Getting it right for people with autism – the research behind the ‘Autism skills and knowledge list’

Part of the ‘Better social care and health outcomes for people with autism’ series.

Summer 2011
Acknowledgements

We want to thank all the members of the focus groups who have shared with us their expertise and experiences of health and social care services. We particularly want to thank them and their supporters for the time and effort they have put into contributing to this report. We have used this information in the report but have made it anonymous, it has been used to illustrate individual experiences and does not reflect an evaluation of the types of services referred to.

Skills for Care and Skills for Health wish to acknowledge the work of the National Autistic Society (NAS) in researching and drafting this report, in particular the NAS staff members Karen Hynes, Steven Owens and Dorothy Lowe.
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1. Introduction

This project was undertaken by workers from Skills for Care and the National Autistic Society (NAS), funded by the Department of Health and managed jointly by Skills for Care and Skills for Health. This publication is very closely modelled on the project report that Skills for Care and Skills for Health received from NAS.

The aim of the project
To create a framework to guide the delivery of autism training for the generic or mainstream health and social care workforces, i.e. those who are not working in autism-specific services, across all age ranges but with a focus on adults.

As a result of this work three main products have been developed under the series heading ‘Better social care and health outcomes for people with autism’:

- Autism skills and knowledge list, for workers in generic social care and health services
- Implementing the ‘autism skills and knowledge list’ through staff training and development. For those who plan, commission and deliver workforce development for workers in generic health and social care services.
- Getting it right for people with autism – the research behind the ‘autism skills and knowledge list’. (This is the present document.)

All the documents are free from the autism sections of www.skillsforhealth.org.uk and www.skillsforcare.org.uk where there are also links to other autism resources.

Why we use the word ‘autism’

For clarity, Skills for Care and Skills for Health have chosen to use the same terminology as in the government’s ‘autism strategy’ of 2010, which says:

“…there are a number of terms that different individuals and groups prefer to use, including autistic spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity. In this strategy, we use the term “autism” as an umbrella term for all such conditions, including Asperger syndrome. This is in line with the approach to terminology adopted by key autism representative organisations, including the National Autistic Society (NAS)...”


The project objectives
1. Gather views on what is important in delivering services, from people with autism, carers* and supporters of people with autism and a wide range of health and social care staff at all levels in their organisations.
2. Conduct a literature review of existing guidance and frameworks.
3. Draw conclusions to inform a recommended framework to guide employers, managers and staff within the health and social care workforces.

* ‘Carer’ is used throughout to indicate family and friends who give social care or health support, as distinct from workers including volunteers.
Who are the materials for?
The resulting framework has been published as the ‘Autism skills and knowledge list’ and is designed to inform and guide health and social care commissioners, employers, managers and workers to ensure that they create the right environment with appropriately competent and knowledgeable staff to provide a fair and equal service to people with autism.

Implementing the ‘autism skills and knowledge list’ through staff training and development has been published as an accompanying document particularly for the benefit of managers and trainers responsible for workers’ development.

2. Recommendations

1. Training the workforce is part of the solution but there is also a need for changes to the infrastructure of organisations to enable staff to use their knowledge and skills. Commissioners and senior managers need to focus on strategic planning to meet the needs of people with autism.

2. The underpinning values and attitudes of staff are critical. Recruitment practice, the use of probationary periods and longer term performance management and disciplinary processes all need to be used to ensure that staff with the right attitudes are in post and are operating in the right way.

3. There is a need for specialist services and/or expertise for generic service providers to call on or refer to.

4. Autonomy and flexibility is reasonably high. This needs maintaining and increasing.

5. There are several suggested and acceptable methods of training delivery. The need to use Information and Communications Technology in learning is increasing for both practical and cost reasons.

6. Learning directly from people with autism and their carers is seen to be highly desirable by all groups.

7. People with autism and their carers could support workers to offer a better service by providing written guidance about their needs, but this would need to be kept brief to ensure workers have time to read it.

8. All workers in health and social care should have the required underpinning values and attitudes and the basic level awareness of autism. At least one person in each service or team should have intermediate level knowledge and skills.
3. Methodology

This section will outline the methodology used to develop the framework and present the findings from this.

