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Adult Autism Strategy consultation

A summary of the submissions received in response to the online consultation

Prepared for the Department of Health

By Dialogue by Design Ltd

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1. Executive Summary

The Department of Health's *A Better Future — A consultation on a future strategy for adults with autistic spectrum conditions* has attracted responses from a wide range of people and institutions, including people with an autistic spectrum condition (ASC), their families and carers, professionals involved with people with an ASC, and campaigning organisations.

Respondents to this consultation commented on some or all of the questions posed in the consultation either via the standard consultation, the easy-read version or sometimes both.

Throughout the responses to all questions, respondents express frustration at the way people with an ASC are so little understood not only by the public at large, but often by the professionals who determine the care they receive and the quality of their lives in terms of housing, education and employment. A theme which emerges in response after response is a sense that there needs to be a concerted effort to raise awareness and understanding both of what it means to have an ASC, and what it means to be the carer of someone with an ASC.

There is a strong sense in responses that this increase in understanding needs to include more differentiation between different types of ASC, in particular between high-functioning and low-functioning conditions; and that generalisations about people with an ASC need to be replaced by an appreciation of the abilities and needs of each individual with an ASC.

This leads to the call for services that are designed for each individual, which in turn means developing well-funded and resourced local services that can be provided by specialist teams using multidisciplinary approaches within a national framework. Many people call for advocacy and training, or support for self-advocacy, as an empowering way of ensuring personalised services.

There are particular problems expressed within the responses, such as the difficulty for adults to get an ASC diagnosis in the first place and thus enable them to access services and support. There is a suggestion that a national standard for such diagnoses is required, and that this standard should be recognised by bodies other than the National Health Service. There are also concerns that there need to be efforts to prevent adults with an ASC being labelled as having learning difficulties if their IQ is under 70, or having a mental health problem if it is over 70, or falling into the gap between the two – and being denied access to services as a result. Respondents argue that health professionals need to be aware of the other health problems, both physical and mental, to which an ASC can lead and that such problems can mask the underlying existence of an ASC.

Once a diagnosis of an ASC has been achieved, respondents would like to pave the way to lifelong care and support for those with the most serious conditions. They would also like to see an appreciation of the difficulties many experience with crowded and noisy environments such as doctors' surgeries, hospital waiting rooms, and public transport. Those with sensory sensitivities may need living, learning and working environments that take careful account of these sensitivities if they are to avoid further problems and lead even approximately normal lives.

A theme which is raised by a great many respondents across all the sections is the need for the provision of adequate and supported housing so that people with an ASC can live more independent lives.

Respondents talk in detail about the need for trained professionals in many walks of life to be available to help explain and guide people with an ASC. Respondents provide examples from experience of the difficulties they have engaging with many aspects of life such as seeking employment, housing and benefits. There are few examples in the consultation responses of positive experiences with these services and correspondingly many people also talk of how easy it is for ASC behaviour to be misinterpreted and for them to fall foul of the criminal justice system. There are many calls for people working within the judicial system to be trained to deal with people with an ASC better.

Another issue that recurs throughout the consultation is the need for improved transition planning: how the shifts from childhood through adolescence to adulthood are managed and the support that is required at different stages. It is emphasised time and again that different people have different needs. Some adults with an ASC can live independently, raising their own families, earning their own living, and contributing positively to society. Others, meanwhile, are dependent on parents and other carers throughout their lives.

It is clear from responses that someone’s place on the autistic spectrum largely determines what they can and cannot do, and what support they need at different points in their lives. People at the high-functioning end of the spectrum, for example, may achieve academic excellence but struggle with everyday tasks; others may hold responsible jobs but find basic social communication extremely difficult and become progressively more isolated. Those with fewer abilities may still find satisfying jobs and build an active life in their communities. But all too often the absence of information, of choice, of support from sympathetic employers and colleagues, or indifference and abuse from the gatekeepers of the services that are available, can prevent people with an ASC living even minimally happy lives, let alone realising their full potential.

For these reasons the work of carers, whether professional or voluntary, is recognised by respondents to be of critical importance. It is often noted that carers too need care, support and respite. There are also a great many concerns expressed, in the case of parents and relatives, about the future as they age and worry about those they will leave behind.

2. Introduction

2.1. Background

The Department of Health (DH) is planning to publish a strategy on autistic spectrum conditions (ASC) 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 External Reference Group (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.

2.2. How the consultation process was managed

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 easy- 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.

The e consultation website served as an information hub during the project showing background material, news items and a toolkit for participants to download and run their own discussion events. The outputs from these discussions can be found in the reports by Opinion Leader Research.

2.3. Responses

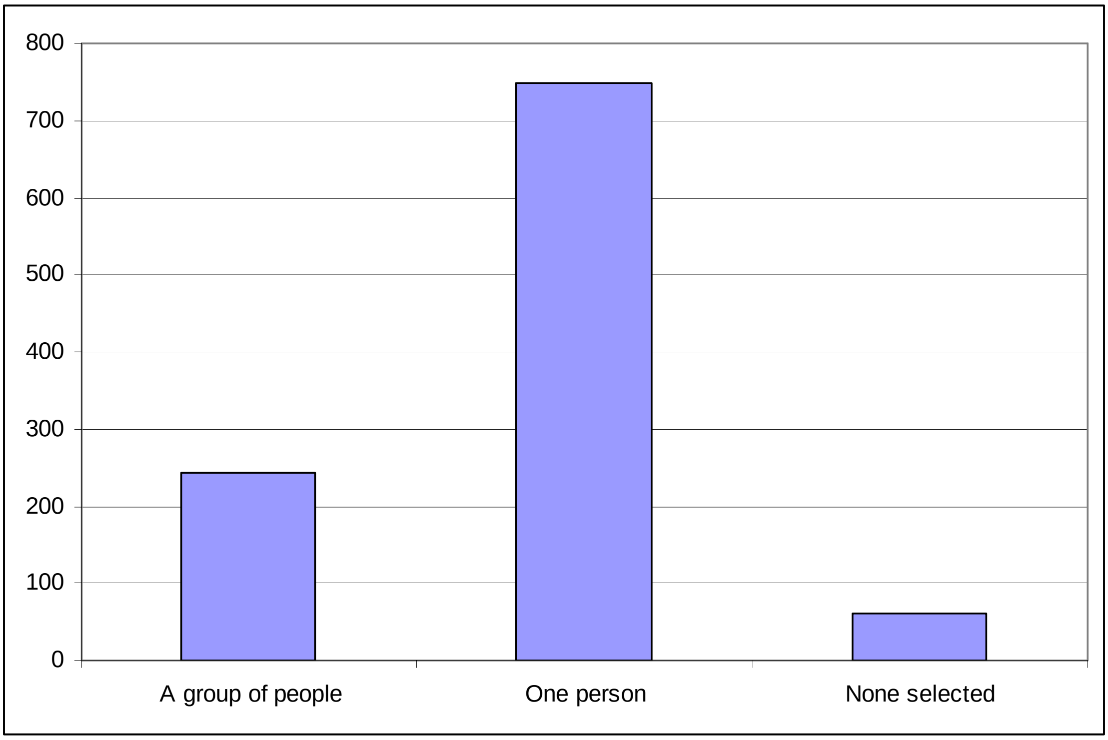
A total of 1,025 people registered on the site during the submission phase, and 643 of these took part in the consultation. 490 offline submissions were received, 190 of these by email and 300 by post. Therefore a total of 1,133 submissions were received. Submissions received after the closing date were logged and forwarded to DH to be read in full but not included in this analysis.

2.4. Participation statistics

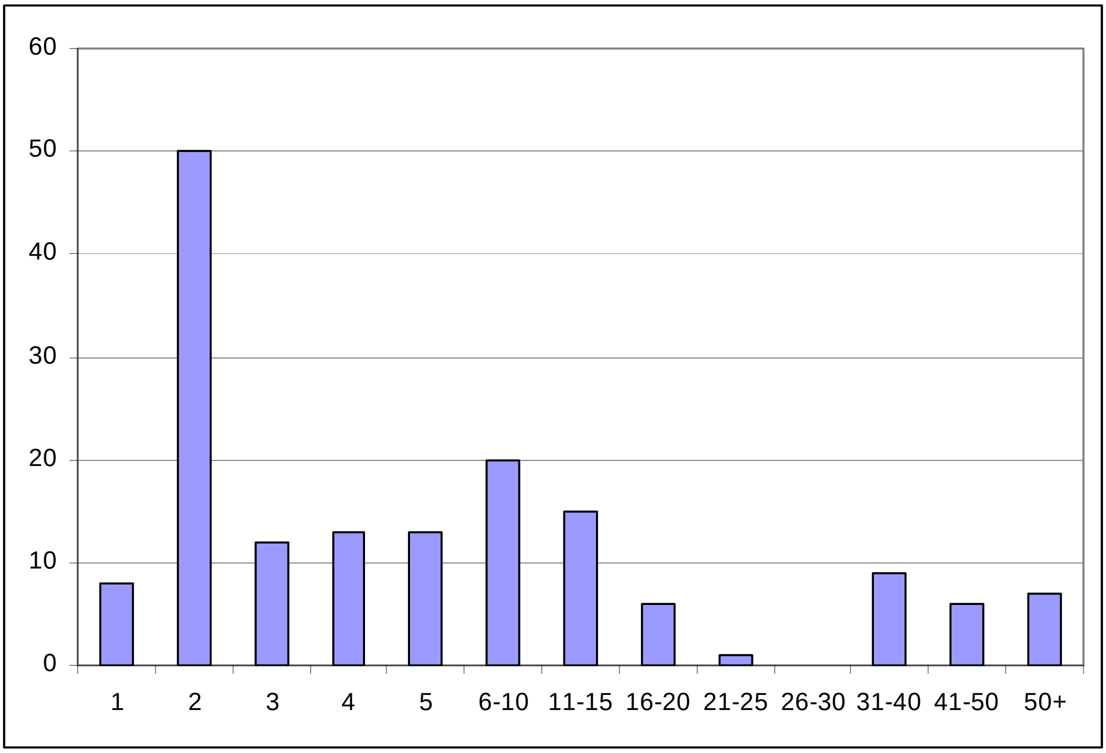
A series of personal and organisational questions were asked when people registered to take part in the consultation and on the paper forms. This section displays the results of these questions for those that responded to the consultation.

Participants who submitted responses by email have been counted as ‘none selected’ in the participation statistics, unless it clearly stated otherwise in their submission. A full list of the organisations that responded is listed in Appendix 1.

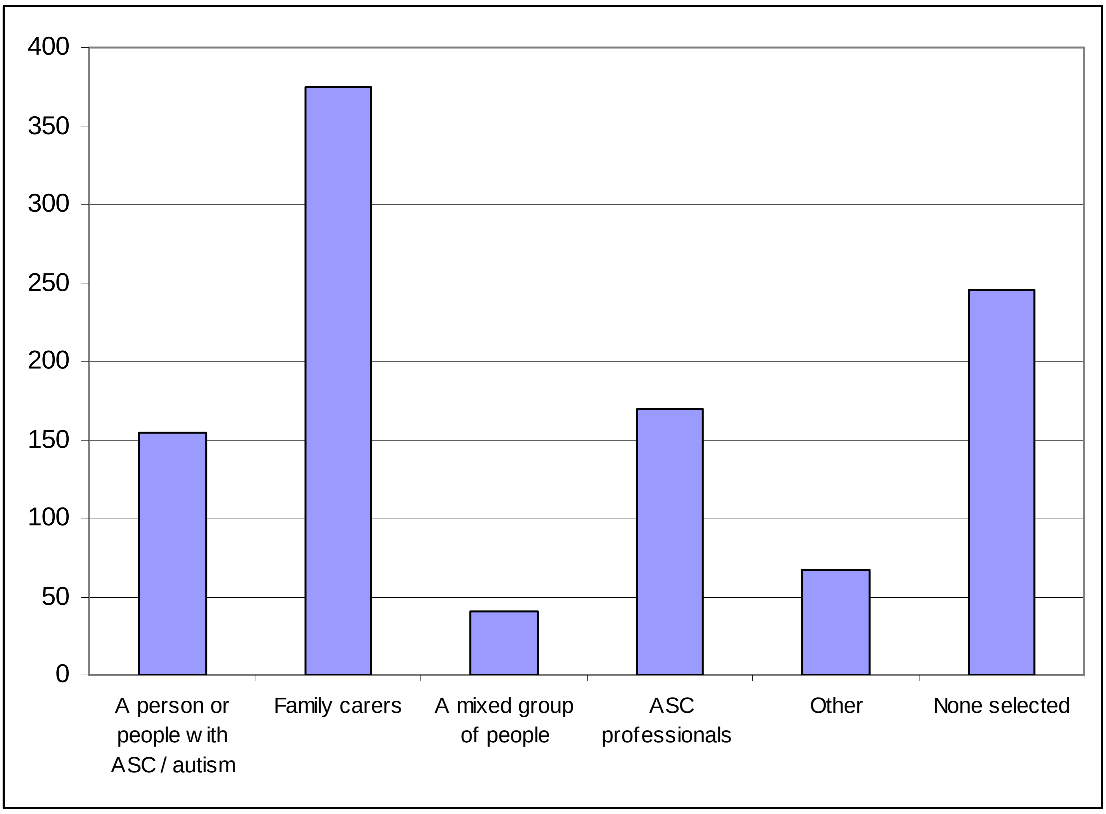
1. Are these comments from?



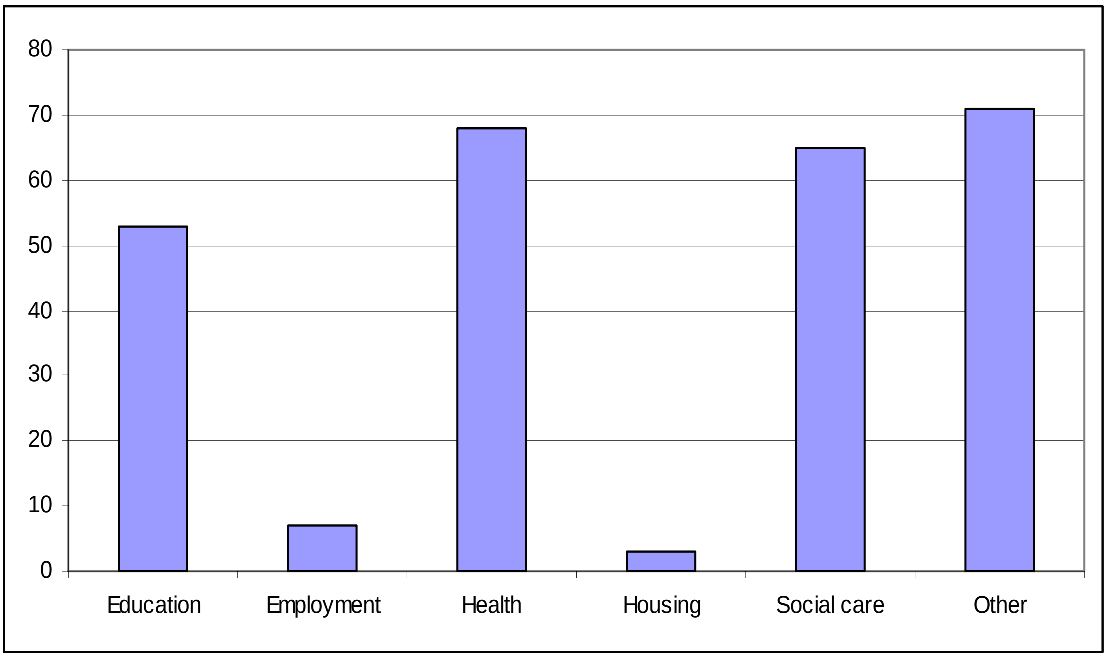
2. If in a group, how many people were involved in producing the response?



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



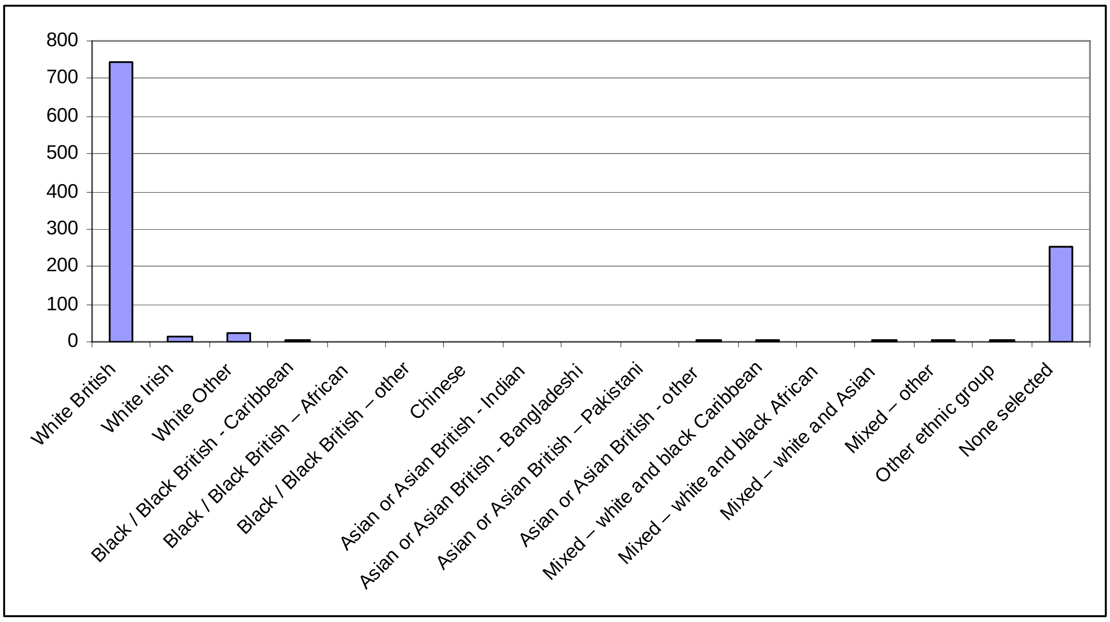
4. If you are a professional involved with people with an ASC, in which area do you work? (267 people responded to this question)



One particular organisation, Autism Anglia, prepared a shorter version of the questionnaire which asked a different set of profile questions. The results of these questions are shown in Appendix 4.

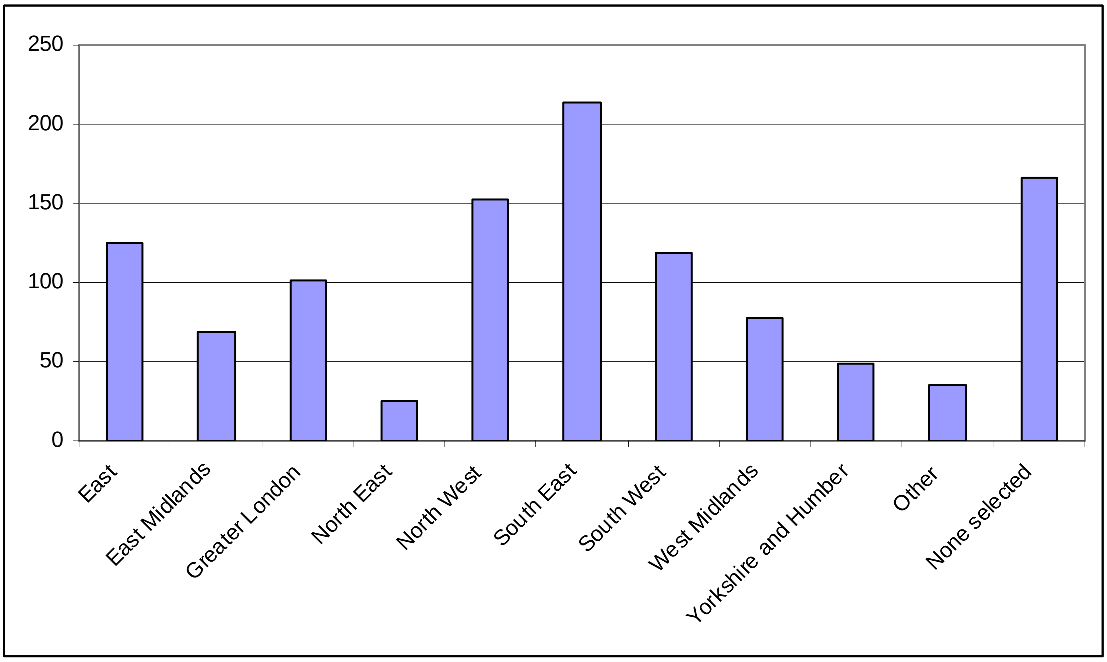
Demographic questions

6. What is your ethnic origin?



7. In which region do you live?

(The ‘other’ answers to this question are listed in Appendix 2.)



Please note, for this graph we have inferred that all of the Autism Anglia responses could be classified as ‘East’.

2.5 Reading this summary and interpreting the results

The collation process involved reading each response and allocating it to one or more theme headings. A long and detailed response may have been allocated to six or seven theme headings while short comments were allocated to just one or two. The groupings are useful indicators of where there is common ground. Full lists of the group headings are listed in the appendix of the report.

This summary has been prepared by independent facilitators of the process, Dialogue by Design. In reading this report care must be exercised in attributing significance to the numbers of reported responses arguing for a particular point (or to the numbers of responses collated under theme headings). Readers should remember that this was a qualitative consultation process, not an opinion poll; the summary or responses on the website are not representative of the population as a whole. The executive summary provides a short overview of the themes that emerged across the whole consultation but in addition a summary has been produced at the start of each chapter.

We were particularly concerned that the summary should give a voice to people with an ASC and to their carers and so have wherever possible, quoted directly responses that describe first-hand the challenges faced by these individuals. It is however important to emphasise when reading this summary, that many of the responses did not provide examples of solutions or initiatives, but simply provided more detail on their experiences and current service provision. Therefore in many places the summary focuses on the challenges faced rather than the solutions needed.

The full responses to each question will be available online at http://adultautismstrategy.dialoguebydesign.net during the review stage of the consultation.

3. Consultation overview

3.1. Summary of responses to this chapter

This chapter covers responses to a number of questions about the selection of main themes for the consultation, the merits of existing services and potential issues around equality and diversity.

3.1.2 Main themes of the consultation

Respondents strongly agree with the five themes that 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; and employment). Even though it is usually acknowledged that housing is included within social inclusion, many feel that housing and supported or independent living should be added as a theme in its own right, since suitable housing is regarded as a prerequisite for many adults with an ASC to be able to achieve progress in other areas and have the opportunity for independent living. There are also many suggestions to put more emphasis on supporting those who care for adults with an ASC, as it is felt that they receive too little support even though they are often indispensable to adults with an ASC. Responses to the questions in this chapter also stress the need to raise awareness among professionals dealing with people with an ASC, and amongst the general public.

Another issue many would like to see highlighted is the transition from children’s to adult services since this is relevant across many of the selected themes. Education, skills training and employment, though included in the consultation themes, are stressed in many comments.

3.1.3 Existing services

Service providers and commissioners answer the question about the merits of existing services mainly by giving examples of services they are involved in. Most are descriptive and do not give detail of costs, benefits, risks and outcomes; it is clear that these are all highly dependent on the individual client’s needs.

3.1.4 Equality and diversity

Many respondents explain how, for adults, it is particularly difficult to obtain access to services and a satisfactory quality of outcomes, their age thus having a negative impact. This is seen to be partly a consequence of diagnostic methods, which tend to rely on descriptions of childhood behaviour. Gender is also mentioned repeatedly as an area where inequalities are experienced by adults with an ASC, with a strong sense that women with an ASC are often overlooked due to false assumptions: many believe that ASC occurs almost exclusively in men, while women with an ASC are often perceived as shy, but neuro-typical. Although heard less often, some respondents provide examples where culture, ethnicity or disability have impacted on the care for adults with an ASC; respondents cite training and awareness raising as possible measures to tackle these equality issues.

3.2. Standard consultation questions on the overview chapter

The themes that have been identified as areas where action needs to be taken to improve the lives of adults with an ASC are:

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

3.3 Are there other themes that need to be included? Please tell us what they are. (This question corresponds to Q1a of the standard consultation)

631 people responded to this question.

While many (86) respondents agree that the five themes cover everything that needs to be included, some use this first overview question to prefigure their responses to other questions, and to highlight the issues that are of particular concern to them even if they are already included in the five areas for action. Others do identify themes that they feel are missing, or which are so important that they deserve a theme and chapter of their own.

3.3.1 Housing, and supported and independent living

This subject is addressed in the social inclusion theme but there are comments on it in response to virtually every question throughout the consultation. It is a subject of such concern that many respondents (117) feel it deserves to be a theme in its own right.

> *Housing. As this is so important I think it should have a heading of its own. (ASC professional)*

Among the reasons given for respondents' desire to treat housing as a theme in its own right is the perception that there is insufficient specialist sheltered housing for people with an ASC, or that what is available is in some way unsuitable either for all people with an ASC, or for the particular individual about whom a respondent may be concerned.

It is not just that in many areas people cannot find the accommodation they need; the stresses of not being properly housed or being unsuitably housed often, according to many respondents, trigger mental health problems such as depression.

> *Supported independent housing for adults who might partially cope on their own if backed up by a trained warden to help with new situations/ problems arising.*
> *If this is not available some will end up on the streets or as suicides. (Family carer)*

3.3.2 Education and employment

These again are among the themes covered in the five areas of the consultation, but they are high on the lists of issues that respondents want to emphasise (117), mainly because they link to so many other aspects of life for adults with an ASC and those who care for them.

Education is not just important because it can pave the way to employment and independent living, but because it can mitigate some of the impacts of a condition that lasts a lifetime and imposes enormous burdens on others:

> *Continuing with basic education is vital. People with autism never stop learning and they continue to learn throughout their lives, but this needs to be at a very basic level, like a continuation of school. (Family carer)*
>
> *Education. Some adults with ASC may not be able to be employed. Continued access to education and ongoing life skills (some with ASC have memory issues and other disabilities) would be a real benefit to carers. We need more dedicated and structured educational programmes to continue post 19yrs. (Family carer)*

3.3.3 Support and involvement of families and carers

There are many responses about the need to provide support for families and carers (65), covering respite care, the financial costs of care, the need to consider the mental health of carers and the emotional support that they, as well as adults with an ASC, need.

It is apparent in responses throughout the consultation, though it is not always openly and clearly articulated, that many carers feel somewhat taken for granted by those who would otherwise have to shoulder the burdens and costs of care for adults with an ASC.

One particular issue of concern to both people with an ASC and carers, and which many feel needs more attention, is what happens as they get older:

> *What happens when we are old and our ASC adults are no longer able to access education and can't be employed? We couldn't cope having them home full time. Caring exhausts us and leaves us with ill health and no money due to being full time carers, we are seriously worried about the future. (Family carer)*

Some respondents draw attention to the problems faced by older people with an ASC. Often they have struggled through life with no formal diagnosis of an ASC and therefore little help or support, and sometimes there are no family or friends left who will care for them. In this situation the assumption of or even references to ‘families and carers’ may be misleading.

3.3.4 Transition issues

The period of transition from childhood to adulthood, and therefore of seeking support from the services appropriate to children and those for adults, is another issue that is raised in relation to every theme, and again there are respondents who argue that transition issues should be a stand-alone theme (55) because they pose such problems.

> *We believe that a separate focus on education and transition should be added to the Adult Autism Strategy rather than transition just being an element within the 'Choice and control' theme….. Through the Strategy, we would like to see transition of young people with autism become a priority for public services and hope that the specific needs of young people with autism are given the focus needed to improve this woefully poor area of service provision. (ASC professionals group)*

The argument is that transition planning cuts across all of the themes identified and falls under the jurisdiction of different government departments and public service agencies. It is considered that ensuring transition planning for groups with complex needs should be a central government priority leading to strong action. This reflects the anxiety that people with an ASC can be left with no support after the age of 18.

Some respondents argue that this issue concerns transitions at every stage from initial diagnosis onwards:

> *These 5 themes are clearly very important and successfully addressing these will provide massive improvements in the lives of adults with ASC. Feedback, particularly from carers, suggests that Transition to adulthood is so important that this should also warrant a specific focus. (ASC professionals group)*

For some types of ASC any type of change can be extremely stressful and trigger other health problems. Managing transitions is therefore of prime concern to many people with an ASC, and there is concern that the impact on families and carers of transitions such as moving away from home into supported accommodation should also be more clearly addressed.

3.3.5 Information and awareness raising

One issue that comes up frequently (51 comments) is the lack of awareness of ASC among both public and professionals. This results not only in people with an ASC not receiving the support or care that they need, but also in insensitivity towards the condition across the board, from people in the street to service providers.

The fundamental problem is summarised by a carer:

> *….one of the greatest problems is that other people, professionals included, do not understand persons with an autistic spectrum condition, and in particular that communication is impaired. This is the very first hurdle to tackle, educating others. None of the other themes will work if information regarding how persons on the spectrum relate to others, attempt to comprehend the correct meaning of what is being said and respond appropriately unless this issue is addressed first. (Family carer)*

The difficulties with communication that result from ASC are likened to attempting to make a hearing-impaired person understand speech through hearing. ASC requires that other people have to learn to adapt the way they communicate, and that means understanding the condition and exercising tolerance. Questions are also raised about whether people with an ASC can socially include themselves: some argue that the onus is on others to accept and include them, and this requires much wider understanding of the condition.

This argument is reinforced for some respondents by the new figures suggesting that ASC affects many more people than was previously realised, and there are many calls for systematic attempts to increase public understanding of what it means.

> *There is a great need for General Public Awareness campaigns, like the National Autistic Society's 'I Exist' videos….. Such a TV campaign would need to be shown very regularly so that the subject of Asperger's Syndrome and Autism in general would be more likely to 'stick' in people's minds, just like the Anti Drink and Drive, or 'Kill Your Speed' campaigns. (A person with an ASC)*

It is argued that this subject is just as important as other government campaigns on health or safety issues, and the fact that such a campaign would need to touch people from all age groups and backgrounds, and would greatly increase general awareness of ASC. It would also ease situations where people with an ASC come into contact, and sometimes conflict, with others.

Particularly mentioned in this regard are the criminal justice and benefits systems, with which people with an ASC can sometimes become unintentionally entangled through incomprehension on their part and lack of understanding on the part of the officials involved. There are 36 comments about the criminal justice system and an equal number about the benefits system.

3.3.6 Access to healthcare and other forms of support

Access to healthcare and day-to-day support are issues of great concern both to people with an ASC and their carers (45 comments), and again, as mentioned above, worries about the future add to the stress with which they already live:

> *Without adequate professional support there is an over-reliance on parents to help with this and I am concerned about how I will cope with my life when my parents are no longer around to help and support me. (A person with an ASC)*

This is not the only form of care and support required, however, and there is concern that the emphasis on practical care and support is in danger of eclipsing the need for other forms of support. It is argued that emotional support, expressed and conveyed through, for example, advocacy, befriending and counselling, can make an enormous difference to people's lives and their ability to live independently. There are 42 comments specifically about emotional, spiritual and social support and guidance.

It can enable people with an ASC to talk about other aspects of their lives, such as spirituality, religion and culture and other issues which, if not discussed, can contribute to the pressures on them. It can help people with an ASC and their carers to cope, for example, with the pressures of relationships and parenting:

> *Need to ensure that health includes information on sexuality, sex and staying safe. People with Autism can find it hard to stand up for themselves and understand that some things that people do or say are acceptable and appropriate and some aren't. This stands for their own behaviour too - understanding what is appropriate and inappropriate. (ASC professional)*

3.3.7 Difficulty with diagnosis

Another issue that features in many responses (36 comments) is the difficulty of achieving a diagnosis of ASC in some localities, in part caused by lack of understanding of the condition among doctors and other health professionals. Respondents express their frustrations at achieving what seems to them to be quite straightforward:

> *Training should be given by individuals with ASD not neurotypical people going by 60 year old diagnostic criteria. They say autism is hard to diagnose. I disagree I can spot someone with Autism 200 yards away. (A person with an ASC)*

It is argued that a quicker route to assessment would ease much of the pressure placed on undiagnosed adults and their families when they are trying to gain access to the services they need.

Some professionals, however, point out that diagnosis is not always straightforward and that some people diagnosed with a form of schizophrenia or other mental health problems may in fact have an ASC:

> *Only a psychiatrist experienced in assessing both types of condition is able to 'spot the difference' in many cases as the presentation can often be subtle especially if the person has high intelligence. There is also the potential scenario that the patient has both ASD and schizophrenia/psychosis. In my experience, patients with ASD can present with psychotic-like symptoms due to overwhelming anxiety. A similar mechanism/process occurs in e.g. borderline personality disorder. (ASC professional)*

For these different reasons respondents would like to see more in the strategy about improving the whole process of diagnosis and assessment.

3.3.8 Dealing with multiple conditions

An issue stemming from the points above is the need to respond more effectively to those with multiple conditions, both physical and mental. This, it is argued, leads to people with an ASC being misunderstood and mishandled and can be extremely difficult for those suffering with such conditions.

While the emphasis here is on the mental health problems that people with an ASC may suffer, in other responses throughout the consultation the problem of related physical conditions is raised, and the danger of prescribing medication that has unintended effects on people with an ASC.

There is also a cautionary reminder that while the focus of this consultation is on ASC, other conditions that may create similar needs should not be ignored:

> *This should not just be about autism. It is ridiculous to be diagnosis-led rather than needs led. There are millions of other children/adults with learning disabilities who commonly also have autistic features and they are being ignored. (No sector selected)*

3.3.9 Personalisation of services and care

This leads in turn to another point that respondents are particularly anxious to communicate throughout the consultation: that ASC is indeed a spectrum, and that the individuals on it are unique, with each person having different talents and needs, abilities and problems.

This leads to the argument that there is no generic plan that will meet the needs of every person, and in fact the only answer is to invest in plans that fit the needs of each individual, and in services that have the flexibility to accommodate these plans. These points are made repeatedly and clearly by people with an ASC and by their carers:

> *We are NOT all the same, but are very individual and have different issues and difficulties e.g. Not all people on the Autism Spectrum struggle with eye contact. Girls as well as boys are significantly affected by Autism Spectrum Conditions. Some people on the Autism Spectrum are HYPER-sensitive to some types of sensory stimuli or environments, whereas other people are HYPO-sensitive. (A person with an ASC)*
>
> *The five main areas stated appear to cover most themes; whilst I can not think of another "theme" I believe it to be through person-centred planning that the individual's needs should be identified and invariably those needs will cross the demarcation lines. (Family carer)*

Many of them seem to feel, however, that these basic points are still not always sufficiently appreciated by those charged with delivery of services to people with an ASC.

3.3.10 Service provision

The policies and mechanics of commissioning and providing services are of particular concern to professionals and others charged with delivering care and support for those with an ASC. This begins, in the view of many professional respondents, with the need for more research and better data about the prevalence of different forms of ASC in each area.

This is seen as an essential precursor to effective commissioning of services, and for some it is sufficiently important to merit a place of its own in the strategy:

> *Commissioning, which is the key to the implementation of change, has experienced substantial difficulties. Commissioning is a gradual developmental process and information is vital to monitoring its achievements. It therefore merits being a theme in its own right including the issue as to how to acquire the information necessary to any strategy. (ASC professionals group)*

Another issue mentioned throughout responses to the consultation is multi-agency working, with emphasis being put on the need for different agencies to coordinate their activities and work together to ensure seamless provision.

3.4. If yes, are your suggested themes more or less important than the five key themes in improving the lives of adults with ASC? (This question corresponds to Q1b of the standard consultation)

478 people responded to this question.

It is apparent that whether people think their additional theme is more or less important than the five key themes already identified depends in large part on their personal situation or on the situation of the person or people for whom they are caring.

While about half of respondents to this question say that their additional theme is equally as important as those already identified, a relatively small proportion see their additional theme as more important. Of those who see their theme as more important, the majority focus on the aspects of everyday living that pose most problems, whether employment, education, housing or finance. Those who focus on education and housing are more inclined to see them as more important than other issues. Many respondents, however, prefer simply to explain their particular concerns in more detail.

A relatively small number of professional respondents see their additional themes as more important. The themes mentioned are transition issues, commissioning, social inclusion, and the problem of ageing carers of people with an ASC.

Some also point out areas of overlap both within the five themes and with their own, or suggest that some issues are so fundamental that they underlie others.

3.5. If you are involved in service delivery or commissioning, can you tell us about the costs, benefits and risks of the services you are involved in and what outcomes they have achieved for adults with ASC. Please provide details below. (This question corresponds to Q2 of the standard consultation)

312 people responded to this question.

Many respondents say that this question does not apply to them (107). Of those who do reply, many describe the services they are commissioning or delivering (107) without being specific about costs, benefits, risks and outcomes.

3.5.1 Costs, funding and resources

58 people talk about costs, funding and resources, with a number of ASC professionals providing examples of the costs involved in caring for adults with an ASC:

> *The annual costs can range from £25,000 to £166,000 per individual depending on the needs assessment with an average cost of £90,000. The weekly cost for someone needing 1:1 support at all times during the day and sleep night support would be £113,000 a year. (ASC professionals group)*

The variations depend upon the needs of the individual and the support he or she requires. Some people with an ASC require only minimal support in their homes while others need full residential care twenty-four hours a day. This can lead, according to some respondents, to misperceptions about how services need to be delivered:

> *Costs tend to be comparatively high for specialist services for people with ASCs. There is a common perception that needs are always best met by specialist providers, whilst the reality is that there are many good outcomes delivered by non-specialist providers whose staff have received good quality training. (ASC professionals group)*

Other respondents explain in detail what determines their costs. The response from one group, for example, says that their commissioning strategy advocates supported living to enable people to have person-centred support options.

This is regarded as more cost effective for some people than residential care services, though for others it is more costly due to the needs of the individual and improvements to the existing services. It does however allow for greater flexibility and consequent reductions in costs due to the development of skills, the reduction in challenging behaviour and increase in independence. Such costs can also be offset by greater access to benefits such as housing, higher rate DLA care and mobility allowances.

3.5.2 Benefits, including social, employment and other life skills

The general benefits of support to people with an ASC are listed by some respondents (25), with some, including professionals, carers and people with an ASC themselves surprised by the outcomes achieved. With support and advocacy, for example, people with an ASC are studying at colleges and universities and holding down voluntary and paid employment.

They are also becoming more involved in mainstream activities:

> *…a significant proportion of service users who were identified to be the most isolated and vulnerable are now socialising, rock climbing, attending concerts, football matches, going down to the pub and going on holidays without their family for the first time. For specific service users [there have been] decreased signs of depression, anxiety and self harm. (ASC professionals group)*

It is also argued that this approach encourages people with an ASC to express their needs, raise concerns about services and engage actively in the review and development of their support plans. The use of risk assessments also decreases the vulnerability of people with an ASC to exploitation and abuse, which in turn enables them to integrate better into local communities.

There are responses that have less positive experiences to relate, for example:

> *Unfortunately we also have too many students who haven't been able to progress because supported work is hard to find and there are almost no other services offered to young people on the spectrum when they have left full time education. (ASC professional)*

One debate throughout responses to this question is about the comparative advantages and disadvantages of different approaches to independent and sheltered living from the commissioners' points of view.

Those advocating supported living argue, for example, that it offers more flexibility and responsiveness, with people with an ASC living nearer to their families, while owning their own homes can give them greater legal and financial security. They also argue that it enables people to choose who they live with and means they do not have to share their accommodation with others whose behaviour may affect them negatively. This approach also encourages specialist providers to move into local areas and develop new services.

Another area of benefit mentioned is that of diagnosis. A number of professionals assert that providing a diagnosis of an ASC can not only enable people to seek and achieve the services to which they are entitled, where available, but can resolve doubts and uncertainties for both the person with an ASC, leading to a sense of relief and a new understanding of themselves and their identity, and for their families and carers.

3.5.3 Risks

Respondents describe a wide range of risks, including both the general and the specific, for people with an ASC, for their carers, and for commissioning authorities.

There are the financial risks for social care commissioners, for example, of taking responsibility for young people at the time of transition to adulthood, particularly those who have been in specialist provision. Mental health services can be reluctant to take the risk of engaging with some people with associated learning difficulties. There are the risks faced by people with an ASC in court, where they may be remanded in custody because there is a lack of screening for ASC.

There is also the more general risk of raising the expectations of people with an ASC, and their families and carers, that will not be delivered because of financial stringencies.

Some respondents identify the risks of not doing things, as well as doing them. There are the risks of not providing the right services, leading to discrimination and harassment from the community, sectioning under the Mental Health Act, extreme social isolation, development of mental health concerns, and decreased quality of life due to restrictive environments. There are the risks of not diagnosing correctly people with specific types of ASC, such as Asperger's Syndrome, leading to them developing mental health issues.

Other risks mentioned are more institutional or a consequence of the wider environment within which ASC occurs:

> *The big risk is that services for adults with autism will continue to be funded using the same model as that for people with learning disabilities. It is hoped that the new prevalence studies will tease the two groups apart in an effort to get support right for both parties. A final risk relates to the numbers of adults with autism being supported at home by their parents. We support many such people around the country providing outreach services. Unfortunately, this type of support is unsustainable due to the ageing population of parents. It seems that many parents choose to support their own children in to adulthood due to the lack of suitable and specialised service provision locally. (ASC professionals group)*

Some respondents describe in detail the risks associated with working with people with an ASC, such as ensuring compatibility if someone with ASC has to share living space with others. Others are concerned about the risks involved with working with 'experts' who are less expert than they should be:

> *We are aware that a number of providers claim to be 'experts' in ASC. When we have been commissioned to provide some of these organisations with training, however, we find that they have little knowledge of the condition. Claims about expertise need to be evaluated. (ASC professionals group)*

3.5.4 Personalisation of services

Some respondents (25) provide lengthy and detailed case studies that describe the outcomes for individuals with an ASC which emphasise the extent to which services need to be personalised if the best outcomes are to be achieved. The common elements in many of these stories are the combination of a diagnosis of ASC, moving to an appropriate physical environment and having a well-trained and competent staff team who understand precisely the type of support required.

A number of respondents believe that the focus on outcomes may in some circumstances be misleading unless they are documented by service users rather than service providers:

> *Autistics should be the ones to say whether or not a service has worked for them. Also, autistics should have more say not only in what services they receive but in the*

> *delivery and running of those services. Asking people involved in service delivery and commissioning to comment on what they provide may well lead to inaccurate and biased responses as the people involved want to keep getting government funding and want to keep their jobs! (A group of people with ASC)*

It is apparent that for respondents the achievement of the best outcomes relies heavily on people with an ASC being able to gain access to the specialist services or appropriately tailored mainstream services they need. When this happens they move towards independence, if that is appropriate, and may find the education and employment that will enable them to flourish. Their and their family's health and general wellbeing improves as they receive better information, advice and support.

3.5.5 Improved skills, awareness in staff and wider professions

Another outcome of value to people with an ASC mentioned by some respondents (21) is the improvement in skills and awareness of ASC generated by the services they commission and deliver.

The specific benefits mentioned include annual multi-disciplinary training on ASC offered to carers and parents. They also encompass improved multi-disciplinary work within a health team, the setting up of a Special Interest Group to consider broader issues for ASC and contributing towards diagnosis of ASC and differential diagnosis to help define the levels of service provision. Other benefits can be: providing training for carers and staff facilitating more effective support of the individual with ASC; and the comprehensive assessment of communication and social skills of individuals and provision of appropriate intervention.

The benefits of multi-disciplinary working are mentioned by several respondents. One describes, for example, a committee of workers from housing, mental health services, learning disabilities, the local service users network, adults with an ASC themselves, and staff who understand the condition and work positively with it. This respondent also notes, however:

> *…..the invisibility of our work to commissioners and the absence of a primary care assessment and diagnostic service that GPs can refer to in order to deliver equality of health care for adults with AS/HFA. (ASC professionals group)*

3.6. In your experience does ethnicity, gender, disability, age, sexual orientation and religion or belief have an impact on how adults with an ASC access and experience services and the quality of outcomes? Please highlight any measures we can take to reduce adverse impact and promote positive impact. *(*This question corresponds to Q3 of the standard consultation)

560 people responded to this question.

Many although not all respondents are aware of differences in access to, and experience of, services for people with an ASC. Where respondents are aware of such differences, the ones most often mentioned are age followed by gender, ethnicity (which is often combined with religion or belief) and disability. Awareness of sexual orientation as a source of different experience is relatively limited.

3.6.1 Age

Age is certainly regarded as one of the key determinants of whether people receive the services they need. It was identified by 105 respondents.

> *Treatment seems to be focused on children and young people and any available service targeted towards them. As an adult (especially female) getting a diagnosis is extremely challenging, and no or very little access to services/ support/ therapy is available. (A person with an ASC)*

The experience of many respondents is that ASC is less recognised in older people for a number of reasons. Diagnostic methods, for example, tend to rely on descriptions of childhood behaviour, and the older a person is the less vivid and well remembered this may be. The fact that ASC was less well recognised or understood in the 1970s and 1980s also means that fewer older people have been diagnosed, and there is generally less experience of diagnosing ASC in older people.

3.6.2 Gender

There is also concern among respondents (90) that ASC may be being under-diagnosed in women, and again there is speculation about why this should be. The belief that ASC is more prevalent in men than women may lead some clinicians away from a diagnosis of ASC, and this may in turn lead to the perpetuation of the belief and the further under-diagnosis of women.

There are other reasons why there may be some gender discrimination in diagnosis:

> *The diagnosis of women with ASC appears to be more difficult as a result of them having a greater social awareness; the descriptions of ASCs in diagnostic guidelines favouring male diagnosis. There is some evidence that women with ASC are more likely to be diagnosed with personality disorders. (ASC professionals group)*

It is also argued that girls and women can display different kinds of problems and may not immediately present the sort of symptoms that are deemed typical of an ASC; this leads some to believe that there needs to be more awareness of ASC as a disguised disability.

Similarly it is suggested that the differences between men and women as they relate to ASCs are not fully appreciated:

> *The statistics say 4:1 male: female with ASC. The experts think it is more likely to be 2.5:1, which suggests serious under diagnosis. Personally I think the numbers are to equal! I know several members of my family that I am fairly sure have an ASC and it is*

> *simply due to lack of understanding of how the condition manifests in women. (A person with an ASC)*

A number of respondents suggest that women with Aspergers are often misunderstood and undiagnosed, perhaps because they are better at hiding their condition, and because every individual experiences it differently.

3.6.3 Ethnicity and culture

A number of respondents are equally concerned that ASC is being under-diagnosed in BME communities (80), and again there is speculation about why this should be:

> *There may be cultural or religious reasons why BME adults with ASC are less likely to access services – perhaps because ASC may not be recognised as such in some communities, because some family carers are more likely to wish to care for adults with ASC within their own communities (or are perceived to do so by local services), or because there is little information about ASC in community languages. (ASC professionals group)*

It is suggested that BME people with an ASC may also suffer from racial stereotyping by local services, with their behaviour more likely to be seen as challenging, but some respondents believe that cultural difference can as easily lead to over- as under-diagnosis:

> *Lack of familiarity with an individual's culture (whether that culture is derived from ethnicity or sensory impairment) brings the risk that the assessor will misattribute behavioural anomalies. This can happen in both directions: a cultural behaviour being misattributed to ASC, and vice versa. This can result in both over diagnosis as well as under diagnosis of the ASC. (ASC professionals group)*

It is argued, in the light of this, that it is essential that any assessments involve informants familiar both with the individual and with his or her culture. It is also important to appreciate that a person's ability to seek help, and perhaps refuse inappropriate services, may be influenced by his or her social class as well as ethnic and religious background.

3.6.4. Disability

As regards discrimination due to disability, responses are somewhat confused as some respondents see ASC as a disability and comment on its effects while others assume the question refers to forms of disability such as loss of sight, hearing or mobility.

This aside, the impression is that some disabilities can act to overshadow ASC:

> *I have encountered instances where it isn't picked up in deaf or blind people or is recognised later, and there do seem to be situations where it isn't picked up in association with ADHD or dyslexia. My experience of this is observational - disability*

> *support and working on disability related committees, rather than direct contact with individuals, except in one case of impaired hearing. (A person with an ASC)*

Disabilities causing lack of mobility can also, of course, limit people's ability to gain access to services, and this in turn leads to de facto discrimination. It can also, as one respondent suggests, have the opposite effect:

> *Having an accompanying learning disability can actually be positive in enabling adults on the autism spectrum to get a service. (ASC professional)*

3.6.5. Sexual orientation

The question of whether sexual orientation has an impact on how adults with an ASC gain access to and experience services is addressed by relatively few respondents (15), but those who do mention it are clear that this affects people with an ASC in diverse ways and is another area that needs more attention.

> *Homophobic abuse is often used in bullying situations and this will be very confusing for people with an ASC. Gay people with an ASC may have their differences attributed to their sexuality. Social skills training may not be able to give appropriate relationship support. There may be problems relating to social gender roles. (A person with an ASC)*

Among professionals there is some belief that more people with an ASC will define themselves as bisexual than among the general population, perhaps because they may be less constrained by social convention and concerned about what others think and so less likely to say 'heterosexual' when they define themselves as bisexual.

It is argued that services need to be aware of this, and have their staff trained to understand the additional problems this may cause a person with an ASC, for example:

> *There seems to be a lack of specific services for those with an ASD, like me, who are of a non-heterosexual orientation. As a 'lesbian' there seems to be nowhere to go where I can feel comfortable to deal with my sexual identity. It is hard enough to make and find relationships, but it is made harder still if one is autistic lesbian, gay, bisexual and transsexual to meet with one another. At present there seems to be no such group. (A person with an ASC)*

3.6.6. Measures that can be taken

As regards the measures to address all these potential sources of discrimination, inadvertent and otherwise, the most frequent answer from respondents here, as in the responses to many other questions, is a call for more and better training for professionals and awareness raising for the general public.

There are suggestions for how this should be done, starting with a fundamental belief in the importance of equal opportunities and an understanding of the complexities of ASC, because it is only with a good understanding of ASC that it is possible to understand how other issues, such as religion or ethnicity, may affect an individual. This is a precondition, it is argued, for ensuring that an individual's ethnicity, religion or sexual orientation does not impact on the quality of support they receive.

It is also suggested that at times interventions will have to be specific as well as general, for example:

> *Due to misunderstandings that can develop between neighbours and [place] tenants the importance of an understanding and supportive local community police service has been invaluable in mediating and diffusing disputes. For example, one resident has an obsessive love of mini-coopers and spends time looking out of his bedroom window at the traffic, counting minis. Neighbours thought he was looking at children in their gardens and were concerned he was a paedophile. (ASC professionals group)*

It may also be necessary to develop measures that target specific parts of the population:

> *In the Asian community there is lack of knowledge and understanding of Asperger's Syndrome or autistic spectrum disorders which may be due to lack of English on the parts of mothers/grandparents/family etc. Some forms of disability may not be acknowledged e.g. OCD, depression, anxiety etc. which may go hand-in-hand with Asperger's syndrome or autistic spectrum disorders. One way to raise awareness is through temples etc. where the community meet up or through ethnic minority newspapers/articles/radio/TV or setting up helplines through certain radio programmes in minority languages. (Family carer)*

The other measures mentioned to address these problems focus on the better provision of services and more support for people with an ASC.

3.7. Easy-read consultation questions on the overview chapter

There are five areas where we think we need to make changes to make life better for adults with autism. These are:

- ***helping adults with autism where they live. This may mean help with things like finding somewhere to live, help with travelling where they need to go and help to do things in their free time***
- ***making healthcare better for adults with autism***
- ***adults with autism choosing the services and support they need***
- ***helping people like doctors, social workers, teachers, the police and housing officers to understand more about autism***
- ***helping adults with autism get jobs and training.***

3.8. Are there any other areas that you think we need to include?

(This question corresponds to Q0a of the easy-read consultation*)*

Group	Count	Proportion
Yes	138	58%
No	94	39%
No answer	6	3%

3.9. If you answered yes, please tell us what the other areas are.

(This question corresponds to Q0b of the easy-read consultation)

238 people responded to this question.

Just over half the people who answered this question say there are other areas to be considered, though many of the issues they raise are covered under the five areas. Some people simply want to emphasise issues that they think are particularly important.

3.9.1 Public and professional awareness raising

The issue most identified is the need for awareness raising both among the public at large and for professionals who may come into contact with people with an ASC.

