently do. Flexibility and transparency around different agencies' budgets to allow for this should be encouraged so that savings can be made. Joined up working is particularly critical at times of transition between services. This is especially pertinent in terms of transition from children's to adult services but is equally valid to changes to living arrangements or in older age.

Key priority actions

- The establishment of local multidisciplinary ASC teams to take a lead on the provision of services. These teams should ensure that adults with an ASC are eligible to receive the services they require and that these services are provided adequately. Someone at a local level needs to be responsible for ensuring that adults with an ASC receive the support they need to live full and equal lives in the community.
- In order for services to better meet the needs of adults with an ASC, professionals should receive training and resources should be made available to reinforce learning.
- Adults with an ASC get the right kind of support which meets their individual needs – it is important that support needs are tailored to the specific needs of each adult with ASC.
- Having a person-centred plan for every adult with an ASC to help to ensure that their needs and aspirations are recognised and steps taken towards realising these.

Employment and other meaningful activity

Adults with an ASC often have additional needs and requirements in respect of education. Some need support to access courses as well as support during their course to help with a range of needs, for example in filling in forms or help in social situations. Some colleges and higher education organisations provide help by providing buddying and mentoring schemes to help adults with an ASC, however these are not universally available. Some adults with an ASC want to be able to access training courses which help them with some of the social skills and other skills required in the workplace, however again, access to these courses is limited. Some feel that professionals working in further and higher education organisations should receive training so that they can better meet the needs of students with an ASC.

Employment is perceived to have significant benefits for adults with an ASC in terms of improving their self esteem, enabling them to live independently and increasing their confidence in social situations. However, accessing and retaining employment can be particularly difficult for adults with an ASC. The application process can be very difficult for adults with an ASC, many of whom find it difficult to fill in application forms and/or find job interviews very difficult due to having communication difficulties. Many

adults with an ASC who had had a job in the past felt they lacked support at work to enable them to continue in their job. Some said that their ASC was misinterpreted as them being anti-social or 'difficult' at work. Many call for employers to be better informed about ASC and offer alternative ways of applying for jobs - for example, job trials - and for them to be made aware of the benefits of employing adults with an ASC. The work and training environments are also a barrier for some adults with ASC and employers/training providers need to be made aware of the steps they can take to make these environments more suitable for adults with ASC.

Adults with an ASC across the spectrum also want to be able to access meaningful activities. Getting involved in regular activities helps adults with an ASC avoid social exclusion and isolation. Whilst some people with an ASC are able to access a range of meaningful activities, others feel constrained by a lack of available activities, information about the activities which are available in their area, funding and limited availability of transport.

The benefits system is perceived to be very difficult for adults with an ASC to find their way through. Many adults with an ASC across the spectrum have difficulty filling in forms, attending appointments and taking part in benefits interviews. This is a particular problem for adults who have not received a formal diagnosis who are unable to give a reason for their behaviour.

Key priority actions

- Greater access to activities people want to do, and which make best use of their skills and interests in order to reduce isolation.
- Making sure that adults with an ASC get the support they need to stay in activities, including employment e.g. buddying and mentoring schemes.
- Greater awareness amongst society in general and employers in particular so that they can understand the benefits of employing adults with an ASC.
- Providing support for employers to help them ensure that they have the knowledge and skills to be able to support adults with an ASC in the workforce.

Housing and support

Having an appropriate home is a fundamental part of an adult with an ASC's sense of security and independence. Whilst there are some good examples of housing needs being met, this is not the case for everybody and many rely heavily on family members to accommodate them which may not be sustainable in the long term and often places huge burdens on family carers. Those in the middle of the autistic spectrum were perceived to be the poorest served in terms of housing and support since they may not meet eligibility criteria for services, although their needs may still be acute. This theme concerns ensuring that adults with an ASC are able to get the right housing and support to live as independently as they want to.

Some families and adults with an ASC have had a real struggle getting the accommodation they want, and in some areas, little respect for client or families wishes. Funding for residential care is also mentioned as being very dependent on the area people are living in. Some have had help to get funding for people at the lower end of the spectrum to move into residential care, while others have struggled. This is particularly difficult for out-of-county care, if nothing suitable is available within their county. Many people talk about the lack of information or signposting to what is currently available for housing.

Getting the right housing environment is essential for adults with an ASC. If the environment is over stimulating, for instance, if there is too much noise, the lighting is too bright or under stimulating e.g. too quiet, this can cause adults with an ASC to become distressed and feel uncomfortable in their housing.

Key priority actions

- Housing which meets individual needs; for example increasing the housing supply, increasing the range of housing available, housing to take into account sensory needs and access to crisis support.
- Trained support workers - need to understand how to communicate with adults with an ASC and how to tailor their service to meet the needs of adults with ASC.
- Flexible housing support options - having a range of support options which can be adapted to fit the needs of the adult with an ASC e.g. long term floating support.

Health

Holistic approaches to the healthcare needs of adults with an ASC were perceived to be important in order to ensure that the range of healthcare needs that adults with an ASC have are recognised and treated. It was perceived to be important that the diagnosis of ASC does not overshadow the recognition of other co-morbidities.

Participants in the consultation events called for healthcare settings to better accommodate their needs. In GP surgeries people wanted to be able to make appointments at times where they would not have to wait too long, have appointments long enough for them to explain their healthcare issue and be able to see the same GP. In hospital settings people wanted healthcare professionals to be able to recognise that adults had an ASC and, as a result, make adaptations to how they communicated with the person, as well as creating ASC-friendly environments e.g. having quiet areas available.

Participants in the consultation events highlighted the lack of awareness and understanding of ASC amongst health professionals. This lack of awareness results in people with ASC often not accessing health services they need, being given inappropriate treatments and symptoms being treated rather than the cause being tackled.

Mental health is an area which many felt was not meeting the needs of adults with an ASC. Many claimed that mental health professionals did not recognise ASC and were not able to provide treatment which met their needs. Some participants in the consultation events claimed that mental health professionals often treated the symptoms of the mental health problem rather than addressing the cause which was often the product of the ASC not being identified or people not receiving adequate support. There were calls for greater access to alternative therapies such as cognitive behaviour therapy which were perceived by some to be more effective than drugs.

Key priority actions

- Professionals' awareness of the needs of adults with an ASC – this can be achieved through dedicated training which is tiered to ensure that all healthcare professionals receive basic training and that others working more closely with adults with ASC receive additional training.
- Treatment for the person's entire health needs – this can be achieved through implementing person-centred plans, training and providing appropriate mental health interventions (treating the cause of the mental health problem rather than the symptoms).
- Making it easier to receive treatment by for example having flexible appointment times, better access to advocates, recognition of carers opinions alongside adults with an ASC and having more accessible waiting areas.

In conclusion

Adults with an ASC face many challenges to leading full and equal lives. These range from ensuring that their health needs are met to accessing employment and meaningful activities. The potential solutions to improve the lives of adults with an ASC are varied, numerous and require a range of organisational, attitudinal and practical shifts in the way services are designed, developed and delivered. However, raising awareness and understanding of ASC amongst practitioners working with adults with an ASC emerged as the catalyst for change and a key to providing the personalised approach which adults with an ASC need.