3.1 Gathering initial findings

The main source of data used was an online questionnaire covering:
- people with autism
- carers and supporters of people with autism
- a wide range of health and social care staff at all levels in their organisations.

An online and paper-based literature review was undertaken to understand, consider and possibly incorporate existing research and supporting frameworks in to this work. Additional information on this search can be found in the references and bibliography. In addition, we were able to incorporate the data from an allied project, conducted by a separate team within the National Autistic Society (also funded by the Department of Health), which carried out focus groups in England and Wales with health and social care commissioners and service providers to help in developing online resources and materials that will assist in implementing the Autism Strategy. These resources are available at www.autism.org.uk/autismstrategy

3.2 Survey response rates

A breakdown of the responses received to the online survey is outlined below:

<table>
<thead>
<tr>
<th>Group</th>
<th>Individual responses</th>
<th>Percentage of total responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Commissioners of social care services</td>
<td>76</td>
<td>3%</td>
</tr>
<tr>
<td>Managers &amp; employers of social care services</td>
<td>296</td>
<td>13%</td>
</tr>
<tr>
<td>Social care workers</td>
<td>239</td>
<td>10%</td>
</tr>
<tr>
<td>Commissioners in health services</td>
<td>30</td>
<td>1%</td>
</tr>
<tr>
<td>Managers &amp; employers in health services</td>
<td>84</td>
<td>4%</td>
</tr>
<tr>
<td>Health care workers</td>
<td>634</td>
<td>27%</td>
</tr>
<tr>
<td>People who support a person with autism</td>
<td>836</td>
<td>36%</td>
</tr>
<tr>
<td>People with autism</td>
<td>120</td>
<td>5%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>2,315</strong></td>
<td>(percentages rounded)</td>
</tr>
</tbody>
</table>

More than a third (36%) of respondents to the on-line survey were **carers and supporters of people with autism**. This group made good use of the opportunity to provide additional comments which provided insights into a broad range of experiences relating to accessing services.

One in twenty respondents (5%) were **people with autism**. This group also made good
necessitated follow-up phone calls to elicit further information or to clarify the researchers’ understanding.

The documents and frameworks identified provided data which highlighted gaps in the existing research and also provided some additional information to corroborate the findings of the online survey. In addition, the documents provided useful ideas and possibilities for ways to format and present the recommendations.

3.4 Drawing conclusions, drafting and consulting on the autism skills and knowledge list

Findings and conclusions, which are covered later, informed our first draft framework. We then held two focus groups for people with autism to elicit their views on the main points of the draft. Those meetings took place in Cardiff and Manchester.* Respondents to the online survey had been asked to provide their address or email address if they were willing to review the draft and approximately 400 people agreed to comment.

3.5 Amending the draft and publishing the autism skills and knowledge list

Most of the feedback was supportive of the first draft so there was relatively little fundamental change to be made. Many people provided helpful suggestions and ideas to add to the existing draft and these were incorporated prior to publishing.

* Although Skills for Care’s remit is England-only, Skills for Health’s is UK-wide. In this project there was a focus group in Wales and desk research included literature from Scotland.
4. Findings and recommendations

4.1 Key findings which support the need for changes to service provision

The following views provide a compelling argument for investment in improvements to the services for people with autism in order to both improve the quality of life for these people and to reduce the cost of service provision.

Over half (52%) of carers indicated that the person they support had avoided using health or social care services that they needed. 47% said that this could lead to additional pressure, stress and isolation on families and 41% felt that the main impact on the person with autism was that a lack of access to key specialist services resulted in an adverse effect on their health and wellbeing.

A slightly higher percentage (57%) of people with autism indicated that they had avoided using health or social care services they needed. The majority (37%) agreed with the carers that the main impact was an adverse effect on their health and wellbeing.

The following additional comments illustrate some of the feelings expressed:

- “I get forgotten and lost in the system”
- “Suicide attempts”
- “Isolation, anxiety, depression, fear of approaching services in the future”

From the health and social care worker point of view, the consequences of people with autism having difficulties in using a service included:

- the need for more intensive services as the person’s health and well-being deteriorated (22% of workers responding)
- longer than usual appointments, meetings and visits being required (18%)
- needing to provide information in other formats (17%)
- aggression against staff (15%).