> *We need to raise awareness of the Autistic condition and indeed other syndromes such that those affected can be more included within the society in which they belong. (Family carer)*

It is argued that allowances are made for lots of disabilities in the public arena but few for people with an ASC, and there is particularly little awareness of sensory problems (which can be an issue). Businesses as well as the general public need to be more informed on these issues.

Among professionals it is people who work in the wider mental health field, as well as General Practitioners, who are often most singled out for needing greater awareness of ASC.

> *Psychiatrists and other professionals and support workers in the 'mental health' field need to be a lot more ASD aware. (ASC professional)*

Professionals from the social services, police and other public services who also come into contact with people with an ASC need to be made more aware, in particular, of how people with autism react and behave when their senses are overloaded, for example:

> *The NHS needs to have specific rooms for them with the correct type of lighting, noise reduction and whatever else may cause sensory overload as most people with autism may not be able to be treated on a main ward. (Family carer)*

3.9.2 Diagnosis and assessment

Another area that people feel is missing from the five areas, and which follows directly from the awareness raising mentioned above, is that of diagnosis and assessment.

While these may be considered by some to be part of awareness raising, others regard these as vital and needing to be recognised separately because on them hinges so much else:

> *Getting a diagnosis in the first instance does not appear in your list of 5 areas. Part of your strategy should be geared towards having a clear and easy accessible route to a diagnosis, particularly for Adults outside the school education system. This route should be visible and clear to parents/carers, persons with autism, health professionals, G.P.s and teachers. (Family carer)*

One of the suggestions is that a national network of diagnosis centres, to which people can self refer, be established. The reasoning behind this is that diagnosis at present is a long and lengthy process, and incorrect diagnoses by psychiatrists, for example, can result in people being treated for schizophrenia or other mental illnesses with powerful drugs.

3.9.3 Access to care and support

Another issue for many people is access to and assistance with all kinds of services, from simple everyday help, through education and employment, to financial benefits, support groups and social activities.

While these are again mostly covered by the five areas identified, the importance of such access is emphasised repeatedly, and many people explain in detail why particular issues are important, for example:

> *Assistance with day to day skills like feeding and cooking their meals, getting dressed, toileting, bathing, brushing their teeth, haircuts etc (Family carer)*

It is suggested that achieving access to such services is sometimes only possible for people with an ASC with the help of professional advocates who need to be fully trained in the various laws relevant to the care and protection of vulnerable adults.

This needs to be coupled with more general support for families and carers, and help for people with an ASC who come into contact with institutions such as the criminal justice system. Two further areas where care and support is particularly required are the workplace and education.

3.9.4 Access to employment and support in the workplace

While getting a job is a considerable achievement, maintaining it and thriving in the workplace can sometimes be difficult for people with an ASC. There is support for the idea of advocates and mediators who can help to sort out workplace problems, for example.

Their role would be to help resolve problems arising from communication and other difficulties. They could explain to people with an ASC what is expected of them and where they might be going wrong, and to employers and colleagues the problems that people with an ASC may have and how they can be overcome.

This sort of initiative would encourage people with an ASC to try to enter the workforce, would help employers to offer suitable jobs, and would help other employees to accept a new colleague with an ASC.

3.9.5 Education

The importance of education for people with an ASC is emphasised throughout responses to the consultation. It is regarded as particularly important that people with high-functioning autism and Aspergers should be supported to go to college or university if they wish to.

It is argued that the school system needs to be more flexible about the needs of these students by, for example, giving them more time for examinations and having an assistant to time their answers so they know when to stop answering a question and continue with the next.

There is concern that some teachers tend to lower their expectations for students with an ASC, while others do not offer support because they do not consider them in any way disabled.

3.10. If you answered yes, do you think the other areas you have included are more or less important than the five main areas? (This question corresponds to Q0c i of the easy-read consultation)

Group	Count	Proportion
More important	40	29%
Less important	1	1%
About the same	94	67%
No answer	5	4%

3.11. Why do you think this? (This question corresponds to Q0c of the easy-read consultation)

140 people responded to this question.

In response to this question some people say more about the additional issues they have identified, though they do not always explain what exactly has led them to their conclusions, while others argue why they think some issues should be regarded as particularly important.

3.11.1 Social inclusion

The need for more social acceptance and inclusion of people with an ASC is the issue most frequently mentioned, albeit by a relatively small number of respondents (13).

One family carer, for example, explains why social activities are particularly important for people with an ASC:

> *I think helping adults with autism socialise is extremely important because research shows that many of them with higher functioning autism often suffer with mental health problems because they are made to feel different and because they are lonely and isolated and desperate for friends and desperate to be accepted. (Family carer)*

3.11.2 Awareness

Some of those who think better awareness is particularly important argue that unless care staff and other professionals including the police have a thorough understanding of people with an ASC, problems are inevitable and can seriously affect the person's quality of life, even causing them to lose their placement in a home or on the job training, for example.

Awareness raising is also vital to secure early intervention and the necessary care and support:

> *I fully believe that all people with autism should be given the best possible support, but it does not need to wait until they become adults. Frequently by that time they will be*

> *incapable of any great achievement, but if their difficulties are dealt with at as early an age as possible and if the people who care for them, both professionally, like teachers, and at home, are given the information and the tools to help them, the outlook for them when they become adult could be totally different…. (ASC professionals group)*

3.11.3 Support and care

There are other examples of why those who respond emphasise particular issues. The need for consistent support is one reason why people emphasise social care:

> *Because people with ASD need consistent, reliable support in all areas not a mismatch of good and bad support, it simply confuses them more. (Family carer)*

Another is simply the absence in some areas of any support for people with an ASC and those who care for them:

> *Because there doesn't seem to be any help for people living caring for somebody with autism and it is a 24/7 job which is exhausting. (Family carer group)*

3.11.4 Diagnosis

Diagnosis is regarded as fundamentally important because, it is argued, there is no point in improving the advice and support available if those in need of it are unable to have access to it because of an unclear or obstructive route to diagnosis, or because the route into getting advice and support after diagnosis is unclear or there are obstacles to it.

3.11.5 Discrimination and exclusion

Discrimination also needs to be taken more seriously because it prevents people with an ASC enjoying a full life as part of mainstream communities. Some of this relates back to the point about awareness raising:

> *People think that Autistic people are being rude or arrogant and ban them from cafes, pubs, cinemas etc. They call the police who also believe the autistic person to be arrogant, rude etc and then arrest them for a public order offense. (No sector selected)*

3.11.6 Help with finance

More help with finance needs to be provided because red tape and form filling can present serious difficulties to some people with an ASC and effectively prevent them from gaining access to benefits and other forms of financial support.

3.12. Are you involved in giving or buying services for adults with autism? (This question corresponds to Q0d of the easy-read consultation)

Group	Count	Proportion
Yes	59	27%
No	161	73%
No answer	1	0%

3.13. If you answered yes, please tell us what these services are and how they have helped adults with autism. (This question corresponds to Q0e of the easy-read consultation)

221 people responded to this question. The great majority (161) of people answering this question in the easy-read document are not actively involved in giving or buying services for people with autism.

3.13.1 Social care and support

The majority of the 59 who answer ‘yes’ to this question are involved in delivering care to people with an ASC, including providing social care and support, enabling people to maximise their independence, and working with others to enable this to happen, for example:

> *We give a full care service 24 hours a day 365 days a year. We buy education such as courses and materials. This has enabled people to learn new skills, visit new places, meet new people, do normal things. We buy fitness and social activities such as the use of the local swimming pool, gym, keep fit class, trampolining and bowling alley. (ASC professionals group)*

Half of these deliver care as parents or family members, for example:

> *As a divorced single parent of a self funded adult with Autism I give as well as buy services. As primary care giver for my daughter I have had to wear many hats, not least of which being an "expert" in Autism to communicate her needs to professionals in education, GP's, social workers and her mental health community team. My services are free but would appreciate recognition and more support. My daughter would not survive without me. (Family carer)*

3.13.2 Education, teaching and mentoring

Some respondents are involved in areas such as education, for example getting support for people with an ASC to attend colleges and other institutions so that they do not fail but have a worthwhile and fulfilling experience.

The experience of caring for a family member with an ASC can also lead respondents into a wider role:

> *My husband was diagnosed with Asperger's Syndrome at the age of 56 and suddenly everything about his life made sense. I have now become an expert in the condition and am mentoring students with Asperger's Syndrome. I have been able to advise their teachers on how best to manage the students' education and what they can and cannot expect from the students. (Family carer)*

3.13.3 Social and leisure activities

The range of social activities organised by professionals and volunteers is very wide, for example there are adult evening groups that alternate monthly between discussing issues, problems and learning to understand ASC and going out for social activities including meals, pub quizzes and bowling, and daytime groups that organise excursions to galleries and theatres.

Respondents say that such groups are of significant benefit to participants, many of whom find friends for the first time in their lives as well as allowing them to explore a wide range of issues and concerns in a safe setting**.** Book clubs can have a similar value:

> *The club allows the members to share their thoughts and understanding about a variety of different genres in a safe and supportive environment. This is valuable and enjoyable of itself but it also allows for amazing insights into the core diagnostic aspects of AS and has facilitated some incredible learnings about what it means to have AS. "It has really shown me how Neurotypicals view things so differently." "I have learnt more about my Autism through reading these novels together with this lot [others with AS] and the two neurotypical facilitators than through any social skills training or Autism book I have previously read"' The book club and film club and cooking sessions all allow those with AS to learn through 'real experiences' and this seems a far more effective way to effect positive change and integrate new learning. (ASC professionals group)*

Some of the services provided to people with an ASC seem to rely not on any form of institutional support, but on basic kindness and neighbourliness such as, for example, helping a socially isolated person with an ASC to obtain payments to employ a personal assistant to accompany her on outings to garden centres. This both reduced her isolation and counteracted the signs of agoraphobia which would have led to more problems.

3.13.4 Therapy and counselling

Counselling, coaching and mentoring are other ways that people help to meet the needs of those with an ASC. One-to-one Asperger Specialist Coaching and counselling is mentioned as being of significant benefit as it is person-centred and tailored to meet the individual’s specific needs.

One respondent reports its value as follows:

> *"Builds self esteem and develops strategies to overcome or compensate for my particular difficulties." “Develops skills and self awareness and understanding of 'the other'.” "There is now one person I can turn to who understands how to help me"'*

> *"Changes and turns the negativity you have carried since you were a child to a positive'" "Helps with my anxiety'" "Get another perspective on your problems'" (ASC professionals group)*

3.14. Do you think that some adults with autism get better services because of who they are? For example, because they are a man or a woman, because of how old they are, because of their religion or their race because they are gay or lesbian or because they have other disabilities as well as autism. (This question corresponds to Q0f of the easy-read consultation)

Group	Count	Proportion
Yes	104	52%
No	91	46%
No answer	5	2%

3.15. If you answered yes, how do think we could make services better for all adults with autism and not just for some adults with autism? (This question corresponds to Q0g of the easy-read consultation)

200 people responded to this question.

The people who answered this question are fairly evenly divided on the issue of whether some people get better services because of who they are. The majority of those who do think it makes a difference do not explain how services could be made better for all adults with an ASC.

3.15.1 Improve overall access to services

Of those who do put forward ideas for improving services, the majority say that the answer is simply to provide proper services for all. Those who discuss the effect of differences tend to focus on how different degrees of ASC result in different levels of services, for example:

> *As previously mentioned, I feel that Autistic people at the more able end of the spectrum have less help, support and resources than more severely affected adults. These are the people who can live and work in the community and there isn't support to help them do this. Particularly with speech and language issues. (Family carer)*

3.15.2 Age

There is also some perception that more is available for younger people, and that the level of services available varies from area to area:

> *The term "post-code lottery" is as applicable here as in almost every part of NHS/Social Services, but in addition the young, the otherwise disabled, the more*

> *severely autistic etc. will receive more help because they can access other departments of services. (A person with an ASC)*

3.15.3 Gender

Some feel that it is harder for women than men to be diagnosed with an ASC. It is perceived, for example, that women with an ASC are not recognised as easily by services and professionals as they present themselves very differently to men and feel they are more likely to be misdiagnosed with depression, anxiety or premenstrual tension rather than with an ASC.

3.15.4 Disability

The presence or absence of an advocate can also make a difference, as can the presence of more obvious disabilities:

> *Those adults who have advocates are more likely to have needs recognised. Also if they have other disabilities, those disabilities are more easily seen so those people are more likely to get some help. (Family carer)*

On the other hand, other disabilities can lead to autism being ignored, particularly if it is visible. Please note responses on specific consultation themes are shown from Chapter 4 onwards.

4. Social inclusion

4.1. Summary of responses to this chapter

This chapter covers responses to questions about problems that adults with an ASC can face when trying to access the support they need to live more independent lives or become more a part of the community in which they live. Respondents are asked whether they agree with four key areas for improvement that were identified prior to the consultation (strengthening local leadership, improving data collection, improving access to community care, and improving access to housing). They were also asked to indicate which actions should be taken to address concerns and to give examples of challenges and solutions they have encountered.

4.1.1 Main issues

There is broad agreement among respondents that the key areas identified are the right ones. Numerous accounts underline existing challenges in these areas and emphasise the need for action. Respondents draw attention to how people with an ASC can fall into the ‘gap’ between learning difficulties and mental health, and end up not being eligible for the services or support appropriate to either. Respondents believe it is crucial to improve data collection in order to tailor local services to (very diverse) individual needs. There is also a need for leadership and accountability at a local level. The importance of recognising individual needs is reflected in responses about housing, transport and other public services and spaces. There are comments, for example, about the sort of housing that is suitable for people with an ASC. Many responses emphasise the importance both of raising awareness of such needs and of the training and resources that should be made available to meet them.

4.1.2 Examples of challenges

In a wide variety of comments respondents describe both the problems with social interaction and participation adults with an ASC are facing, and the lack of support many are experiencing with regard to engagement in meaningful activities. Part of the problem is that people with an ASC are often not (made) aware of the services available.

4.1.3 Actions to be taken

The action most people believe will help enable this is the establishment of local multidisciplinary ASC teams taking a lead on the provision of services. They should ensure that adults with an ASC are eligible to receive the services they require and that these services are provided adequately. In order for the services to work, professionals should receive training and resources should be made available.

4.1.4 Examples of solutions

While there are numerous examples of positive experiences thanks to training or awareness raising, support groups and local ASC teams, many people state that they cannot provide an example of a successful intervention.

4.2. Standard consultation questions on social inclusion chapter

The external reference group identified the following as key areas where action is needed to improve social inclusion:

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

4.3. Do you agree that these are key areas where action is needed to improve social inclusion for people with an ASC? (This question corresponds to Q4a of the standard consultation)

Group	Count	Proportion
Yes	599	86%
No	15	2%
Unsure	41	6%
No answer	38	5%

4.4. Please explain your answer. (This question corresponds to Q4b of the standard consultation)

693 people responded to this question.

There is broad agreement that the key areas identified are the right ones and where a lot of work is needed, and the majority of responses provide insight into what needs to be done under each.

4.4.1 Minding the gap – learning disability and mental health

Many respondents (128) uphold the notion that adults with an ASC are at considerable risk of ending up in the gap between services for people with learning difficulties and mental health services. There are numerous examples, provided by professionals, people with an ASC and their carers, of situations where adults with an ASC cannot access the support they require due to this gap. Among respondents there is a strong sense that the criteria used to determine whether people qualify for services are unfit for adults with an ASC, resulting in poor outcomes: an adult with an ASC either receives inappropriate services or none at all. This has led some to believe that ASC should be considered a separate category, in addition to learning disability and mental health.

> *My adult AS son has constantly, over the years, been tossed between learning disability and mental health. I have often said, and still believe, that those with ASC should belong to a category of their own as they do not necessarily belong to either LD or MH. It is of no benefit for someone with AS to be in the same unit as people with a far less IQ than themselves (i.e. a learning disability) nor with people with a severe mental illness (e.g. a psychotic condition). (Family carer)*

> *I have personal experience of the 'gap' between mental health services and learning disability services and have yet received NO support from any NHS services despite the efforts of myself, my family and my GP (who has referred me to three hospitals: two have not responded and one admitted it was unable to help). (A person with an ASC)*

There is a further line of argument that ASC need be neither a learning disability nor a mental health problem if it is diagnosed early enough and the person provided with the necessary care and support. If it is diagnosed later in life, however, then it can cause mental health problems such as depression, anxiety and stress.

It is also argued that some people are more likely than others to fall into the gap between learning disability and mental health services. Those less severely affected by autism, for example, may be more likely to fall into the gap because their problems and disabilities can be quite subtle and not immediately recognised by health professionals such as general practitioners. This point is made in comments from all types of respondents.

> *We are very aware that many ‘high functioning’ adults with Asperger Syndrome fall through the gap between learning disability and mental health services. This seems particularly marked in regards to accessing social care. (ASC professionals group)*

Another reason why high-functioning adults with an ASC are most likely to encounter the gap between learning disability and mental health services is that their IQ disqualifies them from any learning disability service. Respondents raise the issue that criteria for access to services are not designed to take ASC into account in 36 comments:

> *There are an increasing number of individuals who do not meet the criteria for accessing the learning disability or mental health services and for whom there is currently no service provision. (ASC professionals group)*

Some respondents suggest that there is a lack of readiness among organisations and professionals to take on care and support for adults with an ASC:

> *Mental health teams try to avoid any involvement if at all possible and unless there is a significant associated learning disability LD teams also tend to avoid picking up cases if they possibly can. (ASC professional)*

A few comments however acknowledge that it is not easy to properly identify the needs of adults with an ASC, thus avoiding the gap:

> *The gap between learning disability/autism and mental health is a very complex one. Professionals find it hard to decide whether new difficult behaviours are the result of the ASC or a mental health need. (No sector selected)*

It is even suggested in one comment that the gap is based on a misunderstanding:

> *Is there really a gap between learning disability and mental health for Asperger syndrome adults? I don't believe there is. Many A/S adults have a range of complex mental health problems - these stem from the single cause - social exclusion - the inability to integrate or build up a support network. (Family carer)*

There is considerable debate about 'the gap', whether it provides a useful backdrop to the provision of services, or whether there is a danger of polarising the diagnosis of ASC into 'low functioning' and 'high functioning' when the reality is that the functioning of some individuals may fluctuate right along the spectrum in the course of a single day according to context or environment.

Many respondents describe how the gap and the resulting trouble accessing services have done damage to the lives of adults with an ASC and the people who care for them.

> *It isn't just that there is a big gap between learning disability and mental health, you have to manifest a problem big enough to justify treatment before you can access any help. So you can have Aspergers, and the problems identified with Aspergers, but have ZERO recourse for help, because you haven't got a clinical problem with it. This applies right across the questionnaire. (A person with an ASC)*
>
> *As long as people continue to fall through the gap between services they will continue to be isolated and misunderstood. (ASC professional)*

As regards the solutions to the gap problem, there is widespread agreement that leadership and accountability are very important, and this should mean that there should be someone in every area with an in-depth knowledge of ASC conditions who draws together all information and resources and acts as a key contact point for professionals, carers and people with an ASC.

> *Local Leadership: the critical issue of falling between the gaps between learning disability and mental health can be addressed by developing close links such as joint appointments between the two services and with clinical professionals in service providers. (ASC professionals group)*

This sort of local leadership would be particularly important in ensuring that people with an ASC do not fall between different services during the most risky periods in their lives, such as the transition from children's services to adult services. It could also prevent problems such as parents finding themselves without support when the close relationships they may have developed with paediatricians, for example, cease when the child turns 18.

The focus on leadership and accountability could also be complemented by more multi-disciplinary working:

> *There needs to be a multi-disciplinary commissioning and planning group established including commissioners, family carers, Local Authorities, PCT's, Learning Disability Services and Child and Adolescent Services to take the work forward. (ASC professionals group)*

4.4.2 Improving data collection and research

The importance of data collection is emphasised in numerous responses (134) to this question, with many emphasising that the availability of reliable data is a prerequisite for dealing with the other issues in this chapter. This would have to start with knowing the numbers:

> *Firstly, we need to know how many persons have autism so that services can be tailored appropriately for them. (Family carer)*

Professionals, people with an ASC and carers agree that proper collection and storage of data about adults with an ASC is at present non-existent, although some progress is being made thanks to the systematic tracking of young people with an ASC. Yet, while local authorities are responsible for planning and commissioning services, they often do not know how many people with an ASC may be requiring these services.

> *People within the authority who have an ASC, particularly those who are higher functioning or have Aspergers, are largely unknown to services and this means it is impossible to know the extent of the needs of the client group and potential demands on services which has a knock on effect into planning and commissioning. (A mixed group of people)*

There are a range of comments about how data should be gathered, and from whom:

> *The needs of local populations should be locally defined based on consultations with people with an ASC, their families and services who support them, rather than nationally defined broad directives. To ensure that we are providing appropriate services for the people who need it, there needs to be clearly defined pathways mapping the service provision for those with an ASC throughout their lives - from diagnosis to old age. (ASC professionals group)*

One concern is that information should be gathered from a range of sources, such as professionals, carers and other family members as well as from people with an ASC themselves to ensure that the information fully reflects needs and concerns. It is highlighted in several comments that data collecting processes will need innovation, as asking people with an ASC to complete a questionnaire is likely to produce inappropriate data:

> *There is a readiness to think that everything can be solved by data collection. What the database owners appear to forget is that the data collected needs to be appropriate. (No sector selected)*

> *I think it's well known that adults with an ASC often do not themselves understand their plight in any depth, nor their vulnerabilities. In addition, they are likely to paint things in a too-positive light, and most worryingly, they are likely to invent and harbour odd (to us) but fully justified (to themselves) reasons for NOT mentioning one or more facets of their thoughts, their beliefs, their fears etc. (Family carer)*

It is self-explanatory that if the data obtained from individuals was found to be unreliable, so would the total figures be, leading to an imperfect allocation of resources to services.

It is also emphasised in many comments that data about adults with an ASC should include more detailed information about a person’s condition, as there is a wide variety in the individual needs from one person to another:

> *Robust data collection is a primary requirement to assess how many people may require these services. This data will undoubtedly show that people on differing areas of the Autistic spectrum have varying service requirements, so it is important that services are layered, as opposed to compartmentalised. (A person with an ASC)*

Information sharing between service providers comes up in a number of comments, with respondents sometimes wondering why this is not undertaken more thoroughly:

> *I was shocked that there was little coherent collection of data from children’s services to adults services, or proper assessment of future needs. It would be very easy for residents to fall through the net after they left school, and very hard for families struggling to cope. (No sector selected)*
>
> *Service providers need to show joined up thinking and share information to help with forward planning. (A group of family carers)*

There are also comments about the data recording systems that local authorities work with, which some respondents believe are inadequate and make it more difficult to properly record the individual needs of people with an ASC:

> *SWIFT and other electronic recording systems currently in place do not allow the user to effectively reflect service user needs. Care managers are making the information fit the system rather than the system gathering this much needed information. (A group of ASC professionals)*

The following comment, from a mixed group of people, neatly summarises why many people agree that data collection is so important and suggests national monitoring to assist further improvements:

> *Improving information through data collection is a fundamental issue of equity and citizenship; people should be able to access community services and opportunities, and if they are unable to do so themselves they should be supported to do so. As we have stated above the strategy will require national monitoring of prevalence rates, recognition rates, use of services and treatments in order that the success or failure of the strategy can be measured and addressed. (A group of ASC professionals)*

4.4.3 Access to community care and other support services

The importance of improving access to community care and other support services is emphasised in comments from 123 respondents. It becomes very clear from these comments, made be people with an ASC, carers and professionals, that the current availability of care and services is inadequate for adults with an ASC. Many reasons are given as to why constraints exist:

> *It is almost impossible for anyone to access services if care managers refuse to acknowledge them and deny them any funding. This is particularly relevant for people with Aspergers Syndrome. (ASC professional)*
>
> *Identification in primary care of people with ASC is variable. Practitioners need clear pathways to diagnosis and treatment /support. (A group of ASC professionals)*

An issue strongly intertwined with access to care and services is the need for those to be tailored to individuals. A great number of comments (96) are made to emphasise this point:

> *Support for people with ASC must be specific as they have specific needs that must be understood or else the support is worse than useless – in fact it can be damaging and prevent people from engaging in further support that might be more appropriate. (Family carer)*
>
> *Services need to understand the needs of people with ASC. They need to appreciate that they do not fit neatly into existing service provisions, and that new services and supports may need to be created. (ASC professional)*

Many people feel that where services are currently available, they do not meet the needs of adults with an ASC. Several comments stress that alongside improvements to the accessibility of services there should be improvements in quality, including provision of services beyond office hours. Some explicitly refer to the involvement of private companies in the delivery of services, which respondents feel hampers quality while involving a high cost:

> *Community care: this service has been allocated to private companies where profits exceed care. Cheap labour does not equate to care for the elderly and disabled. Any support needs to be appropriate; however, cost will always take precedence. (No sector selected)*

Specific concerns exist around the access to community care and support services for young adults. A total of 40 comments mention transition issues and highlight the challenges people with an ASC are facing when they are no longer eligible for children's support services:

> *Some of the Social workers for young adults leaving care are great - but their remit stops around age 22. Then the young adult is on their own because they are not picked up by adult services. I have seen many social workers desperate to get their clients into adult services, rather than see them dumped at age 22, but they do not fit adult services criteria. (No sector selected)*

Some respondents propose institutional changes or monitoring mechanisms to ensure better accessibility and better quality, ranging from making the provision of ASC-specific services mandatory to establishing guidance around FACS assessments:

> *Access to community care is essential and I strongly feel that whilst FACS is under review the opportunity should be taken to issue clear guidance to those undertaking assessments. In my experience, Social Workers would be only too happy to provide low-cost, preventative services but are under the impression that this does not meet FACS. With this strategy I would like to see Central Government effectively giving Social Workers the green light to do this by giving clear practice based examples. (ASC professional)*

Pressures on budgets and the practicalities of providing services can mean, however, that there is a tension between the provision of universal and specialist services:

> *We feel that generally these points are essential issues that need addressing, however we did feel that they were overly around specialist provision and did not appear to consider the importance in this area of universal services. We felt that with the focus on specialist services there is potentially a risk of raising expectations and supporting risk aversion (ASC professionals group)*

4.4.5 Improving access to housing, transport and public spaces

Numerous respondents emphasise the importance of improving access to housing, transport and public spaces, with most comments (95) focusing on housing. People with an ASC and their carers stress that finding the right sort of accommodation can be very difficult:

> *…….no adult can achieve independent living without access to their own home. However, being housed alone on a council housing estate is not suitable for vulnerable adults with ASC and providers should plan housing provision for them in supported 'clusters', where they can receive support together and support each other, or actual blocks or units set aside for ASC adults to use exclusively with integral support. (Family carer)*
>
> *Getting on a housing scheme is very difficult without a mentor to verify your status, you are not taken seriously. Only one agency would talk to me on my last move I encountered untrained snooty attitude and was treated like a criminal. (A person with an ASC)*

Several respondents indicate that local authorities and their social housing policy are insufficiently adapted to people with an ASC:

> *In my experience Local Authorities have given no real attention to the housing of ASD people who are often with their parent until either physical or mental disability renders the parent(s) no longer capable of fulfilling that role. When I asked the Local Authority what arrangements there were housing wise for ASD people I was told there was a waiting list of 10+ years and no real knowledge of the potential size of the requirement! (No sector selected)*

Various other comments, including comments from professionals, outline what is needed to accomplish suitable housing opportunities for adults with an ASC. Again, there is a strong sense that individual needs should be taken into account, which would mean that different types of housing, independent or supported living should be realised on a local level. Some respondents suggest specific solutions:

> *In regards to Housing it may be that the needs of autistic people are similar to other groups who require social housing and may encourage the development of new types of community. For example, some people with autism may require extra-care type housing, albeit a different kind of extra-care but where, perhaps, older people might also require this type of service. The Housing needs may be similar but personal needs may differ and the two could be combined to provide new methods of service delivery and social opportunity. Perhaps, even employment possibilities. (ASC professional)*

Respondents also make comments about the nature of the accommodation available and how this is tailored to the specific needs of people across the autistic spectrum. According to one person, for example, neutral and muted colours are preferable for accommodation:

> *Colours should be neutral such as beige and grey on walls and floors with doorways, skirting, and window frames in a different colour to mark the edges. There are no patterns used or wallpaper. There are no shiny floors – either matt vinyl or cork if needed in areas where there is spillage. Laminate floors echo too much and are to be avoided unless it is known they are acceptable to the person. (A person with an ASC)*

There are suggestions from respondents about many other aspects of accommodation, from the type of staircases that are suitable to how furniture should be arranged. Also, several respondents explain the importance of ensuring the social environment is right:

> *The principle should also be established that autistic people should be able to choose where and how they live, and (crucially) with whom. (No sector selected)*
>
> *They may also need help with housing suitable for themselves and shown how to look after themselves (cooking/cleaning) etc. They don't like having to share facilities. (A person with an ASC)*

Besides comments about housing, there are also many comments about access to public spaces and, particularly, transport (49 comments). One point made very strongly by respondents with an ASC is that there is little understanding of the extent to which many people with an ASC are powerfully affected by the sensory impact of their surroundings. This can make public transport difficult to manage:

> *Transport is a big issue, judging speed of traffic, the noise and business of it, seeing the number and being able to react quickly, pushing and shoving that goes on, all makes it impossible for those with ASC. (No sector selected)*

The same factors make many public spaces very difficult for people with ASC to navigate: the oppressive combinations of noises, sounds, sights and movement can result in people becoming confined to their homes unless they receive the help they need:

> *Adults with ASC need help to be included into social and public spaces. This could be via increasing the "buddy scheme" into adults or by enabling some form of direct payments for a PA to help negotiate into "public" spaces. A gradual withdrawal could be made once adult is feeling, more confident and has maybe got confidence in routines/ other regular contacts at venues if applicable. (Family carer)*

4.4.6 Local and regional ASC teams, leadership and accountability

As a general point in comments about the four key areas discussed above, many respondents (89) raise the issue of leadership and accountability, mostly in the context of establishing local and regional ASC teams. For many of these respondents the answer to providing proper care and support for adults with an ASC is, as mentioned above, to have ASC-specific multi-disciplinary teams in every area:

> *We believe that every local authority in the UK needs a multidisciplinary ASC team, led by someone with experience and credibility within the field of providing services to people with autism and their families. (ASC professionals group)*

It is also argued that this would also begin to tackle the problem of accountability. Many people’s frustrations are about organisations involved in commissioning and providing services pointing to one another if a person with an ASC has no access to services. A local team dedicated to ASC would have to take on responsibility and respond to people’s demands:

> *An important benefit resulting from a multidisciplinary team with clear lines of leadership and responsibility will be increased accountability… Increased accountability will provide adults with autism and their parents with a defined contact or at the very least, a defined team, responsible for an individual’s welfare. (ASC professionals group)*

The question of whether services should be organised on a local or regional basis is also raised. Some point out the disadvantages for adults with an ASC of thinking too regionally:

> *I would have to travel to my nearest City (Newcastle) to access any form of support group. Newcastle is an hour’s bus ride away from me (I don't drive) which makes for very late nights, especially when working full-time. There are no support services in my local area. (A person with an ASC)*

At the same time a focus on local provision should not, however, prevent a regional approach that would facilitate cooperation and the sharing of knowledge, training and resources; a case study conducted in the Greater Manchester area is mentioned as an apparent demonstration of the value of such an approach. An example of a successful initiative in the Greater Manchester area is included in the last section of this chapter.

4.4.7 Funding and resource issues

A question often raised alongside comments about developing and improving (access to) services for adults with an ASC is how this should be funded.
The connection is made with research and data collection:

> *Improving data collection and the way local authorities plan and commission services is the only way of gaining adequate funding for this much ignored area of need. (No sector selected)*

39 respondents mention the lack of funding available, the need for consistent funding over many years, and different ways of using funding, such as pooled budgets:

> *The ability to pool budgets is key to the on-the-ground effectiveness of multidisciplinary teams. In many cases preventative services end up saving another budget-holder's money rather than the budget of the team actually commissioning the service. All too often time is wasted once an appropriate service has been identified while teams quibble about which budget holder will contribute. This does not benefit the adult the service is intended to help. If budgets were pooled according to need, services could be commissioned faster. (ASC professionals group)*

There are also examples of where funding is going where it is needed:

> *We would like to see further promotion and extension of Direct Payments to people with an ASC…. Direct Payments are effective and can be used creatively but access to these is not universal because of Local Authorities Eligibility criteria – i.e. financial threshold of £23k & Fair Access to Care Services (FACS).* (ASC professionals group)

4.5. Please provide details of your experiences of the challenges faced by adults with an ASC in the area of social inclusion (e.g. problems in accessing necessary support). (This question corresponds to Q5 of the standard consultation)

592 people responded to this question.

Many of the experiences of challenges described by people with an ASC, carers and professionals relate to the issues discussed in the previous question. A large number (167) of comments include examples illustrating the lack of adequate support in the current situation. More specifically, some of these examples address the areas of housing and independent or supported living (89), social inclusion and leisure activities (76), and community care, support and services (67).

> *There needs to be an Independent ASD trained Family Key Worker available for all families and the adult they support, so that they have access to advice and support when dealing with services, be they Social or Health. (Family carer)*

> *Many parents commented that the adults with ASDs need somewhere to get ongoing support….most felt that if something was available their sons and daughters would not*

> *need continual support but that the knowledge that help is available would also prevent crises. This applied to all kinds of support including employment, housing, and social. Most do not feel confident that this is available. (No sector selected)*

> *Because of the typical difficulties faced by individuals with ASC, sharing a home can be very challenging in itself. A preference for routine, often accompanied with obsessive compulsive disorder can make a shared environment with other people, where things move & change very stressful for someone with ASC. (No sector selected)*

The experience people describe is one where they perceive little chance of support, and so their best hope of trying to live a ‘normal’ life is to try to fit in. But this too can be difficult:

> *There is no support. Full stop. End of subject. You see so many comments from carers and from parents and it's not something even they can understand. So much attention gets given to 'curing' or 'normalising' the kids with AS so that they can function in mainstream society. But that's often a change that can only happen on the surface. What the current system creates are children who understand how the rest of the world works and therefore adjust to fit in with it. But because they're constantly trying to fit in with it, they're not able to be themselves. Hence they have no confidence in themselves and their real opinions and thoughts, and wind up second-guessing their abilities. From that point, mental health issues such as anxiety and depression are a natural consequence. (No sector selected)*

Respondents often provided detailed stories describing how adults with an ASC struggle to deal with social inclusion issues in a society they feel is not ready to properly include them. A total of 158 comments include examples of difficulties with social skills or socialisation and the consequential isolation perceived. There are many stories of bad experiences (93). Respondents further provide numerous examples of the lack of understanding people with an ASC are subjected to, generally (83) as well as from professionals (116):

> *A person with an ASC was barred from attending their local college as a result of behaviour that could have been risk managed and supported more effectively had the college worked alongside the provider and had an awareness of ASC. (ASC professional)*

> *I am a single mother with Autism/Aspergers (undiagnosed) My mother cared for me until she died in 2005. I am now alone with an ASD child and can get no support whatsoever. I had to threaten my doctor with legal action as he wouldn’t take my problem seriously (I even had to make out I was a bit mad in order to try and get something done) he sent me to local health dept at the hospital who promptly told me they deal in mental health. Aspergers is NOT a mental health issue so they cannot help me. MORE threats to my doctor and I was referred to Lincoln hospital but it is stalemate now as due to my age and all my family are dead there are no records of my past at schools, or family who can fill out forms as to how I was as a child. I am being told I am too OLD to get a diagnosis. I cannot get help for anything even filling in forms, or legal advice or access to a arbitrator without a diagnosis and I cannot get a diagnosis without help. Meanwhile I am struggling alone and trying to raise an ASD child (now age 7) HELP ME SOMEONE PLEASE!! (A person with an ASC)*

It becomes apparent that if adults with an ASC are unable to get the right diagnosis or assessment (67 comments, with 77 on the wider issue of criteria, labels and policy of provision), they are also unable to get any assistance or support to deal with its consequences, which may in turn lead to further complications, for example:

> *The first battle was to get my son a community care assessment in order to support a move to independent living. Mental health services initially did the assessment listing his needs etc but finally stating that although he needed full supported residential accommodation run by an Aspergers provider they said he was not a mental health responsibility. With much battling regarding IQ Learning Disability assessed his needs and took 18 months to find him supported living, out of borough with a private care provider. This provider had no experienced staff and his Aspergers needs were not accommodated. Within 18 months he developed severe mental health needs. He became more and more involved in drugs and alcohol, stopped eating, washing etc although technically being supported! (Family carer)*
>
> *Gateways to services often do not understand ASD e.g. initial screening into adult services do not ask appropriate questions and do not understand the difficulties. This process is difficult for a professional to navigate, extremely difficult for families/ carers and near-impossible for individuals themselves. (ASC professional)*

In other responses there are stories of the difficulties adults with an ASC have experienced in relation to virtually every aspect of life, from using public transport (45) to simply walking in the street:

> *As a user of public transport, I experience great discomfort at the modern trend for loud buzzers used on buses when there used to be a simple bell. I contacted Arriva buses headquarters to explain my problem, only to be told that more buzzers were to be installed and nothing could be done. I have also been bullied on buses and in the street; I find teenagers and schoolchildren specially frightening because of peer pressure to bully me with unkind words and I have to devise strategies like leaving a bus early or finding a different route. (A person with an ASC)*

There are other examples of the common difficulties involved in access to benefits, education and, most frequently (52), work. Many of these are explored in more length in the appropriate chapters.

Some of these stories also point to possible solutions, and there are some positive experiences (48) that demonstrate successful social inclusion, for example:

> *Together with a drama therapist in my department, I ran a therapy group for young men with an ASC who wanted to socialise, to have girlfriends and so on, but found the unwritten rules of social contact very confusing. Through sharing their experiences together, and expressing their feelings creatively, they became more able to cope with social situations. (No sector selected)*
>
> *One example from a service in Herefordshire is of a service user with ASC who finds being around people very difficult and whose behaviour in the past when in public places has been extremely challenging…. His week now consists of going out every day but he goes to large open spaces i.e. the beach, the forest, fields near to a stables where he feeds the horses. In all of these areas he sees people but the size of the space enables him to cope and outbursts of challenging behaviour caused by high anxiety have been dramatically reduced. (ASC professionals group)*

> *….my son's care home staff ….support him to go rock climbing, cycling, swimming, country walking and out for meals. It is incredibly rare for me to see anyone else like my son out and about in the community. I'm sure that most families have little option but to keep people like him at home and if they travel anywhere they do so by car. Indeed, the carers of many people with similar needs are excluded from society themselves. (Family carer)*

As this last story suggests, however, the overall impression from responses is that such positive experiences are the exception and are usually down to the commitment of a few individuals who are determined that adults with an ASC should not be excluded.

4.6. What actions do you think should be taken to address the concerns raised in the social inclusion chapter (e.g. development of a specific local or regional ASC team, training of community care assessors, changing the application of eligibility criteria)?

(This question corresponds to Q6 of the standard consultation)

566 people responded to this question.

4.6.1 Local ASC teams and multidisciplinary approaches

Nearly half of the responses (225) to this question focus on the need for local ASC teams and multi-disciplinary approaches. Setting up local or regional specialist teams with experienced leaders is mentioned in response to this question as it was to earlier questions, with emphasis on the need for leaders to understand the full range of ASC and its consequences (50 comments on local leadership and accountability).

The question of whether this means establishing specialist services, or whether existing services can be simply better coordinated, is debated, the argument being that too much specialisation can enhance the sense of isolation, while others are concerned that over-specialisation in one area of need could reduce services in others, for example:

> *People need to find services within the community. Too much specialist autistic support might add to the sense of social exclusion and isolation. (ASC professionals group)*

A suggestion to bridge this debate is that the requirement for specific local or regional ASC teams should be based on evidence about the need rather than a blanket approach. The need for local consultation about the services required, also argued here, is another approach:

> *Most vitally of all, I want to be consulted on the planning and delivery of any such service; this has tended to be conspicuous only by its absence up until now. (A person with an ASC)*

4.6.2 Provision

Another key area which was identified was the policy of provision in terms of eligibility criteria, with 113 respondents identifying this as an area of possible improvement, most just indicating that the criteria should change to be (more) inclusive towards people with an ASC. Fair Access to Care Services (FACS) is mentioned several times:

> *Urgent review of FACs for both people with mild/borderline LD and high functioning ASC and Aspergers to have access to services and support. NOT focusing on IQ-cognitive functioning and ability for eligibility. (ASC professional)*
>
> *Changing the eligibility criteria is essential, as at present those with high function autism or Aspergers are being told they do not have a FAC's need. (Family carer)*

This is not universally supported largely because of the consequences for other services and the distribution of resources, for example:

> *Changing application of eligibility criteria runs real risk of increasing population served exponentially e.g. increasing IQ cut-off has major impact on LD services. (ASC professional)*

60 people comment that they feel diagnosis and assessment should also improve.

> *Establish the requirement for each area to have clear pathways to a diagnostic assessment. This should not be an end in itself but should be part of a wider assessment that leads on to measures to programme of management (not 'treatment') that includes teaching, training and support. (No sector selected)*

Many comments on eligibility criteria or diagnosis also touch on the gap between learning disabilities and mental health (30), the need to abandon any generalised approach and treat people as individuals (38). They argue that this is turn would improve access to community care and support (79 comments). Quite a few respondents feel that action should be taken on the local level and that it should be aimed at helping adults with an ASC to access non-specialist services:

> *More low cost preventative and proactive services rather than waiting until a crisis occurs. Low cost services would have a big impact on the number of people needing support. (No sector selected)*
>
> *Working with local service providers to encourage them to make their services accessible to people with ASC would be very worthwhile. (A mixed group of people)*
>
> *Everyone with a diagnosis should get a needs assessment. There should be a system of befrienders, personal assistants that would help individuals to access the services, activities and workplaces that are right for them. (ASC professional)*

4.6.3 Training and awareness

Training is another subject that is raised here as it is in response to every question. 93 people comment on training across all professions, with others focusing on specific professions which they feel need more training, notably community care assessors (55), health professionals (28) and social care workers (25). Very few people specify how they think professionals should be trained; many comments state that training should make people aware of the variety of conditions on the spectrum and able to make better judgments regarding the needs adults with an ASC may have.

> *Community care assessors need to be trained to respond appropriately to people identifying themselves / a family member with an ASC not just in making the assessment but also in sign-posting with knowledge of what is available in the community. (ASC professionals group)*
>
> *There must be education of ASC developed and aimed at Schools, Police, Health professionals and Social Care professionals and other agencies. (Family carer)*
>
> *The ASC team should be given the role to visit 6th form colleges, universities and work places to promote techniques, knowledge, awareness and an understanding of ASC to lecturers, teachers and employers so as to improve the performances of people who have ASC. (A person with an ASC)*

According to many, training of professionals alone is not enough. They feel it should go hand in hand with raising awareness (61). Some people advocate a national awareness campaign; others believe encountering adults with an ASC on a more regular basis will make members of the public (more) aware:

> *Finally, [people with an ASC] need acceptance from the community. In order for this to happen people with autism need to be integrated in mainstream settings as much as possible (starting with education but with sufficient support to ensure success) so that other people get accustomed to people with diverse skills and needs and in particular to the skills and needs of people with ASC. (ASC professionals group)*

4.6.4 Meaningful activities

Also widely recognised is the importance of developing social inclusion activities, leisure and day activities (60), help with learning social skills (36) and ASC support groups or networks (21).

> *Structured activities which assist adults with ASC to develop coping strategies to enable them to develop their social skills and deal with the confusing world in which they live. These need to be long term schemes as the development needs to be in manageable stages and can take a long time. They also need to be flexible and tailored to the individual's needs. (Family carer)*
>
> *I think social services should be encouraged to set up user group meetings so that social issues can be recorded and worked on. Social skills training, social groups, independent living skills training and befriending are all essentials to prevent isolation, but I get the feeling that these areas aren't considered to be seriously important for implementation, more a 'nice to have' as the understanding just isn't there. (Family carer)*

This, though, is only one approach to social inclusion. There are also responses suggesting an alternative approach, enabling adults with an ASC to socialise with and be accepted by neuro-typicals:

> *Not all people with ASC want to attend 'special' clubs and facilities. Some would like to be part of 'neurotypical/normal' clubs and facilities but need support to achieve that! (No sector selected)*
>
> *Social inclusion means by definition that those with Aspergers are included in ordinary social settings and places. It should not mean having separate groups! (Family carer)*

In addition to this approach it needs to be remembered that there are also those who absolutely do not want to do any socialising, and who cannot or do not want to belong to a group.

While numerically the weight of responses to this consultation is in favour of making special social provision for adults with an ASC, the range of responses also underlines the extent to which people have different needs and need to be approached and supported as individuals.

4.6.5 Housing

There are 47 comments suggesting actions to improve access to housing and supported or independent living. Many of these only state that there should be more and better housing opportunities for adults with an ASC. Some also make suggestions as to how suitable housing can be accomplished or funded, with some emphasis on integrating housing options for people with an ASC in local or national housing strategies. The involvement of people with an ASC is also tabled:

> *Funds for local authorities to build suitable housing for people with ASC. A specific ASC team to be included with the planning of new developments. Housing forms with specific Autism questions. Local authorities to work in partnership with councils, housing associations and social services. Being guided by people with ASC with planning and social care. (A person with an ASC)*
>
> *The needs of people with an ASC should be considered within wider government housing strategies and schemes especially those seeking to develop and create more social housing. People can be very vulnerable and living on their own can significantly expose the risk to abuse, however people have a right to live independently and there are few housing options that allow this in a more protective environment. Housing models that allow for support to be available when required and that allow for a good level of personal security need to be developed – link in with the government housing strategy. (A mixed group of people)*

4.6.6 Funding of services

How funding should be managed and distributed is also an issue, with funding and resource issues being raised in 64 comments. Respondents often argue that establishing better (access to) services for adults with an ASC will require substantial resources. Resources that, many believe, will result in savings in other areas as they can help to avoid people with an ASC developing more severe problems, or simply improve efficiency:

> *The multidisciplinary team must be local in order to understand and respond to local needs. The team needs to oversee a pooled budget, so that time is no longer wasted haggling over resources. (ASC professionals group)*

There is a sense that funding and resource issues require action on the local as well as on the national level:

> *Government and local authorities should get together and provide money and research to address theses issues. (No sector selected)*

Funding and awareness raising are sometimes brought together:

> *Proper fund-raising needs to be carried out, and leaflet campaigns could accompany this, to emphasize that those with ASC are HUMAN BEINGS and need to be acknowledged as such. (A person with an ASC)*

4.7. If possible, please give examples of where these concerns have been successfully addressed at a local level. (This question corresponds to Q7 of the standard consultation)

367 people responded to this question.

The overwhelming majority (116) of respondents state that their concerns have not been successfully addressed; many say that none of them have been addressed.

> *None of my concerns have yet been successfully addressed at local level, I'm still fighting, but I have to work full time to support my son 100% & keep a roof over our heads. I don't have the time to keep writing letters & speaking to people to get help (two years & more now). We seem to be 'left in the lurch'. (Family carer)*
>
> *These are not being addressed successfully. We end up in crisis management most of the time, because the right support or service has not been provided. (ASC professionals group)*

However there are some examples of positive initiatives (85) and suggestions for improvement often based on what has been learned from these. Some of these examples are linked to local ASC teams (39), to the National Autistic Society (13) or to other specific agencies or services (37).

> *In Windsor and Maidenhead, we have a new team for Adults with autism. It was reported by staff and people using the service that the care and support and consistency have made a real difference. Just having a point of contact has been found to be really valuable and important. (A mixed group of people)*
>
> *One such example is Autism Plus that provides training to their staff so that they have the necessary skills to be able to support people with complex needs to enjoy an inclusive life. (ASC professionals group)*

There is also the example of the Autistic Society Greater Manchester Area (ASGMA), which is referred to in the first section of this chapter, and provides leisure activities and various types of support for people with an ASC, including support in accessing all kinds of transport.

Diagnosis and/or assessment (23) is one of the areas in which some of such teams or agencies have made progress:

> *In our local team psychology and care management carry out joint assessments to establish whether someone has a learning disability. This means that psychology are then able to flag up any concerns around whether someone may have an ASC and then sign post that person to the appropriate services (where they exist). (ASC professionals group)*

As regard respondents who have positive experiences, these are often with regard to training and awareness raising (50). This mainly includes initiatives to train professionals, but examples are also given of training for family carers.

> *In Norwood we are setting up a group of trainers comprising staff and service users who will deliver training to the local community (shopkeepers, publicans, transport providers etc) to help develop an understanding of how to communicate effectively with people with special needs including those with ASC. (ASC professionals group)*

Examples are also given of positive experiences with various types of support for adults with an ASC. Social groups, support groups and peer networks are mentioned in 43 comments:

> *In view of the complete lack of provision for adults with ASC, the most successful local example in my experience is a self help group set up in Coventry by and for people with ASC. It has been in existence for about 3 years and plays a vital role in enabling people on the autistic spectrum to meet each other, socialise and share experiences. It is mainly attended by adults with Aspergers because there is such a lack of recognition of this sector that there was nowhere for people to go where they could feel safe and accepted. People with any autistic spectrum condition are welcome, also parents and supporters. (A person with an ASC)*

Other types of support with which respondents have positive experiences include leisure and day services (27), support around finding and keeping employment (17), support at school or university (15) and support with transition (13).

> *Somerset Court, like other autistic communities have established links with local pubs, sports centres, riding centres and other appropriate organisations over the 25 years plus of its existence. It is very well known in the community and as such is recognised as a point of reference on autism. (Family carer)*

These forms of support are sometimes provided by charity, church or voluntary sectors (17) and in other cases by the local authority (12). There are also several examples of successful cooperation between organisations, helping to meet a person’s individual needs.

> *In Lincolnshire we have introduced a service called Green Light which supports individuals with a Learning Disability to access mainstream and specialist Mental*

> *Health services. This service has been highly effective in ensuring appropriate partnership working and ensuring individuals are supported by the appropriate professionals or services that meet their individual needs. Although this is not an ASC service we believe that we could transfer the idea to ASC to examine the LD/MH cross over issue. (A mixed group of people)*

Support can also be provided to a community which includes adults with an ASC:

> *….we are setting up a group of trainers comprising staff and service users who will deliver training to the local community (shopkeepers, publicans, transport providers etc) to help develop an understanding of how to communicate effectively with people with special needs including those with ASC. This will in turn assist service users with independent communication and so aid their inclusion. (ASC professionals group)*

Some responses illustrate how ‘ad-hoc’ support can be provided by ASC-aware professionals:

> *My daughter who has a gentle and higher functioning ability, likes drama in mainstream school. Conversation skills were difficult and sociability unless others gave input. Life was quite lonely at lunchtimes and friendliness was very limited. A drama teacher included her in her class. Leaving school she was encouraged to join a drama class. This has helped enormously; the drama group have included her. Although conversations and social functioning are difficult for her. This fact that she can join in with scripts and routines has meant such a lot. (Family carer)*
>
> *BAT’s Independent Lifestyles Service has supported a young man to address issues of bullying in his workplace. This young man buys just two hours a month support, but the delivery of these two hours by a support worker fully sensitive to the complexities of his ASC has been invaluable and resulted in this young man remaining in employment. (ASC professionals group)*

A few respondents provide clear illustrations of results achieved, in this example thanks to one-to-one support:

> *Local authorities have supported my daughter by providing a one-to-one support via social services, at after school clubs so she can be with her community peer group and be included in the community whilst I work…. These are examples of where the support she needed was provided when she needed it and helped her be included in community ‘neurotypical/normal’ clubs and then later she was able to cope on her own because she had had that important support at the time she needed it! (No sector selected)*

It is also suggested that providing support to adults with an ASC can be regarded, in purely pragmatic terms, as a sensible investment:

> *Regular long term family counselling via the Sheffield NHS Aspergers support centre has been essential to maintain a cohesive family support network and the long term financial benefits of this type of talking therapy far out-weigh the costs in social intervention and local social care. (A person with an ASC)*
>
> *The level of care that my son needs is gradually being reduced therefore costs to the LA will be reduced, if his needs had been addressed earlier he would not have needed high levels of support. (Family carer)*

For a large proportion of respondents, imaginative use of resources and greater care and awareness across sectors would result in increased social inclusion for people with ASCs.

