



Department
of Health

The Government response to the consultation on revised statutory guidance to implement the Strategy for Adults with Autism in England

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Prepared by the Department of Health

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Section 1

Revision of the Guidance, the Consultation Process and Analysis of Responses

This Document

1. This document is a summary of the responses received during the consultation on revised statutory guidance to implement the Strategy for Adults with Autism in England. It highlights the key themes and common issues from the consultation responses and sets out the Government's response that has shaped the statutory guidance.

2. Autism is a lifelong condition that influences how people interpret the world and interact with others. It is estimated that more than 500,000 people in England are on the autism spectrum, which includes people with high functioning autism and Asperger Syndrome. Autism is something that people and their families live with permanently so gaining the right support at the right time can make a significant difference to people's lives.

3. The statutory guidance updates the original guidance,¹ taking into account progress made since 2010 and changes in line with recent legislation such as the Care Act 2014² and the Children and Families Act 2014.³

¹ Implementing Fulfilling and Rewarding Lives – Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy, December 2010 <https://www.gov.uk/government/publications/implementing-fulfilling-and-rewarding-lives>

² Care Act 2014 <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

³ Children and Families Act 2014 <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

Revising the Guidance

4. The Autism Act 2009⁴ places a duty on the Secretary of State for Health to prepare and publish a strategy for meeting the needs of adults with autism in England by improving the provision of relevant services to such adults by local authorities and NHS bodies. That strategy was published in 2010, and was then followed by statutory guidance issued to local authorities and the NHS about the exercise of their, respectively, adult social care and health service functions for the purpose of securing the implementation of the strategy. An updated strategy, Think Autism, was launched in April 2014.

5. Under the Autism Act, the Secretary of State must keep the autism strategy under review, and this led to Think Autism being published in April 2014.⁵ Think Autism is clear that, rather than being a replacement for the 2010 Autism Strategy,⁶ it is an update to that strategy and the Government stands firmly

⁴ Autism Act 2009 <http://www.legislation.gov.uk/ukpga/2009/15/contents>

⁵ "Think Autism" – Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update (2014) <https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>

⁶ "Fulfilling and rewarding lives" The strategy for adults with autism in England (2010) http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

behind the vision and direction of travel that the original strategy set in train. It was also thought appropriate to update the statutory guidance.

The coverage of the Statutory Guidance

6. As required by the Autism Act, the original guidance was issued to local authorities and NHS bodies. These organisations were asked to ensure that the guidance was followed by other organisations that deliver services under contract for them, such as organisations contracted to provide residential or day care on behalf of a local authority. Other providers of public services, such as employment services, police and probation, were not legally required to follow it or to take it into account. However, by following the guidance, as an example of good practice, those bodies could help improve the delivery of the services they provide: for example, ensuring that staff who provide services to adults with autism have received autism awareness training would clearly be of value across all public services.

7. In the revised guidance we remind local authorities and NHS bodies of the need to work with partners, for example in the criminal justice system or helping people with autism in to employment, to achieve much wider benefit.

The Consultation

8. Between 7 November and 19 December 2014 the Department of Health consulted on draft statutory guidance for local authorities and NHS organisations to support implementation of the updated adult autism strategy for England.

9. The main consultation document was published on the Department of Health

website, along with an easy-read version and guidance on holding local and regional consultation events. The consultation was well publicised by social media and with main autism stakeholders.

10. A series of engagement events on the draft guidance with people with autism, family carers, voluntary and independent organisations and statutory bodies also took place. Events were run by organisations including the North East Autism Consortium, Autism West Midlands, Autism Plus and Autism Anglia. The National Autistic Society, the Association of Directors of Adult Social Services (ADASS) and the Local Government Association (LGA) hosted meetings too, in addition to submitting their own responses.

Analysing the Responses

11. In total, 118 responses were received; 53 from organisations (45%), 57 from individuals (48%) and eight sets of notes summarising 17 meetings with more than 230 people (7%). The organisations that responded were mainly voluntary and community groups (40% of organisational responses) and local authorities (30%). Further details about them is found at Annex A and B. Most individuals did not state their roles (44% of individual responses) while of those that did people with autism (21%) and carers (28%) were the main groupings.

12. The numbers and percentages reported in this response cannot be used to indicate strength of feeling or relative importance. Some responses were from organisations or groups representing many hundreds or thousands of people or comprised notes from discussion events with many participants. One response does not equate to one person.

13. The results of the consultation were assessed by the Evidence Centre,

an independent organisation who were commissioned by the Department of Health to draw together key themes from responses to the consultation. The analysis team was not involved in any aspect of the consultation and had no vested interest in the outcome. The purpose of the analysis was to summarise the comments made by respondents, so the Department could make decisions about whether changes should be made to the draft revised guidance.