4.2 Fair and equal access

Overall almost one in seven respondents (14%) thought that people with autism have the same fair and equal access to services as those who are without autism. This fell to one in ten (9%) among people with autism and one in twenty (6%) among carers.

4.3 Awareness of autism among health and social care workers

A quarter (25%) of health and social care workers said that people with autism accounted for fewer than five per cent of people using their services, while two-fifths (43%) felt the figure was somewhere between 5%-20% and three in ten (30%) felt it was more than 20%. Social care workers were likely to report a higher proportion of people with autism than were health workers.

The majority of people thought that the percentage of people using their services who had autism was higher than the actual national average within the population.
There could be several explanations for this view:

- people with autism are more memorable
- there may be health issues which mean that people with autism are using particular services more than the general population
- from the findings there is evidence that some people with autism do need longer, duplicated or follow-up appointments and procedures
- people may be recorded as having a learning disability but the system may not allow staff to record the specific needs associated with autism.

Some 43% of health and social care workers said that they were *always* informed if a person using their services had autism, nearly half (46%) that they were *sometimes* informed and one in ten (11%) that they were *not* informed. Health workers were more likely to say that they were *not* informed if a person using their services had autism.

Commissioners, managers and employers in social care services

Forty per cent of this group were unable to record the percentage of people using their service who they thought had autism. The same number of people were unable to record if they are told when a person using their services has autism.

4.4 Commonly experienced points of difficulty in service provision for people with autism, from the perspectives of workers and of people who use services

The combined top five problems (across all groups) were:

1. Knowing that the service exists (24%)
2. Lack of knowledge and awareness of the nature of autism and the potential needs of people with autism (24%)
3. Lack of understanding when people with autism have become stressed or anxious (20%)
4. The application / referral process (17%)
5. General misunderstandings at any stage (16%).

People with autism and those supporting them generally rated these five problems as more important than did the professional respondents. People with autism also included staff not understanding them or being judgemental about their behaviour in their top five. They also were more likely to say that it was difficult to choose only five problems from the list of options.

“All the above boxes apply, not just 5!!”

This view was also echoed by some workers.

The additional comments from people with autism and those supporting them suggested that they are “not believed or listened to” or that those dealing with them are “patronising”.

The additional comments from health service workers highlighted the need for:

- better access to specialist diagnostic services
- more specialist services
the use of specialist teams, both within health services and multi-disciplinary teams with social care colleagues.

A recurrent theme in the additional information section of the survey across several groups was the need for specialist services for people with both autism and mental health needs.

4.5 Guidelines to prevent the consequences of these difficulties

The consequences of difficulties experienced by all groups have already been described above. In summary they result in people avoiding services that they need and extra costs for the service providers.

The health and social care respondents were asked about the existence of guidelines which improve the services delivered to people with autism. Only 21% of professionals overall were confident that they have adequate written guidelines, with slightly more confidence on this among social care workers than among their health counterparts.

This would seem to suggest that employers and managers in both sectors need to review the existing guidelines where they do exist, write suitable guidelines where they do not exist and ensure thorough communication and use of those guidelines within services.

This conclusion and recommendation for action is supported by the findings to another question in the survey which explored the best ways for workers to learn. This is described in section 4.11 below, where it is indicated that workers find written guidelines a good way of learning about autism. These points may be significant when considering the infrastructure to enable staff to provide a high quality service.

4.6 How services for people with autism could be improved by minor changes

Given the opportunity to select as many answers as they wished, respondents across all groups supported the range of suggestions put forward:

- Understand that the person with autism may take things literally, so communicate and check carefully (34%)
- Help prepare the person for the visit (32%)
- Provide a calm and quiet place for the person with autism to go if stressed (30%)
- Be very clear in explaining procedures (29%)
- Maybe adapt the way they communicate and provide information (28%)
- Give people with autism more time to think about what you are saying (27%)
- Ask what they can do to help or if there is anything the person with autism needs (26%)
- Longer / more flexible appointment times (24%).