4.8. Easy-read consultation questions on the social inclusion chapter

People have told us that we need to do four things so that there is better help for adults with autism where they live. These are:
1. make sure that the people who provide help for adults with autism understand what help adults with autism need
2. make sure that the people who provide help for adults with autism give the help that adults with autism need
3. make sure that adults with autism can get the help they need where they live both in their home and with their day-to-day activities
4. make it easier for adults with autism to get help with finding a house or flat and looking after it, get help with travelling where they need to go, and get help so they can do the things they like to do in their free time.

4.9. Do you agree that these are the main things that we need to do so that there is better help for adults with autism where they live?

(This question corresponds to Q1a of the easy-read consultation)

Group	Count	Proportion
Yes	139	79%
No	15	9%
Not sure	20	11%
No answer	2	1%

4.10. Please tell us why.

(This question corresponds to Q1b of the easy-read consultation)

176 people responded to this question.

The majority of people who answered this question agreed that these are the main things that would help adults with an ASC where they live. 54 people did not make any further comments. People who did often explained why they agreed with the four main things. In fact, 28 people made clear that all of these were important to them.

> *1 and 2 are clearly important and related to provision of proper autism training for all professionals providing help / advice / support services to adults with Autism. (Family carer)*

> *It is important that people have a good understanding of what a person with autism needs and that the service provided is of the highest standard and is consistent in meeting the needs and promotes social inclusion. (No sector selected)*
>
> *Services need to be linked adequately to offer skilled staffing to support people with ASC to live as independently as they are able and with as little anxiety as possible. (ASC professional)*
>
> *More focus needed on housing services for people with Aspergers/Autism – need for detailed scoping of environmental/Social needs when considering housing options. (A mixed group of people)*
>
> *People with autism can be isolated due to behaviour and understanding of the world and social life. Important they need consistency from agencies to help be part of community. (Family carer)*

It is also pointed out (in 16 comments) that ASC affects people differently, and individual needs are different.

> *It is not possible to generalise as you have! Adults with Asperger Syndrome have very different needs to Adults with standard Autism. Adults with Asperger Syndrome tend to be noticed for being any combination of the following:- (a)'A Bit Odd' (b)'Eccentric'(c)'A Geek' (d)(self-obsessed'(e)very introverted.(f)unable to initiate contact. (g) unable to handle unexpected contacts. (h) unable to understand how to make themselves understood.(i) willing to be side lined - as that is their enduring experience! (j) reclusive. (k) have special communication needs. (L) unable to imagine the needs of their contact for them to conform or be compliant. (No sector selected)*

19 respondents write about the need for other people, such as professionals, to be aware of ASC. This could be achieved through training. The following comment highlights the general point that people with an ASC are most helped by other people simply taking time to understand them and make allowances for them:

> *Because the crux is other people understanding, making adjustments/allowances to enable that individual to gain in self-confidence and self esteem and not feel pressured into doing things that just add to the ever present stress of being an autistic person trying to fit in to an existing system. (Family carer)*

Some people added points about things that they think would also help, ranging from the specifically practical to the basic and fundamental, such as:

> *I agree but I also need help with making appointments and dealing with official things like letters that I don't know what to do with. (A person with an ASC)*
>
> *I personally feel that I would benefit from having someone to talk to regularly to keep on top of things and to check things with would be of great help. (A person with an ASC)*

There are a range of practical things with which people say they need help.

4.10.1 Housing and independent living

There are 25 comments about housing and independent living. It is one of the basic needs and yet people say it can be very difficult to find suitable housing:

> *The above does not include finding 'appropriate' accommodation. Simply finding 'a house' is very simple. Finding one adaptable or suitable for a person with an ASC is as complex and involving as finding a house for a disabled child - the above is far too nebulous. (A person with an ASC)*
>
> *There is an additional need to ensure that housing takes account of the sensory issues frequently accompanying ASC. (Family carers)*

4.10.2 Making friends and communication

There are 18 comments from people saying that making friends and improving social skills are important. Having friends and a social life is as important to many people with an ASC as it is to everyone else, and in some ways more important in that autism can lead to problems such as depression and isolation. But the less able a person on the spectrum is, the less likely they are to go out and meet people, which in turn leads to further isolation, less experience of the social settings that others take for granted and, as one person points out, fewer opportunities to help other people understand people with an ASC:

> *If we had help to meet new people, and how to deal with them, perhaps we could begin to explain to others in a healthy way what our problems are, which would be better for everyone. (A person with an ASC)*

Communication is often mentioned as a problem for people with an ASC. They can be misunderstood because of the way they behave or communicate. 6 who answered these questions say they need consistent staff support**,** to prevent them from becoming isolated and to make sure they feel safe:

> *People with autism can be very vulnerable and some like my son have communication and learning difficulties. (Family carer)*
>
> *Because people with autism often have difficulty interacting, travelling and building and engaging in relationships. This can often leave the individual feeling isolated, withdrawn and in some cases a deterioration in mental health. (A person with an ASC)*

4.10.3 Life skills

People with an ASC can need help and support to solve life's daily problems**,** to look after their own physical and emotional health, and to make sure they are safe both inside their homes and in the wider world (13).

> *Because people with autism find it difficult to make choices. They may be intellectual and know a lot about computers, for example, but have no idea about all that is entailed in running a home. They have to be advised about what constitutes good*

> *decision-making, who and where to go to for appropriate advice and, sometimes, be warned about falling victim to predators. (Family carer)*

> *Because not all people on the autistic spectrum need full care and attention but guidance to help them support themselves. (Family carer)*

4.10.4 Information

Providing the right information in the right way is a challenge because people with an ASC often find it hard to identify the information they need and harder still to find it. There are 8 comments on this subject with some suggesting ways to overcome this, for example:

> *Help is available but it is offered in a very fractured way with many different suppliers. The best way would be a 'one stop shop' with staff educated in autistic traits to help individuals understand what is available to them. (Family carer)*

4.10.5 Care

There are 10 comments about care, or community care. Because of the range of different ways in which ASC affects people it is essential that care is tailored to each individual, taking full account of his or her abilities and particular sensitivities, and based on an environment that caters to his or her needs:

> *People with autism cannot cope with change, so help and services should be provided, if possible close to their home environment. Supported living may be ideal for those who can cope with it, but residential services must be available for the most severely affected. (Family carer)*

4.10.6 Employment

For people with an ASC, employment (7) can provide not only an income, but a structure and purpose to their lives, colleagues and a social life:

> *You have not included employment in this last section. For people who often have problems with social interaction and relationships, a satisfying job may be essential in giving them fulfilment in life. (No sector selected)*

4.10.7 Transport

All forms of transport (3) can potentially be challenging for people with an ASC, though public transport, with its noise, crowds and unpredictability can be particularly difficult:

> *I don’t use public transport cos I find it difficult with noise being pushed in with people of all ages, young difficult people. I have a car but find it hard to get to places I do not know. Could suffer bullying on public transport as well if people think you are strange. (A person with an ASC)*

Amidst all these practical things, however, it is important not to lose sight of how the basic problems that affect people with an ASC also limit their ability to take advantage of the help, however little it may be, that is offered:

> *Yes but specifically you need to make sure that something is done to address the issues caused by anxiety/avoidance of the unfamiliar in relation to autistic people who need help with these areas. I find it confusing and daunting when I need help from these kinds of services. I don't know how to find out what help is available and the stress of seeking help because of the unfamiliar systems and break from the routine required often leads to problems, delays and failings to get help. (A mixed group of people)*

4.11. Do you need help with any of these things? (This question corresponds to Q1c of the easy-read consultation)

a) help with finding a house or flat and looking after it
b) help to look after yourself in your own home
c) help with travelling to where you need to go
d) help to make friends
e) help so you can do the things you like to do in your free time.

Group	Count	Proportion
Yes	95	71%
No	33	25%
No answer	5	4%

4.12. If you answered yes, please tell us why you need help with any of these things: (This question corresponds to Q1d of the easy-read consultation)

a) help with finding a house or flat and looking after it
b) help to look after yourself in your own home
c) help with travelling to where you need to go
d) help to make friends
e) help so you can do the things you like to do in your free time.

138 people responded to this question. 40 did not make any further comment.

4.12.1 a) help with finding a house or flat and looking after it

Finding somewhere suitable to live was identified as an issue by 30 people. A common theme was a lack of understanding/ awareness from landlords and housing associations. Finding the right accommodation is the first challenge; making it serve the needs of the individual, and in particular feeling safe in it, comes next:

> *I usually need help in finding accommodation that is SAFE, In the past I have been terrorised by my neighbours. I also sometimes need help in keeping the place clean and tidy due to depression and forgetfulness. (A person with an ASC)*

> *I'm forever at a) trying to find a house. This is because of my sensory problems, mostly noise. Also the lack of understanding and abusive treatment of people with autism. I have been looking for a home for years now. I will try and soundproof a room and see if it works. Then I can hideout in a back room and try and survive until a proper solution can be found. (No sector selected)*

4.12.2 b) help to look after yourself in your own home

It is clear from responses throughout the consultation that many people with an ASC do have problems looking after themselves. Some people already mentioned life skills in their response to question 4.7. This question (4.9) received 30 comments about finding a house and looking after it and a further 40 comments about independent living and life skills. The reasons why people with an ASC need help with this can vary quite considerably, for example:

> *I find cooking and cleaning jobs hard to do, I find it hard to choose what to eat before I get to hungry, I find I need emotional support, whilst I'm aware of others' emotions I am often not [unsure of word] my own, like different gradients of one colour in a colour chart there are subtle differences between different emotions. (A person with an ASC)*

> *I have problems organising myself and often fail to keep on top of the many disparate tasks required for day-to-day independent living. I fail to keep my house tidy (at all), do washing up promptly, wash my clothes before I run out, put rubbish out etc. I feel stressed and overwhelmed by the organisation required and tend to procrastinate and avoid them where possible. This state of affairs stresses me out more – my house and life are chaotic. I need the support to help me attain the structure that I need. (A mixed group of people)*

4.12.3 c) help with travelling to where you need to go

Travelling, particularly on public transport, is difficult for many people with an ASC both because of the stress of noise and contact with other people, and the difficulty of knowing where, when and how to catch trains and buses. 30 people made specific comments about this:

> *There are activities are currently inaccessible because public transport is too terrifying to contemplate. (Family carer)*

> *I suffer with severe anxiety and need someone to take me places or to accompany me on public transport. I cannot talk to strangers, so am unable to seek assistance for myself when travelling, and need someone else with me who can sort out any problems we may have whilst travelling. I get easily overwhelmed by crowds and sensory stimulus, so feel safer if I have someone with me, especially if that person knows me well enough to help me avoid overly difficult situations. (A person with an ASC)*

4.12.4 d) help to make friends

Relationships with others are among the things that people with an ASC find most difficult, with 44 people citing this as an issue, making it the subject receiving the highest number of comments in responses to this question. Many people with an ASC find problems both with finding the right people to be friends with, and maintaining friendships once made. This is very often a result of different social skills and communication issues:

> *Help with making friends as I find this hard and I tend to pick the wrong kind of friends the ones that will just use me and not really want to be my friend, having a support group of some form in my area would be a great help to me and many others. (A person with an ASC)*
>
> *Help making friends. I find it very hard to find and make friends, and usually do not know what to say, or do. Due to my way of thinking in black and white I easily offend people, and do not understand how to be tactful. I do not understand a lot of social skills, and communication, what is being said to me and how I should react. (No sector selected)*

4.12.5 e) help so you can do the things you like to do in your free time.

Some people with an ASC are just as anxious to enjoy their leisure time as people without, but in many cases they cannot do this without proper support. These are two of 25 comments about leisure activities:

> *Help with accessing forms of exercise, I learnt to swim,18 months ago in a private pool, but unfortunately can no longer afford the fees, but am too scared, and overwhelmed with the local swimming baths, both the crowds, and smells, to go there. (No sector selected)*
>
> *I need someone to take me places. This can include walking to the cashpoint with me so I can take out money, accompanying me to the station so I can top my Oyster card up, accompanying me via train or bus, or walking with me, or driving me to places such as band practice or drum lessons or to the shop or the theatre/zoo/museums. I need people to make phonecalls for me (to make enquiries or to book things such as theatre tickets). (A person with an ASC)*

4.13. What do you think would be the best ways to help adults with autism to do these things? (This question corresponds to Q1e of the easy-read consultation)

a) to find a house or flat and look after it
b) to look after themselves in their own home
c) to travel to where they need to go
d) to make friends
e) to do the things they like to do in their free time

138 people responded to this question.

Some suggestions are made generally, or with regard to several themes. According to many (45 comments) the best way to help adults with an ASC where they live is to have someone supporting them whenever they need this. Throughout the comments such a person is called a mentor, a buddy, a key worker, a support worker, an advocate or a personal assistant. One-to-one support is seen as an effective way to help people with an ASC overcome barriers and to take some pressure off family carers.

> *To have someone like a social worker who is really keyed in to ASDs, who is easy to locate and approach, and who can then offer practical advice and take time to make sure the person with autism knows what to do. Even go to places with them so that they don't have to do it on their own. Befriending schemes can be really good, and it is something like this but with knowledge and information at their fingertips as well, and well paid so that good people can be found to do it. This person would also call or phone to keep in touch, and become almost like a friend, but a kind of life-helper. I think if autistic people had a person like this, they could talk through other services they want to access before they go there, so it wouldn't seem like such a minefield. (Family carer)*

There are several other suggestions about improving the way services are organised so that they are more accessible for adults with an ASC. This includes comments about local or regional ASC teams (9), an ASC support network (8) and a person-centred plan for adults with an ASC (8). This should be combined with training of professionals (18) so that they are more aware of the needs people with an ASC can have:

> *It is crucial that professionals supporting adults with autism have training in autism. Professionals who carry out community care assessments should be given proper autism training so that those assessments are fair and accurate. A person-centred plan allows adults with autism to plan ahead for all aspects of their lives, based on their own aspirations. (No sector selected)*

Many people have made specific comments about one or more of the main things this chapter is about. They are discussed below.

4.13.1 a) to find a house or flat and look after it

It is evident from responses that many people with an ASC need someone to help them cope with what can be quite complex tasks even for neuro-typical people: finding a suitable house to live in and keeping it in a good state. The quotations below describe the type of help people with an ASC would need:

> *To have an agency / department set up by experienced people working solely to help autistic people find suitable accommodation. (Family carer)*
>
> *Someone to help with minor tasks such as changing lightbulbs, waiting in for tradesmen etc would be a great help especially if they understood the condition and didn't expect too much conversation. If they could give exact times for arriving and leaving it would also help as not knowing when someone is going to be there can add to the stress of a stranger being present. (A person with an ASC)*

4.13.2 b) to look after themselves in their own home

Providing the right level and type of help is not straightforward as people with an ASC are individuals and their needs differ greatly. Some may need support they can call on when they need it, while others need someone to support them most of the time, or indeed all the time. For some, things need to be explained carefully and repeatedly, and tasks modelled in ways that a person with an ASC can follow:

> *The best ways to help adults with autism do the things listed is to show them very explicitly how to do them by modelling and actually getting the adult to copy. Of course everyone is an individual and in some cases it might be difficult, even impossible for some adults with autism to carry out the tasks. Whenever possible, though, I would advocate teaching adults with ASCs to be independent. (No sector selected)*

Others seem to be unsure that a person with an ASC can ever really be fully independent:

> *They are unlikely to be capable of arriving at the appropriate cleaning materials & or doing the domestic chores. They need a proper domestic help service to come with the property. Don't ask them 'do you want this?' they will think they are being treated as incapable people - say 'this service comes with the property until we are sure that you can manage these things unaided.' Review the situation @ 3 monthly intervals... talk to parents... talk to the Asperger Adult... talk to the cleaner...is this Asperger adult ready, willing and able to take more of the domestic tasks on or not? It maybe possible to phase the help out... but 3 monthly reviews should continue for life as the Asperger Adult may manage for a while & then collapse... they will not recognise that they need to ask for help!! (No sector selected)*

4.13.3 c) to travel to where they need to go

Travel is a problem because of the stresses it places on many people with an ASC. The responses to this question suggest a mixture of companions to make travelling easier, subsidies to make public transport and taxis less expensive, and more care to make maps and signs work better for people with an ASC.

> *Accompany the person, at least once for every new journey so that if it's a journey that will become regular they feel more comfortable getting there themselves. Maybe help finding maps or journey routes for the underground or for buses. Or free travel or money towards travel to make it a little easier to get around (if I top up my Oyster card and the machine eats my money I'm unable to get help and so can't travel, and may not be able to get where I need to be or may become stranded). If an autistic person was comfortable with a cab driver/a couple of cab drivers, or knew that a company was aware of their needs and that the cab driver would perhaps not speak to them (if they have problems speaking to strangers) might make it easier for an autistic person to travel by cab. (A person with an ASC)*
>
> *Adults diagnosed with autism should be entitled to free public transport. They should qualify automatically for Mobility Allowance at the highest rate. Each individual is different. The majority have to be taken wherever they need to go. (Family carer)*
>
> *Staff to train the autistic person to use all forms of transport and be a mentor who can withdraw help in a gradual way once the person knows what to do. (Family carer)*

4.13.4 d) to make friends

How to make friends was identified as an area of concern for many people with an ASC, and for their carers. One dilemma seems to be whether to encourage friendship with other people on the spectrum, or to try to learn to integrate with neuro-typical people even if this is much harder until people are made more aware of ASC.

A range of ideas are presented by those who responded:

> *Social scripts can be helpful when meeting people. (ASC professional)*
>
> *Activities encourage better social skills - so gradually it is not such a hugely stressful thing to be with people. (Family carer)*
>
> *Also it would be very useful to match autistic people up with those that share their interests, as often they have a very narrow field of interest and it can difficult to find someone else who will share it. This makes friendships difficult to sustain. (No sector selected)*
>
> *Befrienders are often offered to people with ASD's but many of us find having a complete stranger with you for any activity only makes things harder as one of the main difficulties in people on the spectrum is communicating with others. A system that offers a person with autism or Aspergers syndrome the opportunity to go places with a friend, family member or carer as opposed to a befriender would be better. Things such as activities where family etc can participate or someone can drive the person and whoever they want with them to events, social groups would be more beneficial and give the person chance to start with someone they feel familiar and safe with and then continue alone if they wish. (A person with an ASC)*

4.13.5 e) to do the things they like to do in their free time

For people with an ASC to engage in leisure activities, some degree of support from other people is usually needed. The amount of help and support which is required or which is available depends, of course, on what people want to do, and how capable they are of doing them.

> *Unfortunately, the only solution is to provide them with support workers. It is important that autistic people are not 'wrapped up in cotton wool' with risk assessments being used as an excuse for inactivity. Activities such as the various cadet organisations and Duke of Edinburgh award scheme are excellent but finish at best at age 25. Some form of grant to act as an incentive to voluntary organisations such as museums, gyms, clubs etc to encompass autistic people would help enormously. (A group of family carers)*
>
> *Point us in the right direction towards organisations that offer hobbies/courses that are suitable. (A mixed group of people)*
>
> *I have found the group we work with starting to organise their own free time now they know each other, including having intimate relationships. This needs ongoing support though to untangle misunderstandings. Our group attends music nights, go to the*

> *cinema, go round to each others homes for food and we regularly eat out in local restaurants. With the right type of support all these things are possible. (No sector selected)*

4.14. Do you know of any help that adults with autism can get with these things where you live? (This question corresponds to Q1f of the easy-read consultation)

a) help with finding a house or flat and looking after it
b) help to look after themselves in their own home
c) help with travelling to where they need to go
d) help to make friends
e) help so they can do the things they like to do in their free time.

Group	Count	Proportion
Yes	58	14%
No	72	38%
No answer	22	47%

4.15. If you answered yes, please tell us about this help. Please tell us what you like or don't like about it. (This question corresponds to Q1g of the easy-read consultation)

152 people responded to this question. No further comment was made by 68.

A large part of the responses to this question divide between those who say there is no help available with any of these things (30), and those who refer to specific agencies or support systems (30).

People with an ASC and their carers most often seem to look to their regular sources of support, if they are fortunate enough to have them, for help with all these areas of life.

> *My son attends the Aspire Youth Club at Romsey Mill where he is able to meet other children who share similar interests and be with staff who are able to relate to his unconventional interests and behaviour. (Family carer)*

The quality and consistency of support is of particular importance to those who need it:

> *I really like the fact that I can get one to one and group support and that the support comes from Autism West Midlands, which is an autism specific organisation. I know that the staff there have had experience, knowledge and training of autism and therefore they know how to appropriately support people with autism so I have the utmost confidence, respect and trust in them. (A person with an ASC)*

> *I have no idea what is available in the area I live in as my son lives in Edinburgh. He was referred to Into Work by Herriot Watt University on completion of his degree and they helped him not only with arranging work placements and job applications but also*

> *with claiming benefits, registering with a GP and organising himself so that he is able to continue living away from home. He has a single point of contact so has developed a relationship with that person and she in turn has a good understanding of his strengths and weaknesses and areas which cause him most anxiety. (Family carer)*

There are several (16) examples of positive experiences people have had with services for adults with an ASC. Some people do make comments about the services they use, for instance that they need better funding, longer opening hours or that they are not sufficiently known to people with an ASC.

> *Assert helped me by giving information about housing. I got help looking after myself and with travel from DLA. St Lukes Advice Centre helped me fill in my DLA application. Aspire hold social meetings. I think Assert do too but I haven't been to these. My Aspire mentor is helping me find things to do in my free time. A lot of help seems to be available in Brighton & Hove. I worry that a lot of people do not know about it. More needs to be done to let people know they don't have to manage alone, especially those who are undiagnosed and have not had any encounter with professionals. These people could also do with help understanding autism and guidance on whether seeking a diagnosis might help them. (A mixed group of people)*

> *A local charity, the NSAAA (North Staffs Autism/Asperger Association), is a useful source of help in general, but they often lack specialist knowledge in any particular area. They are also only open during limited working hours, which is pretty useless for someone like me who works full time. (A person with an ASC)*

5. Health

5.1. Summary of responses to this chapter

This chapter covers responses to questions dealing with the challenges faced by adults with an ASC as they try to access diagnosis, post-diagnostic support and other healthcare services. Respondents are asked whether they agree with the four areas where, according to stakeholders, action is most needed in relation to healthcare services (improving access to diagnosis and post-diagnostic support; improving data collection and commissioning of services; making healthcare settings more accessible; and improving the understanding of ASCs among mental health professionals). Other questions are about the actions that respondents think should be taken to address concerns and whether they can provide examples of challenges and solutions.

5.1.1 Main issues

Among respondents there is strong agreement that the areas selected are indeed the ones where action is most needed. Many examples are given emphasising the importance of early and accurate diagnosis, followed by adequate post-diagnosis support. Some respondents describe how individual professionals have made a real difference for adults with an ASC, but most stories are accounts of difficulties and frustrations. Respondents point to the lack of understanding that many professionals display when dealing with adults with an ASC and stress that they need dedicated training. In addition, healthcare settings (including waiting rooms) need improvement in order to be (more) accessible for adults with an ASC.

5.1.2 Examples of challenges

An overwhelming number of examples are given of troublesome encounters between adults with an ASC and healthcare professionals, many relating to poor diagnosis.

5.1.3 Actions to be taken

There is a strong sense among respondents that more and better training for (frontline) health professionals is required to improve their basic awareness and knowledge of ASC, which in turn would enable better diagnosis and support. Respondents feel that this should not be limited to mental health professionals. They also stress the need for local teams of ASC specialists, who can help develop and coordinate a range of accessible and effective services for adults with an ASC, including but certainly not limited to healthcare.

5.1.4 Examples of solutions

Where some respondents do give examples of positive experiences thanks to an individual professional, institutional adaptations made by healthcare providers or a local initiative, the majority of respondents say that their concerns are not being addressed.

5.2. Standard consultation questions on the health chapter

The external reference group identified the following as key areas where action is needed in relation to healthcare services:

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

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

(This question corresponds to Q8a of the standard consultation)

Group	Count	Proportion
Yes	555	89%
No	10	2%
Unsure	23	4%
No answer	39	6%

5.4. Please explain your answer. (This question corresponds to Q8b of the standard consultation)

627 people responded to this question.

Overall respondents strongly support the analysis and the identification of the four key areas and agree that they will definitely improve healthcare for people with an ASC and reduce some of the obstacles to better healthcare that are currently experienced.

Respondents add to their endorsement, however, many detailed qualifications and suggestions for the actions that should flow from them, while those who oppose the key areas do so mostly because they feel they do not go far enough or are insufficiently specific.

A number of issues stand out among responses that cover many aspects of healthcare for people with an ASC.

5.4.1 Better training for health professionals

Better training for health professionals (155 comments), at every level and in every place where healthcare is offered, is a running theme in a great many responses. Respondents suggest that action is required in four respects.

First, there is concern about the general knowledge and understanding of ASC among health professionals at every level.

> *Autism of itself is not a 'health' problem - it is a difference that can lead to accompanying mental health issues and difficulty in getting physical health needs appropriately met. However, all health professionals need to have an understanding of autism, so that people on the autism spectrum's health needs can be fully and appropriately met. (ASC professional)*

It is argued that failures of this basic understanding are leading to people with an ASC not receiving the treatment they need, or receiving treatment that is inappropriate and even harmful.

Secondly, this lack of understanding and particularly of the anxiety that people with an ASC can experience, can lead to ASC patients being regarded as 'difficult' or even obstructive, with the result that they do not receive the services they need. A number of respondents allege that health professionals who do not understand ASC tend to minimise their problems or in some instances even ridicule their behaviour.

Thirdly, another result of the lack of training and understanding means that some of the environments in which people with an ASC are treated are likely to increase their anxiety, lead to challenging behaviour and may result in them not receiving the care they need.

> *Making health care settings more accessible is of utmost importance. A GP surgery is difficult for most people to relax in let alone a person with ASD, most areas are over stimulating and affect the senses in terms of audio, and visionary items, having to speak to someone can be a barrier when checking into reception, buzzer appointment systems can also be problematic. GP practices with large waiting rooms where everyone sits face to face in a public area does not make for best outcomes for a person with ASD. (ASC professionals group)*

Some respondents mention with approval some of the case studies in the consultation document describing how such environments and waiting and treatment procedures can be made better for people with an ASC.

Fourthly, there is sometimes a lack of the specific skills and services that can benefit people with an ASC, for example:

> *Speech and Language Therapists have a vital role in increasing understanding of Autism amongst all relevant professionals and should be deemed as valuable intervention in decreasing the incidence of mental health problems. (ASC professionals group)*

A number of responses suggest that if overall understanding of ASC was better, health professionals would be able to work more creatively with people with an ASC, with consequently less reliance on clinical and medical interventions.

Many of the respondents who mention the importance of training also focus in particular on the training of mental health professionals (64 comments). There is concern that mental health professionals are not always adept at recognising the difference between mental health problems and an ASC. More training would ensure, not least, that mental health professionals do not prescribe treatments, including drug treatments, that can make ASC worse.

5.4.2 Better access to earlier diagnosis

The importance of early diagnosis is made evident from the number of responses (117 comments). Submissions contain stories of how families and carers have struggled to achieve proper diagnoses of ASC. In some areas it seems there is an absence of health professionals able to make such diagnoses, and many respondents report failures of knowledge, understanding and sympathy especially as regards the diagnosis of ASC in adults.

The positive stories come from those who have experienced a sympathetic GP, or whose carers have been sufficiently persistent to overcome the barriers put in their way. The importance of early diagnosis is reflected in the suggestion that referral channels need to be broader:

> *Given the current problems many GPs have with autism diagnosis, it may be worth considering allowing other professionals such as social workers, police and college tutors to make a referral. (Other)*

The problem is not, however, just getting access to people who can make the correct diagnosis, but ensuring that the circumstances are such that the correct diagnosis is made. There are 61 comments about accessible healthcare settings, which focus on the difficulties that people with an ASC can experience, both before and after diagnosis, in noisy and crowded waiting rooms, or with the uncertainties inherent in delayed appointments and long waiting times.

These problems are compounded by the communications problems commonly experienced by many people with an ASC:

> *Although access is one issue, G.P.s also need to be made aware of the communication difficulties experienced by people with Asperger's. It is very difficult for those with Asperger's to make themselves understood to a busy G.P. In fact they are frequently misunderstood and will not receive the help they need. (A mixed group of people)*

The process of diagnosis itself is also raised by respondents. There is concern that some people with an ASC do not receive the diagnosis they need, and are therefore prevented from receiving the services that would be available to them if they did, because the criteria used to diagnose ASC may in some cases be inappropriate or the necessary background information unavailable:

> *The diagnosis process with adults is very significantly different in adults when contrasted with childhood and adolescent diagnosis. This is most stark, as the parents may be dead, not prepared to be involved, school records, difficult to obtain, or have been destroyed etc. Many adults with ASC conditions are estranged from most if not all of their family, often because the family members see them as seriously mentally ill. (A person with an ASC)*

Respondents suggest that diagnosis may be particularly difficult if the person has Asperger's or more limited symptoms of ASC. In these cases the person may be treated as if they have a mental illness such as depression, and sometimes the treatment prescribed, for example if it includes drugs, can make ASC worse.

Equally, if diagnosis of a younger person is refused and they do not receive the special consideration they require, they may for example be sent to a mainstream school and risk the abuse that is commonly meted out to those who appear different.

5.4.3 Recognising multiple conditions and the need for multidisciplinary approaches

It is also important that the diagnosis of ASC does not overshadow, and blind health professionals, to the possibility of other medical problems affecting the person's physical health. A total of 34 comments are made addressing the need to recognise and deal with multiple conditions.

> *This section does not reflect the range of additional conditions e.g. epilepsy, eating disorders, diabetes, osteoporosis, sensory impairment i.e. serious health conditions that people with ASC may have….. ASC is seen as a social condition without understanding there may be important medical conditions compounding the ASC. (Family carer)*

There is also the danger of failing sight or hearing becoming confused with ASC, especially if the frustrations caused by them give rise to the type of challenging behaviour sometimes associated with ASC.

The same considerations apply to the prevention of mental health problems, which, according to many respondents, is a not infrequent consequence of an ASC:

> *I am particularly pleased to see that reducing the risk of developing mental health problems is a major area of concern for this very vulnerable group. The autistic spectrum is associated with high anxiety levels and stress and yet there is currently almost no preventative support available. (Other)*

The training of mental health professionals, as mentioned earlier, is also an issue for respondents, with many reporting either that ASC is misdiagnosed or that, once diagnosed, mental health professionals are unable to respond to it:

> *It is felt that there is a continued problem with undiagnosed autism being misdiagnosed as other mental health problems such as schizophrenia, with some evidence that this may be particularly problematic in the diagnosis of young black men with autistic spectrum conditions. (ASC professionals group)*

These problems can be compounded by how the person is documented and enters ‘the system’:

> *Professionals have a habit of asking the person with an ASC for insight into their own problems e.g. why do you think you are feeling like this? The person in my opinion struggles to find a reason and comes up with whatever they can think of at the time. This gets documented as the cause of the problem and can prevent the root cause being found. (Family carer)*

As discussed in the Social Inclusion chapter, there is also the problem of adults with an ASC falling into a gap between learning disability and adult mental health services (especially if they have an IQ of over 70), which again reflects failures of understanding of ASC among healthcare professionals. The answer, canvassed by a number of respondents, is:

> *We need to classify ASC in its own right and not as Learning Disability or Mental Health ensuring tailored support is available for individuals. (ASC professionals group)*

All such considerations, it is argued, should raise awareness of the need for multi-disciplinary approaches to diagnosing and treating ASC. 37 respondents make suggestions on this issue, arguing that it is important to ensure that a diagnostic service involves healthcare professionals from different disciplines and that professionals are aware of the remit of other professionals, so that adults are referred and signposted appropriately and are not in danger of falling through gaps between services. This should also be taken into consideration when commissioning services for people with an ASC.

5.4.4 Better post-diagnostic support

Another issue that concerns respondents is the provision of post-diagnostic support (93 comments). The general impression conveyed by respondents is a significant lack of institutional support in the wake of diagnosis. Information is obviously welcome, when it is available, but handing out leaflets about autism after the diagnosis is made does not, in the eyes of many, constitute post-diagnostic support.

Signposting to support groups and charities is the sort of post-diagnostic support that people are looking for, many respondents pointing out that it is the carers, as well as the person with an ASC, who need proper support:

> *I don't want other parents receiving an ASC diagnosis for their child being told to go away and find out about it, nor do I want people to be continually told that they won't*

> *get an assessment or that "you don't want to label them". Post-diagnosis support is crucial to enabling families to move forward and to begin to see the positive in the person they care for. (Family carer)*

Post-diagnostic support starts, respondents argue, with recognition that each individual with an ASC has specific needs, and these needs have to be carefully assessed, thoroughly understood, and the necessary support creatively designed and supplied if the person is to flourish and lead as productive a life as possible.

5.4.5 Data collection

The importance of data collection, one of the key areas identified for action, is well recognised by respondents (45 comments), with many stressing the importance of knowing how many people and of what age have ASC so that diagnostic and support services can be organised and provided effectively:

> *It is obviously essential for every health authority to know how many adults with ASC they need to provide for. There also needs to be more co-operation and shared expertise between authorities to ensure that they are all providing the services that are needed in the best possible way. (Family carer)*

Some respondents have reservations about data collection on civil liberties' grounds, or because they fear that data collection could become a substitute for action.

> *We have some concerns that while good data collection is an important element of local needs analysis leading to service planning, a pre-occupation with trying to develop good data as a pre-cursor to commissioning, may deflect from the need and urgency to develop the very same diagnostic/assessment and intervention services that will ultimately help to provide better data for commissioners. We would like to see the development of diagnostic/assessment and intervention services as a priority, with them having a built-in requirement to gather local data on need/prevalence. (ASC professionals group)*

A number of respondents feel that without this data it is unlikely that sufficient resources will ever be made available. Others believe that there is institutional reluctance to acknowledge the challenges that ASC poses:

> *There seems to be a reluctance amongst certain sections of the health industry to understand or recognise these issues because it would add more cost pressure. (Family carer)*

5.4.6 Other issues

While the issues described above feature in a large number of responses to the question, there is a range of other issues that respondents would like to see covered in the strategy.

The physical environments in which people with an ASC have to seek healthcare, and how they can be improved, feature in many responses. How health professionals should respond to people with an ASC and the care they should provide to people with different types of ASC, or to older people, for example, is mentioned. The range of healthcare professionals who should be better trained and informed is discussed; dentists, for example, are recognised as providing a type of care that many people with an ASC can find particularly difficult and may forego as a result.

How information should be provided, and by whom, is important to respondents, as are other ways to support people with an ASC such as buddy systems and advocacy.

5.5. Please provide details of your experiences of the challenges faced by adults with an ASC in the area of diagnosis and health.

(This question corresponds to Q9 of the standard consultation)

533 people responded to this question.

Responses to this question, from adults with an ASC, their carers and professional groups supporting those with ASC, contain minor and major tragedies. The stories of bad experiences outnumber the positive three-to-one, providing a picture of a healthcare system struggling to cope with ASC and many health professionals insufficiently trained to understand ASC or its impact on many adults' lives.

Where the stories are more positive the common denominator seems to be success arising from the initiative of individuals sufficiently kind and concerned to get adults with an ASC properly diagnosed, or who have referred them to others who can offer help and support.

Most of the problems experienced flow from a lack of understanding of ASC and consequent difficulties in acquiring diagnoses and assessments that would lead to treatment, care and support for their health in general. Reports of the lack of understanding come in two main forms: by professionals, which stem from the training and culture of individuals; and the institutional, which stem largely from difficulties with diagnosis and assessment. Following on from these there is concern about the lack of post-diagnostic support. Many of the points made are similar to those made in response to other questions.

5.5.1 Poor professional recognition and understanding of ASC

The skills and conduct of individual 'gatekeepers' is considered by respondents to be a significant barrier to responding to people with an ASC (250 comments). There are concerns that many healthcare professionals have neither the background understanding nor the diagnostic skills to ensure that they recognise an ASC, particularly if the person concerned does not exhibit what they may regard as 'typical' symptoms of an ASC, such as not being able to speak or failing to offer eye contact.

> *I went to my GP who said I didn't have Aspergers as he knew a boy who did and I was nothing like him. I just cried at this as I was pretty sure I did and he hadn't tried to find out anything about me before making this judgement. He told me I was depressed. (A person with an ASC)*

There is sometimes insufficient appreciation that ASC is indeed a spectrum of conditions, and that individuals may not have symptoms that are immediately apparent. Pressure of time may also complicate matters, with healthcare professionals not understanding that people with an ASC may need time to understand the questions they are asked and to formulate appropriate responses.

> *One of the main challenges I have experienced is that doctors, dentists, opticians, health professionals don't listen. They don't give enough time for me to work out what they are asking and what type of answer they expect, they don't give me time to process it and think about how something feels e.g. what type of pain I am experiencing. (A person with an ASC)*

This can affect people with an ASC not only when diagnosis for an ASC is being sought, but also when they are seeking treatment for other illnesses or for documentation that will help them secure the support they need.

> *When I take a long while to come up with an answer they seem to make assumptions and move on too quickly with their agenda. This is precisely what happened to me when I had a 'medical examination' (which turned out to be a ticking boxes exercise) in order to claim incapacity benefit. The doctor fired questions at me so fast and ticked inappropriate boxes on his PC screen. (A person with an ASC)*

Among responses there are illustrations of the consequences of such professional shortcomings. The failure to diagnose an ASC early enough to create an appropriate path to the future can condemn people to years of abuse or neglect which may result in the deterioration of their health and the compounding of their condition.

> *It took professionals 13 years to diagnose my son's Asperger Syndrome. As a result he was forced to attend normal state school without any recognition or support for his condition. He endured years of bullying, resulting in him becoming suicidal, self-harming and severely depressed. (Family carer)*

Such experiences are commonly recounted in these responses, and whilst they relate to the behaviour of individuals, they amount cumulatively to a perception of failures in professional training.

5.5.2 Difficulty with diagnosis and assessment

It is apparent from the 218 respondents who discussed their difficulties with diagnosis in this question that what are ordinary institutional procedures can present extraordinary obstacles for people with an ASC. Among the responses are stories of seemingly minor problems that are in fact significant barriers to people getting the help they require, or even receiving an appropriate diagnosis and assessment in the first place.

Among these are, for example, the failure to understand that people with ASC may be unable to use a telephone, wait in a crowded room, explain clearly how they feel, or accept any form of physical touch.

The solutions to such problems can be as seemingly simple as some of the case studies in the consultation document report: ensuring, for example, that people with an ASC have the first appointment of the day so that they do not have to wait for too long in a crowded room, or sticking to an established routine that does not cause a person anxiety about the unfamiliar.

> *One of the people with ASC talked about her difficulty accessing healthcare due to features of her autism. She said that professionals did not seem to understand that she could access healthcare much more easily if certain familiar routines and procedures were followed. (A mixed group of people)*

Getting past such initial barriers is no guarantee that diagnosis, treatment or support will follow – perhaps in part, as the story below suggests, that health professionals do not believe that ASC can be ‘treated’:

> *To return to the question of diagnosis in our case it took 46 years. I had tried and tried to get a diagnosis because we suspected Autism - no one would listen. One psychiatrist even said to me "How could a diagnosis help? It wouldn't alter your situation.” (Family carer)*

It is suggested by some that health professionals are reluctant to help people with an ASC even to the point of diagnosis because of the resource implications involved, even if they may not be clear what these are:

> *It is very difficult to get a referral. The route is often long-winded, having to go via professionals who have little knowledge of ASCs. Funding is a key problem. (A person with an ASC)*

Another theme of many stories is the relationship between ASC and other mental health problems, and the problems resulting from efforts to medicate people who have multiple problems in parallel with ASC.

One of the consequences of late or inaccurate diagnosis is mental health problems arising from the isolation and unhappiness caused by ASC, as discussed earlier.

> *[Our] son… was not diagnosed until in late 20's, by this time, he had mental health difficulties and had turned to alcohol for support. (Family carer)*

In summary, respondents to this consultation provide a variety of evidence of how people with an ASC are treated which is anecdotal and may or may not be typical. If the latter, it points to inadequacies in healthcare as regards the diagnosis and assessment of ASC.

5.5.4 Lack of post-diagnostic support

The lack of support post-diagnosis is another strand of many stories from both carers and other support groups (103 comments). This is also detailed in the Social Inclusion chapter above. It is suggested that people with a recent diagnosis of ASC, whether for themself or for those for whom they care, are often left to cope on their own with their confusion and their lack of knowledge.

> *…following diagnosis we were given no support, no information that would help us to know if we were doing the right thing. The school had no expertise and some teachers simply could not get their hands around this strange little boy. My eldest son did not fit into LD or MH to get services and we had to just keep doing what we felt intuitively was right for our children. (Family carer)*

It is suggested that the health professionals responsible for diagnosis and assessment also themselves lack the necessary support to provide appropriate services in the wake of diagnosis.

It is apparent that many respondents with an ASC are aware of the challenges that their behaviour may pose for others, and recognise how their inability to explain themselves, and others to understand them, can create an escalating cycle of misunderstanding and even conflict:

> *My behaviour was perceived as anti-social on one occasion, because of the significant difference between my vocal skills and my non verbal skills. I was duly arrested, but not charged, only because the officer had an autistic son, and therefore some understanding. (A person with an ASC)*

Many of the experiences described relate to problems with communication:

> *My daughter has found it difficult to access appropriate help from GP and dental services. Because she looks normal, they do not understand her disability. She has some language and processing impairments, and may not fully understand what she is being told, what is happening, or give the correct information. (Family carer)*

The difficulties that ASC poses for living everyday life are a theme of some stories. In relation to healthcare, it is again doctors' and dentists' waiting rooms that are a major source of anxiety for many people with an ASC, and can result in them leaving before they receive the treatment they need or behaving in a way that results in them being excluded.

5.5.6 Positive experiences

While negative experiences outnumber the positive by more than three-to-one, the latter (22 comments) demonstrate that the negative ones are not inevitable. For many people with an ASC, the first and crucial step is getting a diagnosis that opens the door to the help and support they need to live as they wish to. This is particularly true for children:

> *The 'diagnosis' of ASC is now more clearly being referenced in children's 'statements' as they progress through the education system. Parents appear to be more actively seeking this diagnosis as the national profile is raised. There is some useful early input, i.e. 'Early Bird' service. (No sector selected)*

The initiative for action is as likely to come from carers who have done their homework, or even from people with an ASC themselves, as it is from health professionals. Sometimes it is a negative experience that leads people to press harder for the help they need:

> *An appalling initial interview with the GP - dismissive, patronising. Asked my son how many times he had taken his driving theory test (once) and therefore concluded there couldn't be anything wrong. An interesting form of diagnosis, that drove us to get in touch with an NAS recommended clinical psychologist, who was excellent. Our son said it was the first time he had ever felt anyone understood him (apart from me and his dad!). (Family carer)*

Overall, the positive experiences recounted by respondents tend to be the result of a single individual who is prepared to listen, understand and act to trigger the institutional assistance that people with an ASC and their carers need.

> *Fortunate that our GP is very understanding of the characteristics of our autistic son. This has been particularly valuable in resisting changes in medication suggested by outside bodies which would appear to be associated with reducing costs. (Family carer)*

It is for this reason that respondents emphasise the importance of knowledge and training about ASC among all health professionals.

5.5.7 Other responses

The responses to this question are based mainly on respondents' personal experiences of the healthcare system and therefore include many other issues that have affected them or those for whom they care or support, and complement many of the points made in responses to other questions. They include; experiences leading to mental health problems (77 comments), difficulties associated with multiple conditions (71 comments), inappropriate diagnosis and treatment (70 comments), and poor access to services and support (69 comments).

5.6. What actions do you think should be taken to address the concerns raised in the health chapter (e.g. better record-keeping, the development of diagnostic services, training of key professionals)? (This question corresponds to Q10 of the standard consultation)

525 people responded to this question.

It is apparent from the responses to this question that there is widespread support for the action already identified from across the whole range of respondents. Even where respondents do not specifically endorse the points made in the consultation document, their comments largely follow the thrust of its aspirations. The key areas for action identified fall under nine main headings.

5.6.1 Training for key professionals

As in responses to previous questions, the training of health professionals is perceived to be key (257 comments). It is frontline health service staff who are most perceived to be in need of training, but mental health professionals are also singled out for attention as it is they to whom many people with an ASC are often referred in the first instance, and they can act as the sometimes unwitting gatekeepers to more appropriate services.

The training most frequently cited as essential is that of raising basic awareness and knowledge of ASC, including of the usual traits that may betray it, both to ensure people with an ASC receive the services they need, and also to ensure that the process of assessment and diagnosis is conducted in a way that causes least distress:

> *The awareness training needs to be rolled out right across the health sector. With greater awareness and better understanding of the approaches for people with ASC for healthcare staff, healthcare will be more accessible and less distressing for people with ASC. (Family carer)*

This training must therefore enable health professionals not only to understand the medical implications of ASC, but also to help them relate to people with an ASC on the human level:

> *Medical staff trained to not only deal with the medical aspect, but understand the person and show the human side… (No sector selected)*

This includes being able to adapt their approach, right down to details of the language and words they use, to the needs of the individual – because people with an ASC are unique, the symptoms, abilities and needs of individuals vary greatly and are often affected by their immediate circumstances.

Such training needs to be targeted well beyond health professionals, making the point again that ‘gatekeepers’ as well as medical staff need to understand ASC:

> *….training of individuals who have a direct affect on the lives of people on the spectrum, e.g. assistants, receptionists and other professional bodies. (A person with an ASC)*

5.6.2 Training for mental health professionals

Within many responses asserting the need for more training generally there is a sub-set of responses (36 comments) about training for mental health professionals. There appear to be several reasons for this beyond the obvious one that people with an ASC are often referred to mental health professionals.

One is that ASC and other disorders may be related:

> *Some kind of training for key professionals is important - in particular those who work in mental health provision. None of the services for the mental health difficulties I've had were able to successfully account for and manage ASC-related issues - and often ASCs interact considerably with other disorders. (A person with an ASC)*

Another is that people with an ASC have very particular needs:

> *More flexible mental health treatment - not "1 size fits all". Quiet psychiatric hospital wards with autism trained staff. (No sector selected)*

There is also a fear of drugs being overly used by mental health professionals to control behaviour.

5.6.3 Developing and improving diagnostic services

The importance of diagnosis is also again underlined in 121 responses to this question, and respondents describe the obstacles they have experienced in getting the initial diagnosis that will open doors to other help. The role of Primary Care Trusts is emphasised in this regard:

> *Diagnosis is often the first step for adults with autism to get the support that they need - all PCTs should be made to have a planned, clear pathway that adults with a suspected autism can take to get a diagnosis. (ASC professionals group)*

It is apparent that the provision of diagnostic services is uneven across the country, and this is of particular concern for people with an ASC who may find travelling extremely difficult.

> *Appropriate and accessible diagnostic services where the over-riding concern is the patient and not that of budget or geographical or inter-professional politics.*
> *(A person with an ASC)*

Another problem with out-of-area diagnoses is that their validity is not always recognised when the person returns home and needs to access the services they indicate, so there are calls for clear, simple and universal tests to prevent this problem:

> *Recognition of the diagnosis from other agencies or out of area was also felt to be important. (A mixed group of people)*

There are also calls for more professions to be able to diagnose ASC and for mutual recognition of such diagnoses. Some of the professional respondents argue that a multi-agency approach to diagnosis is in fact essential:

> *We would like to emphasise service rather than team as we do not believe that 'one team will suit all', unless members of the team have diverse experience/ backgrounds and specialised training. The diagnosis of autism in an adult with severe learning disabilities and no verbal communication, who has lived in a variety of institutional settings all their lives, is very different from assessing someone who may have*

> *Asperger Syndrome. Rather than a single team, we would prefer to see the development of a local service that can call upon the relevant specialist clinicians as required. (ASC professionals group)*

This point is also made by those who see the need for holistic responses to the needs of people with an ASC:

> *Diagnostic teams need to be multidisciplinary and multi-agency if they are to be able to provide the broad assessment that then flows onto a multi-agency response that meets the individual's needs…. (No sector selected)*

Further to the many comments about the diagnosis itself, there are 93 respondents commenting on post-diagnostic services, with a variety of suggestions on how to develop or improve these.

> *Once assessments are completed a plan with community support agencies such as Social Services but also housing and employment services needs to be developed with a strong involvement where appropriate of parents or partners. (No sector selected)*

Some other examples are included in the 'Coordinating care' section on the next page.

5.6.4 Developing ASC specialists

This next area for action flows from the last. It is requested by some 103 respondents that there should be specialist disability teams within all local authorities, bringing together health, social and educational services. These specialist teams should include professionals who are qualified to diagnose autism spectrum differences and specific learning differences and also have the facility to assess the support needs and also the strengths and abilities of individuals on the spectrum, allowing them to design and implement a tailored and holistic support package for each individual.

> *This would mean that there would be a cross-departmental autism specialist team in every local authority, thus enabling individuals to access support from any of the component services, including receiving treatment for co-morbidities such as gastro-intestinal problems and epilepsy. (A person with an ASC)*

Other respondents make similar points, some focusing on particular aspects of how such a team could work or what services it might supply, such as information on what help is available and where, what benefits people with an ASC are entitled to and how to apply for them.

Such teams could include various specialisms:

> *Identification of numbers of specialist speech and language therapists & clinical psychologists required to provide adequate multidisciplinary diagnostic teams. (ASC professionals group)*

Another idea mentioned is the creation of a small number of regional specialist diagnostic centres based in various areas of the country, but each accessible via an online triage based diagnostic tools set.

5.6.5 Improving data collection and research

This is another area for action identified by both people with an ASC or their carers and professional bodies charged with responding to ASC. The importance of data collection and record-keeping lies both in the need to develop sufficient services to meet needs that are still often not recognised, and for the benefit of individuals with an ASC who may need to move from one part of the country to another, or whose needs may change with the passing of time.

The national need for improved data collection is articulated by one respondent:

> *Records also need to be kept as there is no idea of how many people actually have ASD's and how big the problem actually are, all the stats produced by the NAS (National Autistic Society) at best are estimates or from their own surveys amongst members and do not cover the wider picture meaning that it makes in difficult to actually programming resources to meeting actual demand as nobody knows at any time what the current issues are facing ASD's either in the local area or on a National Basis. (A person with an ASC)*

One idea suggested to ameliorate the current situation is for standard processes and reporting methods using standardised forms that would be used in all health authorities. These could characterise key features of disability in each individual with an ASC, allowing accurate data collection as well as a summary of essential information that could easily be transferred when the person with an ASC moves to a different part of the country.

Record-keeping could also be integrated with training to ensure that where a person has an ASC the health professionals responding to him or her could be instantly alerted to the special needs that the person may have:

> *I would like to see a tightening-up of cross referencing, with the word "autistic" flagged up on our notes and computer screens whenever we are referred by GPs to hospitals and clinics, to make our disability obvious to nursing staff, and others who come into contact with us, including receptionists, who should also receive special training, along with community care workers - not just ‘key professionals’. (A person with an ASC)*

5.6.6 Coordinating care

Once a diagnosis has been made the next challenge faced by people with an ASC is to receive the care that they need in a way that recognises both the medical and social aspects of ASC. This is reflected in many of the 92 comments about communication, coordination and continuity of the provision of care and services.

> *There should be statutory assessments (including diagnosis) and reviews by professionals’ at all key stages in a person with ASC’s life. These should be at the end*

> *of primary education, the end of secondary education, the end of FE/Specialist College or at least every 10 years. All things should be reviewed: the diagnosis, the support needs, the education, the social care needs, the housing needs, the health needs. (ASC professionals group)*

This in turn means much closer communication and coordination among the agencies with responsibility for supporting people with an ASC. In particular, it means systems to ensure that people with an ASC do not fall foul of the main weakness in multi-agency working - of nobody taking ultimate responsibility for delivery:

> *Protocols should be established between different local authorities and PCTs as well as within local authorities and PCTs for determining who should take responsibility for an adult with ASD and prevent people from falling in the gaps between services. (No sector selected)*

It also means taking a personalised approach to each individual so that, for example, speech and language therapy is not automatically withdrawn once an individual becomes an adult. In fact, the ideal described by some respondents is that every person with an ASC should have a personalised care and support plan that covers every aspect of their life and ensures the care and support they need is delivered comprehensively and consistently, ensuring that information is passed within the network of doctors, social workers and other support workers. This would prevent people with an ASC or their carers needing to explain problems repeatedly to different people, the need for which is itself reported as a regular source of stress and anxiety.