14. The analysis approach involved reading every response individually and extracting comments about each of the consultation questions and other broad feedback. The feedback was included in an electronic spreadsheet. Feedback was then coded to identify trends. The software packages *SPSS, the Statistical Package for the Social Sciences* and *NVivo* were used as tools to help draw out key trends. The analysis focused on identifying points made by a number of responses and issues raised in single responses which had important implications for redrafting the revised guidance. Trends were extracted based on both significance and numbers. The focus was on practical suggestions that could influence redrafting of the guidance rather than suggestions about changes to other systems and processes outside the remit of the consultation.

Main issues to emerge from the consultation

15. Overall, responses to the consultation were favourable about the principles underpinning the guidance and the scope of content within the draft document. In light of some comments we considered that some of the things the consultation draft stated local authorities “should seek to do” were in fact existing legal duties and could be made

stronger. This has resulted in some re-drafting of the consultation draft. Therefore where the document now says that local authorities or the NHS must or should take certain actions, these mostly relate to existing requirements from the 2010 guidance or other current legislation. Others commented similarly on the use of case studies or examples and the status of these. Case studies do not form part of the guidance itself, but are intended as an illustration of the principles outlined.

16. There were some concerns over whether the guidance would be feasible to implement in practice and how it would be monitored. The National Autism Self-Assessment Framework exercises⁷ undertaken by Public Health England are a key means of identifying progress in implementing the strategy as a whole and for demonstrating local accountability and will continue.

17. Many suggestions for refinement related to language, clarity and specific content and we have tried to accommodate these where ever possible. Suggestions for development tended to focus on changes to wording or adding new information, some of which was not within the remit of the guidance.

18. Areas that were repeatedly mentioned included the:

- importance of using more directive and proactive language;
- value of co-production and consultation with people with autism and carers;
- need for good initial and refresher training across organisations and sectors;
- need to allocate dedicated local funding to support service developments;

⁷ The National Autism Self-Assessment Framework exercises – <https://www.gov.uk/government/news/adult-autism-strategy-next-steps-in-the-national-self-assessment-framework-exercise>

- need for health and social services to work together and to work with partners;
- importance of involving the voluntary sector;
- need to set up monitoring processes to assess progress;
- importance of cross-referencing to other guidance, legislation and resources.

Use of language in the Statutory Guidance

19. Throughout this document and the statutory guidance the term ‘people with autism’ is used in line with the wording of the adult autism strategy. However, it is acknowledged that this is not a universally accepted term and some people and groups prefer the term ‘autistic people.’ The term ‘autism’ is also used as an umbrella term for autistic spectrum conditions, including Asperger Syndrome. This ensures consistency of wording across documents, but it is recognised that this terminology may not be preferred by all.

Financial Issues

20. Local Authorities and NHS organisations were asked if there was anything in the consultation draft that they were not already doing or had not planned to do and therefore considered it unreasonable due to reasons of affordability. Only a very small number of bodies and organisations answered these questions, and an even smaller number raised financial concerns (and most of these did not provide specific details). Details are set out in the tables under each feedback section. The small number of financial concerns is judged to be because local authorities and the NHS were already tackling this work through implementing the Adult

Autism Strategy over the last four years or under other legislation. This is borne out by the results of the Autism self-assessment framework exercises undertaken by Public Health England. The 2013/14 results from all local authority areas are found at www.ihal.org.uk/projects/autism2013. The assessments are a key means of identifying progress in implementing the strategy as a whole and for demonstrating local accountability. Responses to the latest exercise are due during March 2015.

Section 2. Feedback and the Government's response on:

1. Training staff
2. Identification and diagnosis
3. Planning for transitions
4. Local planning and leadership
5. Preventative support and safeguarding
6. Reasonable adjustments
7. Supporting people with complex needs
8. Employment
9. Working with the criminal justice system

1. Training staff

Consultation questions	Number of responses	Agree	Disagree	Unknown
Section 1: Training of staff who provide services to adults with autism				
Q1.1 Do you think that this guidance explains the responsibilities that local authorities and NHS bodies have around training for their staff and is sufficiently clear about what they should be doing?	65	40%	40%	20%
Q1.2 Is the guidance on responsibilities reasonable?	67	49%	31%	19%
Q1.3 Do we need to highlight further the role that adults with autism and their families or carers should be playing in training programmes? If so, how?	64	73%	14%	12%
Q1.4 What else do we need to include to ensure specific specialist autism training is provided to staff that carry out statutory assessments?	60	Not applicable – not yes/no answer		
Q1.5 Would a description in the guidance setting out outcomes to be met at a particular level of autism training be helpful?	61	80%	16%	3%
Q1.6 Is there sufficient information on how health bodies should commission training?	49	27%	61%	12%
Q1.7 For local authorities and health bodies – is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?	24 of which 19 were from councils and health bodies	37% of 19	32%	32%
Q1.8 Have you other comments on this section?	53	Not applicable – not yes/no answer		

What we heard

1.1. Opinions were divided over whether the guidance for local authority and NHS responsibilities for staff training was reasonable. Many who responded thought the guidance should further highlight the role that adults with autism and their carers could play in training. It was also thought that the guidance could encourage specialist autism training for staff that undertake statutory assessments. A typical view was that the guidance was clear that local authorities should by now be providing general autism awareness to all frontline staff in contact with adults with autism and that progress should be being made with regard to specialist training for those with direct impact on access to services for adults with autism.