People with autism and those supporting them had stronger opinions about these than had the health and social care workers.
In addition, the following statements were made by people with autism:

1) “Be less bureaucratic”
2) “Make sure they have adequate training in the first place”
3) “No fluorescent or low energy lights on in the place of care – they affect us”
4) “Treat me with respect, as a human being and don’t be patronising; I am different, not defective”

4.7 Staff autonomy

The majority of health care professional respondents said that staff had “some” (58%) or “lots” (38%) of autonomy to vary work to meet individual needs. Social care workers were more likely than health workers to say that staff had “lots” of autonomy (44% vs. 33%).

Autonomy is a vital prerequisite in providing a flexible service and is another part of the infrastructure needed to enable staff to deliver high quality services.

4.8 What health and social care workers need to know

There was broad agreement across all groups, about the knowledge of autism required by health and social care workers. The top three answers were:

1) How autism affects the specific individual they are working with (31%)
2) What changes need to be made to service delivery to meet the needs of the individual they are working with (25%)
3) The vulnerabilities that can be created by autism (22%).

This question yielded a high response rate, indeed many respondents provided additional comments saying that they are all important. In addition, many respondents used the free text comments section to suggest that staff need to know how to support carers as well as the person with autism and have a sound understanding of services available for both carers and the person with autism.

The information submitted by service providers to the Scottish study (MacKay and Dunlop 2004) presented a pattern consistent with these findings, in particular:

- major gaps in training have been recognised at every level across all sectors and services
- a minority of providers viewed their services as having an ‘excellent’ or ‘good’ training profile, even in relation to those personnel with a significant role in autism
- it was estimated that half (54%) of those who work in this field have little (34%) or no (20%) autism training.

This would suggest that there is a requirement for a development of broad background knowledge of autism and the effects of autism on the person and their families. Service providers and workers should also seek to understand the areas of service provision that
seem to cause the most difficulty for people with autism. Developing an understanding of the communication and sensory needs of people with autism would go a long way in supporting people to access a wide range of service provision.

4.9 Practical things health and social care workers need to be able to do

Again, there was broad agreement on the top three answers which were:
1) find out what the individual’s needs are (29%)
2) ensure the individual understands exactly what’s happening now, why they are there and what might happen next (20%)
3) communicate better or in a different way (18%).

For people with autism and those who support them, it was also important that staff involve and work with their families (19%).

Within MacKay and Dunlop (2004), responses focused on what workers need to know and included:
- what Asperger’s Syndrome is
- get to know the individual person
- find out information that will tell the worker about the effects of having autism
- information about individual behaviour and how well the person gets on with others.

In common with the views on knowledge above, respondents in all groups commented that all of the items on the list were important, while additional ideas included:
- “Make adjustments on an anticipatory basis”
- “Listen and believe what parents are saying” (there were several comments on this theme)
- “Offer consistency – one key person who can get to know the person and gain their confidence”
- “Think outside the box”.

There were several comments across the groups which linked to managing waiting times. Although people with autism have particular difficulties in dealing with long waiting times, this is an issue for the general population too and is significant for guiding the infrastructure to underpin a quality service.

4.10 Attitudes that health and social care workers should have or develop

Most people are drawn to a career in health and social care services because they want to help others. However, as independent think-tank the King’s Fund has claimed (King’s Fund 2010), the pressures of working in today’s NHS hospitals, GP surgeries, care homes and community and home support services have led to ‘compassion fatigue’, where staff are unable to react sympathetically because they lack the time to care and they’re overexposed to the demands of too many patients.

There was broad agreement across the groups on the attitudes that health and social care workers should have. The top three answers were:
1) A willingness to do things differently and get it right (31%)
2) More compassion for people with autism, especially when they are having a difficult time (27%)
3) A commitment to delivering an individual service (26%).

There was general agreement, particularly from people with autism and their supporters, but also from the professional groups, that choosing only three answers from the list was extremely difficult.