> *A cradle to grave approach would be appropriate. Because autism is incurable, any strategy document should cover the entire age for people with an ASC. (Family carer)*

This would also achieve a more consistent approach and, importantly, would enable people with an ASC to build deeper relationships with the healthcare professionals in a position to help them.

5.6.7 Involving and supporting families and carers

Sixty-three respondents emphasise that it is difficult to overestimate the burden that falls on the families and carers of those with an ASC. There are a number of actions suggested that would either ease this burden or turn health professionals and carers into allies rather than maintaining, as it is suggested, sometimes antagonistic relations.

The first step would be to recognise the expertise, based on round-the-clock contact, of those who look after a person with an ASC. The next step, it is suggested, would be to train families and carers, perhaps alongside the professionals, in the latest thinking and skills for responding to ASC.

> *Rely on existing information as provided by families, offer sound up to date training for families and professionals alike - it's amazing how far a little well placed knowledge can go, train them so that they have acquired knowledge built on experience and up to*

> *date information from behavioural sciences to offer as a sound base to help other families coming up behind them. (Family carer)*

At the same time more attention could be paid to the needs of carers, providing where necessary psychological support to family members who are coping with the day-to-day stress of living with a person with an ASC.

> *… there needs to be a specific ‘Carers Strategy for ASC.’ This would involve working with carers and families who often have limited or no support in caring for their family member who is living with ASC. (ASC professionals group)*

The thrust of what many respondents are saying is to call for long-term partnerships among professionals, carers and people with an ASC themselves to ensure both that they receive the care they need, and to create a wider community of people and body of knowledge to meet their needs as they become more widely recognised.

5.6.8 Creating accessible and ASC-friendly healthcare settings

Many respondents (69 comments) report the difficulties they have experienced, either themselves, as carers, or as professionals, with the settings in which healthcare is delivered.

Several issues stand out, particularly the problem of noisy waiting-rooms, delayed appointments, and seeing different people on each visit.

> *Appointment times being stuck to, not having to wait. Quiet waiting rooms. Ensuring that the individual with ASC sees the same Health Professional each time (GP, community nurse, neurologist etc). (No sector selected)*

Many responses emphasise the need of people with an ASC for quiet, structure and consistency in their lives generally, and particularly to prevent misdiagnoses based on lack of understanding of how immediate circumstances may affect them.

5.6.9 Providing specific support and advice services

While many respondents focus on the general health needs of people with an ASC that may be overshadowed by the condition, some (46 comments) also suggest specialist support that could help ASC or its symptoms: more speech and language therapists, for example, and specialist SEN coordinators in hospitals and health centres to assist and liaise.

Some respondents would like to see more imaginative approaches to people with an ASC. Several therapies based on art and music, for example, are reported to be effective both in offering comfort to people with an ASC and providing an outlet for frustrated interests and energies:

> *Paragraph 5 [of the consultation document] says that there is little evidence as to what is effective for this client group. Music Therapy has a good, and growing, evidence*

> *database… I believe there should be greater investment in Arts Therapies, particularly Music Therapy, which has proven success in this area. (ASC professionals group)*

5.7. If possible, please give examples of where these concerns have been successfully addressed at a local level. (This question corresponds to Q11 of the standard consultation)

322 people responded to this question.

The largest group of respondents (126 comments) said that their concerns are not being addressed. Some provide examples of bad experiences with local services; others tell of sympathetic health professionals defeated by ‘the system’.

There are a number of respondents, however, who provide examples of what can be achieved at a local level, often focusing on a single individual such as a GP, a dentist, or a social worker.

> *My son had never had dental treatment and could only tolerate short periods of someone looking at his teeth. Locally the dentist was disinterested and lacked any concern about the quality of his teeth. With a referral to Guy's Hospital we found a total contrast. The dentist worked with us planning the appointment (no waiting time, first appointment), building up a trust with my son, experimenting with short acting anaesthetic through nasal spray (no injection) working with timeframe of his tolerance. An excellent example of a good working partnership! (Family carer)*

> *My daughter’s social worker [name removed] has been wonderful. She is usually able to elicit what I believe are genuine thoughts and feelings from my daughter. This is not easy to do, but [she] has taken her time, been patient and understanding and has gained my daughter’s trust. I do not think [she] uses any particular technique and she does not have any special training in AS. So I think she is naturally talented with people, but I wish all professionals could communicate so well with my daughter. (Family carer)*

Not all such individuals are necessarily involved in the caring professions:

> *My son's cleaners are the most valuable support of all his supporters. They have been on the internet, looking up Aspergers and are able to talk with him effectively. They clean his house well and he knows what they are there for. They do not patronise, placate or criticise. (Family carer)*

There are also encouraging stories of institutions which have adapted their procedures to accommodate people with an ASC:

> *An example was given of a GP practice… where the staff do have an awareness of the particular needs and challenges posed by people with ASC but they are very few and far between. The staff there were described as ‘fantastic’ the person with ASC always gets the next appointment after arrival and the reception staff are sensitive to the needs of people with ASC. (Family carer)*

> *A good example can be found at the Chesterfield Royal Hospital NHS Foundation Trust in Derbyshire. The children's outpatient department is adept at handling patients with autism due to its emphasis on specialist training. The department provides specialist ASC training for staff on a regular basis so that all members of the team – not just the medical staff – are equipped to understand the needs of patients with autism. The team recognises the stress that can be induced in children with autism by hospital visits and invasive, unfamiliar procedures. The staff work closely with carers and have taken steps to reduce stress wherever possible. They have ensured that children with an ASC no longer have to endure long waiting times. They also have longer appointments so that time is made to put patients with autism at ease. For example, the adults in the room have their blood pressure taken so the child can watch and make an informed decision to participate. (A group of ASC professionals)*

There are positive stories of the efforts being made to raise awareness of ASC among professionals, for example:

> *A conference event was delivered by RNID and NAS to raise awareness of deafness and autism across service boundaries. A similar health led conference looking at LD deafness and Autism was also delivered by lead professionals in Leicester. (No sector selected)*

There is also evidence of health professionals adapting their normal behaviour in response to the needs of people with an ASC:

> *Once admitted to the hospital with peritonitis, the nurses endeavoured to communicate with our son via Makaton sign language. Our son's communication is very impaired and though taught Makaton, he has been known to sign to a wall, people's backs etc. as he fails to grasp how communication works. But the nurses' actions demonstrated they wanted to engage with him and he responded positively to this. It was the nurses that demonstrated far greater empathy and knowledge with our son than their doctor counterparts for the majority of our experience. (Family carer)*

> *One service user, when attending his GP to seek referral for assessment, was unable to verbalise his concerns. The GP suggested the patient retire and write his concerns in a letter. This evidence, with the patient's consent, was employed in the screening processes of the GP, of the CMHT and of the ASD Assessment NHS Clinic. This ultimately made for a much faster, smoother and less stressful route through those screening processes, as the letter contained most of the required information and the inconsistency of evidence raised by three separate interview/ers was removed. (A mixed group of people)*

Many of the local initiatives described by respondents are apparently very simple, and all have in common a real appreciation of how people with an ASC can be helped by relatively straightforward changes in procedures, or through the exercise of a little imagination:

> *A good practice example from Bedford was where a group of people with LD (Including People with ASD) undertook a time banking initiative. Service users asked to visit the local general hospital setting and shared their fears and good and bad hospital experiences, with nursing professionals. They contributed to nurse training and discussed what helped them and hindered their progress. The service users wanted to see the hospital behind the scenes and saw areas they had initial fears of, which helped them to feel more positive about the hospital. They were also to receive a*

> *named worker to assist them if they were to be admitted to hospital to help with the continuity they said would help them to recover. (ASC professionals group)*
>
> *An individual supported by [name removed] had a wound attended to following a fall, which included the need for stitches. This was very helpfully done by the paramedic in the person's bedroom. GP's have performed home visits to individuals to undertake health assessments or take blood to remove the stress of going to a strange and often noisy environment. (No sector selected)*
>
> *A Berkshire wide Autism Alert Card is also being developed. This will support individuals on the autism spectrum when accessing all services including health. (ASC professionals group)*

One point made by many who responded to this question is that every successful initiative begins with people becoming more aware of ASC, and that most health professionals respond positively when they understand how small changes can make large differences in the lives of people with an ASC.

5.8. Easy-read consultation questions on the health chapter

People have told us that there are four main ways we can improve healthcare for adults with autism. These are:

1. make it easier for adults to find out if they have got autism and get the healthcare they need
2. make sure that people working in the health service have information about the adults with autism who live in their area, so that they can make sure that help is available for them
3. make places like doctors' surgeries and hospitals easier to get to for adults with autism and make sure these places are easy for adults with autism to use
4. help doctors, nurses and social workers who work with people who have mental health problems to understand more about autism. This will mean they can better help people with autism who also have mental health problems.

5.9. Do you agree that these are the most important ways to improve healthcare for people with autism? (This question corresponds to Q2a of the easy-read consultation)

Group	Count	Proportion
Yes	136	87%
No	10	6%
Not sure	9	6%
No answer	1	1%

5.10. Please tell us why. (This question corresponds to Q2b of the easy-read consultation)

156 people responded to this question.

The overwhelming majority of respondents support the four ways of improving healthcare for people with an ASC.

5.10.1 Professional training and awareness

For many respondents (54 comments) the single most important way is to improve information and training about ASC for people working in the health service. It is considered vitally important that healthcare staff have an understanding of ASC, especially in terms of communication and sensory issues.

> *GPs can be incredibly unsympathetic when asked to help get a diagnosis - one I visited said Aspergers is an "excuse" for not doing well in life, another thought I was "trying to get on the sick". Similarly, doctors and psychiatrists are clueless about the mental health issues that arise with Aspergers, and are often unsympathetic, or just don't understand. (A person with an ASC)*

Awareness, knowledge and training are important not only because they help healthcare professionals to understand people with an ASC, but because they also make it easier for people with an ASC to get the help they need. It also encourages professionals to appreciate that while ASC is an important part of such people's lives and has a constant and significant impact on them, it is not the totality of who they are: they are individuals with an ASC, not 'autistics'.

Respondents also want to emphasise that it is particularly important for people working in mental health to understand ASC so that they do not try to treat it using the wrong methods.

5.10.2 Better and earlier diagnosis

24 respondents talk about improving diagnosis and describe the problems they or family members have encountered when seeking diagnosis; some have not been diagnosed until relatively late in life. There is particular concern about the need to improve diagnostic pathways, as in some areas it is reportedly very difficult to get an adult diagnosis of ASC and GPs are prevented from making out of borough referrals.

The result is that adults with an ASC can remain undiagnosed and instead are treated for mental health problems or as having a learning disability:

> *There are a whole swathe of people with autism who do not have a learning disability - where are the services for people in this category (which in itself is a very wide spectrum). Even those with HFA are entering the healthcare system through mental health services when they suffer depression, self-harm, breakdowns and meltdowns. (No sector selected)*

The failure of accurate diagnosis means that people with an ASC are sometimes treated inappropriately or for mental health conditions that they do not have, and do not have access to other services that they need.

5.10.3 Post-diagnostic support, anxiety and mental health issues

Many responses mention the support that people with an ASC need, or which would make their lives better, and provide examples of the sort of support that would be helpful, for example:

> *It is important that adults with autism have appropriate diagnostic services and post diagnostic support**.** This is sadly lacking at the moment. Counselling should be readily available to adults with autism and young people going through transition into adulthood which may prevent potential mental health issues in future life. (No sector selected)*

It is also apparent from many responses that people feel that it would be helpful if there was more general understanding of autism, and more support and understanding from the community as a whole could be expected:

> *I would add to the list that it would be beneficial if autism was promoted more within communities so that the general public could become more aware and tolerant. (A person with autism)*

People with an ASC often have related mental health problems. 18 comments are about mental health issues or anxiety:

> *There can often be other associated health problems when people have autism - dyspraxia, epilepsy, depression, etc. If an adult has combined problems they will need additional support. (Other)*

There are also specific places that increase the levels of anxiety experienced by people with an ASC. Respondents say that busy places like hospitals and doctors' surgeries can be very intimidating for people with an ASC, and make it even harder for them to communicate their health needs to doctors and nurses.

> *I also find hospitals and busy waiting room very difficult and struggle due to sensory problems around crowds. If I could be given appointments on days or times that are quietest it would be a great help to me and many other people on the spectrum. (A person with an ASC)*

3.10.4 Other issues

In addition to these issues, which are regularly mentioned by respondents, there are also comments about a range of other issues, including transition from children's to adult services, the need for more research and better data collection, the value of good information provision, and the importance of involving families and carers.

5.11. How did you find out that you had autism? (This question corresponds to Q2c of the easy-read consultation)

127 people responded to this question.

The responses to this question indicate that people are most likely to discover they have an ASC through friends, family (33 comments), or health professionals (33 comments), for example:

> *My younger sister had just got diagnosed. As I am very much like her in the difficult areas of my life I thought I might also have autism (Asperger's Syndrome) so I asked my doctor to refer me for diagnosis. (A person with an ASC)*

The role of doctors and other health professionals is often to confirm a diagnosis suggested by others or to refer the person to a specialist in ASC, to NAS or for assessment by a communication and social behaviour assessment team (CASBAT).

The processes through which people find out about their ASC vary greatly. Some are diagnosed at an early age because their parents are worried about them; others are not diagnosed until much later in life. Sometimes diagnosis is as a result of something else, such as illness or bullying at school, for example:

> *My son was diagnosed with Asperger's syndrome at 10yrs old as he had become suicidal from bullying at school. We spent 10yrs trying to get help for him, but were denied it, and labelled by doctors as neurotic. He was diagnosed as a result of my stumbling upon the autism handbook in my local library, whilst searching for information on school bullying problems. (Family carer)*

For some it is a matter of chance that they are diagnosed at all:

> *My husband and I were watching a programme about autism on the TV and there was a roleplay involving children and dolls. I answered the question with the same answer as the child who was autistic and my husband pointed out to me what I had done. It was quite a shock to hear but I then knew I had to find out properly and asked my GP to refer me to someone who could tell me whether I was or not. (A person with an ASC)*

5.12. What help did you get to understand what having autism means? (This question corresponds to Q2d of the easy-read consultation)

125 people responded to this question.

Of the people who answered this question, 60 said that they had not had any help. In many cases there was no form of follow-up after diagnosis, for example:

> *None. I saw a neurologist for another condition and he got me three sessions with a psychiatrist to ask any questions I had. No help was offered after I was diagnosed and my GP didn't ask me to come and discuss my diagnosis even though a letter was sent to them from the person who diagnosed me with their recommendations. (A person with an ASC)*

Some were not told about organisations such as the National Autistic Society by those who diagnosed them:

> *None. (We lived in Bromley, Kent, and were not even given the 'phone no. of our local autistic branch). (Family carer)*

Of those who did get help to understand ASC, the majority say they got it through self-help, using books, films or the Internet, for example:

> *I didn't get any help. My understanding of autism comes from intense personal observation, combined with research on many books written by those who are involved, or who have, autism. You can see all the little traits of autism jumping off the page when you read, you can finally identify and say "that's me". Some of the books include:*
> *"Emergence: Labelled Autistic" (Temple Grandin)*
> *"The Complete Guide To Asperger Syndrome" (Tony Attwood)*
> *"Animals in Translation" (Temple Grandin)*
> *"How To Be Yourself In a World That's Different" (Yuko Yoshida)*
> *"Developing Talents" (Temple Grandin and Kate Duffy)*
> *"The Curious Incident Of the Dog In The Night Time" (Mark Haddon)*

> *I have read many more. They do help to understand yourself a little better, even if you can't do anything to help deal with it! (A person with an ASC)*

A relatively small proportion of those who responded say they have had professional help with understanding ASC. Most frequently cited are doctors, social workers, school teachers and specialist clinics. Local voluntary support groups are also regarded as very helpful, for example:

> *Health authority provided me with information about a local voluntary parent support group. This has been invaluable, but shame that health authority were unable to offer support. (No sector selected)*

Often what seems to have been most helpful was meeting and talking to others in the same position, whether other people with an ASC or parents and carers:

> *By joining the NAS and talking to the parents of AS people. I also did voluntary work in a school for AS children and joined the Parents' Group. (Family carer)*

5.13. What do you think we should do to make health services better for adults with autism? For example, how could we make it easier for adults with autism to get the treatment they need, to visit a doctor’s surgery or use a hospital? (This question corresponds to Q2e of the easy-read consultation)

126 people responded to this question.

The most frequent answer to this question is, once again, to train health service staff to respond better to people with an ASC (56 comments).

There are also some specific suggestions for helping people with an ASC to get the treatment they need. Among the most frequently mentioned is the idea of a ‘buddy’ system (25 comments):

> *A buddy you can email and ask them to go with you. The buddy can explain to the doctor. I find talking impossible if I am very ill or stressed. When I broke my hand this was a very bad situation in the hospital because they didn't understand and I couldn't tell them. (A person with an ASC)*

Another popular suggestion concerns appointment times at surgeries and hospitals:

> *Time is a big issue for me personally as I have little concept of waiting. I hate waiting for appointments and become agitated - ideally, I would go straight in for my appointment and not have to wait. (ASC professionals group)*

The environment of waiting rooms is a problem for many people with an ASC: there are suggestions that, if they do have to wait, wherever possible they should be allowed to wait somewhere quiet and away from other people.

Another way that getting treatment could be made easier would be if all communication was made as clear and simple as possible:

> *Communication is the key here. I am literal and quite often misunderstand the jargon used AT ME which is just repeated and almost never explained. Social Services and Government departments are by far the worst offenders. Many autistics simply don't understand the bizarre wording of instructions given to them. Plain English is not the way of governance - unfortunately. (No sector selected)*

A number of responses also refer to specific problems, such as transport:

> *Individual transport to appointments for a person with autism and their carer or a family member would help as group transport is very stressful. (A person with an ASC)*

Most of the other improvements suggested flow from a combination of better awareness and training, better communications, and a better environment in which to seek treatment, adding up to services carefully designed to meet the needs of people with an ASC in the same way as services are designed to meet the needs of other people with particular conditions:

> *You should have Autistic clinics at every hospital in the country. You have them for AIDS, Diabetes, drink and drugs problems. Why is it someone that abuses their body with drink and drugs can get help and support and yet I cannot get any and I was born with this condition? I didn't ask for ASPERGERS, God gave it me for free. (No sector selected)*

5.14. Health services are things like doctor's surgeries and hospitals. What health services in your area are easiest for you to use? Why are they easiest? (This question corresponds to Q2f of the easy-read consultation)

114 people responded to this question.

For people with an ASC life is made easier by proximity, familiarity and basic human kindnesses such as the time and willingness to listen. For this reason many people with an ASC find local doctors' surgeries where they are known, for example, much easier than hospitals which are more impersonal and the environment is more stressful.

> *Our GP surgery is very well organised, helpful and easy to use. However, the hospitals near us can be very confusing in terms of getting to where you want to go. I can imagine an autistic person would find some of these places really bewildering. Clearer signage, pathways to places, and people who can help are all essential. (Family carer)*

For the majority of respondents it is the attitude and knowledge of the health professional that most counts, for example:

> *My doctor is good. I never see him for anything more than my medication review. He has never asked me about my condition. I do like him and he is easy to talk to. Hospitals always seem in a rush to get rid of you and it's some snob of a consultant that knows autism on paper but has no idea about life with autism. (No sector selected)*

Sometimes the differences are made by things that might not even be noticed by people without an ASC, such as the type of phone number a doctor has or whether the GP’s premises are within walking distance:

> *We have just moved to South Wales so I haven't had cause to visit the hospital here but I did have to choose a doctor and that worries me. So I asked my neighbours what their doctors were like and what kind of a phone number they had - an 0845 number or a normal number like my home phone. I thought about how far away they were, what parking would be like and could I walk there. The normal phone number means I don't have to worry about how much the call will cost me. Being close to them stops me worrying about being late for appointments…. (A person with an ASC)*

It is also apparent from the responses that people with an ASC most value things that reduce their anxiety, for example:

> *My local surgery has email prescriptions and self check-in. all these things make it easier to handle the process. (Family carer)*
>
> *My GP is really good because I can email her before the appointment with why I am going so then its easy even if talking goes wrong. (A person with an ASC)*

The help of others is often essential, and CAHMS is mentioned as an example:

> *Child and Family Guidance (CAHMS). It's easier because the professionals know my son well. He can also go to the GP easily. In both cases this is also because he's accompanied by me and I wait outside. (Family carer)*

Receiving support for meetings with doctors and medical staff can however create problems of its own, for example:

> *I don't find any service easy to use by myself, but it's easy to go to the doctor's if my mum phones up to make the appointment and then takes me there. She often comes in and speaks for me in the appointment, although this is difficult in some respects because she could get things wrong, or say things wrong, and if I didn't want her to know about something I'd then not be able to go to the doctor at all because I wouldn't be able to ask her to phone up. (A person with an ASC)*

6. Choice and control

6.1. Summary of responses to this chapter

This chapter covers responses to questions about the barriers that prevent adults with an ASC from having choices and taking control over their lives. Respondents are asked whether they agree with the four areas identified by stakeholders where action is needed to ensure adults with an ASC have more choice and control over their lives (ensuring that personalisation is made to work for people with an ASC; improving transition planning; improving access to advocates and self-advocacy support; and ensuring adults with an ASC are better involved in the development of services and policy that affects them). They are also asked to suggest actions needed to deal with these and to provide examples of challenges and solutions they have come across.

6.1.1 Main issues

There is very clear support from respondents for the four areas selected by stakeholders. Many call for more thorough and person-specific **transition planning** and highlight how changes, such as the transition from children's services to adult services, are likely to cause people with an ASC high levels of anxiety. It is also emphasised by many respondents that every adult with an ASC is unique and therefore requires **individualised support**. Though not all adults with an ASC would be capable of or comfortable being involved in the planning of their services, those who can are keen to **have more of a say**. Support or **training** (and **(self) advocacy** where necessary) may be needed to achieve this.

6.1.2 Examples of challenges

A wide variety of detailed examples suggests many adults with an ASC are **struggling** to gain any meaningful control over their lives, with many carers also feeling **disempowered**. It is strongly felt that support is lacking and real choices are non-existent.

6.1.3 Actions to be taken

Respondents feel that offering adults with an ASC a **person-centred approach** is crucial, adding that the requisite services should be available in every area. Many also urge the establishment of effective **advocacy** for people with an ASC, especially for those not able to argue in their own interests. This will require a better understanding amongst advocates as well as mechanisms for enabling better self-advocacy. Furthermore, some respondents indicate the need for improved **information provision** and signposting. These and other actions, notably the availability of a **personal budget** – provided that it comes with proper support or advice – are considered to be at the heart of the involvement and empowerment of adults with an ASC.

6.1.4 Examples of solutions

Many responses provide examples of **good practice** and case studies describing initiatives that have helped people with an ASC in many different ways, such as self-advocacy training or person-centred plans. There are also many responses saying that people's concerns are not being addressed.

6.2. Standard consultation questions on the choice and control chapter

The external reference group identified the following as key areas where action is needed to ensure adults with ASC have more choice and control over their lives:

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

6.3. Do you agree that these are key areas where action is needed? (This question corresponds to Q12a of the standard consultation)

Group	Count	Proportion
Yes	467	81%
No	14	2%
Unsure	54	9%
No answer	42	7%

6.4. Please explain your answer. (This question corresponds to Q12b of the standard consultation)

577 people responded to this question.

While the majority (467) of respondents support the conclusions of the external reference group, 68 either reject them or are sufficiently unsure about them to avoid offering active support. This rejection or hesitation is mostly because respondents are concerned about choice and control being in the hands of people who may have a lower-functioning ASC.

These apart, respondents' explanations very much reflect and endorse the conclusions of the external reference group. The three issues that most concern respondents, and to which all other issues relate, are transition and transition planning, advocacy and self-advocacy which are also felt to empower people with an ASC, and person-centred approaches.

6.4.1 Transition planning

Many respondents provide examples that highlight the importance of continuity of care and experience to adults with an ASC, explaining the effects of disruption and the distress it can cause. There is concern in particular about transition from children's to adult services, and it is a theme that emerges repeatedly throughout responses to this consultation. This specific question generates 158 comments about transition issues and planning.

Many respondents highlight the adequate or better services currently available to children with an ASC, but many say that once a child reaches adulthood the provisions diminish and in many areas, according to responses, are seriously lacking.

> *…he does not have a learning difficulty he may not qualify for help until we have a crisis… We don't know what is available and nobody is helping us to plan for the future. (A person with an ASC)*

It is also argued that if transition planning happens at all, it is often at the last minute, which can increase uncertainty and anxiety. Respondents emphasise that person-centred plans can help overcome this.

The challenges of transition are illustrated by respondents describing their personal experiences. Some may stem from a fundamental lack of understanding of what ASC is:

> *We had a statement but no transition plan of any kind we refused to be interviewed by people who said, 'Aspergers, what's that?' After years of inappropriate and damaging intervention we were AFRAID of the services that were supposed to support us, what they could do with all their power to trample over the lives of the vulnerable, and those with autism are very vulnerable […]. (No sector selected)*

The importance of transition planning is repeatedly emphasised, with particular stress on the need to prepare people for the transition from youth to adult services. Respondents assert that this planning needs to start at least from the age of 14, involve all the necessary agencies from the outset, and last for as long as necessary to ensure that the person with an ASC is supported throughout a period of change perceived to be extremely challenging.

> *….transition should start properly at 14… there should be a team of people especially to help the person and their family find out what their options are, someone who is independent of social services as well so you can find out all your options - not just the ones that social services tell you about…. Every school should have a team of*

> *people working full time just on the people who are going through transition. (Family carer)*

Respondents mention a range of circumstances that require a special focus, for example:

> *…if a young person has been away from home in a residential special school and now due to return to the home area and go into an adult placement the transition planning for this should take months. It needs to give a great deal of opportunity for the individuals to both understand and become accustomed to the big change that is going to take place in their life. (Professional group)*

It is suggested that changes in care and services are best kept to a minimum due to the vulnerability of some adults with an ASC and the potential impacts on a person's health of sudden or unplanned disruptions: any necessary changes should be carefully considered, fully planned and implemented gradually.

> *Good, effective, straightforward Transition Planning should be a fact of life, an absolute given in the lives of young adults with ASD. It most certainly should NOT be something to have to fumble around for in the dark, searching for scraps that have dropped off the table of life when everyone else more "normal" has gorged their fill. It is absolutely vital for the well-being, self-esteem and future mental health of young adults and their families that Transition Planning is given top priority across the board. (Family carer)*

Another issue that is raised a number of times is the transition from school to university and to employment, and the fact that support may virtually cease when a person leaves school. This is regarded as a particular problem for high-functioning young people with Asperger's who may not appear to need any help or support. One respondent says:

> *Transition from Education to Adult services for high functioning ASD, particularly Asperger's, is virtually non-existent. For example, an Asperger teenager may have a very high Special Education Needs Statement in the school setting because of his needs. Yet when he leaves school he will not qualify for ANY adult social services. The only support he can get is from Connexions […] my own 13 year old son with Asperger's attends a Special Needs school which is funded […] by the local authority. He is thriving and is expected to achieve good GCSEs. However, once he leaves school, he will not be eligible for any services because he is too high-functioning […] (ASC professional and family carer)*

The need for an improvement in the appeals and complaints procedures with regard to transition decision-making is also mentioned to ensure that decisions that turn out to be misguided can be easily and quickly revisited.

6.4.2 Access to advocacy and supporting self-advocacy

Another subject on which many respondents (154) comment is advocacy and self-advocacy. Many feel advocacy is beneficial and supports them in their goal to take control over their lives; they focus on the need for improved understanding and awareness of ASC among advocates, including the need to understand the language of someone with an ASC, which may be different to theirs.

It is argued that effective advocacy is at least part of the answer to ensuring that people with an ASC receive the support and help they need, and that more support for advocacy would free up resources and be cost-effective:

> *Advocacy support from the moment of diagnosis could prevent many from clogging up essential services. (Family carer)*

While the important of advocacy is argued by many respondents, the challenges it poses are also recognised. The fact that there are no established standards for advocacy is noted, for example, and there are concerns that it is relatively easy for people to believe that a close relationship or common interest equips someone to advocate for another. This may be the case when one person with an ASC advocates on behalf of another:

> *For example, his/her limited awareness of the thoughts and feelings of others may make someone with ASC a less than ideal advocate and the situation will be compounded if their own ASC leaves the subject of their advocacy unable to distinguish whether the advocate is being empathic or abusive. It must be also be recognised that assuming choice and requiring choice may generate overwhelming stress in an adult with ASC and, in itself, be abusive. (ASC professional)*

Recognition of such issues encourages respondents to argue for more training for people to act as advocates and to set out a range of roles for them, including the provision of information in a way, in a form and at a time that suits the person on whose behalf they are advocating and causes him or her the least anxiety. Such advocates need to understand the issues faced by someone with an ASC, and also how to help that person appreciate the decisions to be made, the options open to them and the consequences of the decisions that can be made.

The preference of many would, however, be to encourage self-advocacy wherever possible on the grounds that only through this can adults with an ASC ultimately take control of their lives and make their own choices:

> *Whilst there is a definite need for advocacy for people with ASD and often their families, in order to ensure autonomy people need encouragement and training in order to be able to self advocate, they are always their own best advocate but need more help than others in this area. (Family carer)*

Self-advocacy is regarded as particularly useful for people with ASC who know that they are different and need reassurance that other people struggle with similar situations and events, and that a way can be found through them.

The limitations of self-advocacy are also recognised, and the fact that it can even be counterproductive in some cases:

> *Many people with ASC do not have the social or communication skills to advocate for themselves or may be very blunt and appear rude or offensive when trying to be assertive. (ASC professionals group)*

6.4.3 Person-centred approaches

Improved transition planning, advocacy and self-advocacy are often important consequences of the personalised or person-centred approach, and this is one reason why it is so widely supported among respondents (136 comments). It is frequently described as essential and indeed some would like to make it mandatory.

Respondents make points about every aspect of personalisation, including person-centred planning, person-centred caring and personal budgets. Behind the practicalities is the need to start treating adults with an ASC as individuals.

> *Ensuring Personalisation of services is essential including personal/individual budgets to enable people with ASC conditions to live full lives, including work, social etc. in their lives. (A person with an ASC)*

Underlying this emphasis on the practicalities is the recognition that people with an ASC are all individuals with their own needs and personalities, that they are all affected in different ways, and that therefore it is essential that planning and support is on an individual basis.

It can also do much, in the eyes of some, to offer choices that are currently lacking when it comes to support and services, and give adults with an ASC some real control over their lives.

> *There is always the feeling that you are being coerced into a particular choice rather than being given the option. Often, there is only one option: for example group therapy when some people, like myself, are uncomfortable with this and would benefit from one on one support. (A person with an ASC)*

The person-centred approach would also, in the eyes of some professionals, encourage commissioners and service providers to be more imaginative and creative in what they offer by way of help and support for people with an ASC:

> *However there also has to be a range of options out there for people to choose from if they have a personal budget and a person-centred plan should not be limited to only the activities that people have easily available already but should be a catalyst for discovering new ways of helping people try new things and achieve their goals. (ASC professionals group)*

Even among the strongest advocates of the person-centred approach, however, there are words of caution and the realisation of how difficult it can be to implement this approach, and that it may not suit every case because not even two people with the same type of ASC will respond identically to what is on offer:

> *…plans are only helpful if they are implemented and frequently updated. Budgets need to be implemented flexibly, and should not place an unnecessary responsibility on the service user or their family to act as employer, find suitable services or undertake the administration, unless they wish to. (No sector selected)*

A number of respondents (28 comments) who agree in principle with the person-centred approach warn of potential pitfalls, both for provider and recipient. While individualised budgets, for example, have been instrumental in the development of some very creative and person-centred support packages, the actual process of moulding funding to fit the needs of many different individuals with different needs can make receiving funding a long and complex process.

This is not the only problem that is pointed out

> *Person centred plans are a really good idea but the aspirations of someone with Asperger's can be unrealistic. Also handing over an individual budget to someone whose overriding need is to buy a DVD rather than pay the rent because they are unable to acknowledge that they do actually need a house more. (Family carer)*

It is for this reason that a person-centred approach combined with some form of advocacy is seen as a strategy in which principle and pragmatism can work together.

6.4.4 Involving and empowering people with an ASC

The involvement and empowerment of adults with an ASC in all aspects of the services provided for them is another key issue that many respondents (137 comments) feel strongly about. Most responses, in tune with the points above, argue in favour of individuals having a say in their own treatment plans:

> *Many adults with ASC are capable of speaking for themselves and should be given a voice in service development. (Family carer)*

Respondents argue that even adults with an ASC who are perfectly capable of being involved in decision-making processes are often talked about or talked over, and should be more involved in issues that affect them. The involvement of adults with an ASC in how policy and services are conceived, developed and delivered is advocated, providing, as some point out, that thought is given to the methods of consultation and involvement that are used:

> *People with an ASC need the opportunity to have their voices heard so that they can receive the support and services they need. This entails ensuring that they are included in planning and consultation events and given the opportunity to give their feedback via questionnaire and online as this method often suits people with an ASC better than communal events where they are often made to feel alienated and talked over by neurotypical/non-autistic people. Consultation events are not usually autism-friendly. (A person with an ASC)*

Not everybody, however, is interested in policy-making or able to contribute to it:

> *Some people with ASC are not very able or interested in making policies. Of course they should do if they wish to, but some of them may need more support than others […] This is something that is different in different people. Those who can't be involved should not be "ensured" to be. (Family carer)*

It is also argued that some people with an ASC find decision-making in itself quite difficult and that any approach must carry with it adequate support for making choices and reaching decisions, which reflects again the importance of effective advocacy.

6.4.5 Other responses

Other issues mentioned by respondents in relation to choice and control include the need for greater involvement of families and carers; the need for clearer signposting and advertising of services; the need to improve professionals' and service providers' training in ASC; and funding and resource issues.

6.5. Please provide details of your experiences of the challenges faced by adults with an ASC as they try to make choices and take control over their lives. *(*This question corresponds to Q13 of the standard consultation)

448 people responded to this question.

One point widely made by respondents is that this question is rendered irrelevant by the fact that many adults with an ASC do not feel they have any choices or any control over their lives, because of the nature of their ASC, or because they have no access to the support that choice and control requires, or because when it comes to practicalities the options open to them are so constrained.

The issues mentioned in response to this question, and stemming from the whole question of choice, are all interlinked.

6.5.1 Lack of choice and control

The majority of responses to this question come from either family carers or professionals working with ASC, and they set out the multiple challenges and constraints that face those who want to make choices and are ostensibly capable of making them.

Many respondents believe that more choice and control could be within reach for people with an ASC if there was proper support. That this is not currently the case is brought forward in 86 comments testifying of a perceived lack of support or the inadequacy of the support that is available.

One specific element that people with an ASC would require support with is making and understanding decisions. There are 61 comments in which respondents explain how making decisions, be they big or small, can be very challenging for people with an ASC, who require both time and help to come to a conclusion.

> *There is a real need to understand these difficulties if we are to really offer people with ASC choice. It is a process that takes time. For example when trying to move someone on from residential care into a supported living environment it is important for*

> *the individual to really grasp what supported living is in a very concrete way. Just talking about it or even showing photos will not be enough for them to cope with making a real choice. They will need to be reassured and given opportunities to experience supported living, to visit others in this kind of environment. They can then be involved in visually weighing up the good and bad about moving into this new kind of environment. Only with this level of effort can we really enable someone to make a choice without being scared and going for the most predictable. (A mixed group of people)*

For many people with an ASC it is therefore vital to have someone who is entitled to act on their behalf, or to have someone supporting them when they represent themselves. Such support is currently not sufficiently available, judging from 54 comments illustrating a lack of advocacy or self-advocacy support.

In practice, budget restrictions and the lack of a good range of services can mean that there are few choices for anyone with an ASC who is dependent on benefits and social services. For example, people with an ASC may be invited to choose among a range of options only to discover that there is no budget available anyway:

> *It is important not to offer a choice which is not a real option i.e. telling people they can choose who supports them when the funding may not be available for the option they choose or the service they want may not exist. (A mixed group of people)*

The issue of choice and control for people with an ASC can also create pressures and dilemmas for families and carers: whether, for example, to encourage a person with an ASC to be independent or to hold them back for fear of the possible consequences.

> *Families may feel they know what a person with an ASC needs/wants but this may not be the case. Real choices need to be offered. Support, Services and agencies should all be explored. (ASC professional)*

It is acknowledged that one of the most difficult issues is that of conflict between family/carers and people with an ASC, particularly young people who are trying to take control over their lives. Most adolescents gradually develop the confidence to challenge parental views, but those with an ASC may find this difficult well into their adult lives. It is argued that separating from the boundaries and structures provided by parents, for example, can generate difficult and conflicting emotions that may find expression through challenging behaviour. This is perceived to be a further argument for skilled advocacy.

There are a range of other external challenges that people with an ASC and their carers and supporters agree are significant obstacles to choice and control. Bureaucracy and form-filling, for example, are often a problem:

> *Bureaucracy has a large part to play when people with ASCs try to become involved as these are organisationally created barriers. Access to services and support need to be far simpler and more responsive to need through flexible and creative approaches. (ASC professional)*

Lack of basic information, particularly in a format that adults with an ASC can understand, is another frequent complaint (34 comments). Many find it hugely difficult to navigate local authority systems and pathways, for example, and eventually give up and remain unknown to the services that could help them.

Basic failures of communication can also get in the way of progress:

> *Person Centred Plan did not include the views of the professionals working with the individual only the support staff who did not understand the reasons why decisions had been made. The social services department saw it as the private group home trying to hang onto the service user. A best interest meeting was declined. They wanted to move the individual back to area where funding was from which they left 20 years before. No family, relatives and very poor communication skills. (Family carer)*

The general failure of people to understand ASC can undermine motivation and confidence:

> *One of the biggest problems for my sons is that often professionals working with them do not understand ASC and because one presents well, they don't understand why he is unable to do things. For example, trying to explain that my eldest son struggles with social situations has met with "so if he doesn't practice it, he loses it" in fact it is that he doesn't have that intuitive knowledge in the first place. Or comments like "well I feel like that" or "well, isn't that most boys?" In order to provide appropriate services it is essential that people have at least a basic understanding. My eldest son wants to know why he has to teach everyone he comes into contact with! (Family carer)*

6.5.2 Constraints on the desire or ability to have choice and control

A major constraint on the encouragement of people with an ASC taking control over their own lives is perceived by many (76 comments) to be that many people with an ASC have concerns about their own capacities in this regard:

> *….most ASD people I have come into contact with struggle to make decisions on anything. Choosing what to do at college or what to do for a job are all issues that trouble people with ASD as often they are frightened of choices not working out and also often they have no idea of what is involved, overall they might know what they want at the end but they do not know how to map out anything in order to achieve it, I myself often lack this ability. (A person with an ASC)*

It is pointed out that many adults with an ASC find making choices extremely stressful, and can also be open to manipulation and exploitation:

> *People with ASC can often make the wrong choices e.g. can be easily exploited. They will often not make a choice if it involves any element of risk/change/anxiety (e.g. will 'choose' not to buy new clothes if this means having to go to a clothes shop and try clothes on). (ASC professionals group)*

This is compounded for those whose ASC makes it difficult for them to imagine what their options might be or to consider options that are unfamiliar and therefore anxiety-promoting:

> *Often the services ask an open question "What would you like to (do live etc)" and [my son] has no real answer. What he needs is someone who has a lot of knowledge of his*

> *strengths/weaknesses, his successes and his limitations, his sensory issues, his fears and anxieties but invariably when attending services it is not in his environment and often with a complete stranger and therefore he is unable in this stressful situation to make a relevant choice but just wants to get away to return to his comfort zone. (Family carer)*

Professionals and carers, while on the whole acknowledging the desirability of giving adults with an ASC more control over their lives, also say that unless they are able to learn to exercise choice with responsibility it can be counterproductive in terms of the person's overall wellbeing:

> *Control can lead to increased obsession and rigidity…. Unlimited individual choice for many adults with ASC (e.g. to only eat one food type, to watch TV all day, to be able to take someone else's possessions without permission, etc.) can give rise to further problems for the person - a balance is often required, with the person needing to learn about how to exercise 'choice with responsibility'. (ASC professionals group)*

It can also, according to some, lead to unintended consequences, such as developing challenging behaviour as a way of gaining access to preferred activities:

> *We have experience of a young man who rips his clothes to ensure he is taken clothes shopping regularly as this is something he enjoys and he does not have the communication skills to verbalise this. (ASC professional)*

Financial independence can also lead to unintended consequences, such as a person with their own bank account not appreciating that money needs to be set aside for necessities such as rent or utility bills, and social workers feeling unable to countermand such decisions because the person has deliberately been given freedom of choice to make them. Again, the importance of advocacy becomes apparent.

6.5.3 Housing, independent living and effective advocacy

Another major constraining issue for many (50 comments) is finding suitable accommodation. This is often the first step towards choice and control for many adults with an ASC, and it is a perennial problem for a large number of people as discussed earlier.

> *Housing is a big worry for us and our daughter. She needs ASC-specific support either in supported living or in an independent flat. In our area (Staffordshire) this is non-existent. To place her in a mixed environment with other adults of various "needs" would be both cruel and a recipe for disaster. She cannot cope with strangers, excess noise, chaos, disruption, lack of boundaries, etc etc. (Family carer)*

The type of accommodation available to people with an ASC can also be a constraint on their sense of choice and control, though not necessarily in the direction that is always intended:

> *Unfortunately - from my perspective - there has been a move away from residential settings towards "care in the community" over the last couple of decades and more, partly for economic and partly for ideological reasons. That is fine, for those that want it*

> *- but not everybody does; and I believe that, if “choice” is to mean anything at all, that alternatives to the prevailing norm must be made available to those who desire them. Not to do so is to deny choice, offering people not what they want but what Service Providers think they ought to have. (A person with an ASC)*

There is perceived to be an equation that choice and control should mean independent living, but this is clearly not the case for all who respond to this question. For some, independent living may be preferable to the wrong residential setting, but a good residential setting that offers structure, routine and constancy is preferable to living alone. Indeed, some people may never be capable of independent living.

It is argued that the question of choice and control cannot be separated from the issue of independent living, and for that to work there needs to be effective advocacy to ensure that people with an ASC are helped to make the right decisions.

> *There can be little or no support available e.g. when moving to independent living. This is a particular problem for those who are not eligible for support as dictated by the FACS assessment. Whilst providing support will have financial implications, not providing it can lead to crisis which in turn will come at a high cost. All of this provides a negative experience for the individual and their family. (A mixed group of people)*

In summary, the overwhelming sense of responses to this question is that while some adults with an ASC may be unable ever to exercise more choice and control – partly because of their lack of capacity and partly because of their vulnerability in an ASC-unfriendly world – there are others who could lead much more independent lives, and more choice and control, providing they have the necessary support to do so.

6.6. What actions do you think should be taken to address the concerns raised in the choice and control chapter (e.g. ensuring that person-centred plans are more widely available, development of brokerage, advice and advocacy services, including people with an ASC in the development of individual/personal budgets)? (This question corresponds to Q14 of the standard consultation)

426 people responded to this question.

Responses to this question tend to focus on areas for action rather than setting out specific actions that should be taken.

6.6.1 Person-centred plans

Person-centred plans are the starting points for many respondents (114 comments), the key points being that the individual’s needs are identified in parallel with the services designated to meet them:

> *Person-centred planning should be used to ensure that all services work together and that the support needs of the person with ASC are identified along with the service/person who will provide the support. (A mixed group of people)*

The resource-intensity of the person-centred approach does cause concerns, the fear being that it will overload services and make it impossible to deliver care and support of the quality envisaged. This leads to some debate about how such plans should be created and whether they should be independently planned or which support agencies should be involved in the planning process; several points of view are apparent, for example:

> *Person centred plans should be mandatory for those that want them, developed and created with well trained facilitators, preferably independent from Social Services. (Family carer)*
>
> *Person-centred planning sounds like a good idea but must involve all the agencies around a user - social services, Jobcentre, etc. I have no knowledge of these but believe there are services offering this, which I will be investigating shortly. (Family carer)*

Others (42 comments) focus on the importance of providing the right information and the right level of support, and ensuring that it is delivered in a way that meets the needs of people with ASC for stability and regularity:

> *The most important elements to having choice and control is that people are clear with the person about what is available and that there is the right level of support for the person to have what they chose. Consistency will be the most crucial element in success. (ASC professional and parent)*

The actions required come down to making sure the person-centred approach and the requisite services are available in every area, and that people with ASC are able to receive what is offered.

6.6.2 Improving advocacy and supporting self-advocacy

This in turn persuades many respondents that establishing effective advocacy for people with ASC is almost equally important (114 comments), especially for those not able to argue in their own interests and particularly for those living in residential care. Such advocates need an intimate knowledge of the person with an ASC for whom they are advocating.

Self-advocacy also has to be supported, even for those who are relatively capable of making their own decisions, to help them cope with the paperwork, the uncertainties and the decision-making:

> *Advocacy services should be provided. A community type 'PA'. My son heard a Tom-Tom (car navigation system) for the first time and stated that he needs one in his head for his paperwork. He was being serious. (Family carer)*

The role that advocacy should play can be expected to vary from case to case. At the most basic level it should be to help people with an ASC to communicate effectively, remembering that many people with an ASC often have very different understanding of words and phases, even those in common usage, from people who are neuro-typical. When this is added to a misunderstanding of social conventions and non-verbal communication, this can lead to profound misunderstandings and the failure to establish necessary relationships with agencies and, for example social workers, or the unintentional breakdown of established relationships.

One idea around advocacy, 'brokerage', is regarded as unfamiliar and a form of jargon not regarded as helpful; the unfamiliarity of the very term suggests that such services may not be universally available.

6.6.3 Personal budgets and direct payments

The idea of personal and individual budgets is supported in principle (69 comments), but respondents also point out that they may cause as many problems as they cure unless they are again accompanied by proper advice, support and advocacy:

> *Personal Budgets/direct payments need to include learning the process of how to employ someone, learning how to be an employer, how to dismiss someone if not suitable etc, we went down the Direct Payments/individual budget route with no training and not much of an idea of what being an employer was about. Needless to say it did not work out. (Family carer)*

Such concerns lead to the belief that where people with an ASC are eligible for funded services, then they need to be supported by advocates who can work with them and their families to ensure that their individual budget is used in a way best suited to meeting their particular needs. If such help is available, the idea of personal budgets and direct payments becomes very attractive:

> *Improving access to person-centred planning, increasing investment in brokerage, advice and advocacy, and adopting a co-production approach to the implementation of individual budgets would all benefit people with ASC. (A mixed group of people)*

Respondents are anxious to make the point that, as with so much else, the help that people need varies from person to person, and will need to be more intense at certain times, such as when people are planning to move from one type of accommodation to another, or from training to employment.

6.6.4 Involving and empowering people with an ASC

The actions described above are all directed towards helping individuals with an ASC at the point where they need such help. There is another range of responses aimed at encouraging more upstream involvement of people with ASC in the making of the policies that will ultimately determine what help is made available to them (68 comments).

> *Stakeholders should be fully engaged at all levels of policy making. Decision makers should pro-actively make the policy making process accessible to enable involvement*

> *from all stakeholders. All consultation documents should be available in easy read. (ASC professionals group)*

This present consultation (7 comments), though, is not regarded by all as a good example:

> *This consultation has been very poorly publicised and both the ERG and the Opinion Leader consultation events have only included a very small and tokenistic minority of autistics and the voice of the autistic rights movement has been flagrantly disregarded. The events also have not taken places in accessible venues and the days themselves have not been made very accessible. (A mixed group of people)*

The preference is for involving people with an ASC in a way that really enables them to talk directly about the problems they face and the aspirations they have, while at the same time also involving families and carers so that there is a thoroughly holistic approach to understanding what works and what does not work and the impacts that policy decisions and local actions can have.

6.6.5 Training and delivery mechanisms

Training is an issue for 65 respondents in response to this question, with the point being made again that everything rests to a large extent on professionals having a real understanding of ASC and what it means.

A number of the professional groups and organisations responding to the consultation also provide detailed suggestions for how choice and control can best be delivered.

Two of the ideas suggested are Specialist Autism Teams and Autism Planning Groups. In outline the Specialist Autism Teams would:

1. *Provide a diagnostic service and post-diagnostic support, establishing a referral pathway for diagnosis and support*
2. *Provide an ongoing programme of training to frontline staff across health and social care*
3. *Support social services with care assessments in more complex cases*
4. *Ensure that sign-posting and brokerage is available to help adults with autism find appropriate services*
5. *Provide a range of 'low level' services and interventions aimed at reducing social exclusion, promoting well-being and improving employment prospects*
6. *Build local capacity around employing adults with autism (ASC professionals group).*

The Autism Planning Groups, again in outline, would:

- *develop and maintain, through intelligent planning and commissioning, appropriate services to meet the needs of the local autism population*
- *use existing data-sources and proactive measures to lead the way on local data collection and identification*
- *feed into the Joint Strategic Needs Assessment process*

- *be made up of learning disability and mental health commissioners and managers, representative(s) from the SAT, representatives from the voluntary sector, adults with autism and carers and a representative from children's services*
- *be chaired by a commissioner with joint responsibility for commissioning health and social care services. (ASC professionals group)*

There are a range of responses that make similar points in a number of detailed submissions.

6.6.6 Other responses

In addition to these key points respondents mention many other issues associated with ASC and the actions that would enable people with an ASC to exert more choice and control over their lives. Among these issues are transition planning, the provision of information, the importance of different types of support, and the help required by people with an ASC in a range of different contexts.

6.7. If possible, please give examples of where these concerns have been successfully addressed at a local level. (This question corresponds to Q15 of the standard consultation)

237 people responded to this question.

There are many responses providing examples of good practice and case studies describing initiatives that have helped people with an ASC in many different ways.

The largest group of respondents (88 comments) however say that people's concerns are not being addressed. This suggests that either people are not aware of what is available, or that such initiatives are the exception rather than the rule.

6.7.1 Good practice and positive experiences

There are 50 examples and they suggest that 'choice and control' has different meanings for different people. For some, any approach or project that nurtures self-confidence brings an increase in choice and control; for others, providing systematic help that enables people with an ASC to lead better lives achieves the same ultimate end.

> *The [named service] provides a 'consultancy clinic' that can be accessed by staff within the NHS and local authority who want advice about how to support someone with Asperger syndrome (or whom staff feel may have Asperger syndrome) with whom they are working. The service is easily accessible and has seen an increase in demand over the past 12 months. (ASC professional)*

There are also examples of how imaginative initiatives can achieve several ends with the same process. For example, transition processes, which can be stressful, can be eased by providing a film that showcases how others have managed them and flourished as a result. The making of the film benefits those involved, while also demonstrating students' abilities to new staff, carers and support workers who might not otherwise be able to assess their needs accurately due to the stress induced by transition:

> *[named organisation] is working with special schools….. to trial a digital CV project. Pupils with autism and learning disabilities will produce a digital CV on a DVD or CD ROM. The short film will include footage of them doing activities that display their range of talents (e.g. gardening) and life skills (e.g. making a sandwich), as well as expressing their hopes for the future. The digital CV will be played in annual reviews so their views are still heard and taken into account in transition planning. (ASC professionals group)*

A similar approach has been used elsewhere, with teenagers with ASC helping to make a DVD to be used in schools to help others understand the problems, such as bullying and harassment, faced by those with an ASC. Other programmes use a variety of methods to help people with ASC both to develop their abilities and to encourage others to think more positively about people who are in some way different.

> *We run a development program for people called 'Speak Up and Make a Difference'. The year long training program promotes self advocacy and personal development and has recently been nominated for a Third Sector award due to the outcomes achieved for people. This has been developed in partnership with Values into Action (VIA). (ASC professionals group)*

There are descriptions of a range of programmes that use innovative approaches, such as the arts, to give people with an ASC some experience of taking control of their own lives and using their experiences positively.