1.2. Many respondents thought that it should be made clear to local authorities and health bodies that training should cover all parts of the autism spectrum. Some respondents thought that staff should, as a result of training, be able to understand for example the adjustments that they will need to make for someone with less communication ability or who is non-verbal, or be able to identify people with Asperger syndrome whose needs may be less obvious. It is also important that training discouraged reliance on stereotypes of autism. Information on how health bodies should commission training drew a significant amount of comment.

What we have said in the Guidance

1.3. Improving training around autism is seen to be at the heart of the autism strategy for all public service staff but particularly for those working in health and social care. The guidance looks not only at general autism awareness training but also different levels of specialist training. It re-enforces existing requirements that basic autism training should be available to all staff working in health and social care, particularly front line staff who are in contact with adults with autism so that they can make reasonable adjustments for them. This section of the guidance also highlights that the Care and Support (Assessment) Regulations 2014⁸ will require local authorities to ensure that a person undertaking an assessment of an adult's care and support needs is appropriately trained, including in autism or consults someone who is when the circumstances require it. Good practice and advice is provided, including involving people with autism in the planning and delivery of training, as well as how to access some central resources.

1.4. The guidance clearly highlights the roles of service users and their carers/family members in shaping training programmes. Also reinforced in the guidance that local authorities and NHS bodies should look to have a multi-agency autism training plan. This will allow voluntary and other non-statutory organisations who work with service users and their carers/families to be involved in shaping local training programmes.

1.5. It was felt that providing information on how local training should be provided or setting outcomes for training were requirements that were too prescriptive for the statutory guidance.

⁸ Care and Support (Assessment) Regulations 2014 – http://www.legislation.gov.uk/uksi/2014/2827/pdfs/uksi_20142827_en.pdf

2. Identification and diagnosis

Consultation questions	Number of responses	Agree	Disagree	Unknown
Section 2: Identification and diagnosis of autism in adults, leading to assessment of needs for services				
Q2.1 Do you think this guidance explains the responsibilities that local authorities, NHS bodies have around assessment and diagnosis of autism for NHS and local authority staff and is sufficiently clear about what they should be doing?	61	39%	61%	0%
Q2.2 If you are a commissioner of local care services, are you clear about what your responsibilities are? Are they reasonable?	24 of which 16 were from commissioners	81% of 16	19%	0%
Q2.3 If you are a CCG or other health body, are you clear about what your responsibilities are? Are they reasonable?	14 of which 3 were from health bodies	33% of 3	67%	0%
Q2.4 For local authorities and health bodies – is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?	21 of which 15 were from councils and health bodies	47% of 15	47%	7%
Q2.5 Have you any other comments?	56	Not applicable – not yes/no answer		

What we heard

2.1. It was evident that many people responding to the consultation thought that the guidance could better explain the responsibilities that local authorities and NHS bodies have around assessment and diagnosis of autism. A majority of service commissioners and Clinical Commissioning Groups (CCGs) who had responded were clear however about their responsibilities in this respect. Other comments related to ensuring prompt diagnosis and sharing of information between services; seeking clarification on responsibilities such as training for GPs; considering people’s capacity to take part in assessments; demand exceeding the resources available locally for diagnosis and assessments; making reference to other guidance, and mentioning the need for post-diagnostic services and support. Many respondents wanted to see NHS bodies and local authorities working together effectively, and with other public services, to ensure

that where there is need people are referred promptly for diagnosis and assessment. The NICE best practice guidelines were seen as bringing structure to the process but it was felt more areas needed to follow them.

What we have said in the Guidance

2.2. The statutory guidance is very clear that diagnosis can be particularly important for adults who did not have their condition or sensory issues recognised as children. A diagnosis can be an important step in ensuring that support takes account of how a person’s autism affects them and their whole family, as well as their participation in learning, employment or other activities. The guidance provides clarification that while local authorities will lead commissioning for care and support services for people with autism, CCGs are expected to take the lead responsibility for commissioning of diagnostic services to identify people with autism, and

work with local authorities to provide post-diagnostic support for people with autism based on their needs.

2.3. The guidance considers progress that has been made. Each local authority area should have an easily accessible autism diagnostic service and key professionals such as GPs and mental health practitioners should be aware of the pathway and of how to refer to it. NHS England will look at people's experiences of the autism diagnostic process locally and assure themselves that this is acceptable. Good practice is referred to, including the NICE guidelines⁹ which recommend that people seeking an autism diagnosis have a first appointment within 3 months of their referral and the role of other professionals, such as those working in mental health, who with training and support can also play a role in the autism diagnosis process.