The vast majority of additional comments, across all of the questions in the survey, included aspects of workers’ attitudes. Some of the comments highlighted below were not made in response to this particular question but we have highlighted them here to stress the importance of values and attitudes in the feedback.

“Staff need more training on emotional literacy and practice of empathy”
“Staff putting themselves in the person with autism’s shoes”
“Staff feeling under skilled leads to apprehension”
“Assumption that all problems are a result of having autism and that nothing can be done about them”
“Not being judgemental” – several responses on this theme

“Need to understand that each person with autism is different”
“Show respect to the person with autism”
“Please take me seriously, even if I look a bit different”
“I’m quite good at saying what I need. The problem is that people don’t believe me”.

Similarly, within the Scottish study looking at a national training framework for autism (MacKay and Dunlop 2004), the majority of the 130 parents who responded to the survey placed considerable emphasis on the importance of workers being non-judgemental, being able to admit to their own lack of knowledge or experience and having a commitment to parents and workers working together. They emphasised that their children were not naughty, could not help their odd behaviours, might be stressed and should be valued as unique. Parents did not like workers ‘who know best’ and do like workers who are compassionate.

4.11 Continuing professional development
The majority (95%) of health and social care workers felt that staff could spend some time learning and keeping up-to-date with issues relating to people with autism – a quarter (24%) felt that up to five hours a year was practical, a third (32%) felt that it should be 5–10 hours per year and a further third (34%) felt that it should be more than 10 hours a year. Social care workers were more likely than
their health colleagues to say that they should spend more than 10 hours per year on autism training (45% vs 23%).

When asked about the methods for delivery of training, the top five answers were:

- written guidance (24%)
- inclusion in a qualification (23%)
- a day course (23%)
- e-learning (20%)
- books or written materials (18%).

Within the additional comments, a large number of workers wanted to learn directly from people with autism and their families and carers. Although this question was not asked of people with autism and their supporters in the survey, there were several additional comments made to other questions that strongly suggested that these groups feel that staff need to learn directly from people with autism and their supporters. Many suggested that spending a day in a real-life situation would be worthwhile.

**4.12 Usefulness of other people accompanying people with autism to health/social care appointments**

Four-fifths (80%) of health workers feel that having a member of care staff accompanying a person with autism to a health appointment is quite or very helpful. By contrast, when asked about their experience of accompanying people with autism to health appointments, fewer than half the social care workers felt that health professionals were helpful. Both health and social care staff agree that it is very or quite helpful to have a family member or informal carer accompany a person with autism to their health or social care appointment (70% and 68% respectively).

This finding sits in stark contrast with the view of some carers, expressed in the additional comments sections of the questionnaire, where they feel that health service workers do not value their input, do not listen well and are patronising.

**People with autism and those who support them** felt that they could help workers to provide a better service by:

- telling them if they become stressed or anxious or need some ‘time out’ (36%)
- telling them how best to communicate with them (32%)
- providing them with written information about the individual and their needs (31%).

> “Having no-one to take with me is an issue. I provide written info but cannot make people read it. Especially psychiatrists who think that if you can talk you should.”

**4.13 Infrastructure**

Although the research did not include questions relating specifically to the infrastructure, comments made have shown that a suitable infrastructure is necessary to allow competent staff to offer a high quality service. Several comments and suggestions referred to the need to change the way that the service is provided, not just the development of the knowledge, skills and attitudes of frontline staff, e.g.:

- “Lack of knowledge of those who run the system”
- “More joined up services”
- “We need multi-disciplinary teams”
- “Fall in between mental health and learning disability services”
- “No provision in our area”.

11.
The responses received may indicate that health and social care providers and commissioners of services need to consider strategic planning in relation to service provision for people with autism. Some of the key elements that strategic plans take account of include:

- assessment
- service design
- service delivery
- training and workforce development planning
- recruitment—getting it right, and retention when it is right
- performance management processes for on-going development
- partnership working to develop multi-disciplinary working and joined-up services.

To support truly integrated services, a commitment needs to be made to develop multi-agency working. This should not be confined to health and social care services but should include agencies such as education, leisure, criminal justice, housing and local communities. This would help support duties linked to equality.