> *Using a grant received from the Youth Opportunities Fund, a visual arts project in partnership with the Youth Service…. was a great success with 7 young people attending the 12 sessions. Several of the young people aged 17-20 had not previously accessed any service provision outside school and home. They had huge barriers to overcome, from accessing the transport to developing the self confidence to contribute to discussions about the work. The young people were working with an artist to learn about drawing cartoons and to create a good storyline for their comic strip cartoon about Asperger Syndrome…. using graphic art computer packages. It was also about working together, increasing self confidence, developing social skills and making friends. Each young person also achieved an ASDAN Activities award. (A mixed group of people)*

6.7.2 Other responses

Other responses describe different experiences of ASC and argue for various types of service provision to help and support people with an ASC.

6.8. Easy-read consultation questions on the choice and control chapter

People have told us that there are four ways we can make sure that adults with autism can make choices about the help they get and about what they do in their lives. These are:

1. make sure that adults with autism can get person-centred plans and are in control of their lives. Person-centred plans are documents that say what things people want to do and what help they need to do this
2. provide better help for people with autism as they leave school and start doing new things
3. make it easier for adults with autism to find someone to speak up for them or help them to speak for themselves
4. make sure that adults with autism are asked how they think that services they use could be improved.

6.9. Do you think that these are the most important ways to make sure that adults with autism can make choices about the help they get? (This question corresponds to Q3a of the easy-read consultation*)*

Group	Count	Proportion
Yes	112	81%
No	10	7%
Not sure	11	8%
No answer	6	4%

6.10. Please tell us why. (This question corresponds to Q3b of the easy-read consultation)

139 people responded to this question.

6.10.1 Involvement and empowerment of people with an ASC

Those who agree that these are the key areas say it is because people with an ASC should have the right to make choices about their own lives just as everybody else has. What they want is the same as most people want: a good job, a decent life, somewhere to live that meets their needs. The purpose of services for people with an ASC should be to provide these things rather than telling people what they cannot have.

While this is a fundamental belief among respondents, there are some qualifying points, such as the extent to which a person with an ASC can comprehend their problems and the suitability of the services offered:

> *While I agree we should be able to make choices about the help we can get, this only works if a) the adult has sufficient self awareness to know of their problems, and b) there is sufficient flexibility of services on offer. (A person with an ASC)*

But some regard such questions as patronising:

> *Do we not understand that those with Autism have a voice, they are individuals let them contribute. Please call me I need to understand who/why such a condescending questionnaire has be allowed to be published. (Family carer)*

6.10.2 Person-centred plans and transition planning

There is particular support for person-centred plans (13 comments) and for anything that can empower people with an ASC (18 comments:

> *People with autism often have difficulties in making decisions about their life, and can often have difficulty keeping order and self management with daily living, therefore having a person centred plan with actions can be really positive and something to aim for. It can also be good for the person who is providing support to the individuals to have something to work to. (A person with an ASC)*

For some people help with transition planning is a major reason for supporting person-centred plans because changes at any stage can prove extremely difficult; the transition from education to adult life can be particularly difficult because school provides such a structured environment. Transition planning can help that structure continue into adult life and provide the security and continuity that many people with an ASC need.

Not everyone is convinced that plans such as those mentioned will make much difference because they may not in practice be implemented:

> *I worked in the NHS Severe Learning Disability Service. We wrote Person Centred Plans for people, then just filed them away and did nothing about them. The same thing will happen with this. People will get their hopes up, and then nothing will happen. It's just the reality. We need practical action, not pieces of paper. Professionals fill out pieces of paper and think they've achieved something, but it's just another piece of paper. (A person with an ASC)*

Others are more positive about the possibilities:

> *Generally, each point is geared to empowering autistic adults to have a say in the way they want to run their lives and therefore being as independent as they possibly can. I would agree with point 2, in particular. This is an area that in my experience and my son's, needs improving. After Year 11 at school, my son intended to stay on in the sixth form but due to a mix-up his two chosen subjects for 'A' level clashed. The mix-up was due to the School Brochure and other information not making it clear that subjects clashed, but also giving information to my son directly and 'assuming' that he understood it when he didn't. It caused a huge problem and stress, trying to find somewhere suitable for him to go. In the end, he went to the Local College (which turned out to be a 'blessing in disguise'). His tutors had superb understanding of his*

> *needs and were therefore able to give him the necessary support and help for him to fulfil his potential. (Family carer and ASC professional)*

6.10.3 Advocacy and self advocacy

The importance of advocacy is emphasised by 11 people with an ASC, carers and professionals. It is particularly important that service providers recognise this need:

> *The most important thing needed is service providers recognising that people with autism may need someone to speak up for them and act as 'an interpreter' even if they appear to understand and be able to speak for themselves (Family carer)*

But the need for advocates can also be demeaning if it is not handled with sensitivity:

> *Growing up knowing there was a difference about me - I needed an advocate and sometimes one would appear- sometimes people are kind when that can see a problem. But having someone who would do it without me having to appear pathetic in order to get help, that would have been an enormous help. (A person with an ASC)*

6.10.4 Making choices

Responses are divided over whether people with an ASC should be allowed to make decisions that may turn out to be wrong. Family carers are among those who are cautious about putting all the responsibility for decisions into the hands of those who may find it difficult to express themselves or decide what help they need:

> *It is equally important to understand that some adults with autism are not able to express themselves and choose what help they need. In these circumstances it would be necessary and essential to consult persons who know the adult and can assist e.g. family members. (Family carer)*

However, others emphasise the need to recognise that making mistakes is one of the ways that all human beings learn:

> *We need to make our own choices, even if sometimes they are the wrong ones, I have made lots of mistakes and I have learnt from them. (A person with an ASC)*

6.10.5 Other responses

Respondents mention a wide range of issues related to choice and control including the importance of training for healthcare professionals, the problems of communicating with others, the need for financial support and other problems they encounter in day-to-day living.

6.11. Have you been able to make choices about the help you get? This might be help at home, help with your day-to-day activities, help with getting a house or flat, help with meeting new people, or help travelling where you need to go. (This question corresponds to Q3c of the easy-read consultation)

Group	Count	Proportion
Yes	38	34%
No	63	57%
No answer	10	9%

6.12. If you answered yes, please tell us about the choices you made and how you made them. (This question corresponds to Q3d of the easy-read consultation)

111 people responded to this question.

6.12.1 Support from family

Of those with autism who responded, most (15 comments) say the critical help has come from their families and describe choices and activities with which they have received help:

> *I have made a DVD which is my PCPlan/Support plan. Some people who are involved in my care are more helpful than others when I am trying to make choices about my life. The people I trust most to help me make choices are my close family. (A person with an ASC)*
>
> *I haven't really had any help apart from my family, mostly I chose for myself but I didn't always know what was out there and have suffered the consequences which was depression and isolation. I get informal voluntary support from a life coach who helps me to enjoy my life and make choices about things. (A person with an ASC)*

There are also responses from carers themselves who provide examples of how they have helped family members with autism:

> *My daughter has a bus pass, she did not want to join any of the Aspergers groups because she wanted be with normal people, but because she was different they picked on her and bullied her, so her friends are me and her dad and she still lives with us because that is where she wants to be, she is 26. (Family carer)*

6.12.2 Making choices – or not

Respondents describe some of the choices they have been able to make and how this has affected their lives.

> *I chose to apply for benefits to live on so that I was not forced to try to work when I don't feel ready to cope with that yet. I got DLA which helps me be able to travel and do activities when the costs will be high than for other people. (A mixed group of people)*

Several responses mention the lack of help available to help people make their own choices and having to cope on their own despite their efforts to get the help they need:

> *There has been little to no help and especially in making choices. It has been almost luck that my son is now working towards independent living, but this has been greatly hampered by the system. Mainly due to persons not understanding or not willing to get to understand the problems related around someone with this condition. I have approached a number of organisations all have provided at the best zero to inadequate help. (Family carer)*

Some people think that access to the right information would make it easier to make such choices, but feel it would help if first service providers could learn to talk to each other and coordinate their efforts:

> *There is little obvious information about who where why or [how] help can be accessed. Blame it basically on the Social Services but actually it is the Social Services, Education and Health services not being joined up. (Family carer)*
>
> *People would have more choice if they had more information. It is hard to get Person Centred help. I can get help with the NHS or help with social care but they never talk to one another. (A mixed group of people)*

There are also some examples of people who have been able to make choices for themselves, illustrating again the importance of the right help at the right time:

> *I was left a share in a house by my mother when she died 3 years ago. My advocate is helping me to buy the remaining share so I can stay in my home. So far I have a mortgage offer and a solicitor working for me. None of this would have been possible without Rethink. Realistically I would be homeless. (No sector selected)*
>
> *At the local job centre I had support from the Disability officer with helping me find a part time job in which I am still in as this has helped me gain some confidence but work independently with employees there that I can turn to if I need help, and has given me confidence to talk to customers. In higher education I have had support with exams and with any work I may have found difficult (No sector selected)*

Some (10 comments) respond by saying that they have never been able to make such choices, either because the options are limited or not suitable. There is also a perception that the options are defined by people who do not necessarily appreciate the realities of living with an ASC.

6.12.3 Other responses

Other responses illustrate many of the other issues associated with ASC including the need for advocacy, problems with diagnosis, the pain of feeling discriminated against, and the value of carers and their need for respite care.

6.13. What do you think are the best ways to help adults with autism choose the help they need? For example, having more information about what help is available or having someone like a social worker to explain what help you could get. (This question corresponds to Q3e of the easy-read consultation)

120 people responded to this question.

6.13.1 Improve access to information

'Providing more information' comes out as most important (26 comments), with some responses adding notes about where the information should be found or how it should be presented. More information about what help is available is the priority, but how it is delivered is also crucial if it is to be effective, and it also needs to set out exactly who can do what:

> *More information about what help is available. This information should be made available to doctors because the nature of Aspergers makes it very difficult to contact agencies who can help. The system should, once diagnosed, provide help such as an Advocate. They can explain what help is available and help you get it. (No sector selected)*
>
> *More information about what is available and what the help means (for example, what a social worker would do for you, etc.) (A person with an ASC)*

6.13.2 Help, support and advocacy

The next priority (24 comments) is having someone to help, such as a friend, key worker, 'buddy' or advocate; exactly who it is often seems to matter less than that it should be a one-to-one, dedicated relationship:

> *I think there should be more mentors - people who have been there done that. The self assessment form does not cater for most people on the spectrum needs it is too vague, you need someone to get to know the person to help them choose the help they want sometimes when there are too many choices it can be hard to make any choices and become overwhelmed. (A person with an ASC)*

The continuity and stability of such relationships is particularly important:

> *Ensure they have trusted and constant support workers. Changes of faces cause insecurity and anxiety. (Family carer)*

6.13.3 Social workers

The view on social workers (22 comments) is more mixed. While some people see them as the obvious source of help, others say that they often do not have the special skills required to work with people with an ASC even if they have the time and resources:

> *It would concern me that with social workers already stretched to the limit, they would be unable to cope with the rising number of autistic people in this country needing their support and help. There needs to be specially trained and experienced people to be able to offer the help and support necessary. (Family carer)*

There is also some perception that social workers, perhaps because of limitations on their time and their heavy caseloads, can be too detached to provide the intensity of help and support that may be required by people with an ASC. They are good for providing information, but they are not sufficiently hands-on to act as advocates or to provide the consistency of support that may be required.

6.13.4 Other sources of information and support

Respondents suggest that people with an ASC and their carers are keen to seek information and support from wherever they can find it. Some, for example, find the Internet and web forums to be a useful source of support:

> *E-mail or forums would be a better way for people with autism to be able to discuss available help as speaking on the phone or person to person can sometimes be difficult and it is easier to think of all the questions you have if you can write them down and ask them through a non threatening format. (A person with an ASC)*

This again reflects the importance of the medium as well as the message.

6.13.5 Other responses

Training professionals, involving families and carers, personalising plans and the importance of managing day-to-day help are all subjects mentioned in responses to this question.

6.14. Did you get any help with making choices about the services you use and other help you need? (This question corresponds to Q3f of the easy-read consultation)

Group	Count	Proportion
Yes	31	27%
No	75	65%
No answer	9	8%

6.15. If you answered yes, please tell us what help you got to make these choices and how it helped you. (This question corresponds to Q3g of the easy-read consultation)

115 people responded to this question.

6.15.1 Help with bureaucracy

Those who answered 'yes' to this question mostly got help from families and carers (18 comments), including social workers (6 comments), and it was mainly with sorting out administrative matters such as finances and services.

The point is made that most bureaucratic procedures present serious difficulties for people with an ASC, and having someone to help them is essential.

> *In changing his GP. With my help we changed his GP when he was asked to do so by his previous one as he was moving out of his catchment area. He was unaware of the procedure so I arranged everything for him. An adult with Autism and without family or friend support would find this onerous task. (Family carer)*
>
> *I received help off the staff team that supports me, as well as my parents. They help me by obtaining information from different agencies, i.e. communication teams, PCP planners, physios, dieticians, psychiatrists, nurses, social workers, etc. (A person with an ASC)*

6.15.2 Other responses

The range of help required by people with an ASC varies greatly, depending on their needs and circumstances and what in the way of support and help is available to them. One of the main impressions in responses is the extent to which people are dependent on particular individuals who are willing to take the time to explain things clearly, help them to understand their options and make the best decisions, then to fill in the forms and respond to the queries. Whether they meet such individuals and get such help often seems as much a matter of good fortune as effective service provision.

7. Access to employment and training

7.1. Summary of responses to this chapter

This chapter covers the responses to questions dealing with the challenges faced by adults with an ASC as they try to gain access to employment, training opportunities or benefits. Respondents are asked to comment on the four areas identified by stakeholders where action should be taken (access to support to find and hold on to a job; improving awareness among employers; accessibility of the benefits and tax credits system; and better access to training and educational opportunities). Respondents are also asked which actions they think should be taken to address concerns, and whether they can provide examples of challenges and solutions.

7.1.2 Main issues

It is obvious from people's responses that the areas identified are the most important ones, with many respondents mentioning difficulties with regard to employment. Even though many adults with an ASC have excellent skills and qualifications, several factors (including job interviews, and work environment, for example) are likely to stand between them and suitable employment. Similar situations can occur when adults with an ASC want access to further education. The benefits system is particularly difficult to navigate for people with an ASC; some of the activities required to qualify for benefits, such as filling out forms and making phone calls, are perceived as serious barriers.

7.1.3 Examples of challenges

The examples describe how both systems and other people – being inflexible or lacking understanding – prevent adults with an ASC from gaining access to benefits, employment and skills training. The settings of workplaces or training can also contribute to access difficulties.

7.1.4 Actions to be taken

Respondents believe that in order for adults with an ASC to participate more fully in society, society needs to be made more aware of ASC. Employers are mentioned in particular: they should be helped to gain some understanding of ASC, including an awareness of the professional potential of high-functioning adults with an ASC. Similar comments are made with regard to those working in the benefits system. In addition respondents would like to see buddy or mentoring systems established for adults with an ASC, helping them and their social environment to cope with one another.

7.1.5 Examples of solutions

Although many comments focus on problems rather than solutions, there are some examples of solutions, pointing out for instance how employers can be supported and mentioning experiences with social enterprises which can provide a mixture of employment, work experience and training.

7.2. Standard consultation questions on the access to employment and training chapter

The external reference group identified the following as key areas where action is needed:

a) ensuring that adults with an ASC can access the particular support that they need to find and hold on to a job
b) improving awareness of ASC among employers and supporting them to make reasonable adjustments in the workplace for adults with an ASC
c) making the benefits and tax credits system more accessible for adults with an ASC
d) making training and educational opportunities more accessible for adults with an ASC.

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

(This question corresponds to Q19a of the standard consultation)

Group	Count	Proportion
Yes	470	86%
No	13	2%
Unsure	32	6%
No answer	34	6%

7.4. Please explain your answer.

(This question corresponds to Q19b of the standard consultation)

550 people responded to this question.

The majority of responses agree that the four main issues identified by the external reference group (education and training, employment, the benefits system, and the need for support in managing all of these) are the key areas to focus on.

The relatedness of these issues is apparent from many responses, and the fact that adults with an ASC, employers, training providers and tax and benefit offices need to work together if an overall strategy is to work. (For this reason the summary of responses in this chapter has been ordered thematically rather than according to the proportions of issues mentioned in responses.)

Responses to this question describe how adults with an ASC need help with understanding the world of work, particularly when it comes to interview processes, and training providers have a significant role in preparing people with an ASC for work as well as in providing specific training opportunities.

Meanwhile respondents feel that employers need to appreciate the qualities that people with an ASC can bring to the workplace, particularly qualities such as loyalty, consistency, punctuality and attention to detail; and the tax and benefit systems needs to make it as easy as possible for people with an ASC to understand the systems and prevent them becoming an obstacle to employment.

7.4.1 Education and training

There are a number of general points that respondents say need to be remembered in any discussion of this subject. One is brought forward in some of the 49 comments about the need for accessible training and education, arguing that education, training and work is not just about learning things or doing a job: it is also about fitting in to the social context of education and employment.

> *It isn't just about employers understanding ASCs… it is this absurd problem about fitting in. Job specs don't tend to include having to fit in as one of the criteria, but the real challenge for many people with ASCs is that neurotypicals seem to need a social grouping attached to the job in order to be able to do the job. Most ASCs haven't a hope of being accepted in these social groups, and it is usually friction arising from the social aspect that leads to a breakdown. (A person with an ASC)*

Another general point made in many responses is to remember that adults with an ASC vary widely in their needs and abilities:

> *The able autistic people often want to contribute to society, we should where possible enable this* **-** *remembering there will be some who are not able to work and should not be pressured into an unsuitable situation re: training or work. (Family carer and professional)*

Many responses express concern about the general lack of education and training for employment for adults with an ASC, particularly after the age of 16. The emphasis is not just on giving people skills that employers want, it is also on helping adults with an ASC to develop the social skills and instincts that enable them to enter the job market in the first place. This is expressed in 28 comments about the need for employment support systems or programmes.

> *Improving Access to Learning and Vocational Skills development is critical to increasing the employment rate for adults with ASC. Individuals with ASC are often prevented from accessing learning due to personal, system or environmental barriers and don't progress from the FE sector into either Higher Education or employment. Colleges equally identify they have limited knowledge, experience or expertise in supporting disabled learners, including adults with ASC, into employment. (ASC professionals group)*

There is a perception that despite the attention and resources focused on education and social inclusion in recent years, there is still a lot to be done to help prepare young people with an ASC to enter the workforce. It is pointed out that children do not automatically pick up the communication and social skills required for adult work in a classroom with peers. Some respondents add that if people with an ASC can only start developing the social skills they need once they are in a working environment, it may be too late.

> *We have to go right back to basics and include subjects in the curriculum (and not just in special schools we must remember that inclusion means that the majority of children with an ASC are now educated within a mainstream setting) that are going to enable our children to have a much better chance of gaining employment. At the moment we are not doing this and that has got to be our starting point for future generations. Although this strategy is for adults with an ASC we must surely hope to correct some of our mistakes and make the path to employment easier for future generations of autistic adults than it is at the moment. (ASC professionals group)*

It is also argued that the primary target for education and training should not be adults with an ASC, but those who determine their access and experience of it. This relates to 69 comments about employer awareness and support and a further 56 comment about barriers to education, employment and/or benefits:

> *We would like to see more training for staff in higher education, further education and lifelong learning organisations so that they are able to better understand and accommodate the learning styles of people with autism. (ASC professionals group)*

7.4.2 Access to employment

In many responses the approach to employment is similar: employers and colleagues in the workplace need to understand ASC better so that adults with an ASC are not seen as being difficult, or unfriendly (69 comments about employer awareness and support).

> *Supported employment sector needs to have staff that have specialist knowledge about the autism spectrum. Support needed for these individuals is often very different from the norm - support to identify appropriate type of work, support to mix with colleagues and cope with unstructured time, support to flag up difficulties when they arise. Often, core support needs are not around learning the task, but about all the other aspects of working, and these can be overlooked by staff who have no knowledge of ASC. (ASC professionals group)*

Most adults with an ASC want to work and it has huge benefits for their self-esteem quite apart from enabling them to live independent lives (17 comments).

> *Employment is strongly associated with positive self esteem, good mental well-being, inclusion and participation. Employment, education and training are important to us all and should be equally enjoyed by people with ASC wherever possible. It also keeps people out of service provision, maintains independence and provides them with a source of income. (Other)*

Another point made by respondents is that employing adults with an ASC is not a matter of charity: they can prove to be excellent employees and employers need to be more aware of this (13 comments):

> *Employers not only need to be aware of the problems adults with ASC have but, they also need to be made aware that employing someone with an ASC can bring great benefits to a company. (Family carer)*
>
> *Employers - they need to be told about the ADVANTAGES of employing ASD people - there are plenty!! My social services office - where I work - recently employed a young man with Asperger's to collect and distribute our post and internal mail. Our mail service has never been so good!! He is prompt, reliable and efficient. (No sector selected)*

Adults with an ASC do, however, need help and support both to find and keep suitable work (26 comments addressing the difficulties to access and keep employment); at present there is a tendency to channel people towards particular types of jobs depending on where they are on the spectrum:

> *People with an ASC are often 'put into boxes, and are directed to either IT or jobs such as cleaning – people with an ASC need to have access to a wide range of opportunities that match individual skills with jobs rather than a 'job for the sake of a job'. (A mixed group of people)*

In some examples the mere fact of having an ASC tends to relegate people to the more menial jobs, and even those with high intellect can end up performing basic tasks. 20 people make comments about the need for people with an ASC to have employment at the appropriate (intellectual) level. It is acknowledged that professional bodies that interact with businesses may help promote a genuine commitment to consider both the perspectives and the contributions of adults with an ASC in the workplace:

> *I believe that… seminars and workshops [are more] likely to engage and give HR personnel, general managers and others a real awareness of the issues and opportunities of making adjustments for ASC's than might a blanket mail-shot campaign, even if the numbers of such individuals who may be targeted by such campaigns might be relatively small. (A person with an ASC)*

7.4.3 The benefits system

The benefits system is regarded by many (70 comments) as difficult to navigate for people with an ASC. Particular difficulties arise for people who do not have a formal diagnosis of ASC, and the lack of a visible and tangible disability means that staff working in benefit centres are sometimes inclined to dismiss adults with an ASC as just 'difficult'.

The requirement to fill out many forms, attend medicals and interviews and make appointments over the telephone can all accumulate into insuperable barriers for people with an ASC unless they have the right support as and when they need it. A big problem can be a lack of organisational skills: people with an ASC may forget dates and times of appointments such as signing on days. They may also forget or fail to understand renewal forms, such as those for Child Tax Credit. They may struggle with the very lengthy forms for Disability Living Allowance. They may also have difficulties communicating effectively with call centres by telephone. This is outlined in some of the 56 comments about barriers to education, employment and/or benefits.

The system can be particularly demanding for those in supported living situations:

> *The benefit system for individuals in supported living is very complex and time consuming to establish. It can involve 4 sources of income: Disability Living Allowance; Incapacity Benefit; Housing Benefit; Independent Living Fund; Plus all the accompanying entitlements, Council tax rebates, prescription charges rebates, optical and dental charge means testing, travel claims…..It is also insufficiently sensitive in response times to changes due to sickness or variability in hours of work. This is true for the population as a whole but the impact on people with disabilities is felt more keenly and has acted as a disincentive. (ASC professional)*

There are a number of suggestions for how benefits could be made easier for adults with an ASC, such as:

> *Need simpler, tailor made forms that e.g. assume or list the usual disabilities that someone who has an ASC diagnosis is likely to have, and then build on that, rather than including multiple questions about irrelevant physical disabilities. (A mixed group of people)*

But most of all respondents would like to see greater awareness of and training in ASC for those who work in tax and benefit offices as the only real way to overcome the problems that people with an ASC can face. It is argued, for example, that benefits should be assessed by people with full training in ASC and that those who have already been diagnosed and assessed should not be subjected to repeated assessments every time they need something different or, for example, have to apply for student finance. ASC is, it is pointed out, a lifelong condition. 27 respondents make comments about the need for people with an ASC to receive long term support.

Better understanding of ASC would also, for example, perhaps prevent the requirement that people with an ASC apply for jobs that are unsuitable in order that they may continue to claim Jobseeker’s allowance. Another argument is for better information and guidance about both means and non-means tested benefits, and better informed and trained assessors who would take ASC into account.

7.4.4 Targeted training and employment support systems

Removing the barriers to education, employment and benefits are only one half of what is required. The other half involves proactive efforts to train people with an ASC for work and to make it easier for them to stay in work once it is achieved. There are 35 comments about targeted training.

It is suggested that it should begin with better careers guidance for young people with an ASC which takes into account their possible difficulties in conceptualising what the future might be like or what making career decisions might mean for them. This could be complemented by supported work experience and social skills training to help prepare them for the workplace, together with better overall transition planning.

The next stage is to help people through the process of getting a job:

> *People with autism usually show pretty poorly at interview, because of their impaired social skills. So even if they might be more than capable of the job, they are unlikely to get it. (ASC professional)*

If that hurdle is overcome, there needs to be long-term support if employment is to be maintained (27 comments about long-term support; 28 comments about accessing and keeping employment). Mentors for people with an ASC can be useful to help them through any difficulties that they encounter as and when they encounter them; equally, mentors, advocates or mediators may be able to help employers and colleagues understand how people with an ASC may be different to them. This again comes back to the need for employer awareness and support, which is mentioned in 69 comments.

This can prevent discrimination (19 comments) and promote tolerance and, it is noted by respondents, may have to continue for much of a person's working life: most care and support for people with an ASC needs to be planned for the long term.

7.4.5 Other responses

Other responses to this question add colour and detail to the points described above, with many stories that illustrate these points and make detailed suggestions for how access to employment and training could be improved and sustained for people with an ASC.

7.5. Please provide details of your experiences of the challenges faced by adults with an ASC as they try to access employment, training and benefits. (This question corresponds to Q20 of the standard consultation)

455 people responded to this question.

Many responses to this question list the specific challenges that adults with an ASC face and some provide vivid examples to illustrate their points.

7.5.1 Difficulty accessing benefits

An issue that is touched upon in 96 comments is the difficulty for people with an ASC to access benefits. The benefits system creates many challenges for people with and without an ASC. One of the main problems illustrated in responses is the anxiety that getting a job may lead to benefits being cut, and if the job proves unsuitable or unsustainable there are difficulties involved in going back on to benefits.

> *I have often found parents reluctant for their children's positive skills to be reported in case they "lose their benefits". …. One parent recently rang me and told me that if her severely challenged daughter were sent to residential school she would lose £780 per month. Another with a son only mildly affected who could have easily attended a local college and gained employment immediately insisted on his having a specialist placement and complex diagnosis. The father was receiving full time carer's allowance. (ASC professional)*

The paperwork involved with applying for benefits is seen as a huge hurdle for people with an ASC, and many responses argue that there needs to be more help available with this – and not just for adults with an ASC, but also their carers. Some of the experiences related illustrate how difficult the system is for people with an ASC:

> *We have spent many hours trying to make the forms for benefits "fit" the problems which our son has to live with day after day. They just don't work! For example, the question constantly asked is "How many minutes a day does he suffer from this problem?" - ASC is a life-long condition!! (Family carers)*

7.5.2 Difficulties with social interactions and interviews

Job centres and benefit offices can be difficult as noisy, bright environments can be unbearable. Problems continue when people with an ASC have to use the telephone. For some it is difficult to hear and process what is said down a telephone. Moreover, the Jobseeker's Allowance requires that people are looking for work, but this entails social skills, such as using a telephone and visiting prospective employers, that people with an ASC may not have.

Examples are given of difficulties faced by people with an ASC who have qualifications and do not appear to be in any way incapable of such actions. These types of struggles can cause people with an ASC to abandon attempts to claim benefits and result in them having financial difficulties.

There are many responses describing such problems and their effects: 77 comments about difficulties with social interactions or interviews. Quite apart from the financial impacts, such battles can lead to depression and other mental health problems. They are also demeaning and confidence-sapping for people who may be highly intelligent and perfectly capable in many other ways.

7.5.3 Difficulties gaining and keeping employment

There are 64 respondents making the point that people with an ASC experience difficulties gaining and keeping employment. It is pointed out that only 15% of adults with an ASC are in full time employment, though many more are capable and would like to work if they had the necessary support. It is stated that there are very few government funded schemes specifically designed to prepare people with ASC for work, and Jobcentre staff (including disability Employment Advisors) are said to have in general a poor understanding of ASC and of how to meet the needs of people with an ASC. Likewise, awareness among employers is low and therefore many employers fail to make reasonable adjustments to the workplace.

Furthermore, applying for jobs entails interviews and if the interviewer does not understand ASC the likelihood is that he or she will ask questions that the interviewee will either not understand or find impossible to answer. It is suggested that it would be useful for employers to see the interview process from the point of view of a person with an ASC.

Some advise that an interview should only therefore be offered if the job is suitable and there is a serious intention to employ a person with an ASC; the need to tick the relevant box on an equality monitoring form is not a good enough reason to put someone through the pressures of an interview. Other advice, for example, is to review interviewing techniques and replace abstract questions with clearly structured questions which enable the candidate to demonstrate ability and intelligence. Abstract questions can reduce people with an ASC to silence and panic because they find it difficult to relate abstract questions to concrete experience.

Interviews are not regarded by respondents as a good way to select candidates with an ASC for employment. Better, it is suggested, are work placements that allow employers to see how good in practice a person with ASC can be:

> *The main difficulty I had in obtaining work was the interview. I am unable to properly sell myself in interviews so took two years to obtain a job. I only gained my current job because I completed a work placement with them as part of a training course, which allowed them to see I was a good worker. (A person with an ASC)*

Some people with an ASC in fact do not disclose that they have the condition when they go to interviews for fear that it will prejudice employers against them, though this can obviously create problems later.

Holding on to jobs can also be difficult, depending largely on whether employers know about or understand ASC, and whether the work is suitable. Among the experiences described are alienating colleagues by behaviour which was experienced as arrogant or rude; difficulty keeping to working hours and routines; difficulty prioritising; misunderstanding others' responses and feeling sidelined or rejected; problems with assertiveness and being taken advantage of; lack of self confidence; feeling overwhelmed by too much conversation, noise and light.

The need for jobs to be tailored carefully to the individual comes across in many stories. One critical element is that employers need to appreciate that living with an

ASC can be physically and emotionally exhausting, and that full-time work can be too draining to be managed:

> *Another person was given a part-time job which he managed very well. However, he was given additional hours in the company, who were trying to support him, but the pressures became too great. Lesson being, that the anxieties created by working more than two or three days a week may be too great. (Family carers)*

This is compounded by the extreme conscientiousness that can be characteristic of some people with an ASC: they will do whatever they are asked to the point of exhaustion and beyond. Employers need to be aware of this and not ask people with an ASC to do too much even if they say they are willing to. In fact, it is emphasised that employers need to be very aware of everything that may affect how people with an ASC work and how to get the best out of them in a way that works well for everyone:

> *Kind, patient people end up with a loyal, honest, hard-working and efficient worker - who is sometimes late, or early, because he got muddled with times. Critical or impatient people end up confusing him further and hurting his feelings and losing a staff member after a matter of days or weeks. (Family carer)*

7.5.4 The need for support from employers and colleagues

The need for those who employ people with an ASC or work with them to be aware of ASC and to some degree be able to understand and support them is mentioned by 59 respondents. Employers and colleagues who appreciate the qualities that a person with an ASC can bring to the workplace and also understand his or her needs and make allowances for them can find that they have a skilled, loyal and hard-working colleague.

Respondents explain that this cannot happen by chance: it requires awareness of what ASC is and how it affects people, and consequently some thought being given to adapting the working environment and working practices so that the person can give of their best.

> *There is a lack of understanding amongst employers about autism. The challenge is to work with employers for them recognise the contribution that individuals with autism can make to their workforce. (ASC professionals group)*

For this reason, it is argued, employers too need support to understand more about ASC and what they need to do to take advantage of what people with an ASC can bring to the workplace.

> *At present access needs are rarely met as employers have a poor understanding of autism spectrum differences and also tend to…treat the individual as though they are the problem and need to change their ways, rather then accepting them for who they are and accommodating their differences. (ASC group)*

Currently there is a risk that employers who are willing to take on people with an ASC find little support available to help them make it a success.

> *There is often very limited support from [employment support organisations] once the individual is in employment. Often, if an autistic person is having difficulty in their job, such as bullying or lack of 'reasonable adjustments', the employment support organisations either refuse to help at all or display a 'medical model' approach, telling the individual that the problem is with them. (ASC professionals group)*

It is apparent that without some degree of specialist training and support to both the person with an ASC and the employer or immediate work supervisor, many adults with ASC will experience repeated failures in the workplace.

7.5.6 Workplace bullying and prejudice

Because of the general lack of understanding of ASC and the lack of support to make workplaces more ASC-friendly, workplace prejudice and bullying are serious problems that need to be overcome. 35 people commented on workplace bullying and prejudice.

Among the responses there are stories of adults with an ASC being subjected to bullying by managers or colleagues:

> *I eventually got [a job] at a hospital, working as a Clerical Assistant…. I was very badly bullied by the Assistant Specialty Manager who threatened to put me before the disciplinary board and she reduced me to tears. I ended up on the sick and my mother and father requested a meeting with those involved. The people never once asked how I was. My employment was then terminated on the grounds of ill health. (A person with an ASC)*

In some cases the fact of a person's ASC may provide a means for others to manipulate situations to their advantage.

> *One man we know was a very competent carpenter, but his foreman did not like his own mediocre skills being shown up and eventually engineered a situation that allowed him to dismiss him (coming up too close so that our friend had to push him away because he could not cope with his personal space being invaded). (Family carer)*

In others what may be perceived by others as normal workplace interaction becomes bullying if experienced by someone with an ASC who may not be able either to join or respond in a way that would make others understand how it affects him or her. This is particularly the case if the person with an ASC has decided not to tell others about ASC for fear of being discriminated against.

One answer to workplace problems suggested by respondents is that all employees with an ASC should have workplace mentors with whom they can discuss the situations and problems they may encounter whether they are work-related or more to do with fitting in to the social aspects of working. Others would like to see workplace codes of conduct that would make prejudice against ASC a disciplinary offence in the same way as racism or other forms of prejudice are.

7.5.7 Lack of training and support for people with an ASC

One of the main themes in responses to this question, as regards training, is the general lack of appropriate training for adults with an ASC (34 comments). The physical environment of training, such as classrooms, can also be difficult for people with an ASC.

> *About 15 years ago our son began an HND course in Business Studies but found the psychology and sociology components very challenging. Also group activities and knowing what was going on – where to be when. The college referred him to a psychologist but this help tended to be psychiatric and didn't address his ASC problems with the course. (Family carer)*

The stories of particular frustration come from those who feel they are perfectly capable of learning and working but are not offered training that is appropriate for them. People with an ASC find, for example, that they are offered basic skills courses even when they may have good academic qualifications and are capable of more than basic manual labour.

On occasions frustration can turn into serious grievances:

> *What is the thinking behind advertising something called 'New Deal for 50+', encouraging me to see an adviser and do a personal plan and pay for a training course, and then abolishing the scheme and telling me I can't reclaim the money? Yes, this would still have happened if I didn't have AS, but without the AS I might not be so conscientious and guilt-ridden and trying to show I want to help myself. (A person with an ASC)*

The overall picture provided by respondents is of a chronic lack of training and support for those who can and want to work. Where training and support is provided it may be of variable quality or inconsistent in how it is distributed.

7.5.8 Positive experiences

Not all the stories are negative: some demonstrate that it is perfectly possible to construct benefit and payments systems that are intelligent, flexible and fair, for example:

> *Our son is going to York St John University in September. The disability and finance teams have been extremely helpful in ensuring that our son will have everything he needs in terms of monetary and practical support for him to successfully gain his degree. (A mixed group of people)*

Some organisations respond quickly and appropriately to the needs of those who seek their support, recognising, for example, that a person with an ASC may be unlikely ever to cope in a conventional workplace situation but might be able to pursue a hobby or informal work through arrangements such as the Supported Permitted Working Scheme.

It is suggested that all approaches towards work and training for people with an ASC should take close account of their personal interests, skills and limitations and effort. Consequently they should be put into thinking creatively and flexibly about the sort of work and training that may give them a sense of achievement, which in turn will boost their confidence and extend the possibilities for them.

> *Eventually, in my fifties I came across my ideal occupation as a self employed gardener - I was meeting people but in a structured way as clients, getting good feedback and appreciation. This helped my self esteem which was not high having had so many job setbacks and no educational qualifications whatsoever. I was working outside which I enjoyed and keeping fit, earning a reasonable wage, able to develop skills (hedge trimming, turf laying etc) and use my strength to help people enjoy their own gardens. It was a unique and fulfilling time for me in my working life and I knew that I had found my niche at long last. (A person with ASC)*

7.5.9 Other responses

Other responses to this question describe a wide range of experiences of education, training and work, highlighting what help and support has and has not been provided, and what more could have been done to enable people with an ASC to be productive members of society.

7.6. What actions do you think should be taken to address the concerns raised in the training and employment chapter (e.g. training for those who offer employment support, awareness campaigns among employers, changes to contracts so that progress towards work is rewarded)? *(*This question corresponds to Q21 of the standard consultation)

420 people responded to this question.

7.6.1 Training and awareness for employers

Respondents suggest a range of general and specific actions to address the concerns identified. One of the fundamentals that would make a difference, some argue, would be to persuade employers that people with an ASC can make valuable employees with qualities such as honesty, reliability and attention to detail. Awareness-raising among employers is mentioned in 46 comments.

There are some specific examples provided which respondents would like to be more widely known:

> *There is a computer company is Germany (I think) who will only employ ASD sufferers. The reason behind this is that the employer has noticed that ASD sufferers notice problems with products easier than "normal" people. Because ASD sufferers see things as either right or wrong they are more likely to pick up defects. More jobs like this should be made available to ASD sufferers. Employers need to be made aware of*

> *the positive traits of having ASD. ASD sufferers tend to flourish in jobs like - Quality control, analysis, computing, research, data bases, data gathering, project management...etc. (Person with an ASC and parent)*

Some respondents also suggest how this could be achieved or identify those who are well placed to make the case; it is suggested that prospective employers should be approached and the benefits of employing an adult with an ASC highlighted to them (38 comments). There are also some professionals who could assist systematically with this, occupational therapists in particular:

> *Occupational therapists are skilled at helping people to identify their skills to use in an employment selling. Occupational therapists also have a role in highlighting these strengths to employers. (ASC professionals group)*

While the advantages of employing people with an ASC may become clearer, employers may still need to be trained to understand how to work with them (48 comments about training employers), and the rest of the workforce may need help to understand and support them. Some financial incentives may also help to make the case.

> *Training and incentives for employers, plus again a plan to alter things if it is not working so employers are left resentful and unwilling to cooperate in the future, and the ASD person feels they have some control of the situation. The general workforce may also require autism awareness training. (Family carer and professional)*

It is also suggested that training support is essential for employers offering paid or unpaid work to those with an ASC: it is not enough merely for those working in human resources to be aware and trained. For large organisations the general staff training guidance must include ASC awareness training to a level where staff know the potentially difficult situations that could arise and feel confident enough to manage them successfully. It would also be helpful to target those new to business so that ASC training becomes just another part of business development:

> *New employers must receive training and guidance about how to get the best from the person with ASC. For instance, breaking the job into clearly defined units, not making assumption about their understanding. Checking back on understanding and giving positive feed back. (Family carer)*

All this needs to be done, however, with the active involvement and collaboration of the person with an ASC because, as responses throughout this consultation state, there are no ‘one size fits all’ solutions for ASC.

> *If employers want to help, guessing "workplace adjustments" and not allowing the person affected by them a say in what is put into place is the wrong way to go about it. You cannot read a book or information leaflet about a disability and know how it will affect someone. We are all individuals. (No sector selected)*

Some respondents stress that employers also need to appreciate that small things can be very important for people with an ASC, and in particular pay careful attention to the language used in instructions:

> *Sometimes employers get cross because they have to explain things several times. I do try to do the jobs properly. Once I cut some carrots into batons, because they were always done this way. The boss had said "cut them into circles" but should have said "rings". One word makes all the difference. (No sector selected)*

7.6.2 Targeted training such as ‘buddy’ systems

Respondents repeatedly stress that training and support needs to be targeted as much at employers as at people with an ASC. One approach mentioned and approved by respondents (48 comments) is to establish coaching, mentoring and ‘buddy’ schemes.

Employers and potential workmates can be prepared and made aware of the needs and also of the strengths and abilities of a colleague with an ASC and be willing to make any necessary changes in the workplace. It is also recommended by many that support should be made available on an ongoing basis so that an employer can pick up the telephone and seek advice whenever a question or issue arises.

The mentor can not only support the person, but act as a mediator between that person and the employer, and between the person and the rest of the workforce.

> *Employment support in whatever form needs to be long term and it is essential that it is easy to recall a job coach to sort out any difficulties before they escalate and become a major crisis. Employers need to know that support is readily available particularly if there are problems with the person with ASC not complying with his terms and conditions of employment and failing to understand disciplinary procedure. (Family carer)*

The good practice example of the investment bank Goldman Sachs and their mentoring scheme with the National Autistic Society's Employment Service (Prospects), which is provided in the consultation document, is mentioned as an approach that should be adopted widely throughout education, training and employment. It is also suggested that the mentors or buddies could also act as agents to enhance awareness and understanding of ASC within the institutions and organisations within which they work to support the person with an ASC, and perhaps further afield.

Another suggestion is that mentoring needs to be part of a continuing package of support that includes transport and involves parents or other carers so that they can share information, such as changes to medication, with employers (with the requisite permission, obviously). All these types of support could be provided through one-stop-shop assessment centres that could also provide training and employment support and advice, both face-to-face and online, and links with Connexions, Learning and Skills Councils, and other institutions.

7.6.3 Sheltered jobs and incentives for employers

Another area of suggested actions (27 comments) is around sheltered jobs for people with an ASC. Respondents suggest, for example, that employers should receive financial incentives to employ people with an ASC:

> *Use the employer NI system to provide sticks and carrots. eg. Reduce contribution if is employing a reasonable proportion of disabled people; implementing flexible working; locating near to employees residences or in areas with good public transport. Increase for relocating away from where staff live, and/or out-of-town away from public transport. (A person with an ASC)*

Another suggestion is that it would also be useful if there was a register of employers who are both aware of the particular difficulties and challenges faced by an adult with an ASC, and are prepared to make the necessary adjustments to recruitment and workplace practices. Such a scheme could also include systems for review and reporting of performance and accreditation of such employers, with good performance recognised and rewarded and so attracting more support and participation.

This sort of scheme could also include practical support systems to ensure that hard-gained employment opportunities are not lost due to lack of advice and assistance in, for example, day to day budgeting to ensure that each week the adult with an ASC has enough funds to pay public transport fares, and so actually be able to continue to attend work and so maintain employment.

Sheltered employment schemes would also ensure that people with an ASC have their needs taken into account. There are a range of points suggested that would make workplaces more comfortable and sustainable for people with an ASC, as detailed earlier.

7.6.4 Other responses

While these are examples of the main points made in response to this question, there are many other ideas, suggestions and recommendations that would help adults with an ASC to find and keep suitable employment. These include an ASC accreditation scheme for employers, the public sector hiring more people with an ASC to set an example, apprenticeships for people with an ASC and specifically advertising ASC friendly jobs as such.

7.7. If possible, please give examples of where these concerns have been successfully addressed at a local level. (This question corresponds to Q22 of the standard consultation)

257 people responded to this question.

While the largest group of respondents (94 comments) does not provide such examples or say that they have no experience of such concerns being addressed, there are nevertheless some positive stories and case studies.

There are descriptions by respondents of personal experiences of how they have been helped to find training and jobs by various bodies and programmes, for example:

> *Prospects (NAS) provides excellent training and support for employers and people with ASD. After my diagnosis and subsequent breakdown, Prospects helped me to return to my job. My employer (a primary headteacher) said he couldn't cope with me. Prospects provided necessary training over a period of a few months and I was able to return to work with support from my trade union and Prospects. In my most recent job, I have been supported by the Workstep programme. I had to request this support myself but it has been excellent. Recently, I have started working with Workstep, providing ASD training to local employers and support to people with ASD. (A person with an ASC)*

Again, and as in response to other questions, the positive experience often seems to depend on a single individual who is prepared to make the necessary investment of time and effort, and is prepared sometimes to take a modest risk, in order to help:

> *Our son has worked for an outdoor clothing firm (Saturday Job) for at least 3 years, mainly because the team leader was prepared to take him on after he had completed 3 weeks of work experience and was prepared to learn about ASC and make the necessary adjustments. This has been a very positive experience for our son and has given him the confidence to take on another part time job. (Family carer)*

There are also examples of how employers can be supported:

> *….an example to illustrate this would be an individual with ASC who was supported into a job and worked successfully for three years. The office he was based at was to be closed and his job was to transfer to another office within easy travelling distance for him. However the fact that there was going to be such a big change was a tremendous cause of stress for the individual. This was recognised and understood by the employers and the member of support staff from the specialist ASC employment support service was brought back in to help the person concerned manage the change in office base. This may seem time consuming but it worked and enabled him to retain his job. (A mixed group of people)*

Social enterprises meanwhile can provide a mixture of employment and training:

> *Our approach in the Social Enterprises we have developed to offer paid jobs and training have the philosophy that the day should start and end well for everyone but especially for ASC colleagues. We make sure everyone knows what is going to happen in that particular business on that particular day. We watch for body language changes, signs of distraction, discomfort distress and ensure someone who knows the person is around to talk through any anxieties this doesn’t have to be very formal or take very long, it is about getting to know the people in your team. We have found a direct, almost blunt approach works well, too much courteousness and politeness leads to lack of engagement, keep the approach focussed short and reasoned. For some of our colleagues with ASC, we have to start every day as if from scratch and re-*

> *explain the tasks and why we are doing them. This pays off as it ensures engagement and ameliorates anxiety levels. (A group of family carers)*

Some examples illustrate how the presence of a few kind and thoughtful people can make all the difference:

> *On general and further education, our local college Southdowns in Waterlooville have been excellent. They have a disability committee organised by the disability team, run by the students and even have an Aspergers specialist. They have a quiet room for any disabled person to use when necessary. They have an excellent no bullying policy, and all the tutors my daughter has been taught by have been wonderfully understanding and supportive. A wonderful example for other colleges to follow. (Family carer)*
>
> *The bar where my son works (in one part-time job) does not chastise him for being late (or early!). It provides food if he is working late hours. The chef working with him is kind, calm patient, gives good feedback. Consequently, it has retained an intelligent, loyal employee who makes fabulous food and is loved by all the staff. (Family carer)*

7.8. Easy-read consultation questions on the access to employment and training chapter

People have told us that we need to do four main things to make it easier for adults with autism to get jobs and training. These are:

1. make sure that adults with autism can get the help they need to find and keep a job
2. make sure employers know about autism
3. make sure that adults with autism can get the benefits and tax credits they need
4. help adults with autism to get the training and education they need.

7.9. Do you agree that these are the most important ways to make it easier for adults with autism to get jobs, training and benefits? (This question corresponds to Q4a of the easy-read consultation)

Group	Count	Proportion
Yes	93	70%
No	11	8%
Not sure	25	19%
No answer	3	2%

7.10. Please tell us why. (This question corresponds to Q4b of the easy-read consultation)

132 people responded to this question.

7.10.1 Employer awareness and support

There are 21 comments about employer awareness and support. The people who respond to this question agree that adults with an ASC benefit from being able to work, and most agree that the four main things above will help to achieve this. Some add that they will help, providing more is done to tackle discrimination and exclusion:

> *Do we really need to say why? The above are all obvious criteria. The main issue is discrimination and acceptance of an individual's particular circumstance. (Family carer)*

Making sure that employers understand the problems of autism is very important, but it is also seen as equally important for employees to appreciate that people with an ASC can be valuable employees:

> *Many people with ASD are perfectly capable of holding down jobs and are likely to be quite focused. They should be considered on their own merits not interviewed as the token disabled person and employers need to understand this and also that the interviewing process may be more distressing for ASD people than the rest of us. (Family carer)*

It is recognised that employers may need help and incentives to take on people with an ASC; for example grants to provide people with autism with realistic work experience, which will also give them the time and opportunity to adapt to a new work environment and demonstrate their value to an employer.

7.10.2 Help to find and keep a job

21 comments are about finding and keeping a job. To obtain and keep jobs, however, people with an ASC sometimes need the sort of help the strategy suggests, such as help finding job opportunities, support or advocacy at a job interview and help making employers understand ASC. Help can also be important once a person with an ASC is in a job:

> *I also think that in-work support is very important. I work part time and am often unsure about things at work but am not sure who to approach to ask and am too anxious to approach people, especially not knowing which of the staff are aware that I'm autistic. (A person with an ASC)*

7.10.3 Considering the strengths and capacities of adults with an ASC

This is mentioned in 18 comments. It is pointed out that many people with an ASC are perfectly capable of holding down jobs and are likely to be quite focused:

> *They should be considered on their own merits and not interviewed as the token disabled person and employers need to understand this and also that the interviewing process may be more distressing for ASD people than the rest of us. (Family carer)*

Making sure that people are in the right job is also regarded by respondents as very important. It is vital to identify the strengths of a person with an ASC and also what interests them, as this will make it more likely that they are able to get a job and keep it.

What is needed is a person who knows what jobs are available, what kind of skills they require and what kind of challenges there may be, so that a person with an ASC can consider whether the job would fit them:

> *It is also important that a person is asked if they know what job they would like to do and if they know what they like doing and if the do know their strengths but all will need extra help to cope with the whole process which will be quite overwhelming for them/us. (A person with an ASC)*

7.10.4 Accessible benefits and tax credits

Helping people with an ASC to get benefits and payments is something else that is very important, with 14 people making a comment about this issue. Some responses are very critical of the current benefits system, which they feel makes it very difficult for people with an ASC to get the right benefits or indeed any benefits at all:

> *Staff at Job Centres are very adversarial and if they see you are vulnerable they take advantage. The only people who get support are those strong enough to fight back. Claiming benefits and going into Job Centres is often very distressing. (A mixed group of people)*

Others have suggestions for improving it. Some suggest that the system should make it clearer to people with an ASC which benefits or tax credits they could claim. There could also be advertising in newspapers and other media outlets, and there could be posters in public places to inform people with an ASC how to make claims. Some believe that this will not be sufficient and that some may need more hands-on help*.*

> *The idea of autistic people having a 'key worker' seems sensible, who would have extensive knowledge of autism and have links to many other agencies and therefore in a position to advise the autistic person as necessary. (Family carer and professional)*

7.10.5 Training and mentoring

There are 11 comments about training and mentoring. In many cases people with an ASC need support from others to find training and employment. In some cases such help and support could be provided by the staff of, for example, Jobcentres:

> *Jobcentre staff and other similar agencies could also help by advising autistic people how to apply for jobs, how to deal with interviews etc. (perhaps practical training, mock interviews?) (Family carer and professional)*

In some cases a person with an ASC may need more dedicated and professional support, such as an advocate or mentor, who can not only help them into employment, but help them to deal with the challenges that may be inevitable in a new workplace environment:

> *Assistance in the workplace from a key worker, someone already known and trusted to the person seeking employment, would be hugely beneficial...someone to assist with the transition phase and help deal with any initial difficult situations involving people with limited knowledge of autism. (Family carer)*

7.10.6 Other responses

Many responses add other stories and experiences and make points about the various ways and means by which people with an ASC can be helped to achieve and retain employment, and to benefit both themselves and their employers.

7.11. Have you had any problems trying to get a job, training or benefits? (This question corresponds to Q4c of the easy-read consultation)

Group	Count	Proportion
Yes	69	66%
No	24	23%
No answer	11	11%

7.12. If you answered yes, please tell us about the problems you have had trying to get a job. (This question corresponds to Q4d of the easy-read consultation)

102 people responded to this question, with a clear majority agreeing they have had problems.

7.12.1 Bullying, exclusion and discrimination

In response to this question there is clearly some level of concern that people with an ASC are being discriminated against when it comes to gaining employment. 12 comments mention bullying, exclusion and discrimination.