2.4. This section of the guidance also links to Section 9 of the Care Act 2014 where an assessment may be triggered either by a person or their carer requesting it or if the local authority believes community care services may be necessary. This is not dependent on the person having been formally diagnosed as having autism.

2.5. A number of Autism Innovation Fund projects are looking at low level non statutory support for people with autism, including in the post diagnosis period, and the Department of Health will also be undertaking some preliminary research on this issue with the Institute of Education at University College London.

⁹ Autism: recognition, referral, diagnosis and management of adults on the autism spectrum <http://www.nice.org.uk/guidance/cg142/resources/guidance-autism-recognition-referral-diagnosis-and-management-of-adults-on-the-autism-spectrum-pdf>

3. Planning for transitions

Consultation questions	Number of responses	Agree	Disagree	Unknown
Section 3: Planning in relation to the provision of services for people with autism as they move from being children to adults				
Q3.1 Do you think that this guidance appropriately summarises the responsibilities from the Children and Families Act that local authorities and their partners have around transition from child to adult services for young people with autism?	43	60%	33%	7%
Q3.2 In terms of young people with autism approaching transition without SEN statements or Education Health and Care Plan, is there anything further we should be highlighting in the guidance to ensure they receive appropriate support?	45	62%	7%	31%
Q3.3 For local authorities and health bodies – is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?	19 of which 14 were from councils or health bodies	29% of 14	64%	7%
Q3.4 Have you any other comments on this section?	43	Not applicable – not yes/no answer		

What we heard

3.1. The majority of responses thought that the guidance appropriately summarised the responsibilities from the Children and Families Act. Most responses suggested further guidance would be helpful about young people with autism approaching transition without SEN statements or Education Health and Care Plans. Other comments were related to timeframes for transition; highlighting that transition can occur throughout the life of a person; and cross referencing to other documentation; including housing, employment and emotional support in local offers.

What we have said in the Guidance

3.2. The Children and Families Act 2014 provides for a new special educational needs and disability (SEND) support system, covering education, health and social care.

Under the provisions of that Act, a young person (someone over compulsory school age and under 25) can ask the local authority to assess their Education, Health and Care (EHC) needs. Others, including schools and colleges, can also make such a request. This is with a view to an EHC plan being drawn up for the young person that sets out the special EHC provision required. The young person can further expect, when an EHC plan is being drawn up, to be able (subject to certain limited criteria being met) to choose which school or further education (FE) college they are to attend. They will also be given the opportunity of a Personal Budget to control some of the provision set out in an EHC plan.

3.3. However, local authorities, NHS bodies and Foundation Trusts need to recognise that not all young people with autism will have EHC plans. Receiving support in making the transition to adulthood, and accessing appropriate services as an adult should not be dependent on having an EHC plan. Indeed the Care and Support statutory guidance,

issued under the Care Act, sets out that local authorities should consider how they can identify young people who are not receiving children's services who are likely to have care and support needs as an adult. The guidance identifies young people with autism whose needs have been largely met by their educational institution as an example.

4. Local planning and leadership

Consultation questions	Number of responses	Agree	Disagree	Unknown
Section 4: Local planning and leadership in relation to the provision of services for adults with autism				
Q4.1 Are responsibilities for leading and joining up local partnership arrangements sufficiently clear?	53	51%	42%	7%
Q4.2 If you have autism, or are a parent or carer or someone who has, is there anything further that organisations should do to ensure that your voice is heard in local planning?	43 of which 37 were from service users, carers or representatives	78% of 37	0%	22%
Q4.3 Is any further advice or guidance needed on data collection and using data to plan effectively?	46	78%	13%	9%
Q4.4 For local authorities and health bodies – is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?	16 of which 13 were councils or health bodies	38% of 13	46%	15%
Q4.5 Have you any other comments on this section?	48	Not applicable – not yes/no answer		

What we heard

4.1. Opinions were divided with just over half of responses stating that responsibilities for leading and joining up local partnership arrangements were sufficiently clear. Most responses from people with autism or carers thought there were further things organisations should do to ensure that their voices were heard in local planning. Respondents on the whole thought further guidance was needed about data collection and using data to plan effectively.

4.2. A number of respondents commented on the importance of having meaningful local autism partnership arrangement, and that this may take many different forms in different local areas. It was felt that it was still difficult for adults from across the autistic spectrum to be meaningfully involved in the meetings themselves especially if acronyms were used and discussions took place quickly. The meetings can also be large and daunting for people with social interaction

and communication difficulties. There were concerns that representatives from the agencies who attend can change from meeting to meeting and this can result in a series of sporadic actions.

4.3. There was a need to improve the quality of data available, including coding on primary care data systems. Planning and working in partnership was seen as central to providing good support to people with autism and their families.