> *I believe that there is discrimination. I have been turned down for jobs because of communication issues, I believe this is illegal under the DDA. Also, many jobs ads say they want "good communication skills and teamwork skills (cf social skills)". I believe this could be illegal under the DDA. (A person with an ASC)*

Some respondents believe that the basic problem is employers not understanding ASC:

> *Basically employers do not understand autism, they do not want to employ people who 'are not normal' and the current law allows this. (Family carer)*

Job application forms can have the effect of excluding people with an ASC right at the beginning of the application process:

> *Frequently do not understand jargon of forms so "don't make the right noises". Furthermore, I am massively "overqualified". When out of work I took more qualifications like the government told me to. Thus I am professionally, craft, and academically trained. Employers do not like very trained people. (A person with an ASC)*

For some, exclusion and discrimination begins with job interviews, with people with an ASC being labelled as 'weird' or 'odd', sometimes to their faces and actually during interviews. The need to be a team player and fit in with the rest of the team is considered by some employers to be as important as qualifications and knowledge, and this often frustrates the chances of people with an ASC.

> *Like many Asperger jobseekers, I have often felt immediately excluded by requirements in person specifications for "good / excellent communication skills", whilst meeting most other aspects of the specification. The psychological nature of interviews as a means of recruitment selection penalises the less confident, competitive natured person. (A person with an ASC)*

7.12.2 Difficulty communicating with others

People with an ASC often find face-to-face communications difficult, which adds to their problems during interview processes and significantly reduces their chances of getting jobs. There are 10 people who make a comment about this.

> *My strange behaviour put people off when I went to job centres or interviews. I became more and more stressed the more I was rejected and eventually my anxiety levels reached a point where I couldn't go for interviews. I have tried voluntary work in charity shops, but even there they seem to think that because I have an ASC, I'm only capable of sorting clothes. I'm too lacking in confidence to and ambition to say anything. (A group of family carers)*

This also applies to finding jobs that are suitable in the first place:

> *Quite simply, most jobs aren't suitable. They are too socially based***,** *or cause too many sensory issues. Any job that I am interested in often involved having qualifications that I didn't have. I can't afford to study/do training to get those jobs. (A person with an ASC)*

7.12.3 Awareness and support

There are 10 comments about awareness and support. Problems can occur long before people with an ASC apply for jobs. Careers advice, for example, is not always perceived helpful:

> *I also saw a Careers Advisor at college but they also did not know that I suffered from Asperger Syndrome and I do not think that I fully understood what it would mean for me in terms of what training and careers would be available or suitable for me so consequently the Careers Advisor gave me inappropriate advice and I realise now that they suggested careers and training which were completely inappropriate such as careers in the health and social care sector like nursing. (A person with an ASC)*

One of the most important things responses emphasise is for people to realise, employers and co-workers included, that no two people with an ASC are the same, and that every individual with an ASC has individual needs and abilities. If people with an ASC are to have jobs, then employers must have a better awareness of what ASC involves, how people can be affected, and how, with a little care, understanding and flexibility, they can become loyal, trustworthy and valuable employees.

A number of responses set out stories that further illustrate these points and suggest remedies that may help improve the situation.

7.13. If you answered yes, please tell also us about the problems you have had trying to get training. (This question corresponds to Q4e of the easy-read consultation)

98 people responded to this question.

Very few respondents provide a detailed response to this question. Of the few who did, most (8 comments) said that getting training was not a problem:

> *I have 4 N.V.Q.s One 5 (management), one 3 (disabled advocacy), and two 2's (computing & office). I have also the N.V.Q.assessor award. I am on my second undergraduate degree and already have a 2:1 in technology. I am a Master Craftsman, a trained electrician, a computer technician etc. Therefore no problems getting training - just getting training that gives me work. (Family carer and professional)*

Some (5 comments) say that their problems have included bullying and discrimination:

> *I got bullied in class because I came out of school with 1 qualification I ended up in a group with mostly people who weren't very bright and came from lower social economic backgrounds to me naturally they bullied me because I was different and got good grades and tried hard, I had different issues, because I had never had the chance to do what I really wanted to do. (A person with an ASC)*

The nature of training environments can also prevent people getting the training they want. This is mentioned in 5 comments. For some, the physical environment of a training centre provokes such anxiety that they find it impossible to endure. Even if the environment is bearable, it may present other difficulties:

> *Being trained in a classroom environment was very difficult for me as I struggled to concentrate with others in the room and so many distractions but when left to take work home I had difficulty organising my time and motivating myself to do the work. (A person with an ASC)*

9 respondents explain how many of the problems also relate to lack of support available during training, for example with time management:

> *My son had no support whilst at college. He became behind with his work. College did not keep us informed. They did not support him to catch up with his work. They seemed to forget he had difficulties with organizing his time etc. very very hard to work with teachers who are not willing to listen. (Family carer)*

7.14. If you answered yes, please tell us about the problems you have had trying to get benefits. (This question corresponds to Q4f of the easy-read consultation)

99 people responded to this question.

7.14.1 Questions that are not appropriate for people with an ASC

11 people comment about the questions they need to answer when applying for benefits. The basic problems for many people are understanding what benefits they can claim and then filling in the necessary forms:

> *Benefits forms are difficult to understand and the questions often don't apply to people with autism and other co-morbid conditions such as epilepsy. There is also no-one to point out which benefits you can claim and how to try and claim them. (A person with an ASC)*

One of the fundamental problems for people with an ASC is finding out what they are entitled to and then filling out forms that seem to assume physical disability or learning difficulties:

> *Even now I'm not sure what I'm actually entitled to other than DLA and how to find out/how to apply. I was unsure of how to appeal when I first applied for DLA and had to get a friend to phone up to find out. I can't get a Freedom Pass because I don't quite fit the criteria (not learning disabled because have IQ above 70) and am finding it hard to appeal this. (A person with an ASC)*

The fact that the forms do not seem to fit people with an ASC also makes people worry that those taking the decisions do not understand ASC and may therefore make the wrong decision:

> *The benefit forms are very long and complicated and seem to be written for other conditions and not Aspergers. I worry that the people who have to make the decision do not have training or knowledge in Aspergers. (No sector selected)*

7.14.2 Help from family and carers

People with an ASC often need help from family or carers to help them with applying for benefits and there are 9 comments about this, some saying that it can also create difficulties:

> *Benefits agencies won’t let someone help with benefits as they won’t accept third party authority letters to allow someone such as a parent to help and keep an eye on things. They seem to have an all or nothing approach, the person who needs to claim the benefit has to do it all themselves or have someone with power of attorney doing it. (Family carer)*

7.14.3 Other problems with getting benefits

Getting the right assessments can also be a problem. For people with an ASC it is not always easy to have their GP provide a clear and complete assessment of their condition:

> *The biggest problem has been getting a reassessment of his condition carried out or rather, finding who is responsible for doing this. I have made many telephone calls to people in the county council, NHS etc. and thought that our G.P. would be able to refer*

> *my son to a suitably qualified person. As previously mentioned, after a long and frustrating search, including a referral to a Consultant Psychiatrist who was not qualified to do such an assessment, I had no alternative but to find a private Educational Psychologist to carry out the assessment for a considerable fee. (Family carer and professional)*

Just as in many cases help comes from a particular individual who responds with kindness and sympathy to someone with an ASC, so at times the problems seem to be caused by people who lack such instincts:

> *Our Local Authority denied our application for a disabled parking spot, because our son wasn't disabled enough. That hurts - not disabled enough. Can you imagine what that feels like when you read it - not disabled enough. My son's autism is for life - and as parents we will always ensure he gets the best he can get but when some invisible bureaucrat says he isn't disabled enough - I despair…. (Family carer)*

7.15. What do you think we should do to make it easier for adults with autism to get training or a job? For example, we could make sure that people like employers and people who help adults with autism to find a job know more about autism.

(This question corresponds to Q4g of the easy-read consultation)

96 people responded to this question.

Several responses point out that they have already effectively answered this question several times.

Others mention, as already detailed earlier in this chapter, the need to increase understanding of ASC among employers (20 comments); provide support through mentors and buddies (10 comments); provide work placements and volunteer opportunities (8 comments); improve training for people with autism (7 comments); and promote the value of people with autism as employees (5 comments).

There are a number of specific suggestions. Some respondents feel that job centres should be better equipped to provide service to adults with an ASC, including an understanding of the variety of the spectrum. Another suggestion is to provide a specialist advisory service that can train or support employers and colleagues of people with an ASC. Some examples of further suggestions are given below:

> *Government Departments, and the NHS should readily employ adults with autism. It would help them understand the condition and effect changes in the way services and benefits are administered. (Family carer)*
>
> *All colleges and centers for learning disability should have training in ASD so they do not just put you in a place and think you can do it this happened to me. (A person with an ASC)*
>
> *Social services need to step in and provide the sort of support that parents do: advocating, attending interviews, forming a relationship with the autistic adult, understanding how to relate to these people, and realising that they are not awkward, lazy or unreliable. They are anxious, naive and intimidated by a lifetime of bullying. And that means going to the extent of actually VETTING employers, as so many people say they are autistic-friendly when they are not. Anybody who has not read books about autism, or known someone intimately with autism, really has no idea of the difficulties involved. A quick course in autism is nowhere near enough to address this deficit. (Family carer)*

A number of people (3 comments) raise the question of whether it is helpful or acceptable for employers to know that someone has autism:

> *I would not want an employer to know I have autism as every time I have disclosed it I am scrutinised in an unfair way. If there are any problems I get blamed for my difference. It is also normal that all the staff end up knowing so it becomes unhelpful. (A person with an ASC)*

Finally, it is argued that more resources would help:

> *Funding for people with autism as well, especially those who aren't in full time work - some help financially would mean more autistic people got the training they needed and then there might be more autistic people in full time work (or at least more in part time work). (A person with an ASC)*

7.16. What help have you had to help you get a job or training? How has it helped you? (This question corresponds to Q4h of the easy-read consultation)

79 people responded to this question.

Most of those who answer this question say they have had no help (27 comments). Of those who have had help, most only referred to who they were supported by rather than the type of help they got. Help has come mainly from their families or carers, including community support workers (14 comments). A few describe how carers or family members helped them to go to school, take training, or get a job.

Some (8 comments) have had help from independent organisations, mostly local initiatives, with ASPIRE mentioned twice. Another example:

> *My son was referred to a group called Into Work who have regular meetings with him and conducted a lengthy initial assessment of his needs and preferences and also, with his permission, had a similar discussion with me as well as explaining to me how they intended to help him. They have increased my son's self-confidence and helped him to organise various aspects of his life as well as providing ongoing support with job hunting. They arranged a work placement for him so that he gain work experience while he searches for paid employment. (Family carer)*

Others have had help from several organisations:

> *I have had help to get a job and training from the following people: my DEA at my local Job Centre, my Employment Supporter from ASpire (Asperger Syndrome People Into Real Employment), my colleagues from my current job which is Autism West Midlands LPD (Learning and Professional Development) team. (A person with an ASC)*

NAS Prospects and Connexions also receive favourable mentions. The help received from job centres and schools has ranged from the excellent to the limited. A small number of people say they have had great help from employers.

8. Awareness raising and training

8.1. Summary of responses to this chapter

This chapter covers responses to questions about the lack of awareness of ASCs among the general public and the lack of training in ASCs among a number of groups of professionals and some of the problems this can cause. Respondents are asked whether they agree that the three areas identified by stakeholders (national and local awareness raising campaigns; targeted training programmes for certain professions; and the inclusion of ASC in social work degrees and clinical curricula) are indeed the most important ones. Other questions are about the priority groups for awareness raising and further issues around awareness.

8.1.1 Main issues

An overwhelming majority of respondents agree that the areas identified are the right areas to target for awareness raising and training. People especially speak out in favour of raising awareness among the wider public, or all professionals who are likely to be dealing with adults with an ASC, as this is seen as fundamental to the autism strategy as a whole. This should extend to creating a proper understanding of the varied nature of ASC among individual adults, as this is seen to be lacking in many instances, resulting in people having erroneous preconceptions of ASC. Including training about ASCs in higher and professional education should contribute to a better awareness.

8.1.2 Priority groups

Respondents emphasise that no single group should be prioritised for awareness raising and training if this would mean a reduction elsewhere: it is considered of utmost importance that everyone in contact with adults with an ASC is aware and has some understanding of it. The importance of an increased awareness among (mental) health professionals and social workers is highlighted, as for adults with an ASC people in these professions are often the portal to essential services. Police and justice officers are also mentioned frequently as minor issues can escalate if police or justice officers are unaware that an adult has an ASC. Furthermore there are many mentions of education and employment professionals (including employers) whose awareness can help people with an ASC gain access to meaningful activities.

8.1.3 Further issues

In a variety of comments, respondents stress that the need for more awareness and understanding is great, adding suggestions or reservations about how professionals and the wider public can be made more aware. Emerging themes include the importance of ensuring that people have a grasp of the extent of the spectrum and the diversity in the ways that ASC can manifest itself and the need to fully involve adults with an ASC in the development of training and campaigns.

8.2. Standard consultation questions on the awareness raising and training chapter

The external reference group identified the following as key areas where action is needed to improve awareness of and training in ASC:

a) the development of both national and local awareness raising campaigns targeted at both the general public and at more specific groups of people (e.g. employers, those working in the criminal justice system)
b) targeted training programmes for certain professions such as social workers, community care assessors, healthcare professionals, those working in housing and in employment support
c) the inclusion of ASC in social work degrees and clinical curricula.

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

(This question corresponds to Q16a of the standard consultation)

Group	Count	Proportion
Yes	519	90%
No	14	2%
Unsure	16	3%
No answer	26	5%

8.4. Please explain your answer. *(*This question corresponds to Q16b of the standard consultation)

575 people responded to this question.

An overwhelming majority of respondents agree that these are the right areas to target for awareness raising and training, indeed this issue comes up repeatedly in response to other questions in the consultation.

8.4.1 General awareness raising

The need for awareness raising is mentioned in comments from 194 respondents. Those who endorse the awareness raising and training strategy as it is presented in the consultation documents do so because they see it as fundamental to everything else that the strategy will try to achieve. For this reason it is seen as particularly important for people who are likely to come into contact with adults with an ASC, whether as employers, social workers, health professionals or any other group that can materially affect their welfare. As one response points out:

> *This is particularly important. If awareness training gets better and becomes more widespread, it would automatically solve or reduce many of the problems addressed in the other sections of this document. (A mixed group of people)*

One concern mentioned by many respondents is not just that awareness be raised, but that it be a properly informed awareness. The feeling from many is that people in general know little about ASC, and there are also some myths and stereotypes about it, which do not always correspond with the ways people with an ASC may behave, and these can be as damaging as ignorance.

> *Although most people have heard of autism, they do not actually understand the whole spectrum and how it affects people differently. Most will cite 'Rain Man' and assume that all autistic people are the same as the character in the film. (Family carer)*

One of the main reasons for some respondents wanting more general understanding of ASC is that it may prevent people leaping to conclusions about what people with an ASC can or cannot do:

> *General perception seems to be that people with ASD are either locked inside their own world unable and unwilling to communicate with anyone outside of that world or are savants. There needs to be much higher awareness that many are able to function 'normally', with tolerance and support. (Family carer)*
>
> *People think that someone with ASD is of low intelligence, incapable of functioning without constant supervision and support. This is simply not true. There are doctors, teachers, scientists, engineers with ASD. (A person with an ASC)*

Many respondents identify those in society who most need to have an informed awareness beyond that of the public in general. Top of the list are health professionals (33 comments), social workers and care workers (31 comments), and people working in the criminal justice system (27 comments), particularly the police:

> *Police and criminal justice professionals need to be aware of the condition particularly as most methods used in interviewing suspects with result in false positives due to the nature of the condition. Abusive behaviour may simply be an anxiety response to sensory overload and the time required for a person with ASC to comprehend and respond to situations will exponentially increase as stress levels increase. (A person with an ASC)*

Some respondents would like to see this raising of awareness begin within the education system (19 comments) both because teachers are often well placed to help parents and carers achieve an early diagnosis, but also because it reduces the chances of them inadvertently labelling children in ways that may stay with them for the rest of their lives:

> *…..train primary school teachers, it is the first step a child (eventually becoming an adult) takes in to the world of a wider society. Ignorant primary teachers (no fault of their own). It's the system failing teachers and children. Primary teachers can label children as, odd, different, naughty, disruptive, etc. The worse start for any future adult. (Family carer)*

8.4.2 Training for all professionals in contact with ASC

Many respondents discuss the need for specific training for all sorts of professionals in addition to general and more targeted awareness raising. The need to train all professionals who might come into contact with a person with an ASC in the course of their work is emphasised in 111 comments. Some would in addition like to see this become a part of continuous training and professional development.

Furthermore, many suggest that ASC should be included in the curricula and degree programmes for all health and social studies (35 comments). To some it is obvious that knowledge of ASC should be included in relevant degree and professional training curricula, and that where this is not the case it should be introduced urgently.

There are suggestions about exactly where and how this should be pursued.

> *We fully agree that the three areas are a key priority. The general awareness-raising campaign needs to be both national and local with appropriate delivery supports for both. The low level of ASC awareness among social workers and health professionals needs to be addressed urgently. All the appropriate professional training and regulatory bodies should require the study of ASC to the necessary standard in final examinations, written and practical. (No sector selected)*

It is suggested that this might also do something to counteract the belief that it is the role of service users to conform to the expectations of the institutions delivering the service, and that it is reasonable to label those who do not, as is sometimes the case with people with an ASC, as troublemakers. A greater understanding and awareness may do something to persuade institutions that it is up to them to develop services appropriate to their clients' needs.

While the importance of increasing knowledge and understanding of ASC is not questioned, how it should be delivered is argued:

> *Regarding including ASC in curricula for social work degrees, again this teaching / training should be delivered by autistics. Also, it is imperative that it is reinforced that all autistic are individuals and that it is a complex condition. Whilst training is certainly very useful as an introduction, it does not in any way mean that the recipient knows 'everything' or 'a lot' about autism. (A group of people with an ASC)*

This point is reinforced by those who wonder to what extent a real knowledge of ASC can be taught at all:

> *I object to the recently emerging autism qualifications such as MAs in autism. This is ridiculous – how can you do an MA in a neurotype, a culture, an entirely different experience of life and perception of the world? Reducing autism to a 1 or 2 year qualification is utterly insulting and also could lead to people being given extra work or credence because they have completed this ludicrous qualification, when in fact they may not know anything at all about the day to day reality of autism or what it is actually like to BE autistic. Only autistics are the true experts on autism. No-one else. (A group of people with an ASC)*

Some of those who do believe that there are gains to be had from the inclusion of ASC in training discuss the nature of such training, with some emphasising the importance of going beyond text books and having practical training to gain experience of working with people with an ASC.

How to ensure the quality of such programmes is also argued in some depth: some people with an ASC (20 comments addressing involving and empowering people with an ASC) argue that wherever possible training should be run by people with an ASC rather than by neuro-typical people, not least because the latter tend, in the perception of some, to over-emphasise the problems that ASC creates rather than focusing on how people with an ASC can be helped:

> *In my experience people need practical training in providing autistic-friendly information, making sensory environments tolerable for autistics and how to adapt to autistic communication needs. Very little of the training available actually addresses these issues. It is more likely to tell people that we might not make eye contact and will take everything literally. That isn't what most autistic people *need* others to know. (A person with an ASC)*

Another area of concern for some people with an ASC is that while many professionals are well-meaning, they are incompetent in terms of their understanding of ASCs and appropriate strategies. They think the quality of information used to help raise awareness may be too prescriptive and simplistic, with insufficient account taken either of ASC's complexity or variability:

> *ASCs are complex. Most people on the spectrum have co-morbids affecting the presentation of their ASC and it is imperative that professionals….. understand the impact of these co-morbids and why the presentation of ASCs and the needs of individuals vary so widely. Without that understanding it is unlikely that professionals will understand the needs of individuals enough to be able to be flexible in the way they provide support to individuals. (Family carer)*

8.4.3 Specific areas for awareness raising

There are two particular groups of people, in addition to those mentioned above, who are singled out as needing to have their awareness of ASC raised.

The first is employers, not only to prevent them discriminating against adults with an ASC, but actively help them appreciate that many adults with an ASC can make excellent employees:

> *I have known of situations when employers have used the excuse of Health and Safety legislation for not employing high functioning persons on the autistic spectrum. I also know of one employer, who had employed an individual with Aspergers on a trial period as a favour to their parent, came back and asked where he could find "more of 'em". The skills, often attributed to those with Aspergers (impeccable time-keeping, attention to detail, good with computers etc.), could be better marketed. (Family carer)*

It is argued that while people with ASCs can be excellent employees, if employers and employment advisers are unaware of their difficulties they may never get into employment. This is a waste economically to society as well as preventing people with an ASC from experiencing the satisfaction and self-esteem that comes from being self-supporting and an effective worker.

Respondents also report less happy stories about their experiences in the workplace, and again feel that some of these might be reduced if employers had more understanding of ASC:

> *We need a workplace code of conduct so that there is a strong disciplinary procedure for people who refer to colleagues with ASDs as 'mad'. It's now totally unacceptable to be racist, and rightly so, yet making fun of people with ASDs still seems to be acceptable in the workplace. (A person with an ASC)*

People who would also benefit from better awareness and understanding of ASC are those assessing people with an ASC for benefits such as housing allowances:

> *As adults with ASC presently fall outside the eligibility to access support from social services, community care assessors and those working in housing support, there is an urgent need for appropriate training. (No sector selected)*

This point is taken up more fully in the chapter on Employment and Training.

8.4.4 Other responses

Many of the responses to this question are long and detailed, reflecting the extent to which people with an ASC, their carers, and professionals involved with ASC see awareness raising about ASC as crucial to progress in this field. In addition to identifying and discussing the professional groups and institutions that need to be better informed, respondents put forward specific ideas for how this should be done (such as, for example, autism-alert cards to tell the emergency services when they need to be aware that a person has an ASC), and comment on numerous other aspects of ASC, how it affects people, and what help and support need to be put in place.

A few respondents disagree with the target areas identified. Most of their comments focus on omissions from the list of those to be targeted for awareness raising and training. A number, for example, suggest the inclusion of carers, for example:

> *This section also needs to include training for carers and others including strategies for coping with living with a person with ASC and being on the receiving end of a diagnosis…… The document needs to give more direction for commissioners in what to look for in commissioning appropriate services e.g. low staff turnover, predictable staff shift patterns/training in ASC teaching/communication systems." (ASC professionals group)*

There are also a number who would like to broaden the whole approach:

> *All the key areas above are very sensible but only address a few people in society. Because of the high prevalence of autism in the country, an awareness of autism should be introduced into the national curriculum. (Family carers)*

8.5. Who are the priority groups for awareness raising and training and why? (This question corresponds to Q17 of the standard consultation)

451 people responded to this question.

8.5.1 Train everyone in contact with ASC

The straightforward answer from many respondents (170) is that anybody who comes into contact with people with an ASC needs to understand ASC and be trained to respond effectively to it. This is particularly the case if that person is in a position to affect the welfare of someone with an ASC.

There are also some comments challenging the terms or language used in the consultation document. For example, by suggesting a list of professional sector people with whom an ASC might come into contact, this suggests they will not be fully integrated into all parts of society:

> *Prioritising implies that autistic people will only encounter certain public sector professionals engaged in providing autism-specific services e.g. over health, housing, support work etc. In fact, autistic people if fully included in society should be able to access services of all kinds, and will want to do so e.g. law courts, banks and financial services, etc. (A person with an ASC)*

Most respondents do in fact identify their priorities for awareness raising and training, and they do, as responses to the previous question suggested, include those mentioned in the consultation document. In descending order of priority, to judge by the approximate frequency of mentions, these groups are:

- health professionals (159 comments);
- social workers (101 comments);
- police and others working in the criminal justice system and other emergency services (84 comments);
- teachers and others involved in education (82 comments);
- employers (80 comments);
- mental health professionals (38 comments);
- housing professionals (23 comments),
- service commissioners (15 comments);
- families and carers (15 comments);
- staff and managers of public transport (14 comments);
- receptionists and frontline workers (13 comments);
- benefits staff (13 comments);
- people in local government (7 comments) and politicians (6 comments);
- support (6 comments) and community workers (4 comments);
- staff in residential homes (4 comments); people working in banks and financial services (3 comments).

These priorities need to be treated with some care because some respondents, for example, may be describing staff in residential homes as social workers. Overall, however, it gives some sense of which groups of staff people with ASC are most likely to encounter in the course of their lives, and consequently perhaps which are most likely to determine the quality of their lives. There are examples to illustrate the significance of those groups that respondents consider the most important.

8.5.2 Health professionals

Health professionals are probably put first for the obvious reason that for many people their local GP is the first port of call when they are experiencing health-related problems, particularly those that are often confusing and stressful. If they do not know about ASC they may not recognise the condition, or they may misdiagnose and refer the person to the wrong sort of help.

> *The doctors are the most important. You can only be diagnosed via your doctor. They have the power to decide your life. The doctors are pressured, and older people with ASC are not a priority. This means you have to become desperately mentally ill before anything is done…. My doctor treats me for arthritis but refuses to accept I am Asperger. My job situation is impacting on my physical health causing the arthritis to worsen. With help for my Asperger, I would be able to move on in a better job. (A person with an ASC)*

8.5.3 Social workers

Social workers are considered a priority because they again act as important ‘gatekeepers’ to other services.

> *Social workers so that they can offer an assessment in an accessible way but identifies real ways that an adult can be supported. (Family carer)*

Some respondents suggest the level of understanding of ASC among social workers is very variable, perhaps because, it is suggested, they may see relatively few children or adults with an ASC, and they do not always appreciate that ASC is a very wide spectrum of conditions. Others are impressed with the current level of knowledge and the willingness to learn more:

> *In my experience social care professionals have now built up quite a 'body of expertise in this area' whilst always wishing they understood more. (ASC professionals group)*

In some cases it appears that parents and carers can find that they have to take on the role that social workers should be filling:

> *As a parent I have had to email the social worker a list of what she needs to do to get the support my son has been assessed as needing. What happens to those who don’t have a parent to do these things? It is so tiring. I am crying now because really I want to pack a case and just run away. It should not be like this. (A person with an ASC)*

Another reason for focusing on the training of social workers is not only to get them to do the right things, but to stop them doing the wrong things:

> *They need to understand our need for routine, for things being in place. They cannot just steamroller in and rearrange your entire world to suit them. (A person with an ASC)*

8.5.4 Police and the criminal justice system

The police and others working in the criminal justice system are a priority for training because, according to respondents, people with an ASC are particularly vulnerable in this regard, for example:

> *One fear I have is that my daughter will one day say or do something inappropriate to the police and they will arrest her without realising that she finds it hard to control her emotions or know how she is expected to behave in certain circumstances. If she was arrested she is likely to become very upset and appear aggressive and this would worsen the situation. If the police knew about AS then they would be able to handle her appropriately and situations would be unlikely to escalate. I like the idea of having a card or maybe a special bracelet that could id the person as having an ASC. (Family carer)*

The risk that people with an ASC might fall foul of the criminal justice system is emphasised by a number of respondents:

> *The Criminal justice system is a priority group because many people with ASC are naive and easily led and bullied by others. Some get into trouble with the police inadvertently and when in trouble they are often not able to speak up for themselves. The nature of the disability needs to be understood by the police so that miscarriages of justice are prevented. (Family carer)*

People with ASC who are behaving oddly because they are distressed for some reason are often perceived to be drunk, on drugs, or mentally ill. This is particularly true for people with an ASC who are experiencing an emotional ‘meltdown’, which may involve shouting and disturbed behaviour. If the police were more aware of what an ASC can mean, they might check for the condition before detaining a person on other assumed grounds, and seek further assistance:

> *If a person with autism is arrested, then an appropriate adult with knowledge of autism needs to be brought in, whatever the person's alleged crime. Interviewing techniques need to be carefully thought out; this would also apply when interviewing a crime victim with autism. Many of us carry Autism Alert cards; if a person comes across as possibly having autism, the policeman/woman should ask if a person has autism, and if they have an Autism Alert card. (A person with an ASC)*

8.5.5 Teachers and others in education

This group is regarded as a priority because teachers are often well placed to notice children who may have an ASC and can help to secure an early diagnosis and the assistance that this can bring. Respondents see a need for training about ASC at every level of the education system:

> *We should start in schools with young children. Teachers should understand the impact of ASC and classrooms adapted to recognise the special needs of children with ASC such as the importance of routine, building time into lessons for those who need it and so on. The more integrated children are, the more 'second nature' these issues become and everyone is 'unconsciously competent' in their dealings with people with ASC. (ASC professionals group)*

Higher education is another area where it is perceived there is a great need for more guidance about ASC:

> *Higher Education is seen as an important way forward for able people with ASCs to get a better life. I am widely read on ASCs having nearly thirty books to hand, and I know most of the inclusivity and students in HE reports - it isn't enough. (A person with an ASC)*

8.5.6 Employers and employment services staff

Employment, and the people who work in employment services such as Jobcentre Plus, are described as important to adults with an ASC for several reasons. First, there is the stability, as well as the money, that employment can bring:

> *Employment is another key area. It is often vitally important to people with ASC because it provides structure and an opportunity to interact with others when otherwise they could be without meaning to their lives and isolated. (Family carer)*

The employment services may also become involved in one of the crucial transition period's of a person's life:

> *Once outside of school, this service will commonly be the first significant "service" that the now ostensibly "adult" person with ASC will approach. For the person with ASC, this first experience of meeting and calling upon an "adult social service" should be emphatically positive and hassle-free. And the staff who provide that service should (of course) be equipped fully to give an appropriate and "ASC empathetic" response from day 1. (Family carer)*

Another reason for making the world of work more aware of ASC is to prevent the sort of problems that one respondent describes:

> *Job Centres …please can ASC people go back to Disability Employment Advisers and not be interrogated by outsourced contractors who neither have the experience, training or awareness of the support needs and are driven by financial outcomes to get people into work….This misguided, inappropriate process is causing mental damage to people on the spectrum and simply adds to the already alienation of the ASC person to authority. (Family carer)*

Job centres can also be proactive in helping adults with an ASC to find employment providing they are prepared and motivated to do it. They can, for example, have people who are trained to help people with an ASC apply for jobs by assisting with applications and interviews, and matching their interests and capabilities to job prospects. Such people could also build links with local employers prepared to take on people with ASC.

Finally, educating people in the workplace about ASC is another route to wider education of the public as a whole:

> *If employers understand the difficulties and can prepare their staff this should reduce bullying and will encourage greater understanding among the general public. There is also the problem that if a person has poor social skills and communication difficulties they are unlikely to interview well, so some attention needs to be paid to this area of employment. (Family carer)*

8.5.7 Housing and benefits staff

The world of benefits can be a minefield for adults with an ASC, and one where assistance from a carer or other supporter is often essential both to avoid misunderstandings and to ensure that a person with an ASC receives the benefits to which he or she is entitled.

> *If I hadn't been present my son would have lost his benefits due to the ambiguity of the questions. He was asked "How much do you drink of on evening?" My son answered "3". Assessor talking about "alcohol" my son "all drinks" and being on medication knew he couldn't drink alcohol. I had to ask my son what 3 drinks were but assessor had assumed wrongly that they were alcohol. Each question followed this pattern and I was left to show the ambiguity. (Family carer)*

Many respondents also explain the need for people in housing offices to appreciate exactly what sort of accommodation is and is not suitable for an adult with an ASC:

> *We have had a dreadful time trying to get help from Housing Departments. They wanted to put our son into a block of flats with ex-prisoners and those with drug and drink problems. (can you imagine). Whilst I understand these people need help you cannot put someone with an ASC into this sort of accommodation, the housing team had no idea why this would be a problem and could not believe we turned their help down. We have now rented a flat for our son in the private sector, as this was our only option but this is far from ideal as he could have to leave this at any time if the landlord wants to sell, this will cause huge problems as he has been there for 4 years and a move will without doubt impact on his mental health in a very bad way. He should be in a safe and suitable flat in which he should not have to move from so that we know he will be safe when we are no longer here. (Family carer)*

8.5.8 Mental health professionals

This is an important group in the eyes of many adults with an ASC because of the danger of ASC being diagnosed and treated as a form of mental illness.

> *Mental Health professionals need to be far more ASD aware and, better still, if dealing with people who might be on the spectrum have the knowledge to see beyond the mental health diagnosis. (Family carer)*

There is concern about ASC being over-medicated because mental health professionals are unsure of the condition. It is also suggested that the relationship between ASC and genuine mental health problems needs to be properly recognised:

> *The ASC could be causing other mental Health Issues and if recognized could facilitate both access to diagnosis and the right approach during interventions for other co-morbidities. (A person with an ASC)*

8.5.9 Public understanding and awareness

The identification of these and other groups as priorities for awareness raising and training should not obscure the need for this among the population as a whole. The general point is made by one person with an ASC:

> *It needs to be seen as just as unacceptable to be prejudiced and bullying to people with autism, as it is to be racist. You wouldn't ever say a Chinese person "suffers from being Chinese" so why say that a person "suffers from Asperger Syndrome"? We don't suffer from it, we have Asperger's. (A person with an ASC)*

There are many anecdotes among the responses that illustrate not only to what extent ASC is misunderstood and adults with an ASC abused, but the apparently trivial ways in which something that is of no concern to neuro-typical people can affect those with an ASC:

> *Lots of problems with general understanding – I was in a pub with a group of Asperger's men who were having difficulty talking to each other and figuring out who would order their drink first – the barmaid shouted at us all to get out and called us 'timewasters'. She had no idea of our autism even though we were at a Prospects event. (A person with an ASC)*
>
> *Several years ago I saw a young man with some sort of learning or cognitive difficulty in a uncontrollable state of panic because the train as it pulled out of the station had an erroneous tannoy announcement "this train terminates here, please leave the train". For able people these out of synch announcements are just something we get used to, for people with ASCs they can be a matter of concern. The problem ought to be solvable. (A person with an ASC)*

8.6. Is there anything else that you would like to tell the Government about the need for greater awareness of ASC and training in the condition? (This question corresponds to Q18 of the standard consultation)

357 people responded to this question.

8.6.1 General comments on strategy and approach

Many responses to this question repeated the points made in responses to previous questions, covering the need for more resources devoted to ASC; the impacts of

ASC on people's lives; and what a difference greater awareness of ASC and training in it could make. There are also many responses covering remedies for current shortcomings in service provision, including the types of research needed, improvements for the benefits and employment services, the value of music therapy, the need for public campaigns and ways of improving diagnosis and support routes.

Among these responses there are 59 general comments on the strategy; 57 comments on the scope or nature of training that should be provided; 43 comments emphasising the benefits of awareness raising and/or training; and 29 comments on funding and resources for awareness raising and/or training. Additionally there are 35 comments about involving and empowering adults with an ASC and 35 examples of bad experiences.

The responses mentioned here, and the quotations used, are to reflect some of the points that have not been made in response to other questions, starting with one about the wording of the chapter heading:

> *Also please be aware that the term "awareness raising" is likely to cause concern in the autistic community. The term is associated with those who declare that autism is a devastating disease and wish to cure (i.e. eradicate) us. (A person with an ASC)*
>
> *What's with the word 'epidemiological' on the first page? Are you under the impression that you can CATCH autism from me? Seriously, I realise you probably don't have another way of putting it, but you're using the language of smallpox and malaria about a personality configuration that probably helped set up your computer network! (A person with an ASC)*

8.6.2 Public awareness campaigns

Respondents point out in 24 comments that a public awareness campaign on ASC should be undertaken. There are a great many aspects that such a campaign could or should cover, including the avoidance of language or images in the public domain which can upset people with an ASC:

> *I am appalled at some of the shock tactics used by the government in advertising campaigns lately, look at the ad for 'dodgy cigs' depicting a smoker with a rat in his/her mouth. To a person with ASC such a depiction causes shock and horror, my 15 year old son has vomited on seeing that ad we have to avoid it if we can. How is a person with ASC to make sense of this sort of thing-why are you using fear based violent images? The health service is rife with such things no wonder we are afraid of hospitals and doctors and dentists. (Family carer)*

Many responses point out that ASC has been largely hidden until very recently, and it is only now that the true extent of it is beginning to be appreciated. There are both expressions of gratitude that it is finally being recognised and of frustration that it has taken so long. Some see this consultation process as evidence of this, but are still worried that it could slip back into the shadows.

> *I think there are many people out there quietly getting on with their lives, living with an ASC. But as the space in which these people can exist gets squeezed smaller and*

> *smaller over the years, more and more people with ASCs will present themselves requiring help. We live a society that is geared increasingly towards the "hard working family" and aspirational young couple. There is less and less space for those people who do not quite fit in and seem a bit strange. (A person with an ASC)*

While the extent of ASC may be better appreciated, the nature of it is still much misunderstood. When it comes to raising awareness of it, there are a number of points that respondents believe must be made clear; three in particular stand out. The first is to continue to assert that ASC is indeed a spectrum of conditions and that its effects can vary:

> *Autism is a spectrum disorder and impairments/abilities can range drastically amongst individuals. People should be educated not to make assumptions about ASC adults but to interact /support them on an individual basis. (ASC professionals group)*

The very different ways in which ASC affects people is another dimension of it that needs to be constantly emphasised:

> *There are many myths about ASC's, therefore lots of people THINK they are aware of autism. Others are "aware" in the sense that they have heard of it. However, few people really know what ASC's are and understand them. The knowledge and understanding of how it uniquely affects everyone on the Autism Spectrum differently is much more important than awareness alone. I have suggested lots of ways all the way through this consultation which address awareness raising and training. (A person with an ASC)*

The third aspect of public awareness campaigns that needs to be emphasised is that messages about ASC should be positive, highlighting the talents and abilities that people with an ASC can have:

> *Of course a realistic portrait will recognise the challenges the condition poses, but the negative aspects must not be viewed in isolation. People with even the most acute combination of autism and learning disabilities have employable skills and can make a positive contribution to their communities when given the right support. By raising society’s expectations of what people on the spectrum can achieve, we in turn raise the self-belief and confidence of the people with autism themselves. (ASC professionals group)*

This point is further developed by those who argue that adults with an ASC should be directly involved both in delivering services to people with ASC and in developing and providing training on ASC:

> *It is felt by members of this group, that any decision regarding the welfare and wellbeing of people with ASC should be taken into consideration by someone who has the condition/disorder. (A mixed group of people)*
>
> *Autistic-led organisations, alongside other neurodiverse-led organisations, should be central in determining the nature of the training given. (A mixed group of people)*

The extent of ASC is a reason for investing more in responding to it: many responses argue that such public investment will in time lead to savings in time and money for the public services:

> *Effective early intervention will save money eventually. Eg: expensive health care in hospital or residential care in a mental health unit could be avoided if the right kind of support etc had been funded at the beginning. The wrong treatment, or no treatment, makes things very much worse. Also, intensive employment support in the early years could help ASC adults obtain and keep jobs, which could help to reduce subsequent mental health problems and could also cut the costs of providing benefits for the rest of their lives. There is also an enormous loss to the economy from the time spent by parents fighting for care and support for their ASC adult children and dealing with all the problems that arise (and the resulting effects on the parents' health), when those parents could have been working more efficiently in part-time or full-time employment if the right kind of support had been provided form the start. (Family carer)*
>
> *People with ASC are misunderstood and poorly supported far too much. 1% of the population has a diagnosis of ASC. They are a group statistically that we simply cannot ignore. Training professionals of all levels is fundamental to improving the lives of the millions of people who live with ASC, who exist too often in a terrifying and unpredictable world. This training must be mandatory, not additional to basic training standards. With specific ASD training leading to effective support service delivery would ultimately be much more cost effective. (ASC professionals group)*

There are a range of specific issues that respondents would like to see addressed, for example:

> *The government should look at the prison system to see how many people with an ASC are in prison inappropriately, which leads to a need for greater police and judicial system awareness. (A mixed group of people)*
>
> *I would like to emphasise the particular vulnerablity of young adults with an ASC. They are facing major changes in their lives and often just fall off the radar as far as health and social care services. The young people are isolated and unable to participate in normal social expectations and their families are left to cope as best as they can. This is outrageous. (ASC professional)*

Finally, the call to government is simply for help in coping and communicating with a world that does not understand a condition that can be crippling. Respondents do not, however, need or want the sort of help that patronises: many say that they do not need treating as if they have a mental illness, or as if they are deaf and can only be reached by people shouting at them. They want to be recognised as people who, with appropriate help, can function and contribute to society as well as ‘normal’ people.

8.7. Easy-read consultation questions on the awareness raising and training chapter

Many people who work with adults with autism do not understand autism very well. We think there are three things that would help these people understand autism better. These are:

1. give people like employers and the police more information about autism
2. teach people like social workers and people who work in places like colleges, housing offices and Jobcentre Plus about autism
3. make sure that new social workers, doctors and nurses are taught about autism as part of the training they have to do before they can start their new job.

8.8. Do you agree that these are the best ways to help people understand autism better? (This question corresponds to Q5a of the easy-read consultation)

Group	Count	Proportion
Yes	111	79%
No	11	8%
Not sure	16	11%
No answer	3	2%

8.9. Please tell us why. (This question corresponds to Q5b of the easy-read consultation)

141 people responded to this question.

8.9.1 Scope and format of training about ASC

The majority of people (38 comments) who answered this question agreed with educating and training these groups of people to understand ASC better. Some suggested other groups that should be included, such as:

> *Also judges, bus drivers and banks should be aware. (Family carer)*

One group of carers pointed out, making the same case, that it is not just professional people who shape the lives and experiences of people with an ASC:

> *We come into contact as much with the general public and people in positions of authority as we do with those in the above categories. People such as shopkeepers, doormen and security guards can have as much influence on our everyday lives as healthcare professionals. (Family carers group)*

Many of the responses to this question (20 comments) and later ones focus on the nature of the awareness raising and training that should be made available. One point made by many people in response to this first question is that ASC is often best explained by people who have an ASC, or who care for people with an ASC, rather than by those with an academic knowledge of it:

> *Often information given as part of training is out dated and delivered from text books. Only people with autism can tell others about the condition as, especially in the case of Asperger's syndrome, it is still not fully understood and new discoveries are constantly being made about what autism is and how it affects people. If training is to be provided it needs to be based on actual experiences of people with the condition and those who have worked/lived with them, care for them and know them well.). (A person with an ASC)*

This is reinforced by a concern about portrayals of ASC that communicate a negative impression of people who have an ASC, and also that some information on the subject overlooks the difficulties that are most debilitating such as, for example, the sensory difficulties that sometimes make it difficult for people with an ASC to engage with the world.

> *How about asking a person with autism to do the talking to the police and social workers? I would do it, I would go along and say this is me and this is my life and how I see things, what I feel and why I feel it. You want better understanding but you want someone that does not have Autism to do all the explaining. How can someone say what it's like to walk on the moon if they have never done it? You defeat the object of your support plans. (No sector selected)*

Not everyone is convinced, however, that understanding of ASC is enough; it is perhaps just as important that people should learn to recognise when a person has an ASC:

> *I would also suggest that an understanding is not necessarily sufficient. The ability to understand is one thing but the ability to recognise the possibility that a person has autism, is more important. Without the ability to recognise the possibility, people with autism could well be treated unfairly and in a way not in their best interests. (Family carers group)*

For this reason a number of people argue that training about ASC should be made compulsory for everyone employed in the public sector.

Another point made in response to this first question is the importance of realising that autism really is a spectrum and that it affects people differently. In particular there is concern about people thinking either that everyone with an ASC is a savant, or that it is some form of learning difficulty or mental illness.

8.10. Please tell us which people you think most need to have extra training about autism and why. For example, doctors and nurses, social workers, people who work in housing and Jobcentre Plus, people who work in colleges, people who give advice about benefits. (This question corresponds to Q5c of the easy-read consultation)

126 people responded to this question.

8.10.1 Training for all professionals

There is general agreement that all the groups of people mentioned need extra training about autism (52 comments). Some responses emphasise the particular importance of certain groups, including health professionals and those working in the criminal justice system, for example:

> *Doctors, nurses, teachers (who should think about parents with autism not just the children), I have had a big problem with radiographers who think it is ok to pull around your sore bits. Also opticians are a problem at the moment - they want to hoover out my eyeballs. My dentist is good because I can go with my husband and he doesn't expect me to talk. (A person with an ASC)*
>
> *Also social workers so that they can maintain a good standard of support for people with autism. (ASC professionals group)*
>
> *Police, magistrates and judges because more and more people with autism are being found guilty of crimes linked with their autism. Solicitors because people who are being evicted from housing or going through criminal justice system or having their children taken off them, all because of autistic behaviour desperately need to be defended by someone who understands their difficulties (Family carer)*
>
> *All of the above and potential employers. For some employers there could be positive benefits in employing an autistic person with particular skills for a particular job. (No sector selected)*

One group of professionals that come in for particular criticism is psychiatrists, because they are expected to have some expertise in ASC, but are often found to be lacking in understanding.

8.10.2 Importance of continuous training and general understanding

One person makes the point that we need to know more about current levels of knowledge and understanding through some form of assessment or survey:

> *I think that an assessment needs to be carried out to find out what level of knowledge, awareness and understanding the people in these professions really have. It is crucial that all professionals who work with people with autism really understand them so that they can be supported appropriately and in such a way that they are able to be as independent as possible to lead fulfilling lives. (A person with an ASC)*

A number of people make the point that the public as a whole needs a better understanding of ASC because ASC is so common and people come into contact with it all the time.

This point is also made by people with an ASC listing those with whom they may most frequently come into contact and including, for example, taxi, bus, coach and train drivers; ferry boat staff; library assistants; receptionists; shop assistants; one-stop shops; information centres; shopkeepers; and staff in Citizens Advice Bureaux.

8.11. Please tell us the kinds of things you would like people such as doctors and nurses, social workers and people who work in housing to know about autism. (This question corresponds to Q5d of the easy-read consultation)

125 people responded to this question.

8.11.1 What people need to understand about ASC

The responses to this question focus on what the training should cover and offer many examples of how people with autism experience the world. Some responses provide a clear list of what people need to know:

> *That one behaviour could be the sign of another e.g. anger a sign of depression.*
> *That our comments are often aimed at the situation not the person.*
> *That we are female as well :-)*
> *That we can vary in abilities and that includes verbal ability*
> *That we have problems trusting people so the earlier you start with us in age the better.*
> *That we need to be taken seriously*
> *That we need to be told common sense things*
> *That what's bothering us matters to us and shouldn't be dismissed by comments such as "its all about you" or "we all get that".*
> *That if you let us down once you are likely to have some bridges to build*
> *That our intelligence can hide our apparent independence*
> *That we need to word our care plan and be asked why we do certain things. (A person with an ASC)*

Other responses start by emphasising the point that ASC is a spectrum, no two people on the spectrum have the same characteristics and, moreover, that people must understand that certain situations will cause great stress to some people with an ASC. There is also a danger of being fooled by appearances:

> *Even people who present as capable may need help in a specialised area. They do not like meetings and will often say what they think people in authority want to hear to curtail the event, which they perceive as stressful. Distress and anxiety predominate in their lives. (Family carer)*

It is also important for others to appreciate the burdens on those who care for people with an ASC:

> *Owing to damage to the frontal lobe resulting in disorganization, people with Asperger Syndrome need an "executive secretary" who is usually Mum. She is often wrongly labelled by Social Services as "neurotic and overprotective". (Family carer)*

8.11.2 Difficulties with communication

Understanding what helps and hinders communication with people with an ASC is of particular and fundamental importance (43 comments):

> *Don't chit chat. Don't talk in riddles. In fact just stop talking if I get a bit agitated. I really don't want my hand held even if I look terrified. Don't try to take my mind of things by trying to distract me….. Ask the minimum number of questions. I have no idea of time or dates so don't expect me to tell you how long this or that has been. Verbal questions make me stressed. I can't read or talk if I am stressed. Yes or no questions are best. I can look really mentally limited and crazy but I have several degrees and a responsible job. (A person with an ASC)*

There are 14 comments in which people call for an understanding of anxiety issues, stating that these usually account for the shyness and nervousness that people with an ASC exhibit, and explain the need for patience and sensitivity. At the same time, an approach in which they are talked down to is also felt to be counter-productive:

> *Know that they can ask questions about obvious things, and also ask questions which don't seem relevant….Workers must point out the obvious - almost like dealing with a child - but at the same time respect them and try to be really sensitive so that you don't offend them by pointing out things that they already know….. Also patience, because they may ask a question more than once or may go on and on about something which doesn't seem interesting to anyone else. Also, workers and organisations must be aware of the sensitivities to light, sound, smell and so on which autistic people can have. They can be weird and quirky, but to the autistic person they are very important. (Family carer)*

In parallel with this it needs to be understood what problems with communication do *not* mean:

> *I would like them to know that autism comes in varying degrees and that it does not equal inferior intelligence or bad behaviour, being difficult or violent in all cases. I would like them to know that people with ASD may appear sullen, may 'refuse' to speak to them but these are because of anxiety not rudeness. Most of all I would like them to appreciate that new and unfamiliar things cause ASD people great distress and they may react in a way that is unexpected or 'odd'. (Family carer)*

34 comments are about the need for people to fully understand that ASC is a spectrum that includes a great variety of conditions and that the needs of people with an ASC can also be very different from one person to the next (22 comments). Some respondents are particularly anxious to educate others about Asperger's Syndrome, explaining that people with this form of ASC have an uneven cognitive profile which means that they may be very able in some areas and have unexpected gaps in others. People with Asperger's Syndrome often have an average or above average IQ, and this can lead to a mismatch between their levels of intelligence and their abilities. It also leads them to be adept at concealing their ASC because they do not want to appear stupid to others. It means, for example, that they may be able to travel the world independently but be unable to do their own laundry.

8.11.3 Sensory difficulties

Sensory difficulties are another issue raised frequently in responses (16 comments) because they can have a large impact on the things people are able to do. Respondents believe that the difficulties are not fully understood by the medical profession, but emphasise how important it is that people are aware they exist and that they are understanding of the individual needs of people with ASC. It means many adapations and allowances need to be made to suit each individual's sensory needs, which will vary between different settings and different people with an ASC.

These problems most often relate to heightened sensory perceptions, particularly sound and touch:

> *Sensory issues - the impact this has on people with autism, environmental issues, emotional issues - i.e. not liking being touched, making eye contact etc. (A person with an ASC)*

People need to understand that the effect of such perceptions is to increase enormously the anxiety that many people with an ASC experience:

> *They must understand that certain situations will cause great stress to some autistic people. These situations are individual in nature and must be avoided in the best interests of the autistic person. (Family carer)*

8.11.4 Understanding the impact on families and carers

A few respondents stress that it is also important for people to appreciate the impact that ASC can have on families and carers, and the difference that specialist support makes by helping people with an ASC to become more independent and taking undue pressure off family and carers. This is particularly important where the person has ageing parents on whom he or she depends for emotional and often financial support.

Many responses highlight particular situations with which people with an ASC have difficulty or particular traits of character that cause problems in the course of everyday life and which can make living with someone with an ASC extremely difficult. Lack of social awareness is often mentioned, and how people with an ASC perceive and understand truth. Respondents emphasise the importance of routine and consistency, and the obstacles to coping with simple things that other people take for granted, such as doing the washing or meeting a new person.

9. Further comments

9.1. Summary of responses to this chapter

The final question offered an opportunity for respondents to add any points that they felt had not been covered by previous responses or that need particular emphasis.

Many make general comments about the strategy or the consultation document. The issues emphasised once again are the importance of diagnosis and assessment, the need to involve families and carers in planning and decisions, particularly around transitions, and the vital importance of more training and awareness raising both for professionals and the public at large.

The need to improve access to support and services, and concomitant funding and resourcing, is another theme raised, particularly in relation to housing and the issues around supported and independent living. The need to empower people with an ASC in relation to this and other issues is mentioned, and the general importance of personalising plans and meeting individuals' needs.

Among the issues raised here but not elsewhere are diet, driving tests and the importance of regular monitoring of people with an ASC to ensure their health and wellbeing.

9.2. Do you have any additional comments about what should be included in the adult autism strategy? (This question corresponds to Q23 of the standard consultation)

514 people responded to this question.

The responses to this question often reiterate points made by respondents elsewhere in the consultation. Many also use the opportunity to welcome the consultation and emphasise their hopes that it will lead to real change and a better outlook for all people with ASC.

The points included in this final summary are overall and strategic reflections, points that have not been made in response to other questions.

9.2.1 General comments on the strategy and approach

136 people make general comments on the strategy and approach. One of the most fundamental questions raised is whether ASC is properly understood by the people responsible for developing strategy and commissioning services. It is suggested, for

example that the 'triad' approach[1], developed to be used principally by school teachers to enable them to better understand their autistic pupils, was never intended to be used to describe autistic adults, and needs replacing:

> *An alternative to the Triad must be developed. …..The DoH should work with the NAS and, more importantly, with autism-specific user-led organisations to develop an acceptable alternative. I suggest something along these lines. Autism is not a learning disability. It is not a mental health problem. It is neither an illness nor a disease. It is a lifelong neuro-biological condition involving a difference in neurological functioning. This neurological difference results in differences in perception. These perceptual differences include a variety of sensory anomalies. Neurological differences also result in cognitive differences which lead to (what psychologist Francesca Happe has termed) "a different cognitive style". Research indicates that underlying the neurology is a variety of metabolic differences. (A person with an ASC)*

Different approaches are also reflected in different uses of language. In this summary the terms 'ASC' and 'adults with an ASC' have been used as they are in the consultation document, but some respondents would like to see other terminology used, for example:

> *The language used must be Autistic Spectrum Difference (ASD) not "Disorder" or "Condition" (ASC). This reflects how we refer to ourselves, and must be respected. It is also far more accurate as it also encapsulates the positive aspects of autistic differences in the way in which "Disorder" or "Condition" does not. (A group of people with an ASC)*

Along with this a number of people comment on the human rights aspects of ASC:

> *Please bring ASC out of the shadows - into the light - so that everyone can recognise and understand the condition. It should be a recognised Disability, alongside more obvious physical and mental handicaps, so that it becomes a criminal, as well as morally wrong, offence to bully, persecute or discriminate against people with Autistic Spectrum Conditions. Only then will people with ASC be given the freedom and opportunity to live the lives they so richly deserve. (Family carer)*

Two other quite disparate aspects of ASC, both related to human rights issues, are the tendency to under-diagnose ASC in women, thereby denying them access to the services and support they need; and the right to information and communication technology (ICT) for adults with an ASC, especially those with the most severe communication difficulties (which has been explicit in the US since 1993, and consequently there is a more widespread use of augmentative and alternative communication (AAC).

The need to adapt ICT to meet the needs of people with an ASC is also made, with a demand to extend the reach of the Disability Discrimination Act:

> *The DDA must be expanded to prohibit sensory barriers (such as those that can trigger sensory overload in autistics), attitudinal barriers and psychologically distressing barriers. There must be specific legislation to make sure that documents,*

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[1] Definition of Autism, formulated by Wing and Gould (1978); a Triad of Impairments in people with ASD; Impairment of social relationships, Impairment of social communication, and Impairment of imagination.

> *publications and websites are more accessible to people with dyslexia, scotopic sensitivity etc. (A group of people with an ASC)*

The importance of the Internet as a communications medium for people with an ASC is also emphasised by those who would like to see the experience of using email and websites improved to overcome some of the sensory difficulties they currently involve:

> *….it should be compulsory for all documents and publications to be made available in large print, in sans serif text, and with different text/background colour options. Legislation should also be introduced to improve the accessibility of all websites and webmail, including options for people to customise the display to meet their access needs, to minimise visual clutter (such as animated adverts or video advertising) and to make websites more easily useable to people who rely on screen reading technology. (A group of people with an ASC)*

A number of respondents express the concern that the consultation's focus is too much on people at the higher-functioning end of ASC and insufficiently on those at the lower end or with multiple conditions:

> *The "A Better Future" report feels as if it is talking mostly about people at the more able end of the autistic spectrum. This may be because those are the people whose needs have been ignored for so long and who are most in need of new services being set up, but it could also be because it is much easier for those at the high functioning end of the spectrum to make their views known. Those at the most severe end of the spectrum must not have their needs overlooked, or be allowed to suffer poorer services as a result of new services for the more able being provided for the first time. (A mixed group of people)*

Some go further and suggest that there need to be separate strategies for people at different points on the spectrum.

9.2.3 Implementation issues

Many respondents' main concern is with the practical status and implementation of the strategy. Some respondents would like it to have real legal teeth, requiring local authorities and PCTs, for example, to have a service with responsibility for meeting the needs of people with high-functioning autism or Asperger's Syndrome who meet FACS criteria, and FACS assessors who have a good understanding of the autistic spectrum.

> *Authorities must also be required to have low-level "preventative" services for people on the autistic spectrum who are not eligible under FACS. If the strategy does not achieve this, it will be widely perceived to have failed by people on the autistic spectrum and professionals who support them. If it manages to achieve this, it will be very popular, whatever else it says. (No sector selected)*

It appears to some, however, that while this is already the case, the teeth do not appear to be biting due to loopholes in guidance. While the Local Government and Public Involvement in Health Act 2007 required local authorities and PCTs to work together to identify health and social care needs in their area through Joint Strategic Needs Assessments (JSNAs)…..

> *The current guidance on JSNAs does not direct authorities to include data on adults with autism as part of this process, and thereby risks further exclusion of the needs of this population in service planning and commissioning. Research by the NAO supports this and found that currently only 21% of JSNAs included a specific reference of autism. (ASC professionals group)*

The implementation of the strategy is another issue considered by respondents, with many emphasising the importance of clear and determined leadership at national, regional and local levels:

> *It is important that there is both appropriately senior leadership and sufficient capacity within the Department of Health (DH) to ensure that the adult autism strategy is delivered. Senior leadership is absolutely necessary for the strategy to receive the attention and priority it needs. Autism provision is already 'playing catch-up' with provision for other groups, which is the reason why the strategy is being introduced. If responsibility for delivering the strategy is not placed at a senior level there is a real danger that the strategy will fail to close that gap. (ASC professionals group)*

A few more detailed suggestions for effective implementation are made. They propose that all local authorities and PCT partnerships should appoint a named individual, sufficiently senior, as responsible for implementing the strategy; that the strategy should set out clearly who is responsible and accountable for its implementation at all levels of government; that the strategy should put a specific statutory requirement on local authority and PCT partnerships to include the needs of adults with autism in their JSNAs; that the Government must produce world class guidance to improve strategic commissioning for adults with an ASC; and that the strategy should set out how the effectiveness of the strategy is to be monitored and assessed.

Other suggestions include the establishment of Autism Specific Partnership Boards that would operate within the overall framework provided by Local Strategic Partnerships (LSPs); this would, it is argued, ensure a common direction and help to address wider issues, such as access to other local services, including transport. These boards should include senior representatives from all local services, representatives of people with ASC and carers, and people to reflect the cultural diversity of local communities, and would be responsible for delivering the government's objectives, overseeing the inter-agency planning and commissioning of genuine service options for people with ASC in their local communities, and ensuring a smooth transition to adult life for young people with ASC.

Implementation also needs to take into account the effect that delivery in the devolved administrations and across boundaries may have:

> *The consultation stresses that this consultation applies to England and that the devolved administrations have their own strategies. In my view, this is likely to detract from the solution. This is because it is possible and indeed in the case of people located around the borders of jurisdictions that more than one jurisdiction may need to be involved e.g. a person may live in Wales but the closest town where suitable work is available may be in England. That means that there needs to be a strategy to deal*

> *with cross-border issues. It should also be borne in mind that benefits are the subject of national legislation and this should also be reviewed as part of this consultation. (No sector selected)*

9.2.4 Funding and resourcing

Funding is another aspect of implementation that respondents are concerned about. Some are sceptical about the likelihood of the necessary funding being made available at a time of economic constraint; others argue that an investment in better autism services will ultimately save money because there are numerous and significant cost savings to be made from providing a better service to adults with an ASC.

The costs are acknowledged: establishing new teams and new systems to identify, diagnose and assess more adults and provide additional services and support to those adults will all necessitate a significant spending increase:

> *New funding, sufficient to carry out the actions set out in the strategy, including establishing Specialist Autism Teams in every local area, must be provided to local authorities and PCTs. Without this additional spending, local authorities and PCTs, many of whom are already financially-stretched, will struggle to implement the strategy and it will remain a well-intentioned but ultimately undeliverable policy document. (ASC professionals group)*

The need for more research and also for wider awareness of research that has already been done, publications about ASC, and examples of good practice already under way in various communities, will also require resourcing. There are some particular areas singled out for more research funding, such as research into ASC and deafness:

> *The limited research suggests there is a higher incidence of ASC in children who are deaf. Jure et al in 1991 found through research with a group of children with hearing loss that 5.3% met criteria for autism. As both deafness and ASD affect communication there can be profound impacts for this group of people trying to grow up in the world. There is potential for late or missed diagnosis of ASC in deaf people compounding a person's needs and distress. (Jure1991 identified that in deaf children autism is often diagnosed late.) (ASC professionals group)*

There are similar points about ASC and ADHD, ASC and Alzheimer's, and ASC and Down's syndrome:

> *Now, several scientific papers (Lowenthal et al 2007 (1), Howlin et al 1995 (2)) have identified that about 1 in 20 children with Down's syndrome might have ASD – a 25 times higher chance than in the general population. However, it does seem to manifest itself differently in this group of people and research is desperately needed to find out how the Down's syndrome impacts on autism. Families experience real isolation as they do not fit into the Down's syndrome camp or the autism one. This is further compounded in the difficulties they experience in getting a diagnosis often through diagnostic overshadowing or because the current diagnostic tools may not be appropriate for this group of people. (ASC professionals group)*

There is also concern about the direction of some research, with opposition to research that is seeking to find a 'cure' for ASC in parallel with support for research to cure the co-morbidities of ASC and into ways to help people with an ASC to make progress and improve their skills and abilities. There is also suspicion that some organisations with research arms have eugenicist agendas.

9.2.5 Comments on the consultation process

Finally, there are 65 comments about the consultation process ranging from the positive to the negative, for example:

> *I have read the DH Consultation Document 'A Better Future' re. adults with an ASC and I have to say that the document is a refreshing reassurance that the DH are very much on the right lines in our first hand experience. (Family carer)*
>
> *The process has been too prescriptive and repetitive. It has been inhibitive in terms of innovative thinking and has stifled creativity in terms of response. (ASC professionals group)*

9.3. Please tell us anything else you think we need to do to make life better for adults with autism. (This question corresponds to Q6 of the easy-read consultation)

104 people responded to this question.

9.3.1 General comments on the strategy and approach

Many responses to this final question repeat points made in earlier responses. The point most repeated is the need for more public and professional understanding of autism; one respondent summarises for all by saying that what would make life better for adults with an ASC is 'consideration and respect'.

Other responses emphasise their most important points, for example about the importance of education and training, support for parents and carers, better access to suitable housing and adequate benefits, and the chance to find fulfilling employment.

The importance of transitions is again made clear, with many people telling stories of how difficult it is to move from being a child with autism to being an adult with autism. This rests on better diagnosis and the use of multidisciplinary teams to ensure people with autism receive the support they need at the time they need it.

9.3.2 Comments on the consultation process

There are great hopes that this consultation process, which covers all of these areas, may lead to action and improvement to the lives of people with an ASC.

> *Continuing improvement. Better understanding. This survey MUST be listened to and acted upon. This questionnaire should be an ongoing process and this is a start. Please keep going and carry forward the momentum. (A person with an ASC)*

The importance of this is emphasised by those concerned about the apparent increase in the number of people with an ASC:

> *This is not just better diagnosis: there is something serious going on which we have yet to discover. The sooner governments recognise that ignoring the problems will result in fragmented families, heaving prison populations and mentally exhausted carers, the sooner we can repair the damage already done, and attempt to establish a society which truly does care for its disadvantaged. (Family carer)*

Some people are critical of the consultation process and emphasise the importance of listening to the families and carers of those with autism:

> *I believe this consultation paper was made by someone with very little understanding of people on the autistic spectrum disorder in the first place but I do hope that the consultation paper and process will go a long way to helping these very vulnerable and excluded people of our society and not that they are left alone, unloved, to fend for themselves and live in a closed and vegetated state and environment!! (Family carer)*

Others are more positive about the consultation process and supportive of the proposals it contains, but are concerned that previous similar exercises have not resulted in improvements to the lives of people with an ASC. Some respondents conclude their participation with the hope that this time things will be different.

Appendix 1 – Respondents

A full list of those responding on behalf of an organisation is shown below.

'A' Team
A.S.A.P.(Asperger's Syndrome Access to Provision)
AALPS College (Options Group)
Adults Health & Community Wellbeing, Essex County Council
All-Party Parliamentary Group on Autism
AS South West User Rep Group
ASD subgroup for Windsor and Maidenhead
Ash Green Specialist Learning Disability Service
Association for Family Therapy
Association of British Dispensing Opticians, Association of Optometrists, Federation of Ophthalmic & Dispensing Opticians
Association of Directors of Adult Social Services (ADASS)
Association of Professional Music Therapist
Autism Centre for Education and Research
Autism Concern
Autism Diagnostic Research Centre, Southampton
Autism London
Autism Plus
Autism Plus
Autism Service Development Group, Durham County Council
Autism Social Care
autism social care
Autism Steering Group
Autism Sub-group, Hampshire Partnership Foundation Trust
Autism Working Group
autism.west midlands and Birmingham Health and Wellbeing Partnership
Autism-in-Mind
Autistic Rights Movement UK
AutisticAsp Village
AutreachIT
Barking and Dagenham professionals
Barking and Dagenham Professionals
Bath and North East Somerset Council and PCT
Berkshire Autistic Society
Bexley Learning Disability Partnership Group
Birmingham Safeguarding Adults Board
British Association for Counselling and Psychotherapy (BACP)
British Association of Art Therapists - Special Interest Group-
British Association of Dramatherapists
British Association of Social Workers (BASW)
British Institute of Learning Disabilities
Bromley Autistic Trust
Bromley CLDT
Buckinghamshire County Council - Adults and Family Wellbeing

Central & North West London NHS Foundation Trust
Centre for Career Development, The University of Nottingham and Malcolm Johnson, Asperger Management
Centre for Studies on Inclusive Education (CSIE)
Challenging Behaviour Foundation
Cheshire West and Chester Council
College of Occupational Therapists
Community Adult Autism Team
Community Integrated Care, Vocational Support Service
Community Learning Disability Team
Community Learning Disability Team
Coventry City Council Leads for ASC
Coventry and Warwickshire Partnership Trust
Coventry Asperger Group
Coventry Asperger group for adults
Craegmoor Healthcare
Crossroads Care
Cumbria LINk
DANDA
DASH Discovering Autistic Spectrum Happiness
Dimensions
Disability Benefits Consortium
Disability Challengers
Dorset ASC & Asperger's Strategy Development Group
Dorset Healthcare NHS Foundation Trust – LD and MH
DRIVE (Direct Routes into Volunteering and Employment) Vulnerable Adults Service
Ealing Community Team for People with Learning Disabilities
Enfield Consultation workshops - adults on the autism spectrum
Enfield Consultation workshops - parents/carers of people on the Autism spectrum
Enfield Local Authority-Enfield Community Services
Equality and Human Rights Commission
ESPA
Fairmont Residential Ltd
Financial Services Authority
Foundation for People with Learning Disabilities
fpa (Family Planning Association)
Gateshead Learning Disability Partnership Board
Gloucestershire ASD Partnership Board
Governors and staff of Grange Park School, (Special Community Secondary)
Group within London Borough of Newham Partnership for People with Learning Disabilities
Hampshire Autistic Society
Hampshire Connexions Special Needs Advisers Leads Group
Hampshire County ASC Group
Hampshire Learning Disability Partnership Board
Haringey Council - Adult, Culture and Community Services

Harrow Aspergers Project Board
Harry's Aspergers Social Group Oxted
Hertfordshire Partnership NHS Foundation Trust
Hoffmann Foundation for Autism
Home Instead Senior Care
HOPE
HOPE
Joint Lewisham Council/Lewisham Primary Care Trust commissioner for emerging client groups
Jubilee Day Service
Kent County Council, Kent Learning Disability Partnership Board and Kent & Medway Mental Health Commissioners
Kingwood Trust
Lancashire County Council
Learning and Skills Council
Learning Disability Partnership, South Cambs & City
Leicester, Leicestershire and Rutland Strategic Aspergers Syndrome Planning Group
Liaise Loddon Limited
Lifeworks Staffordshire
Lincolnshire County Council / Lincolnshire Autism Spectrum Disorder Development Group
London Autistic Rights Movement
London Borough of Barnet & NHS Barnet
Maidstone Carers Project
Manchester Joint Commissioning Team for Learning Disability Services
Mencap
Mendip Housing Ltd
NAS CHESHIRE BRANCH
NAS South Kent
NAS Swindon & District Branch
National Autistic Society SE Region Partners in Autism
National Autistic Society (NAS)
National Autistic Society (NAS) - Croydon Branch
National Autistic Society (NAS) - South Kent Branch
National Housing Federation
National Institute of Adult Continuing Education (NIACE)
Nestor Healthcare Plc
Neurodiversity International
NGS Stockton/Stockton Borough Council
NHS Bournemouth & Poole
North East Autism Consortium (NEAC)
Northumberland Tyne and Wear NHS Trust
Norwood
Nottingham City Adult Support and Health Department
Nottinghamshire Adults with Asperger's Team
NW ASDG NETWORK MEETING
Oldham Learning Disability Service

One Child and Adolescent Mental Health Service (CAMHS) Group. One Community Learning Disability Team (CTLD) Group. I work across both teams.
Optimum Potential
Outlook Care
Oxford Diocese of the Church of England
Oxford Diocese, Church of England
Pirates are cooler than ninjas.....raising awareness of Asperger Syndrome
Pluss Organisation
Psychology Department, Hounslow CTPLD
Queensmill Special School for children with autism
Redcar and Cleveland Learning Disabilities Partnership Board
Remploy Ltd
Resources for Autism
RNID
RNID
Rotherham Learning Disability Partnership Board
Royal College of General Practitioners
Royal College of Nursing
Royal College of Speech and Language Therapists
Sacar
Sandwell MBC
SCAT - The Somerset Court Autistic Trust
SE Regional Partners in Autism
Shape
Sheffield Asperger Syndrome Service
Sheffield Asperger Syndrome Service
Shelter Somerset
Skills for Care
Slough Borough Council
Solihull NHS Care Trust
Somerset Autism Events
Somerset Partnership NHS Foundation Trust
South Staffordshire PCT
Southdown Housing Association
Spectrumites
St Andrew's Healthcare
St. Luke's Hospital Group
Staffordshire Joint Commissioning Unit on behalf of Staffordshire County Council, NHS North Staffordshire and South Staffordshire Primary Care Trust
Steadway Care Limited
Suffolk Joint Strategic Group for People with Learning Disabilities
Sunderland City Council
Surrey and Border's Partnership NHS Foundation Trust
Surrey Branch of the National Autistic Society
Surrey's County Autism Group
Talkback UK
The Autism & Employment workshop

The British Psychological Society
The College of Occupational Therapists (COT)
The Down’s Syndrome Association
The Princess Royal Trust for Carers
The Retreat, York
Tizard Centre, University of Kent
Treating Autism
TreeHouse - the national charity for autism education
Various groups + Bexley LD partnership group
Wakefield Local Authority and Learning Disability Partnership Board
Walsingham
West Sussex Community Personal Dental Services
Whanganui Disability Resources Centre
Wirral Autistic Society
Wokingham Community Care Services
Wokingham District Mencap
Wokingham Learning Disability Partnership Board
Worcestershire Autism Special Interest Group (ASD SIG)
Worcestershire County Council

Appendix 2 – Group tables

1. Consultation overview and chapters

Standard consultation

The themes that have been identified as areas where action needs to be taken to improve the lives of adults with an ASC are:

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

3.1. Are there other themes that need to be included? Please tell us what they are. *(this question corresponds to Q1a of the standard consultation)*

Group	Count
Housing / independent or supported living	117
Education / skills / employment services	107
No other themes	86
Support and involvement of family / carers	65
Transition issues	55
Awareness raising / education / information	51
Wider professional awareness / training	50
Access to support / health services	45
Emotional, spiritual and social support and guidance	42
Criminal justice / legal system	36
Difficulty with diagnosis / assessment	36
Financial support / economic security / benefits	36
Leisure and day services / social inclusion	29
Communication support / advocacy	26
Person-centred approach / personalisation	24
Consider specific types or levels of ASC	23
Discrimination - gender, ethnicity, disability	22
Relationship / parenting advice and support	22
Age / old age / aging carers	17
Transport / travel	17
Sensory issues	13
Coordination / continuity service provision	12
Need for specific facilities / considerations	11
Dealing with / recognise multiple conditions	11
No comment / not applicable	10

General comment on strategy / approach	9
Local / regional support	7
Overlap between themes / need for partnership working	6
Data collection / research	6
The gap - learning disability / mental health	6
Visible action / implementation	5
Advocacy and rights	4
Involve / empower people with ASC	4
Dietary issues	4
Yes - no further explanation	4
Prevention	3
Funding / resource issues	3
Reference to/need for other research / consultation	1
Commissioning	1
Quality of life	1
Drug use	1

3.2. If yes, are your suggested themes more or less important than the five key themes in improving the lives of adults with ASC? *(this question corresponds to Q1b of the standard consultation)*

Group	Count
Equally important	182
Equally important - with supporting comment	97
Comment / explanation of specific themes	83
More important - with supporting comment	46
Overlap / relate to existing themes	34
No comment / not applicable	33
More important	26
Emphasise importance	19
Other comment	13
Less important - with supporting comment	7
General comment on themes	6
Equal or greater importance	5
Less important	6
General comment on strategy / approach	2

3.3. If you are involved in service delivery or commissioning, can you tell us about the costs, benefits and risks of the services you are involved in and what outcomes they have achieved for adults with ASC. Please provide details below. *(this question corresponds to Q2 of the standard consultation)*

Group	Count
Examples of service delivery / commissioners	107
No comment / not applicable	107
Costs - funding and resources	58
Benefits - social, employment and other life skills	36
Risks	30
Benefits - personalisation of services	25
Benefits - improved skills, awareness in staff and wider professions	21
Examples of bad experience - service user	19
Examples of positive experience - service user	17
Difficulty with diagnosis / assessment	15
Need professional training / awareness	10
Transition issues	10
Comments on the consultation	8
Post-diagnostic issues	7
Current support inadequate / non-existent	7
Benefits - enable access to services	6
Person-centred approach / personalisation	6
Benefits - carer support	6
Data collection / research	6
Need for earlier intervention	6
Inappropriate services	5
Costs - high due to complexity	5
Benefits - networks	5
Costs - lack of support, increased isolation	5
Ideas for service improvement	4
Coordination / continuity of service provision	4
Need for advocacy	4
Benefits - feed into planning/partnerships	3
Local leadership and accountability	3
Costs - poor long term support	2
The gap - learning disability / mental health	2
Costs - stigma and labels	1
Dealing with / recognise multiple conditions	1
Difficulty accessing education services	1
Access to transport	1
Housing / independent or supported living	1

3.4. In your experience does ethnicity, gender, disability, age, sexual orientation and religion or belief have an impact on how adults with an ASC access and experience services and the quality of outcomes? Please highlight any measures we can take to reduce adverse impact and promote positive impact. *(this question corresponds to Q3 of the standard consultation)*

Group	Count
Yes - age	105
Yes - gender	90
Yes - ethnicity / culture	82
No / no experience	81
Yes - disability	78
Measures - more/ better professional training	57
Exclusion / discrimination because of ASC	54
Measures - education / awareness raising	44
Other - perception of disability level	37
Yes - all	32
No - with supporting comment	32
Current support inadequate / non-existent	26
Example of bad experience	25
Difficulty with diagnosis / assessment	20
Measures - improve access to support / services	20
Yes - religion or belief	20
Other - socioeconomic	15
Yes - sexual orientation	15
Transition issues	14
General comment on attitudes in society	14
Other - language	13
Measures - sensitivity to different beliefs	13
Data collection / research	12
Measures - better diagnostic services	12
Measures - carer / family support	12
Other - multiple disabilities	11
Example of positive experience	11
Measures - appropriate communications	11
The gap - learning disability / mental health	10
Other - region / geography	10
Measures - consider differing degrees of disability	9
Measures - services / awareness of females with ASC	8
Measures - specially trained translators	8
Measures - earlier intervention and support	8
Understand - individual needs	7

Measures - listen to carers/ family	7
Measures - help with socialisation and relationships	7
Measures - more / better engagement	7
Measures - more outreach to different sectors of society	6
Measures - improve access to employment	6
Measures - more resources	6
Measures - improve access to education	5
General comment on strategy / approach	5
Unsure	5
Comments on the consultation	4
Measures - equal services everywhere	4
Other - quality of actual service	3
Reference to NAS	3
Reference to publication/further information	3
Measures - supportive faith environments	2
Positive discrimination	2
Measures - recruit staff from different ethnic groups	2
Measures - take into account sensory issues	2
Other - self-belief	2
Measures - Community not hospital based	1
Measures - monitoring / evaluation	1
Other - size	1
Privacy	1
Time / help to make and understand decisions	1
Need to include ASC in degrees / curricula	1

Easy read consultation

There are 5 areas where we think we need to make changes to make life better for adults with autism. These are:
social inclusion

- ***Helping adults with autism where they live. This may mean help with things like finding somewhere to live, help with travelling where they need to go and help to do things in their free time.***
- ***Making healthcare better for adults with autism.***
- ***Adults with autism choosing the services and support they need.***
- ***Helping people like doctors, social workers, teachers, the police and housing officers to understand more about autism.***
- ***Helping adults with autism get jobs and training.***

3.5. Are there any other areas that you think we need to include?
(this question corresponds to Q0a of the easy read consultation)

Group	Count	Proportion
Yes	138	58%
No	94	39%
No answer	6	3%

3.6. If you answered yes, please tell us what the other areas are.

(this question corresponds to Q0b of the easy read consultation)

Group	Count
No comment / not applicable	97
Public awareness raising	22
Help with life skills / challenges	16
Wider professional awareness / training	16
Access to care / support	14
Diagnosis / assessment	14
Access to employment / support at workplace	14
Education services	12
Financial support / access to benefits	11
Support for parents / family carers of ASC adults	9
Social groups / networks	9
Local / regional ASC teams	7
Consider specific types of ASC	6
Leisure and day services / social activities	6
Exclusion / discrimination issues	5
Criminal justice / legal system	5
Relationship / parenting advice and support	5
Current support inadequate / non-existent	5
Example of bad experience	5
Mental health	4
Transition issues	4
Information / service directory	4
Stop generalised approach / treat as individuals	4
Impact on family	4
Housing / independent or supported living	4
Data collection / research	3
Self awareness ASC adults	3
Advocacy support	3
Sensory issues	2
The gap - learning disability / mental health	2
Reference to specific service / agency	2
Person-centred approach	1
Anxiety / mental health issues	1

Helpline / gateway	1
Comment on disclosure of diagnosis / privacy	1

3.7. If you answered yes, do you think the other areas you have included are more or less important than the five main areas? (this question corresponds to Q0c i of the easy read consultation)

Group	Count	Proportion
More important	40	29%
Less important	1	1%
About the same	94	67%
No answer	5	4%

3.8. Why do you think this? (this question corresponds to Q0c ii of the easy read consultation)

Group	Count
No comment / not applicable	26
Social inclusion / acceptance	13
Equally important	11
Current support inadequate / non-existent	10
Issues with public ignorance of ASC	10
Wider professional awareness / training	10
Diagnosis is vital	9
Consider specific types / different levels of ASC	8
Impact of discrimination / exclusion	6
Support for parents / family carers of ASC adults	5
Benefits of support in communication skills	5
Importance of help with life skills	5
Funding / resource issues	5
Other comment	4
Benefits of education	4
Local leadership / accountability	4
Impact on family	4
Benefits of employment / support at work	4
Would improve quality of life	3
Financial support / access to benefits	3
Recognition of complexity of needs	3
Improve access to housing	2
Need a holistic approach	2
Example of bad experience	2
Issues with late / adult age diagnosis	2
Criminal justice / legal system	2

More important	2
Equal access to services everywhere	1
Need for adjustments at work/home	1
Bureaucracy issues	1
Peer support is helpful	1
Comment on consultation / document	1
Involve / empower person with ASC	1
Areas are not compulsory	1
Areas are too vague / no specific outcomes	1

3.9. Are you involved in giving or buying services for adults with autism? (this question corresponds to Q0d of the easy read consultation)

Group	Count	Proportion
Yes	59	27%
No	161	73%
No answer	1	0%

3.10. If you answered yes, please tell us what these services are and how they have helped adults with autism. (this question corresponds to Q0e of the easy read consultation)

Group	Count
No comment / not applicable	159
Social care and support	20
Education services / teachers / mentors	10
Parent / family carers	10
Reference to specific service / agency	8
Social / leisure / day activity services	7
Housing services	7
Therapy / counselling	5
Personalised budget / direct payments	5
Example of bad experience	5
Other / unspecified help	4
Awareness raising	4
Fund raiser	2
Respite care	2
Helped with social inclusion / tackling isolation	2
Helped with building self confidence	2
Helped with reducing anxiety	2
Mentoring schemes	2
Private medical care	1
Example of positive experience	1

Youth service	1

3.11. Do you think that some adults with autism get better services because of who they are? For example, because they are a man or a woman, because of how old they are, because of their religion or their race because they are gay or lesbian or because they have other disabilities as well as autism. *(this question corresponds to Q0f of the easy read consultation)*

Group	Count	Proportion
Yes	104	52%
No	91	46%
No answer	5	2%

3.12. If you answered yes, how do think we could make services better for all adults with autism and not just for some adults with autism? *(this question corresponds to Q0g of the easy read consultation)*

Group	Count
No comment / not applicable	92
Improve overall access to services	25
Consider specific types of ASC	20
Local access to support / equal access everywhere	18
Treat all equally	17
Wider professional awareness and training	16
Stop generalised approach / treat as individuals	9
Need for earlier and improved diagnosis	9
Funding / resources	8
Example of bad experience	8
Information / service directory	7
Improve access / services for higher-functioning people	6
Support in advocacy / self advocacy	6
Holistic approach for multiple conditions	5
Public awareness raising / campaign / education	5
Need for Adult ASC services	5
Better services for females	5
Change criteria	4
Involve adult with ASC and their family	3
Combined / specific Autism service	3
ASC team / multidisciplinary approach	2
Comment on consultation / document	2
Automatic referral	2
Buddy system	1
Discrimination inevitable	1
ASC appropriate communication	1

Establish minimum standard of care	1
Consider cultural background	1
Helpline / gateway	1
Improve transition	1
Reduce stigmatisation	1
Consider changes good/bad periods in ASC adult	1
Support for parents / family carers of ASC adults	1

2. Social inclusion chapter

Standard consultation

The external reference group identified the following as key areas where action is needed to improve social inclusion:

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

4.1. Do you agree that these are key areas where action is needed to improve social inclusion for people with an ASC? *(this question corresponds to Q4a of the standard consultation)*

Group	Count	Proportion
Yes	599	86%
No	15	2%
Unsure	41	6%
No answer	38	5%

4.2. Please explain your answer. *(this question corresponds to Q4b of the standard consultation)*

Group	Count
No comment / not applicable	162
Data collection / planning / research	134
The gap - learning disability / mental health	128
Access to community care / support / services	123
Need to consider specific needs / types of ASC	96
Access to housing / independent or supported living	95

Local leadership and accountability	89
Current support inadequate / non-existent	86
General support for key areas	80
Need professional training / awareness	54
Develop social inclusion / communication support	53
Example of bad experience	50
Access to transport	49
Local ASC teams / multidisciplinary approach	45
Poor professional recognition / understanding	41
Diagnosis / assessment issues	41
Transition issues	40
Coordination / continuity of service provision	39
Funding / resource issues	39
Criteria / labels / policy of provision	36
Example of good practice / positive experience	35
Lack of / need public understanding	34
Access to public spaces	27
General support for key areas with caveat	21
Access to advocacy services	17
Involve / empower families / carers	16
Dependence on family care / support	15
Difficulty accessing / keeping employment	15
Involve / empower people with ASC	13
Exclusion / discrimination because of ASC	13
Sensory issues	12
Cannot / don’t want to fit in / join a group	12
Develop / improve post-diagnostic services	12
Refers to other response/s	12
Difficulty communicating	11
Difficulty accessing education services	11
Comment on consultation / document	11
Take a local approach	9
Take a national approach	9
Impact on family	8
Concerns on death of parents / carers	6
Difficulty accessing benefits	5
Other comment	4
Criminal justice / legal system	3
Reference to/need for other research / consultation	2

4.3. Please provide details of your experiences of the challenges faced by adults with an ASC in the area of social inclusion (e.g. problems in accessing necessary support). (this question corresponds to Q5 of the standard consultation)

Group	Count
Current support inadequate / nonexistent	167
Difficulty with social skills / socialising / isolation	159
Poor professional recognition / understanding	116
Example of bad experience	93
Access to housing / independent or supported living	89
Lack of public / general understanding	83
Criteria / labels / policy of provision	77
Lack of social inclusion / leisure activities	77
Diagnosis / assessment issues	68
Access to community care / support / services	67
Funding / resource issues	53
Difficulty accessing / keeping employment	52
Not enough trained professionals	51
Transition issues	49
Example of good practice / positive experience	48
Access to transport	45
Stop generalised approach / treat as individuals	44
Need help with social skills / self awareness	43
Coordination / continuity of service provision	43
The gap - learning disability / mental health	42
Information / service directory - lack of / need for	41
Dependence on family care / support	39
Exclusion / discrimination because of ASC	39
Difficulty accessing education services	33
Difficulty with life skills	27
Reference to other support group	26
Sensory issues	26
Refers to other response/s	24
Need for advocacy	20
Impact on family	19
Reference to NAS	18
Local leadership and accountability	18
Lack of support for carer / family	17
Data collection / planning / research	16
Difficulty accessing benefits	15
Need for earlier intervention	14
Involve / empower family / carers	11
Concerns on death of parents / carers	11
Criminal justice / legal system	11
Removal or reduction of support	10

Develop / improve post-diagnostic services	9
Other comment	8
Local ASC teams / multidisciplinary approach	8
Involve / empower people with ASC	8
Adjust workplace / setting / forms	8
None / no experience	8
Reference to publication / further information	7
Cannot / don't want to fit in / join a group	6
Impact of family action or attitudes	5
Reference to Connexions	4
Difficulty accessing health services	4
Reference to Prospects	3
Comment on consultation / document	1

4.4. What actions do you think should be taken to address the concerns raised in the social inclusion chapter (e.g. development of a specific local or regional ASC team, training of community care assessors, changing the application of eligibility criteria)? *(this question corresponds to Q6 of the standard consultation)*

Group	Count
Local ASC teams / multidisciplinary approach	226
Change eligibility criteria/ policy of provision	114
Train - all professionals / staff	93
Improve access to community care / support and services	79
Funding / resource issues	64
Awareness raising/education	61
Improve diagnosis / assessment	60
Involve / empower people with ASC	60
Develop social inclusion activities / leisure	60
Coordination / continuity of service provision	56
Train - community care assessors	55
Local leadership and accountability	50
Involve / support families / carers	49
Improve access to housing / independent or supported living	47
Agree with actions suggested	40
Stop generalised approach / treat as individuals	38
Current support inadequate / non-existent	38
Need help with social skills / self-awareness	36
Data collection / research	36
Transition issues	34
Information / service directory / signpost	31
One to one support	31
The gap - learning disability / mental health	30

Train - health professionals	28
Train - social care workers	26
Improve access to employment	25
Person-centred planning - use / improve	24
Train - all / everyone in contact with ASC	24
Example of bad experience	23
Improve access to transport	22
Reference to good practice example in consultation document	22
ASC support groups / peer groups / network	21
National government responsibility	20
Need help with life skills / independent living / routine	18
ASC specialists / champions	18
Example of positive experience / good practice examples	18
Need for advocacy	18
Support from charity / church / voluntary sector	17
Accountability of service providers	17
Need for earlier intervention / preventative	15
Reference to other specific service / agency	14
Poor professional recognition / understanding	14
Learn from others / previous experience	12
Train - employers / educators	12
Refers to other response/s	10
No comment / not applicable	10
Improve access to education	9
Difficulty communicating / need support	8
Reference to publication / further information	8
Personal budgets / direct payments – use / improve	8
Improve access to public spaces	8
Cannot / don’t want to fit in / join a group	8
Change / introduce legislation	8
Need to get on with it / do something	8
Vulnerability / safeguarding	7
Other comment	7
Monitoring / evaluation / quality control	7
Reference to NAS	6
Concerns on death of parents / carers	4
Helpline / gateway	4
Dealing with / recognise multiple conditions	3
Online tools / communities	3
Reference to other research / consultation	3
Train - police / justice / legal services staff	3
Train - families / carers	3

Train - advocates / support workers	2
Need help with benefits / financial support	2
Train - public services	2
Reference to Connexions	1
Comment on consultation / document	1
Consider checking ASC in family	1

4.5. If possible, please give examples of where these concerns have been successfully addressed at a local level. (this question corresponds to Q7 of the standard consultation)

Group	Count
None / they have not been addressed	116
Example of positive experience / good practice	85
Provision of training / awareness raising	50
Social groups / support groups / peer network	43
Local ASC teams / multi disciplinary approach	39
Reference to other specific service / agency	37
Leisure and day services / social inclusion	27
Improve diagnosis / assessment	23
Current support inadequate / nonexistent	22
Cooperation/continuity of service/support person	22
Access to housing / independent or supported living	21
No comment / not applicable	20
Support from charity / church / voluntary sector	17
Support finding / keeping employment	17
Involve / support family / carers	16
Support at school / university	15
ASC specialists / champions	14
Help with - social skills	13
Data collection / research / learn from best practice	13
Reference to NAS / prospects	13
Support with transition	13
Support from local authority	12
Example of bad experience	12
Information / service directory / signpost	11
Personalisation / direct payments	11
Successful initiatives overstretched, unable to help everyone	10
Access to transport	10
Access to funding / resources	10
Help with - communicating	9
Refers to other response/s	9
Advocacy / brokerage services	7

Involve / empower people with ASC	6
One to one support	6
Access to community care / support	6
Influencing commissioning	6
Poor professional recognition / understanding	5
Support from national government	5
Other comment	5
Reference to good practice in document	4
Helpline / gateway	4
Support from NHS	3
Counselling / therapy	3
Dealing with / recognising multiple conditions	3
Reference to Connexions	3
Reference to publication / further information	3
Concerns on death of parents / carers	2
The gap - learning disability / mental health	2
Help with - life skills	2
Help with - benefits/financial support	2
Early intervention	2
Vulnerability / safeguarding	2
Change / introduce legislation	2
Autism alert card	1
Access to public places	1
Online tools / communities	1

Easy read consultation

People have told us that we need to do 4 things so that there is better help for adults with autism where they live. These are:

1. Make sure that the people who provide help for adults with autism understand what help adults with autism need.
2. Make sure that the people who provide help for adults with autism give the help that adults with autism need.
3. Make sure that adults with autism can get the help they need where they live both in their home and with their day-to-day activities.
4. Make it easier for adults with autism to get help with finding a house or flat and looking after it, get help with travelling where they need to go, and get help so they can do the things they like to do in their free time.

4.6. Do you agree that these are the main things that we need to do so that there is better help for adults with autism where they live? *(this question corresponds to Q1a of the easy read consultation)*

Group	Count	Proportion
Yes	139	79%
No	15	9%
Not sure	20	11%
No answer	2	1%

4.7. Please tell us why. *(this question corresponds to Q1b of the easy read consultation)*

Group	Count
No comment / not applicable	54
Key areas - all important	28
Access to housing / independent living	25
Wider professional awareness & training	19
Help with making friends/social skills	18
Consider specific individual needs	16
Help with life skills / independent living	13
Access to community care / support	10
Information / service directory	8
Current support inadequate / non-existent	8
Public awareness / understanding	7
Access to employment	7
Example of bad experience	7
Consistency in services / support person	6
Equality	6
Anxiety	6
Vulnerability / safeguarding	5
Contribution to society / self esteem	5
Example of positive experience / Good practice example	5
Financial support / access to benefits	4
Involve adult with ASC and their family	4
Dealing with / recognise multiple conditions	4
Dependence on family support	3
Difficulty communicating	3
Lifelong support	3
One to one support / buddy / keyworker	3
Access to education / training	3
Key areas - more areas needed, not specified	3
Concerns on death of parents / carers	3
Access to transport	3
Refers to other response/s	2
Exclusion / discrimination issues	2

ASC specialist services	2
Funding / resource issues	2
Key areas - unrealistic	2
Transition issues	2
Impact on family	2
Crisis support	2
Local leadership / accountability	2
Monitoring / quality control	1
Need to get on with it	1
Help with making decisions	1
Data collection / research	1
The gap - learning disability / mental health	1
Need flexible services/support	1
Difficulties with diagnosis / assessment	1
Reference to specific service / agency	1
Criminal justice / legal system	1
Comment on consultation / document	1
Access to public spaces	1

4.8. Do you need help with any of these things?
(this question corresponds to Q1c of the easy read consultation)

a) help with finding a house or flat and looking after it
b) help to look after yourself in your own home
c) help with travelling to where you need to go
d) help to make friends
e) help so you can do the things you like to do in your free time.

Group	Count	Proportion
Yes	95	71%
No	33	25%
No answer	5	4%

4.9. If you answered yes, please tell us why you need help with any of these things *(this question corresponds to Q1d of the easy read consultation)*

a) help with finding a house or flat and looking after it
b) help to look after yourself in your own home
c) help with travelling to where you need to go
d) help to make friends
e) help so you can do the things you like to do in your free time.

Group	Count
Help with making friends / social skills	44
No comment / not applicable	40

Help with independent living / life skills	40
Help with travelling	30
Help with finding a house / looking after it	30
Help with leisure activities	25
Help with all areas	16
Dependence on family support	9
Need for awareness / acceptance / understanding	8
Anxiety	6
Consider specific individual needs	6
One to one support	6
Help with budgeting/administration	6
Difficulty communicating	5
Current support inadequate / non-existent	5
Help with finding/keeping employment	5
Sensory issues	5
Wider professional awareness / training	4
Example of bad experience	4
Need 24 hour care	3
Other comment	3
Contribution to society/self esteem	2
Transition issues	2
Learning disability	2
Dealing with / recognise multiple conditions	2
Refers to other response/s	2
Example of positive experience / Good practice example	2
Comment on consultation / document	2
Reference to specific service / agency	2
Concerns on death of parents / carers	2
National and local leadership/accountability	1
Information / service directory	1
Consistency / coordination in services / support person	1
Equal access to support	1
Involve parents	1
Difficulties with diagnosis / assessment	1
Self awareness	1

4.10. What do you think would be the best ways to help adults with autism to do these things? *(this question corresponds to Q1e of the easy read consultation)*

a) to find a house or flat and look after it
b) to look after themselves in their own home
c) to travel to where they need to go

d) to make friends
e) to do the things they like to do in their free time

Group	Count
One to one support	45
Help with making friends / social skills	43
Help with independent living / life skills	40
Help with finding suitable / sheltered housing	32
Help with travelling	31
Help with leisure activities	26
Train professionals	18
Consider specific individual needs	15
Information / service directory	9
Local / regional ASC teams	9
Person-centred plan	8
ASC support network	8
Consistency in services/support person	7
Example of positive experience / Good practice example	7
Help with finding a job / employment schemes	7
Funding / resources	7
Involve / support families / carers	6
Take time for / spend time with the ASC person	6
Personal budgets / Direct Payments	5
Refers to other response/s	5
Reference to specific service / agency	5
Involve / empower people with ASC	4
Build self esteem/confidence	4
Help making decisions / choices	4
Help with all areas	4
Improve diagnostic / assessment services	4
Need for awareness / acceptance / understanding	4
Help with communicating	3
Help with budgeting / administration	3
No comment / not applicable	3
Lifelong support	3
Data collection / research	2
Equality	2
Access to community care / support	2
Flexible services	1
Financial support / access to benefits	1
Current support inadequate / non-existent	1
Dealing with / recognise multiple conditions	1

Support employers	1
Fund voluntary organisations	1
Support from local authority	1
Improve transition	1
Support from family	1
Example of bad experience	1
Support for elderly people with ASC	1
Need to get on with it	1
Psychological therapy	1
Websites / online forums	1
Comment on consultation / document	1

4.11. Do you know of any help that adults with autism can get with these things where you live? *(this question corresponds to Q1f of the easy read consultation)*

a) help with finding a house or flat and looking after it
b) help to look after themselves in their own home
c) help with travelling to where they need to go
d) help to make friends
e) help so they can do the things they like to do in their free time.

Group	Count	Proportion
Yes	58	14%
No	72	38%
No answer	22	47%

4.12. If you answered yes, please tell us about this help. Please tell us what you like or don't like about it. *(this question corresponds to Q1g of the easy read consultation)*

Group	Count
No comment / not applicable	68
Reference to specific service / agency	30
Current support inadequate / nonexistent	30
Example of positive experience / Good practice example	16
Help with finding suitable / sheltered housing	13
Support available / local support	12
Help with making friends / social skills	9
One to one support	7
None / no help	7
Help with travelling	6
Support from family / carers	6
ASC support network	5

Help with leisure activities	5
Help with independent living / life skills	5
Example of bad experience	5
Information / service directory	4
Consider specific types of ASC	3
Dependence on volunteering / good will	3
Funding / resource issues	3
Anxiety / mental health issues	3
Lack of support from Local Authority / Government	3
Need for awareness / understanding	2
Poor professional understanding	2
Transition issues	1
Education / training schemes	1
Person-centred plan	1
Other comment	1
Personalised budget / direct payments	1
Helpline / gateway	1
Help with budgeting / administration	1
Equality	1
Change criteria	1
Concerns on death of parents / carers	1
Impact on family	1

3. Health chapter

Standard consultation

The external reference group identified the following as key areas where action is needed in relation to healthcare services:

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

5.1. Do you agree that these are key areas where action is needed? *(this question corresponds to Q8a of the standard consultation)*

Group	Count	Proportion
Yes	555	89%
No	10	2%
Unsure	23	4%
No answer	39	6%

5.2. Please explain your answer. *(this question corresponds to Q8b of the standard consultation)*

Group	Count
Train - health professionals	155
Key areas will help people with ASC	153
No comment / not applicable	142
Need better access to / earlier diagnosis	117
Need better post-diagnostic support	93
Train - mental health professionals	64
Need accessible healthcare settings	61
Example of bad experience	55
Need preventative support for mental health	50
Data collection / research	45
Specific support / advice services	43
Need for equal service everywhere	38
Need ASC specialists/ multidisciplinary approach	37
Inappropriate referrals / diagnosis / treatment	35
Dealing with / recognise multiple conditions	34
Family / carer support and involvement	32
Difficulty with waiting rooms	30
Need for specific facilities / considerations	28
Funding / resource issues	26
Lack of coordination / continuity	26
Refers to other response/s	26
Measures - appropriate communications	23
Sensory issues	21
Transition issues	21
Difficulty during health appointment	21
Current support inadequate / non-existent	20
Regular checks / health checklist	19
The gap - learning disability / mental health	16
Example of positive experience	16
Change criteria / labels / legislation	14
Consider specific types of ASC	14
Other comment	12

Concerns - other issues	10
Need for ASC specialists in mental health service	10
Concerns - data collection	9
Include dentists in the strategy	8
Reference to publication/further information	7
Need support for elderly people with ASC	7
Involve / empower people with ASC	6
Monitoring / evaluation	6
Need Buddies system	5
Comment on consultation / document	5
Difficulty using telephones	5
Health action/Person-centred plans - health passport	4
Helpline/gateway	2
Reference to NAS	2
Offer of help / involvement	2
Awareness raising / education / information	1

5.3. Please provide details of your experiences of the challenges faced by adults with an ASC in the area of diagnosis and health. *(this question corresponds to Q9 of the standard consultation)*

Group	Count
Poor professional recognition / understanding	250
Difficulty with diagnosis / assessment	218
Lack of post-diagnostic support	103
Difficulty explaining feelings / talking to people or GP	97
Development of mental health problems	77
Example of bad experience	71
Dealing with / recognise multiple conditions	71
Inappropriate diagnosis / treatment	70
Poor or no access to services / support	69
Suggested improvements / changes	61
Need for equal service everywhere	46
Difficulty with waiting rooms	44
Sensory issues	42
Lack of appropriate healthcare settings	38
Difficulty during health appointment	36
Coordination / continuity of service provision	36
Refers to other response/s	36
Dependence on family care/support	32
Funding / resource issues	30
Need for earlier intervention	30
Transition issues	27

Exclusion / discrimination because of ASC	27
The gap - learning disability / mental health	23
Example of positive experience	22
Difficulty understanding health professionals	20
Other comment	17
Consider specific types of ASC	14
Difficulty with bureaucratic procedures	8
No comment / not applicable	8
Refuse advice from health professionals/ deny	7
Difficulty using telephones	7
Reference to other research / consultation	3
Impact on family	1
Comment on consultation / document	1
None / no experience	1

5.4. What actions do you think should be taken to address the concerns raised in the health chapter (e.g. better record keeping, the development of diagnostic services, training of key professionals)? *(this question corresponds to Q10 of the standard consultation)*

Group	Count
Train - key professionals	257
Develop / improve diagnostic services	121
Need for ASC specialists/team locally	103
Agree with actions suggested	100
Develop / improve post-diagnostic services	93
Communication/coordination/continuity of care/service provision	92
Need accessible/ASC friendly healthcare settings	69
Family / carer support and involvement	63
Data collection / research	57
Specific support / advice services	46
Train - mental health professionals	36
Regular checks / health checklist	36
Need a multidisciplinary approach	32
Involve / empower people with ASC	27
Awareness raising / education / information	24
Consider specific types of ASC	24
Transition issues	22
Need preventative support for mental health	22
Refers to other response/s	21
Health action/ Person-centred plans - health passport	20
Monitoring / evaluation	20
Information / service directory - local	19

Funding / financial support	18
Learn from others / previous experience	18
Need for earlier intervention	18
Continuous professional development/training	16
The gap - learning disability / mental health	14
Other comment	12
General comment on strategy / approach	10
Touring ASC specialists	9
Example of bad experience	8
Need Government recognition / awareness	7
Concerns - other issues	6
Reference to good practice in document	6
Reference to publication/further information	4
No waiting lists	4
Comment on consultation / document	3
Example of good practice / positive experience	2
No comment / not applicable	2
Self-referral diagnostic service	2
Dependence on family care/support	1

5.5. If possible, please give examples of where these concerns have been successfully addressed at a local level. *(this question corresponds to Q11 of the standard consultation)*

Group	Count
None / they have not been addressed	126
Education/training of professionals	36
Help from GP/Local surgery/dentist	36
Adjustment to the patients needs	24
Suggested improvements / changes	22
Help from other group/ organisation	20
Help from specialist unit / team in hospital	20
Communication/coordination/continuity of care/service provision	19
Creation of diagnostic/ support services	16
Help from other professionals	14
Other comment	14
Refers to other response/s	13
Examples of service delivery	11
Creation of ASD point of contact/coordinator in the hospital	10
Regular checks / health checklist	9
Education/training family/carers	8
Local Authorities involved	8
No comment / not applicable	8

Technique - other	8
Data collection / research	8
Transition issues	8
Health action/ Person-centred plans - health passport	7
Post-diagnostic support helpful	7
Leisure and day services / social inclusion	6
Example of bad experience	6
Help from social worker	5
Not local	5
Help from university/ specialist school	5
Lack of early support / diagnosis	4
Technique - Mental health counselling	3
Monitoring / evaluation	2
Funding / financial support	2
Public awareness campaign	2
Autism alert card	2
Technique - Cognitive Behavioural Therapy	2
Comment on self-worth/social isolation	2
Specific health route for people with ASD	1
Comment on consultation / document	1

Easy read consultation

People have told us that there are 4 main ways we can improve healthcare for adults with autism. These are:

1. Make it easier for adults to find out if they have got autism and get the healthcare they need.
2. Make sure that people working in the health service have information about the adults with autism who live in their area, so that they can make sure that help is available for them.
3. Make places like doctors' surgeries and hospitals easier to get to for adults with autism and make sure these places are easy for adults with autism to use.
4. Help doctors, nurses and social workers who work with people who have mental health problems to understand more about autism. This will mean they can better help people with autism who also have mental health problems.