What we have said in the Guidance

4.4. This section provides an overview of the planning and leadership needed locally in relation to the provision of services for adults with autism. The role of Health and Wellbeing Boards in overseeing local implementation of the Adult Autism Strategy and the development of strategies based on local evidence contained in Joint Strategic Needs Assessments are crucial in

improving outcomes for people with autism. A key action for local authorities is to have a joint commissioner/senior manager to lead commissioning of care and support services for adults. Also ensuring that there are meaningful local autism partnership arrangements that bring together different organisations, services and stakeholders locally, including the CCG and people with autism, and sets a clear direction for improved services. It is important that these arrangements continue and strengthen.

4.5. Information on good practice in planning and commissioning effectively for people with autism is outlined, and this will be supplemented in due course with further information from the data group action set out in Think Autism. The work by the Royal College of GPs Autism Initiative on GP coding may also help in this area if adopted widely. There are parts of the local population where more awareness is needed including supporting older adults with autism and people with autism from BAEM communities and they are considered in more detail. Further work in this area involving people with autism and their gender, sexuality and sexual orientation, beliefs and race will be undertaken by the Department of Health in 2015.

5. Preventative support and safeguarding

Consultation questions	Number of responses	Agree	Disagree	Unknown
Section 5: Preventative support and Safeguarding in line with the Care Act				
Q5.1 Are the new duties on delivering preventative support at each tier of prevention under the Care Act sufficiently clear in relation to autism services, including how to promote wellbeing for a young person transitioning to adulthood?	48	40%	60%	0%
Q5.2 Do you agree with the description of preventative services provided?	46	48%	26%	26%
Q5.3 Is it clear how to develop preventative services according to local needs?	41	41%	32%	27%
Q5.4 For local authorities and health bodies – is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?	18 of which 13 were councils or health bodies	54% of 13	46%	0%
Q5.5 Have you any other comments on this section?	52	Not applicable – not yes/no answer		

What we heard

5.1. Many respondents wanted more information about the new duties about preventative support. Most responses however agreed with the description of preventative services in the guidance. Other comments related to preventative care and safeguarding included the need for better promotion of existing services; the need for proactively reaching out to support people with autism and carers; the desire to see carers' needs more explicitly represented; suggestions about specific preventive services; and the need to highlight potential cost benefits from prevention.

5.2. A majority of respondents thought the description of preventative services was reasonable and good, especially the recognition of local user led support groups, and also that lessons could be learned from existing preventative service models and from Autism Innovation Fund projects.

5.3. Some people with autism and carers attested to the benefits of preventive support. One person said that low level support is the key to high functioning autistic people not needing far more expensive high level support. A visit from a housing support officer once a month for just half an hour, meant they could navigate welfare and council services. Another said that even something with hardly any costs such as peer support can make a difference between a person dealing with a situation and starting to make a difference in their life and the expense of a psychiatric section.

What we have said in the Guidance

5.4. Preventative support is important for people with autism. When people with autism do not have the right preventative support the result can be that they can spiral into mental health crises with parents/carers left to pick up the pieces or, if they are not available, expensive and inappropriate inpatient

admissions or even contact with the criminal justice system.

5.5. From April 2015, section 2 of the Care Act will place a duty on local authorities to provide or arrange preventative services for people within their communities. In discharging their duties on prevention, local authorities should, in particular, ensure they are considering the needs of their local adult population who have autism, including those who do not meet the eligibility threshold for care and support.

5.6. The term “prevention” or “preventative” measures can cover many different types of support, services, facilities or other resources. There is no one definition for what constitutes preventative activity and this can range from wide-scale whole-population measures aimed at promoting health, to more targeted, individual interventions aimed at improving skills or functioning for one person or a particular group or lessening the impact of caring on a carer’s health and wellbeing. In considering how to give effect to their responsibilities, local authorities should consider the range of options available, and how those different approaches could support the needs of people with autism.

5.7. Local authorities must make information and advice available on how to raise concerns about the safety or wellbeing of an adult who is at risk of abuse or neglect because of their needs for care and support and should support public knowledge and awareness of different types of abuse and neglect and how to keep or support people with care and support needs to be physically, sexually, financially and emotionally safe. This information and advice should also cover who to tell when there are concerns about abuse or neglect and what will happen when such concerns are raised, including information on how the local Safeguarding Board works.

5.8. The Care Act makes the local authority’s adult safeguarding duties statutory, in recognition of the need to proactively help and protect people with care and support needs, including people with autism, to keep safe from the risks of abuse or neglect. It places the establishment of Safeguarding Adults Boards on a statutory footing, so as to ensure local authorities, CCGs and chief police officers work together to develop and implement adult safeguarding strategies. This will better prepare local agencies who have relevant care and support functions both to prevent abuse or neglect and to respond to it when it occurs.

6. Reasonable adjustments

Consultation questions	Number of responses	Agree	Disagree	Unknown
Section 6: Reasonable adjustments				
Q6.1 Is the approach to reasonable adjustments for people with autism sufficiently explained?	51	49%	37%	14%
Q6.2 Are the responsibilities of public services clear in regard to making reasonable adjustments to support people with autism?	49	43%	49%	8%
Q6.3 For local authorities and health bodies – is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?	16 of which 14 were councils or health bodies	50% of 14	50%	0%
Q6.4 Have you any other comments on this section?	43	Not applicable – not yes/no answer		

What we heard

6.1. Most responses thought the approach to reasonable adjustments for people with autism was sufficiently explained, particularly the physical adjustments that can be made to support people with autism. However just under half of responses thought the responsibilities were clear regarding public services making reasonable adjustments. Other comments about reasonable adjustments included a desire to involve people with autism in defining what is needed; and linking to the Equality Act.

6.2. Some respondents thought that emphasis should be placed on the duties of other organisations under the Equality Act 2010.¹⁰ This was felt especially necessary in relation to support on employment and in the criminal justice system. These areas were seen as having statutory duties under the Equality Act 2010 and should, under that Act, be making adjustments for all people with disabilities including those with autism.

What we have said in the Guidance

6.3. Under the Equality Act 2010, all public sector organisations, including employers and providers of services, are required to make reasonable adjustments to services with the aim of ensuring they are accessible to disabled people, including people with autism. Without reasonable adjustments many services can be inaccessible for adults with autism. It is made clear to public services that putting in place reasonable adjustments can ensure that adults with autism are able to benefit fully from mainstream public services to live independently and healthily. Examples of reasonable adjustments for people with autism have been outlined.

¹⁰ Equality Act 2010 – <http://www.legislation.gov.uk/ukpga/2010/15/contents>

7. Supporting people with complex needs

Consultation questions	Number of responses	Agree	Disagree	Unknown
Section 7: Supporting people with complex needs, whose behaviour may challenge or who may lack capacity				
Q7.1 Do you think that this section of the guidance is sufficiently clearly worded and will be understood by health and social care professionals, commissioners, people with autism and parents/carers?	46	57%	26%	17%
Q7.2 If not, what changes would you propose?	25	Not applicable – not yes/no answer		
Q7.3 Does it cover all relevant requirements on the Mental Capacity Act, and the Mental Health Act?	36	42%	44%	14%
Q7.4 Is the guidance sufficiently clear about what NHS and local authority organisations and staff should be doing to improve services for people?	38	50%	37%	13%
Q7.5 If you are a commissioner of local care services, are you clear about what your responsibilities are?	16 of which 11 were commissioners	82% of 11	18%	0%
Q7.6 For local authorities and health bodies – is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?	12 all of which were councils or health bodies	33%	58%	8%
Q7.7 Have you any other comments on this section?	25	Not applicable – not yes/no answer		

What we heard

7.1. Most responses stated that the section about supporting people with complex needs was clearly worded and easy to understand. About equal proportions said this section did and did not cover all relevant requirements from the Mental Capacity Act 2005 (MCA)¹¹ and the Mental Health Act.¹²

7.2. Opinions were divided on whether the guidance was clear about what NHS and local authority organisations and staff should be doing to improve services. A significant number of commissioners said

they were clear about their responsibilities for supporting people with complex needs.

What we have said in the Guidance

7.3. People with autism or learning disabilities, who also have mental health conditions or behaviours viewed as challenging are entitled to get good quality safe care, whether at home, living in the community or in hospital. This section provides guidance on how to effectively support individuals with the most complex needs wherever they are receiving care and treatment.

7.4. It is important that those who support people with complex needs, whose behaviour

¹¹ Mental Capacity Act 2005 – <http://www.legislation.gov.uk/ukpga/2005/9/contents>

¹² Mental Health Act 1983 – <http://www.legislation.gov.uk/ukpga/1983/20/contents>

may challenge or who may lack capacity should have a good understanding of supported decision-making; understand the principle that people should not be treated as lacking capacity simply because they make an unwise decision; should consider their wishes and feelings; and all health and social care organisations need to understand the principle of least restrictive care – which means identifying a range of interventions and seeking the least restrictive ones for people with autism.

7.5. Support for complex needs is not just about those people currently within inpatient settings but also about ensuring support for those who may be at risk of going into them in future. Care staff both in local authority teams such as those assessing adults' care and support needs and NHS funded providers need to have a good understanding of the MCA in order to help people with autism. Professionals working with those with autism must be aware of and act within the MCA. The guidance highlights that they must have an understanding of what restrictions may be imposed through a person's care and the need to minimise restrictions and maximise individual freedoms. In accordance with the MCA's guiding principles, that professionals who provide care to an individual who lacks capacity must consider whether the care is being provided in the least restrictive way possible to achieve the intended outcome. Where restrictions on an individual are of a degree that may amount to a deprivation of liberty, this must be authorised under the Deprivation of Liberty Safeguards or by an order of the Court of Protection under the MCA.