5.6. Do you agree that these are the most important ways to improve healthcare for people with autism? *(this question corresponds to Q2a of the easy read consultation)*

Group	Count	Proportion
Yes	136	87%

No	10	6%
Not sure	9	6%
No answer	1	1%

5.7. Please tell us why. *(this question corresponds to Q2b of the easy read consultation)*

Group	Count
Need professional training / awareness	54
No comment / not applicable	40
Need better access to / earlier diagnosis	24
Anxiety / mental health issues	18
Agree with key areas	14
Difficulty communicating with others	13
Need for post diagnostic support	13
Example of bad experience	11
Need accessible healthcare settings	10
Inappropriate referrals / diagnosis / treatment	9
Sensory issues in waiting rooms / surgeries / hospitals	9
Stop generalised approach / treat as individuals	8
Difficulty during health appointment	8
Poor public understanding	6
Transition issues	6
Lack of understanding/ knowledge from health professionals	5
Lack of coordination / continuity	5
Need for specific help/ support	4
Data collection / research	4
ASC specialists/ champions in each healthcare establishment	3
Local access to support / equal access everywhere	3
Importance of diagnosis	3
Other comment	3
The gap - learning disability / mental health	2
Monitoring/quality control	2
Example of positive experience/good practice example	2
Involve families / carers	2
Contact point / information / service directory	2
Train - mental health professionals	2
Advocacy support	2
Crisis support / helpline	2
Current support inadequate / non-existent	2
Regular checks	2
Difficulty accepting diagnosis	1
Comment on consultation / document	1

Offer of help / involvement	1
Refers to other question	1
Check ASC in family	1
Funding issue	1

5.8. How did you find out that you had autism? *(this question corresponds to Q2c of the easy read consultation)*

Group	Count
Through GPs/paediatricians/other health professionals	33
Family / friend suspicion	33
Diagnosis in childhood / child development assessment	22
Late diagnosis / assessment	17
Do not have an ASC	17
Through psychologist/psychiatrist	10
No comment / not applicable	10
Through school / special education	10
Identify with story in news / book / TV	10
Example of bad experience	9
Self referral	6
Private diagnosis sought	6
Access to care / support	2
Through NAS	2
The gap - learning disability / mental health	2
Comment on consultation / document	2
Through criminal justice system	1
Through jobcentre	1
Refers to other question	1

5.9. What help did you get to understand what having autism means? *(this question corresponds to Q2d of the easy read consultation)*

Group	Count
None / no help	60
Literature/ books/ films	28
NAS	14
Parent / family carers	14
Personal research	14
Through GPs / other health professionals	11
Websites / online forums	10
Through school/special education	9
Social care and support	8
Support group / peer group	8

No comment / not applicable	7
Other organisation dedicated to autism	4
Difficulties with diagnosis / assessment	3
Do not understand what autism is	3
Improve access to information	3
Poor professional understanding	2
Comment on consultation / document	2
Through jobcentre/employer	2
Through psychologist/psychiatrist	1
Example of bad experience	1

5.10. What do you think we should do to make health services better for adults with autism? For example, how could we make it easier for adults with autism to get the treatment they need, to visit a doctor's surgery or use a hospital?

(this question corresponds to Q2e of the easy read consultation)

Group	Count
Train - health professionals	56
Buddy system	25
Communication - plain English / visual / simple	20
Health appointment - on time/ no waiting	18
Health appointment - flexible/quiet time	17
Combined / specific Autism service	16
Quiet / specific waiting room	14
Train - receptionists / staff	10
Health appointment - extra time	10
Sensory issues in waiting rooms / surgeries / hospitals	9
Increase resources in local surgery	8
Local access to support / equal access everywhere	6
Health appointment - visit at home	6
Health appointment - see same doctor	6
Communication - email / post in advance	6
Train - HP on challenging behaviour	5
Data collection / research	5
Improve coordination between services	5
Difficulty communicating with others	5
Passport - ASC written on medical file	4
Example of bad experience	4
Consider specific types of ASC	4
Need for family / carer support and involvement	4
Need for post diagnostic support	4
Need better access to / earlier diagnosis	4
Stop generalised approach / treat as individuals	3

Example of positive experience/good practice example	3
Not sure	3
Other comment	2
No comment / not applicable	2
Consistency of services / support person	1
Prepare ASC people to health appointment/ hospital	1
Involve / empower people with ASC	1
Special mental health service	1
Refers to other question	1
Regular checks	1
Individual transport	1

5.11. Health services are things like doctor's surgeries and hospitals. What health services in your area are easiest for you to use? Why are they easiest?

(this question corresponds to Q2f of the easy read consultation)

Group	Count
Local GP surgery	58
Easy - health professional shows understanding	29
Easy - local access	23
Lack of understanding/ knowledge from health professionals	18
Easy - same person, knows history	17
Dentist	16
None, all difficult	16
Specific hospital	10
Bad experience with hospital	10
Other health professionals	8
No comment / not applicable	7
Avoid health services as much as possible	7
Difficulty communicating with others	7
Need for more Adult ASC services	5
Easy - email, telephone communication	5
Easy - less waiting time/quieter	5
Easy - family or advocate can accompany	5
Difficulty with appointment system / opening times	2
No problem using health services	2
CAHMS	2
Easy - separate waiting area	2
Easy - flexible appointments, opening hours	1
Refers to other question	1
Easy - different health professional services offered	1

4. Choice and control chapter

Standard consultation

The external reference group identified the following as key areas where action is needed to ensure adults with ASC have more choice and control over their lives:

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

6.1. Do you agree that these are key areas where action is needed? *(this question corresponds to Q12a of the standard consultation)*

Group	Count	Proportion
Yes	467	81%
No	14	2%
Unsure	54	9%
No answer	42	7%

6.2. Please explain your answer. *(this question corresponds to Q12b of the standard consultation)*

Group	Count
No comment / not applicable	158
Improve transition planning / transition issues	158
Improve access to advocates / self advocacy support	154
Involve / empower people with ASC	137
Person-centred approach - support	136
Key areas will help people with ASC	94
Choice - cannot make / do not want to make choices	57
Personal budgets / direct payments	49
Current support inadequate / non-existent	46
Involve / support families / carers	45
Difficulty communicating / need support	37
Example of bad experience	36
Example positive experience/Good practice	30
Person-centred approach - concerns	28
Information / service directory	26

Train all in contact with ASC	21
Coordination/continuity of service/support person	19
Choice - no choices available / no control	19
Stop generalised approach / treat as individuals	18
Funding / resource issues	17
One to one support	16
Reference to other specific service / agency	16
Comment on consultation / document	16
Choice - time / help to make and understand decisions	13
Improve diagnosis / assessment	13
Dependence on family care / support	12
Change / clarify eligibility criteria	10
Help with - life skills	9
Other comment	8
Support from charity/church/voluntary sector	8
Access to education/further training	8
ASC teams / multi disciplinary approach	7
Help with - social inclusion / social skills	7
Reference to NAS	7
Refers to other response/s	7
Access to employment	6
Support from local authorities	6
Impact on family	6
Reference to Connexions	6
Equal access to services for everyone / everywhere	5
Exclusion / discrimination because of ASC	5
The gap - learning disability / mental health	5
Access to housing	4
Support from national level / government	4
Difficulty coping with change	4
Support groups / network	4
Poor professional recognition / understanding	4
No / no experience	4
Data collection / research	4
Help with - budget / administration	3
Code of conduct for financial institutions	3
Reference to good practice in document	3
Criminal justice / legal system	3
Public understanding / awareness	2
Quality control	2
Access to leisure activities	2
Accountability	2

Issues with - bureaucracy	1
Access to transport	1
Need to get on with it	1
Concerns on death of parents/carers	1
Concerns on privacy	1
Need for earlier intervention	1
Dealing with / recognise multiple conditions	1
Reference to other research / consultation	1

6.3. Please provide details of your experiences of the challenges faced by adults with an ASC as they try to make choices and take control over their lives. *(this question corresponds to Q13 of the standard consultation)*

Group	Count
Current support inadequate / non-existent	86
Choice - no choices available / no control	83
Choice – can’t make / don’t want to make choice	76
Choice - time / help to make and understand decisions	61
Issues with - transition	55
Issues with - employment	54
Example of bad experience	54
Lack of advocacy / self advocacy support	54
Dependence on family care/support	50
Issues with - housing / independent or supported living	50
Difficulty communicating	48
Poor professional recognition / understanding	47
Person-centred plans - use / improve	44
Issues with - social inclusion / social skills	41
Issues with - benefits/financial support	41
Lack of information / service directory	34
Issues with - life skills / independence	34
Lack of understanding / awareness	34
Personal budget / direct payments	31
Example of positive experience / good practice	31
Anxiety	31
Involve / empower people with ASC	28
Issues with - education	28
Refers to other response/s	24
Funding / resource issues	21
Involve / support families / carers	21
Difficulty with diagnosis / assessment	20
One to one support	19
Exclusion / discrimination because of ASC	18

Issues with - forms/bureaucratic procedures	18
Change criteria / labels / policy of provision	17
Stop generalised approach / treat as individuals	16
Vulnerability / exploitation	15
Reference to other specific service / agency	15
Coordination/continuity service/support person	15
Train all in contact with ASC	13
Difficulty coping with change	13
Dealing with / recognise multiple conditions	11
Lack of social / leisure activities	11
Criminal justice / legal system	9
Other comment	8
Sensory issues	8
Impact on family	8
No comment / not applicable	8
Develop / improve post-diagnostic services	8
None / no experience	8
Consider specific types of ASC	7
Support groups / network	7
Comment on consultation / document	7
Reference to NAS	6
Reference to Connexions	6
Reference to publication / further information	5
The gap - learning disability / mental health	5
Data collection / research	5
Support from charity/church/volunteers	4
Concerns on death of parents / carers	4
Issues with – transport	2
ASC teams / multi disciplinary approach	2
National approach	2
Reference to Prospects	2
Concerns on disclosure of diagnosis	2
Complaints/appeals possibilities	2
Local government support	2
Change / introduce legislation	1
Lack of role models	1

6.4. What actions do you think should be taken to address the concerns raised in the choice and control chapter (e.g. ensuring that person-centred plans are more widely available, development of brokerage, advice and advocacy services, including people with an ASC in the development of individual/personal budgets)? *(this question corresponds to Q14 of the standard consultation)*

Group	Count
Person-centred plans - use / improve	114
Improve advocacy / self advocacy support	114
Personal budget / direct payments	69
Involve / empower people with ASC	68
Training	65
Improve transition planning / Transition issues	46
Information / service directory	42
Involve / empower families / carers	38
All of the above	35
One to one support	33
Coordination/continuity service/support person	31
Funding / resource issues	31
Current support inadequate / nonexistent	30
Difficulty communicating / support communication	30
ASC teams / multi agency approach	30
Choice - time / help to make and understand decisions	25
Awareness raising / education	23
Help with - life skills	20
Help with - social inclusion / social skills	18
Improve access to local care / services	16
Help with - housing / independent living support	16
Improve diagnosis / assessment	15
Stop generalised approach / treat as individuals	15
Help with - benefits/financial support	13
Reference to other specific service / agency	13
Accountability / commitment Las	12
Change / clarify eligibility criteria	12
Example of bad experience	12
Choice - cant make / don’t want to make choices	10
Change / introduce / clarify legislation	10
Refers to other response/s	10
Help with - finding/keeping employment	9
Choice - no choices available / no control	8
Support groups / network	8
Example positive experience/Good practice	8
Monitoring services / quality control	7
Comment on consultation / document	7
No comment / not applicable	6
None / no experience	6
Other comment	5

Help with - education/further training	5
Help with - budget / administration	4
Support at school / university	4
Exclusion / discrimination because of ASC	4
Online tools / communities	3
Role models	3
Support from charity/church/voluntary sector	3
Vulnerability / exploitation	2
Impact on family	2
Data collection / research	2
Reference to NAS	2
National approach	2
Reference to Connexions	2
Help with - filling in forms	2
Need to get on with it	2
Local leadership and accountability	1
Help with - leisure and day services	1
Complaints and appeals possibilities	1
Concerns on death of parents / carers	1
Dealing with / recognise multiple conditions	1
Reference to other research / consultation	1
Consider parents / family with ASC	1

6.5. If possible, please give examples of where these concerns have been successfully addressed at a local level. *(this question corresponds to Q15 of the standard consultation)*

Group	**Count**
None / they have not been addressed	88
Example of positive experience/Good practice example	50
Reference to other specific service / agency	37
Person-centred plans	35
No comment / not applicable	33
Advocacy services / self advocacy	27
Transition planning	20
Involve / empower people with ASC	18
Personal budget / direct payments	14
Train all in contact with ASC	13
ASC teams / multi disciplinary approach	13
Example of bad experience	11
Current services / support inadequate	11
Help with - housing / supported living	9
Help with - finding/keeping employment	9

Social groups / help with social skills	8
Information / service directory	8
Support from charity/church/voluntary sector	8
ASC specialist	7
Reference to NAS	7
Help with - life skills	6
One to one support	5
Involve / empower family / carers	5
Help with - benefits/financial support	5
Refers to other response/s	5
Help with - leisure and day services	5
Other comment	4
Help with - communication	4
Funding / resource issues	3
Local Authority should help	3
Assessment tools	3
Support from schools / universities	3
Choice – can’t make / don’t want to make choice	2
Poor professional recognition / understanding	2
Monitoring services / quality control	1
Reference to other research / consultation	1
Helpline	1
Online tools / communities	1
Help with - filling in forms	1
Support from social services	1
Reference to Connexions	1
Awareness raising / education	1
Change / introduce legislation	1
Support outside office hours	1
Comment on consultation / document	1

Easy read consultation

People have told us that there are 4 ways we can make sure that adults with autism can make choices about the help they get and about what they do in their lives. These are:

1. Make sure that adults with autism can get person-centred plans and are in control of their lives. Person-centred plans are documents that say what things people want to do and what help they need to do this.
2. Provide better help for people with autism as they leave school and start doing new things.

3. Make it easier for adults with autism to find someone to speak up for them or help them to speak for themselves.
6.6. Make sure that adults with autism are asked how they think that services they use could be improved.

6.7. Do you think that these are the most important ways to make sure that adults with autism can make choices about the help they get? *(this question corresponds to Q3a of the easy read consultation)*

Group	Count	Proportion
Yes	112	81%
No	10	7%
Not sure	11	8%
No answer	6	4%

6.8. Please tell us why. *(this question corresponds to Q3b of the easy read consultation)*

Group	Count
No comment / not applicable	31
Agree with key areas	20
Involve / empower people with ASC	18
Improve transition planning / transition issues	14
Person-centred plan support / use / improve	13
Access to advocates / self advocacy support	11
Example of bad experience	9
Choice - Right to make choices / mistakes / risks	8
Choice – Don't like / can't make choices	8
Information / service directory	7
Choice - Time / help to make and understand decisions	6
Consistency of services/support person	6
Involve families / carers	6
Current support inadequate / non-existent	6
Example of positive experience	6
Need for professional awareness / understanding	5
Train professionals	5
Difficulty communicating with others	4
Dependence on family support	4
Need for early intervention	4
Comment on consultation / document	4
Financial support	2
Stop generalised approach / treat as individuals	2
Local / regional ASC teams	2
Depends on individual needs / circumstances	2

Funding / resource issues	1
The gap - learning disability / mental health	1
Help with social skills	1
Equality	1
Improve diagnosis / assessments	1
Choice - No choice available / no control	1
Need to get on with it	1
Routine	1
Flexible services	1
Self awareness	1
Reference to specific service / agency	1

6.9. Have you been able to make choices about the help you get? This might be help at home, help with your day-to-day activities, help with getting a house or flat, help with meeting new people, or help travelling where you need to go. *(this question corresponds to Q3c of the easy read consultation)*

Group	Count	Proportion
Yes	38	34%
No	63	57%
No answer	10	9%

6.10. If you answered yes, please tell us about the choices you made and how you made them. *(this question corresponds to Q3d of the easy read consultation)*

Group	Count
No comment / not applicable	56
Support from family	15
Choice - choices available / ability to make choices	10
Choice - no choices available	10
Current support inadequate / non-existent	9
Information / service directory	6
Good practice example	6
Example of bad experience	6
Support from social services	5
Reference to specific service / agency	5
Example of positive experience	5
Support at home / personal assistant	4
Person-centred plan - use / improve	2
Refers to other response/s	2
Support in education	2
Choice – don’t like / can’t make choices	2
Exclusion / discrimination issues	2

Support from advocate	2
Choice - time / help to make and understand decisions	2
Help with communicating	1
Respite	1
Consistency of services/support person	1
Support in finding a house	1
Difficulty with diagnosis / assessment	1
Support in employment	1
Social inclusion / acceptance	1

6.11. What do you think are the best ways to help adults with autism choose the help they need? For example, having more information about what help is available or having someone like a social worker to explain what help you could get. *(this question corresponds to Q3e of the easy read consultation)*

Group	Count
Improve information access	26
One to one support / buddy	24
Comment on social workers	22
Advocates / self advocacy support	13
All the above	12
Choice - time / help to make and understand decisions	12
Depends on individual needs / circumstances	9
Involve families / carers	9
Train professionals	8
Involve / empower people with ASC	7
No comment / not applicable	7
Use - Pictures / photos	6
Need for social worker	5
Use - Verbal information / one to one explanation	5
Diagnosis/Assessments/Regular reviews	5
Example of bad experience	5
Use - Websites / online forums	5
Use - Written material/Leaflets/Easy to read	4
Coordination/sharing knowledge between services	4
Funding / resources	4
Dependence on family support	4
Continuity of support person	4
Creating more choice / access to choice	4
Help with filling in forms	3
Refers to other response/s	3
Current support inadequate / non-existent	3
Reference to specific service / agency	3

Personal budgets / Direct Payments	2
Follow through plans	2
Person-Centred Plans - use / improve	2
Improve transition	2
Through GPs / other health professionals	2
Comment on consultation / document	2
Example of positive experience/Good practice example	2
Help with finding housing	1
National and local leadership/accountability	1
Explain the organisation of services	1
Support from church/charity/volunteers	1
Train ASC person	1
Change criteria	1
Equal access to help everywhere	1
Support groups / network	1
Lack of awareness / understanding	1
Data collection / research	1
Use - Organised displays	1
Need to get on with it	1
Choice – don’t like / can’t make choices	1
The gap - learning disability / mental health	1
Autism specialist teams	1
Choice - no choices available	1

6.12. Did you get any help with making choices about the services you use and other help you need? *(this question corresponds to Q3f of the easy read consultation)*

Group	Count	Proportion
Yes	31	27%
No	75	65%
No answer	9	8%

6.13. If you answered yes, please tell us what help you got to make these choices and how it helped you. *(this question corresponds to Q3g of the easy read consultation)*

Group	Count
No comment / not applicable	73
Help from - family / carers	18
Help from - social worker	6
Current support inadequate / non-existent	6
Reference to specific service / agency	6

Help from - teachers / school	4
Example of positive experience/good practice example	4
Example of bad experience	4
Choice - no choices available	3
Helped with - information access/explaining	2
Help from - health professionals	2
Helped with - filling in forms	2
Help from - one to one support / buddy	2
Help from - advocate	2
Choice - time / help to make and understand decisions	2
Helped with - transition planning	2
Lack of information	2
Changing services / trying different services	2
Help from - other	2
Respite	1
Help with day activities	1
Help with life skills / independent living	1
Help from - mental health professional	1
Helped with - personalised budget / direct payments	1
Help from - local authority	1
Funding / resource issues	1
Choice - choices available	1
Choice – can’t make / don’t want to make choices	1
Lack of awareness / understanding	1
Help from - employment advisers	1
Pay for advice	1

5. Access to employment and training chapter

Standard consultation

The external reference group identified the following as key areas where action

a) ensuring that adults with an ASC can access the particular supports that they need to find and hold on to a job
b) improving awareness of ASC among employers and supporting them to make reasonable adjustments in the workplace for adults with an ASC
c) making the benefits and tax credits system more accessible for adults with an ASC
d) making training and educational opportunities more accessible for adults

with an ASC

7.1. Do you agree that these are key areas where action is needed? *(this question corresponds to Q19a of the standard consultation)*

Group	Count	Proportion
Yes	470	86%
No	13	2%
Unsure	32	6%
No answer	34	6%

7.2. Please explain your answer. *(this question corresponds to Q19b of the standard consultation)*

Group	Count
No comment / not applicable	164
Need accessible benefits / tax credits	70
Need employer awareness / support	69
Agree with actions suggested	63
Barriers to education / employment / benefits	56
Need accessible training / education	49
Need targeted training	35
Need employment support systems / programmes	28
Need long term support	27
Difficulty accessing / keeping employment	26
Employment at appropriate (intellectual) level	20
Need to tackle discrimination/isolation	19
Unable to work	18
Need for specific facilities / considerations	18
Employment/training good for social inclusion/self esteem	17
Refers to other response/s	15
Example of bad experience	14
Adults with ASC have right / want to work	14
Valuable for employers and adults with ASC	13
Transition issues	13
Awareness raising	11
Funding / resource issues	10
Need Buddies system	10
Reference to Prospects	10
Consider specific types of ASC	8
Financial support / economic security	7
Need suitable employment	7
Impacts on quality of life	7

Need for routine/structure	7
Comment / explanation of specific themes	7
Train - all professionals in contact with ASC	6
Need for colleague awareness	6
Reference to Connexions	6
Diagnosis / assessment issues	6
Reference to publication/further information	6
Example of positive experience	6
Need for work experience/job trials	5
Reference to Supported Employment	5
More focus on voluntary work	5
Change attitudes towards ASC	4
Need help with social skills / self awareness	4
Reference to local experience	3
Unsure	3
Autism Anglia Questionnaire	2
Support for self-employed	2
Don’t want help	2
Reference to international experience	2
Lack of advocacy services	2
Coordination / continuity of service provision	2
Incentives for employers/ sheltered jobs	2
Disagree	1
Central government role / issues	1
System too rigid	1
Numbers with ASC diagnosis are increasing	1
Share experiences	1
General comment on strategy / approach	1

7.3. Please provide details of your experiences of the challenges faced by adults with an ASC as they try to access employment, training and benefits.

(this question corresponds to Q20 of the standard consultation)

Group	Count
Difficulty accessing benefits	96
Difficulty with social interactions / interviews	77
Difficulty accessing / keeping employment	64
Need employer/colleague awareness / support	59
Lack of understanding / awareness	51
Autism Anglia Questionnaire	46
Workplace bullying / prejudice	35
Lack of appropriate training/support for people with ASC	34
Lack of workplace/forms adjustments to accommodate	25

Services / professional awareness inadequate	22
Inappropriate training/education for people with ASC	22
Employment at appropriate (intellectual) level	21
None / no experience	21
Refers to other response/s	21
Issues with not having a diagnosis	17
Need targeted training/Buddies system	16
Example of bad experience	16
Funding / resource issues	16
Issues with advisors	15
Need support before/during employment	15
Difficulty accessing education services	15
Comment on benefit system	14
Lack of willing employers	13
Need accessible training / education	13
Need long term support	12
Difficulty in applying for jobs	12
Example of positive experience	12
Difficulty filling in forms	12
Benefit cuts/changes/reviews	11
Train - all / everyone in contact with ASC	10
Difficulty with workplace skills	10
Transition issues	10
Need help to find suitable jobs/training	9
Families providing support	8
Details of personal experience	8
Need to consider all spectrums of ASC	8
Employment not possible	8
Need positive image of ASC condition	7
More focus on voluntary work	7
Support at school / university	7
Barriers to education / employment / benefits	7
Transport / travel	7
Reference to Connexions	7
Suggested improvements / changes	7
Difficulty using telephones	7
Need suitable employment	6
Need for advice about employment for ASC sufferers	6
Reference to Prospects	6
Difficulty coping with change	6
Employment/training good for social inclusion/self esteem	5
Difficulty with attendance on specified dates/times	5

Lack of confidence	5
Lack of advocacy services	4
Incentives for employers/ sheltered jobs	4
Inappropriate work placement	4
Lack of day activities	3
Financial support / economic security	3
Don’t want to access training/benefits/support/employment	3
School/college bullying	3
Lack of information / service directory	3
Support not consistent across country	3
No comment / not applicable	3
Educated but unable to find a job	3
Reference to publication/further information	3
Need for ASC specialists/dedicated team	2
Increase workplace opportunities	2
Support for self-employed	1
Need organisations to work together	1
Work experience placements not leading to anything	1
Comment on web based response system	1
Reference to Employability	1
Communication employers with family/support	1

7.4. What actions do you think should be taken to address the concerns raised in the training and employment chapter (e.g. training for those who offer employment support, awareness campaigns among employers, changes to contracts so that progress towards work is rewarded)? (this question corresponds to Q21 of the standard consultation)

Group	**Count**
Need targeted training/Buddies system	48
Train - employers	48
Awareness - employers	46
Awareness raising	44
Train - all / specific staff	41
Adjust workplace / interview/ forms settings	39
Demonstrate advantage for employers to hire people with ASD	38
Autism Anglia Questionnaire	37
Need accessible training / education	35
Agree with actions suggested	34
Train - Benefits professionals	28
Train - employment support	28
Incentives for employers/ sheltered jobs	27
Support people with ASC in employment	23

Benefit system needs to be more flexible	20
Training	18
Need for work experience/job trials	18
Employers need support	17
No comment / not applicable	17
Transition issues	17
Need long term support	16
Funding / resource issues	16
Need for ASC specialists/dedicated team	16
Improve access to advocacy / advice services	15
Recognise the positives	15
Coordination / continuity of care / service provision	13
Need accessible benefits / tax credits	12
Need help to find suitable jobs/training	12
Refers to other response/s	12
Train - other comments	11
Employment agreements / expectations	10
Support people with ASC in education	10
Need for equal service everywhere	9
Learn from others / previous experience	8
Financial support / economic security	8
Family / carer support and involvement	7
Central government role / issues	7
General comment on actions	7
More focus on voluntary work	6
Apprenticeships	6
Help needed to overcome fears	6
Comment on current economic situation	6
Share best practice	5
Accreditation schemes	5
Legislation should be used	5
Employment at appropriate (intellectual) level	5
Need for adequate reward/s	4
Employment/training good for social inclusion	4
Train - education services / teachers	4
Issues with not having a diagnosis	4
Support for self-employed	4
Example of positive experience	4
Monitoring / evaluation	4
Involve / empower people with ASC	4
Public sector leader in ASD employment	4
Increase workplace opportunities	4

Awareness - public	3
National indicator/PSA 16	3
Don't assume ASC sufferers are the same	3
Workplace bullying / prejudice	3
Therapy - others	2
Comment on sheltered employment/workshop	2
Transport / travel	2
Lack of willing employers	2
Need appropriate employment / daily activity	2
Data collection / research	2
Train - health professionals	1
Autistic friendly jobs should be advertised	1
ASC only educational facilities	1
AS not a general disability	1
Support for initiatives to succeed	1
Person-centred plans	1
Free training in higher education	1
Improve careers advice	1
Need to tackle bullying	1
Reference to publication/further information	1

7.5. If possible, please give examples of where these concerns have been successfully addressed at a local level. *(this question corresponds to Q22 of the standard consultation)*

Group	Count
None / they have not been addressed	94
Example of positive experience	31
Autism Anglia Questionnaire	23
Local charity	23
Reference to NAS	15
Local government support	11
Reference to local experience	11
No comment / not applicable	11
Refers to other response/s	11
Other employment support services	9
Reference to Prospects	9
Local school / college	8
Support from schools / universities	7
National charity	6
Local company	6
Help from other group/ organisation	6

Work experience placement	5
Support from manager	4
Train - employers	4
Support not consistent across country	4
Need for specific facilities / considerations	4
Benefits advice & support	4
Train - all / specific staff	3
Funding / resource issues	3
Reference to Connexions	3
Other company from abroad	3
National company	2
Suggestion for employment	2
Support from mentor	2
Need for colleague awareness	2
Tailored support / buddies	2
Local farm/animal centre	2
Need positive image of ASC condition	1
Awareness - employers	1
Person-centred plans	1
Sheltered workshops	1
Develop good systems	1
Support from small business	1
Example of bad experience	1
Reference to Workstep	1

Easy read consultation

People have told us that we need to do 4 main things to make it easier for adults with autism to get jobs and training. These are:

1. Make sure that adults with autism can get the help they need to find and keep a job.
2. Make sure employers know about autism.
3. Make sure that adults with autism can get the benefits and tax credits they need.
4. Help adults with autism to get the training and education they need.

7.6. Do you agree that these are the most important ways to make it easier for adults with autism to get jobs, training and benefits? *(this question corresponds to Q4a of the easy read consultation)*

Group	Count	Proportion
Yes	93	70%

No	11	8%
Not sure	25	19%
No answer	3	2%

*7.7. **Please tell us why.** (this question corresponds to Q4b of the easy read consultation)*

Group	Count
No comment / not applicable	35
Help to find and keep a job	21
Need employer awareness / support	21
Consider strengths / capacities of ASC adults	18
Need accessible benefits and tax credits	14
Key areas are important	13
Accessible training / mentoring for ASC adults	11
Difficulty with socialising / interview	10
Bullying / exclusion / discrimination issues	9
Example of bad experience	7
Awareness from co-workers	6
Independence /self-esteem through work	6
Need for specific adjustment in workplace/contract	5
Work is not possible for all	5
Need support to work/train	4
Need to tighten regulation	4
Need to remove stigma of autism	3
Consider different levels of disability	3
Buddy / carer at the workplace	3
Transition issues / improve transition planning	3
Need to promote services available	2
Continuity of support person	2
Lack of appropriate jobs	2
Need for targeted/earlier training	2
Questioning disclosing diagnosis to employer	2
Train - employment advisers	2
Refers to other response/s	1

*7.8. **Have you had any problems trying to get a job, training or benefits?** (this question corresponds to Q4c of the easy read consultation)*

Group	Count	Proportion
Yes	69	66%
No	24	23%
No answer	11	11%

7.9. If you answered yes, please tell us about the problems you have had trying to get a job. *(this question corresponds to Q4d of the easy read consultation)*

Group	Count
No comment / not applicable	38
Bullying / exclusion / discrimination issues	12
Difficulty integrating working environment	10
Difficulty communicating with others	10
Lack of awareness / support of employer	10
Example of bad experience	10
No help available to find and keep a job	8
Difficulty with interviews	7
Difficulty accessing benefits / tax credits	7
Other comment	4
Lack of understanding employment advisers	4
Difficulty accessing training / support	4
Never found suitable jobs	4
Consider strengths / capacities of ASC adults	3
Difficulty filling in application forms	3
Need for incentives for employers	2
Comment on consultation / document	2
Refers to other response/s	2
Only volunteering work available	2
Example of positive experience	2
Lack of jobs in the area	1
Impact on family	1
Advocate / support at interview	1
None	1
Good practice example	1
Difficulty using the phone	1
Late diagnosis / assessment	1

7.10. If you answered yes, please tell also us about the problems you have had trying to get training. *(this question corresponds to Q4e of the easy read consultation)*

Group	Count
No comment / not applicable	47
Lack of support / services	9
Refers to other response/s	9
No problems accessing training	8
Inappropriate training	5

Lack of understanding of teachers / trainers	5
Difficulty with classroom environment	5
Bullying / exclusion / discrimination issues	5
Training not helpful in finding job	4
No training available	3
Anxiety / mental health issues	2
Other comment	2
Difficulty organising its time	2
Lack of understanding employment advisers	2
Budget issues	2
Difficulty with interviews	1
Never tried to get training	1
None	1

7.11. If you answered yes, please tell us about the problems you have had trying to get benefits. *(this question corresponds to Q4f of the easy read consultation)*

Group	Count
No comment / not applicable	43
Questions do not apply to ASD	11
Difficulty filling in forms	11
Unaware of all benefits available	10
Help from family / carers	9
No problem getting benefits	6
Example of bad experience	6
Need help to access benefits	5
Level of benefits not high enough	4
Too able to get benefits	4
Takes too long to access benefits	4
Difficulty with being assessed/re-assessed	4
Difficulty using the phone	4
Refers to other question	3
Do not understand questions	2
Comment on consultation / document	1
Reference to specific service / agency	1

7.12. What do you think we should do to make it easier for adults with autism to get training or a job? For example, we could make sure that people like employers and people who help adults with autism to find a job know more about autism. *(this question corresponds to Q4g of the easy read consultation)*

Group	Count
Awareness raising	20

Help to find and keep a job	18
All the above	12
Buddy / carer at the workplace	10
Need work placements/trials/experience	8
Accessible training / mentoring for ASC adults	7
Refers to other question	6
Other comment	5
Support employers	5
Consider strengths / capacities of ASC adults	5
Employment at appropriate (intellectual) level	5
No comment / not applicable	5
Train - all in contact with ASC adults	3
Valuable asset to employers	3
Need to promote services available	3
Work is not possible for all	3
Questioning disclosing diagnosis to employer	3
Need for incentives for employers	3
Social services to do more	2
Public sector should employ ASC people	2
Need accessible benefits and tax credits	2
Reference to current job market	2
Not sure	2
Dependent on level of autism	1
Funding / resource issues	1
Need for specific adjustment in workplace/contract	1
Transition issues / improve transition planning	1

7.13. What help have you had to help you get a job or training? How has it helped you? *(this question corresponds to Q4h of the easy read consultation)*

Group	**Count**
None / no help	27
No comment / not applicable	16
Help from family / carers	14
Through local service/organisation	8
Through jobcentre	5
Other comment	4
Through Connexions	4
Help from employer	4
Through school	4
Through NAS Prospects	2
Through college	1
Comment on consultation / document	1

6. Awareness raising and training chapter

Standard consultation

The external reference group identified the following as key areas where action is needed to improve awareness of and training in ASC:

a) the development of both national and local awareness raising campaigns targeted at both the general public and at more specific groups of people (e.g. employers, those working in the criminal justice system).
b) targeted training programmes for certain professions such as social workers, community care assessors, healthcare professionals, those working in housing and in employment support.
c) the inclusion of ASC in social work degrees and clinical curricula.

8.1. Do you agree that these are key areas where action is needed? *(this question corresponds to Q16a of the standard consultation)*

Group	Count	Proportion
Yes	519	90%
No	14	2%
Unsure	16	3%
No answer	26	5%

8.2. Please explain your answer. *(this question corresponds to Q16b of the standard consultation)*

Group	Count
Need awareness raising	194
No comment / not applicable	158
Train - all professionals in contact with ASC	111
Include ASC in degrees/curricula	35
Train - health professionals	33
Example of bad experience/practice	33
Train - social workers / community care assessors	31
Stop generalised approach / treat as individuals	30
Key areas will help people with ASC	28
Train - police / justice / legal services staff	27
Campaigns	26
Need employer awareness / support	24
Involve / empower people with ASC	20
Train - education professionals	19

Suggested improvements / changes	18
Example of positive experience/practice	18
Train - employers / employment services	17
Public understanding / awareness	16
Poor professional recognition / understanding	14
Reference to other specific service / agency	10
Refers to other response/s	10
Criminal justice / legal system	7
General comment on strategy / approach	6
Autism alert card	6
Train - support workers	5
Involve / empower families / carers	5
Importance of continuous professional development	5
Train - mental health professionals	4
Train - housing professionals	4
Quality of training	3
Train - general public	3
Train - emergency services	3
Data collection / research	3
Current support inadequate / nonexistent	3
Difficulty with diagnosis / assessment	3
Inclusion of adults with ASC	3
Need self-awareness raising	3
Take a national approach	3
Support from charity/church/volunteers	1
Train - religious and faith groups	1
Train - residential home staff	1
Comment on consultation / document	1
Reference to NAS	1
Reference to good practice example in consultation document	1

8.3. Who are the priority groups for awareness raising and training and why? *(this question corresponds to Q17 of the standard consultation)*

Group	Count
Train - all / everyone in contact with ASC	170
Train - health professionals	159
Train - social workers / CCAs	101
Train - police / justice / legal services staff	84
Train - education services / teachers	82
Train - employers / employment services	80
Awareness - general public	51
Comment on scope / nature of training	44

Train - mental health professionals	38
Train - housing professionals	23
Example of bad experience	19
Train - service commissioners	15
Train - families / carers	15
Train - public transport staff / managers	14
Train - receptionists/front line workers	13
Train - Benefits professionals	13
Train - people with ASC	12
Refers to other response/s	12
Reference to NAS	10
Train - emergency services	9
General comment on awareness raising	9
Agree with priority groups in consultation document	8
Example of positive experience	7
Train - assessors	7
Comment on consultation / document	7
Central government role / issues	7
Train - local authorities	7
Train - support workers	6
Train - politicians / policy makers	6
No comment / not applicable	5
Train - community workers	4
Train - residential home staff	4
Train - banks and financial services	3
Reference to Autism Research	3
Transition issues	2
Train - person-centred planners	2
Person-centred plans - use / improve	2
Involve / empower people with ASC	1
National training strategy	1
Train - the NAS	1
The gap - learning disability / mental health	1
Train - funds	1

8.4. Is there anything else that you would like to tell the Government about the need for greater awareness of ASC and training in the condition? (this question corresponds to Q18 of the standard consultation)

Group	**Count**
General comment on strategy / approach	59
Comment on scope / nature of training	57

Benefits of awareness raising / training	44
Example of bad experience	35
Involve / empower people with ASC	35
Comment on funding / resource	29
No additional comments	26
Public awareness campaign	24
Train - all / everyone in contact with ASC	23
Difficulty with diagnosis / assessment	18
Need Government recognition / awareness	18
Reference to NAS	16
Example of positive experience	15
Need for awareness within specific groups	13
Family / carer support and involvement	9
Refers to other response/s	8
Need for equal service everywhere	6
Reference to research	6
Train - police / justice / legal services staff	6
Coordination / continuity service provision	5
Exclusion / discrimination because of ASC	5
Start awareness raising at school	5
Autism alert card	4
Transition issues	4
Train - community workers	3
Help with life skills / challenges	3
Comment on consultation / document	3
Need to get on with it	3
Comment on benefit system	2
Supported living / residential services	2
Comments on disclosure of diagnosis / privacy	2
Vet Government literature / adverts	2
Offer of help / involvement	2
Stop generalised approach / treat as individuals	1
Relationship / parenting advice and support	1
Music therapy	1
Need to include ASC in degrees / curricula	1

Easy read consultation

Many people who work with adults with autism do not understand autism very well. We think there are 3 things that would help these people understand autism better. These are:

***1. Give people like employers and the police more information about autism.
2. Teach people like social workers and people who work in places like colleges, housing offices and Jobcentre Plus about autism.
3. Make sure that new social workers, doctors and nurses are taught about autism as part of the training they have to do before they can start their new job.***

8.5. Do you agree that these are the best ways to help people understand autism better? *(this question corresponds to Q5a of the easy read consultation)*

Group	Count	Proportion
Yes	111	79%
No	11	8%
Not sure	16	11%
No answer	3	2%

8.6. Please tell us why. *(this question corresponds to Q5b of the easy read consultation)*

Group	Count
Agree with key areas	38
No comment / not applicable	26
Comment on training – scope / format	20
Train - all in contact with ASC adults	18
Poor professional understanding	18
Example of bad experience	17
Importance of in depth/continuous training	14
Train - police / justice / legal services staff	8
Train - health professionals	8
Train - teachers / educational services	7
Stop generalised approach / treat as individuals	7
Train - public service workers	6
Train - social services	6
Involve ASC adults in training / work based training	5
Train - government agencies	5
Train - employers / employment services	5
Train - all professionals	4
Importance of diagnosis	4
Autism alert card	3
Involve families / carers	3
Comment on ASC behaviour	3
More areas needed	3
Lack of understanding	2
Refers to other response/s	2

Involve adult with ASC	2
Awareness raising campaign	2
Train - general public	2
Train - benefits services	1
Specialist ASC service	1
Need to get on with it	1
Continuity of support person	1
Comment on consultation / document	1
Train - emergency services	1
Evaluation	1
Train - dentists	1
Keep training material up to date	1
Example of positive experience	1

8.7. Please tell us which people you think most need to have extra training about autism and why. For example, doctors and nurses, social workers, people who work in housing and Jobcentre Plus, people who work in colleges, people who give advice about benefits. *(this question corresponds to Q5c of the easy read consultation)*

Group	Count
All the above	52
Train - health professionals	32
Train - social workers / community care assessors	20
Train - all professionals in contact with ASC	16
Train - police / justice / legal services staff	15
Train - employers / employment services	14
Train - teachers / educational services	13
Train - all in contact with ASC adults	11
Importance of in depth / continuous training	10
Train - general public	10
Train - housing professionals	8
Comment on training – scope / format	7
Train - benefits services	7
Train - public service workers	6
Train - other professionals	5
Train - mental health professionals	4
Importance of diagnosis	4
Train - emergency services	4
Involve ASC adults in training / work based training	4
Stop generalised approach / treat as individuals	3
Train - dentists	3
Train - support workers / advocates / volunteers	3

Example of bad experience	3
Train - government agencies	3
Train - transport workers	2
Poor professional understanding	2
Example of positive experience	2
Autism alert card	1
Awareness raising campaign	1
Refers to other response/s	1
Involve families / carers	1
The gap - learning disability / mental health	1

8.8. Please tell us the kinds of things you would like people such as doctors and nurses, social workers and people who work in housing to know about autism. *(this question corresponds to Q5d of the easy read consultation)*

Group	Count
Understand - communication differences	43
Understand - all about ASC / the Spectrum	34
Understand - ASC behaviour / traits	23
Understand - individual needs	22
Understand - sensory issues	16
Understand - anxiety issues	14
Understand - cognitive differences	13
Consider specific types / different levels of ASC	6
Understand - consistency and routine	5
Understand - perception of truth	5
Understand - lack of social awareness	5
Dealing with / recognise multiple conditions	4
Understand - impact on family	4
Understand - capacities and limitations	3
Example of bad experience	3
Understand - isolation / not in groups	3
Understand - difficulties with life skills / day to day life	3
No comment / not applicable	3
NAS	2
Follow-through after diagnosis	2
Help with - housing	2
Understand - difficulty making choices / decisions	2
Involve families / carers	1
Equality	1
Understand - effect on mental health	1
Lifelong support needed	1
Information is sufficient	1

Refers to other response/s	1
Reference to other source / literature	1
Understand - female ASC adults	1
Involve / empower people with ASC	1
Train - housing professionals	1
Reference to specific group / profession	1
Understand - negative effects of lack of support	1
Help with - employment	1

7. Further comments

Standard consultation

9.1. Do you have any additional comments about what should be included in the adult autism strategy? (this question corresponds to Q23 of the standard consultation)

Group	**Count**
General comment on strategy / approach	136
Comment on consultation / document	65
No additional comments	53
Diagnosis / assessment issues	49
Family / carer support and involvement	46
Wider professional awareness / training	45
Improve access to support and services	44
Example of bad experience/practice	43
Awareness raising / education / information	41
Transition issues	40
Funding / resource issues	40
General comment on attitudes in society	38
Housing / independent or supported living	32
Need for equal service everywhere	29
Need long term support	26
Engagement / partnership	24
Reference to publication/further information	23
Involve / empower people with ASC	23
Communication support / advocacy	21
Reference to NAS	20
Reference to/need for other research / consultation	18
Education / skills / employment services	18
Understand - individual needs	17
Local autism teams	16

Person-centred plans - use / improve	16
Discrimination - gender, ethnicity, disability	15
Human rights/equality issues	15
Consider specific types of ASC	15
Example of positive experience/practice	14
Specific support / advice services	14
Police/CJS	8
Financial support / economic security	8
Information / service directory	7
Concerns on death/aging of parents/carers	7
Peer group support	6
Offer of help / involvement	6
Dealing with / recognise multiple conditions	6
Learn from others / previous experience	6
Problems with life skills / socialising / isolation	5
Commissioning	4
Medication issues	4
Refers to other response/s or Qs	4
Transport / travel	3
Need for quick implementation	3
Need better alignment NHS - LEA - LA	3
Dietary issues	3
Stereotypes	2
Accessible information - people with ASC	2
Dentist issues	2
Employment at appropriate (intellectual) level	2
Driving tests	2
Sensory issues	2
Alternative to triad needed	1
Comment on scope / nature of training	1
The gap - learning disability / mental health	1
Regular checks of people with ASC	1
Good ASC environments	1
Centre of medical excellence	1
Managing risk	1
Autism alert card	1

Easy read consultation

9.2. Please tell us anything else you think we need to do to make life better for adults with autism. *(this question corresponds to Q6 of the easy read consultation)*

Group	Count
Perception and understanding of people with an ASC	31
Education, training and awareness raising	29
Access to employment, education and training	12
Consider specific individual needs, personalisation	10
Comment on consultation / document	9
General comment on strategy / government	8
Improve transition planning / transition issues	8
Financial support / access to benefits / form filling	8
Involvement and empowerment	7
Access to / support with housing	7
Improve diagnostic / post-diagnosis services	7
Local ASC teams / multidisciplinary approach	6
Consistency / reliability of services	6
Example of bad experience	6
Support for parents / family carers of ASC adults	6
Social / leisure / day activity services	6
Revise conditions / legislation	5
Improve overall access to services	5
Equality of opportunity / services	4
Support with accessing services, one to one	4
Reference to policy	4
Specific measures, initiatives to improve lives of ASC people	4
Data collection / sharing information	3
Begin support at a young age	3
Other comment	2
Social Inclusion is not the solution	2
Awareness and support for victims of bullying	2
Reference to other source / literature	1
Concerns on death of parents / carers	1
Access to counselling	1
Example of positive experience	1
No comment / not applicable	1

Appendix 3 – Glossary

This glossary was created by Dialogue by Design during the analysis phase. It is not intended to be a complete glossary of terms for this field but covers the acronyms provided in the responses.

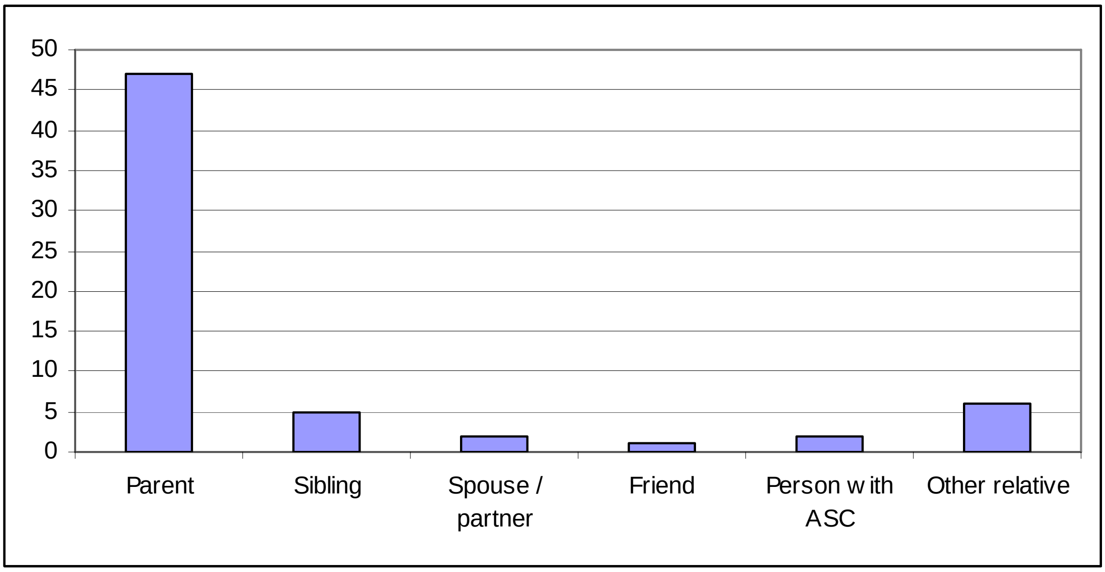
CABS	Citizens Advice Service
CAMHS	Child and Adolescent Mental Health Service
CBT	Cognitive Behavioral Therapy
CCA	Community Care Assessors
CMHT	Community Mental Health Team
CTPLD	Community Team for People with Learning Disabilities
CQC	Care Quality Commission
DASS	Depression Anxiety Stress Scales
DDA	Disability Discrimination Act
DEA	Disability Employment Adviser
DED	Disability Equality Duty
DLA	Disability Living Allowance
DSS	Department for Social Services (currently DWP)
DVLA	Driver and Vehicle Licensing Agency
DWP	Department for Work and Pensions
ESA	Employment and Support Allowance
FAC	Family Autism Centre
FACS	Fair Access to Care Services
HFA	High-Functioning Autism
IAPT	Improving Access to Psychological Therapies
IB	Individual Budget
IEP	Individualised Education Programme
ILF	Independent Living Funds
JSNA	Joint Strategic Needs Assessment
LAs	Local Authorities
LDPB	Learning Disability Partnership Board
LEA	Local Education Authority
LSC	Learning and Skills Council
LSP	Local Strategic Partnership
MDT	Multi Disciplinary Team
NAS	National Autistic Society
NT	Neurotypical
OT	Occupational Therapy
PALS	Patient Advice and Liaison Service
PECS	Picture Exchange Communication System
PCTs	Primary Care Trusts
PMLD	Profound and Multiple Learning Disorders

Prospects	Specialised employment service for people with autism and Asperger syndrome
SEN	Special Education Needs
SENCO	Special Education Needs Coordinator
SLD	Severe Learning Disabilities

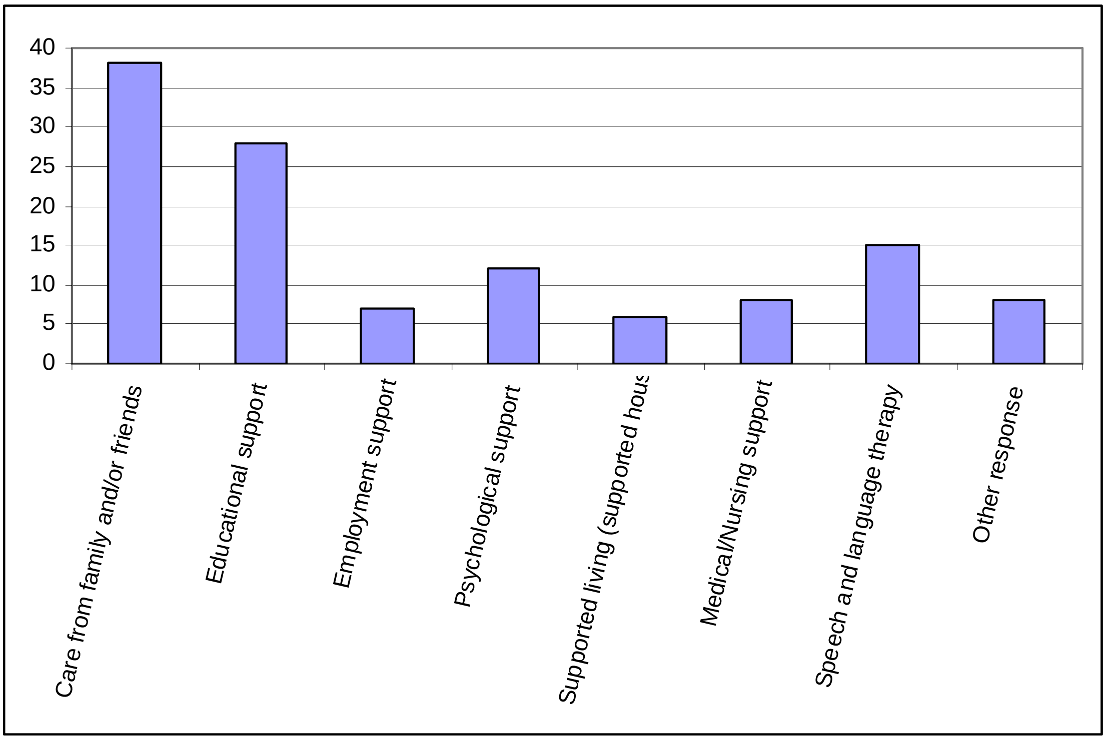
Appendix 4 – Autism Anglia Responses

One particular organisation, Autism Anglia, prepared a shorter version of the questionnaire which asked a different set of profile questions. They sent the revised version to their members and received 80 in return. The responses to the consultation questions were integrated with the other responses but the profile data collected on the participants is shown below.

5a. Relationship to person with an ASC:



5b. What services does the person you care for receive?



5c. Service you work in (total responses = 12):