8. Employment

Consultation questions	Number of responses	Agree	Disagree	Unknown
Section 8: Employment for adults with autism				
Q8.1 Do you think that this section of the guidance is clearly worded and will be understood by health and social care professionals, people with autism and parents/ carers?	49	57%	33%	10%
Q8.2 If not what changes would you propose?	26	Not applicable – not yes/no answer		
Q8.3 Do you have any other comments on helping adults with autism into work?	43	Not applicable – not yes/no answer		
Q8.4 How should local authorities ensure that social care support and planning for people with autism is working effectively with employment support, including Job centres?	40	Not applicable – not yes/no answer		
Q8.5 For local authorities and health bodies – is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?	17 of which 14 were councils or health bodies	29% of 14	50%	21%
Q8.6 Have you any other comments on this section?	34	Not applicable – not yes/no answer		

What we heard

8.1. Most responses thought the guidance about employment was clearly worded and easily understood. Other comments about helping adults with autism into work included the need to raise awareness amongst potential employers of the benefits of working with people with autism; strengthening the description in the guidance of different types of support available; working in partnership with the Department for Work and Pensions; considering what reasonable adjustments may be feasible in the workplace, and recognising the value of volunteering and self-employment.

8.2. Suggestions about how to ensure social care support and employment support worked together included improving awareness and skills among Job Centre staff; increasing awareness amongst employers; and getting more employers and Job Centre staff to participate in local autism partnership boards.

What we have said in the Guidance

8.3. Local authorities can play a key role in supporting adults with autism in their area to gain employment by making sure that participation in employment is a matter considered in needs assessments, and in the exercise of their other care and support functions in respect of an individual, and that the care planning process takes account of existing or future work opportunities.

8.4. Local authorities also have a role to play in the provision or arrangement of preventative services and facilities; and in effective transition planning to ensure successful transition of young people with autism from education into employment.

9. Working with the criminal justice system

Consultation questions	Number of responses	Agree	Disagree	Unknown
Section 9: Working with the Criminal Justice system				
Q9.1 What more could be included on how local authorities and the NHS should work with Criminal Justice System partners?	40	Not applicable – not yes/no answer		
Q9.2 Is the process for Liaison and Diversion sufficiently explained?	32	63%	34%	3%
Q9.3 Do you have any other comments on helping to support people with autism who come into contact with the criminal justice system?	35	Not applicable – not yes/no answer		
Q9.4 For local authorities and health bodies – is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?	14 of which 13 were councils and health bodies	15% of 13	54%	31%
Q9.5 Have you any other comments on this section?	32	Not applicable – not yes/no answer		

What we heard

9.1. Most responses said the process for liaison and diversion was sufficiently explained. Suggestions for how local authorities and the NHS should work with the criminal justice system included providing joint training for health, social services and criminal justice system staff; clarifying the responsibilities of the criminal justice sector; and including representatives from criminal justice on autism partnership boards. It was also felt that the guidance needed to make the process on discharge from prisons clearer.

What we have said in the Guidance

9.2. People with autism need access to support whether they are a victim, or witness, or are suspected of committing a crime. Local authorities, NHS bodies and Foundation Trusts can play a key role in supporting adults with autism who come into contact with the criminal justice system.

9.3. Wherever possible, local authority based Community Safety Partnerships (CSPs) should be used as a vehicle for bringing agencies together to develop plans to support the Autism Strategy. CSPs are an important feature of the network of partnerships that help to tackle crime, and usually work at district or unitary authority level. Five ‘responsible authorities’ have statutory membership. These are the local authority; police; probation; CCGs; and the fire and rescue authority.

9.4. There is a need for the criminal justice system to refer people with autism for appropriate health and care support to divert them from offending, where appropriate, and prevent re-offending. Most usefully, as the Liaison and Diversion approach is rolled out, local authorities in partnership with NHS bodies and Foundation Trusts could connect the local authority autism leads, relevant community care assessment teams, and local preventative services with local Liaison and Diversion services.

9.5. Local authorities have responsibilities, under the Care Act from April 2015, to assess the care and support needs of adults (including those with autism) who may have such needs in prison or other forms of detention in their areas (and to meet those needs which are eligible). NHS England is responsible for arranging the provision of health services for prisoners. This will include offering access to the local diagnosis pathway and access to assessment of care and support needs in advance of release from prison.

Annex A

Organisations and groups that named themselves in consultation responses

- Adult Autism Diagnostic Service for Suffolk
- April Centre
- ASPIE
- Association of Directors of Adult Social Services (ADASS) and Local Government Association
- Autism Sussex
- Autistic UK
- British Association for Counselling and Psychotherapy (BACP)
- British Association for Supported Employment (BASE)
- Cheshire and Wirral Partnership NHS Foundation Trust
- Children and Families team at NHS Cumbria Clinical Commissioning Group
- Children's Services Development Group
- East Midlands Adult Asperger Support Group
- Essex County Council
- Hao2.eu
- Hull County Council
- Kent County Council
- KeyRing Living Support Networks
- Lancashire County Council
- Lincolnshire County Council
- London Borough of Barnet and Barnet Clinical Commissioning Group
- London Borough of Bexley
- London Fire and Emergency Planning Authority
- Mental Health Lawyers' Association
- National Autistic Society
- National Autistic Society – Cheshire West and Chester Branch
- National Autistic Society Avon Branch
- North Yorkshire County Council
- Optical Confederation and the Local Optical Committee Support Unit (LOCSU)
- Prison Reform Trust
- Pure Innovations – High Functioning Autism & AS Employment Support Team
- Real Life Options
- Royal College of Psychiatrists
- SAFE South
- The Disabilities Trust, Autism Spectrum Partners
- Waltham Forest Borough Council
- Warrington Borough Council
- West Hampshire Clinical Commissioning Group
- Worcestershire County Council
- Zarbanoo

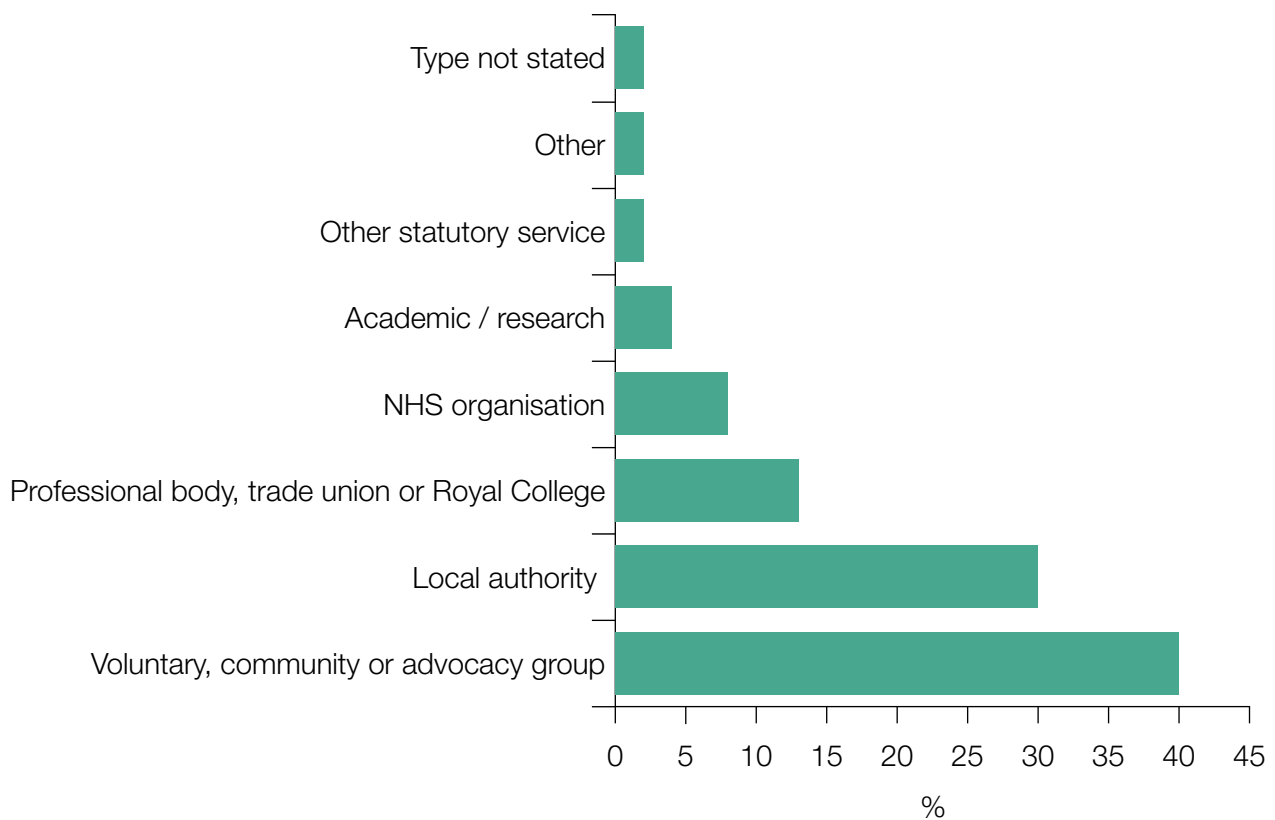
Note: Responses from the Newham Clinical Commissioning Group and Ambitious about Autism were also received by the Department but were not available for inclusion in the independent summary of consultation responses analysis by the Evidence Centre. They were considered by Department of Health and other Government department officials. Other organisations completed the online feedback form but did not provide their names.

Annex B

Types of organisations responding to the consultation

Figure 1 provides a summary breakdown of the types of organisations who responded to the consultation.

Figure 1: Types of organisations responding to the consultation



Note: 53 organisations and groups responded to the consultation. In one case the type of organisation was not given.



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