Similarly, there were no specific questions directly linked to diagnosis, yet several comments across the groups stressed the need for access to services which could provide an accurate diagnosis. The need for follow-up advice to understand the implications of that diagnosis and access to appropriate services, funding and support was also mentioned by a number of respondents from across all groups.

4.14 Findings from focus groups

Two focus group sessions involving a facilitator and people with autism (in some cases supported by staff or carers) were held near Cardiff and in Manchester. The groups were asked to comment on the recommendations and the practical advice in the first draft of what has subsequently been published as the *Autism Skills & Knowledge List* and its accompanying *Implementation Guide* for staff training.

The consultation was undertaken with the National Autistic Society North of England Consultation Group and the National Autistic Society Wales Consultation Group members and supporters: these are groups of people with autism or Asperger’s syndrome from across South Wales and the North of England.

The groups were in agreement with the recommendations and suggestions that we had made in the draft. In addition, they offered further practical suggestions which have been incorporated into the final versions of the skills and knowledge list and the implementation guide.

The key feedback from the focus groups is outlined in parts 4.15.1 to 4.15.4, following.

4.14.1 Accessing services

Participants agreed that knowing about and having access to services is problematic and this links to the infrastructure recommendations that have been made previously.
“Not at first and only because of the hard work of my parents”
“I usually got told there was nothing in my area”

“Didn’t even know they existed”

4.14.2 All staff understanding autism

Participants in the focus groups agreed that all staff in all health and social care services should have some knowledge and understanding of autism in order to provide a good service.

“It is difficult to know if my social worker understood me”

“My social worker knew about autism. Everyone who I come into contact with should at least know a little bit about it”

“Do not know… but they do not believe what I have said”

“I was judged by my intelligence and not by my social skills capabilities or vulnerability… it was the old chestnut: “You are not mentally ill or learning disabled”

I had to have a second social care assessment this time with an NAS advocate with me which made all the difference; and this time I got a social worker, two-and-a-half years after my Asperger syndrome diagnosis when I was 21.”
Group members told us that a barrier to their physical well-being is a general lack of understanding and acceptance of adults with autism. This made it very challenging for adults with autism to access health and social care services when needed. Focus group members told us that they do not find respect for their differences, and their disability is not seen as part of human diversity.

These views reinforce the recommendations linked to underpinning attitudes. Staff who are willing to try to understand and be flexible were seen by the participants to be much more helpful and acceptable than those who stick to the rules and procedures.

4.14.3 Communication and preparation

The group members felt it was particularly important that health and social care workers talked to the person they are working with and made sure the person understood what the worker was going to do.

There was general agreement that if the person has not had a particular test or treatment before, the health or social care worker should explain what the treatment is and what will happen. [It might be observed that this should apply to all patients.]

“I have blood tests every few months. Now that I know what is happening and why, it does not worry me any more”

“She told me I had to have an injection. She told me it would hurt”

“I think it was really important that the dentist explained to me why they want to give me the treatment and what they thought might happen if I did not have the treatment”

“They treated me with respect. They explained everything to me.”

“Doctors and nurses did not understand that I take longer to process things. I feel scared in hospital that I will be pushed into making decisions that I don’t really understand”
The group members want to have health and social care staff working with them who understand their needs. This supports the suggestion in the framework that those who have significant contact (be it long term / intense interaction or short term but high impact interaction) should have knowledge and skills beyond.

Some members needed help to understand the treatment. Some had several medical conditions. It was important that they were given time and listened to so that they got the support and care they needed.

“When I was in hospital after an operation I would not eat. I did not want the nurses to help because they could not understand me. My mum was able to help me to eat by giving me the foods I like and by gentle persuasion”

People said they want to be treated as individuals. Everyone is different, some people in the group had co-occurring conditions and all wanted different support:

“I need to have things that have happened or I have done written in my book – that is very important to me”

“I don’t like to be surrounded by people. Clear a space. I want just one person near me to reassure me”.

Most people need help with paperwork. One person said that the family helped with paperwork.

Everyday functions, which the majority of individuals take for granted, can be negative and upsetting experiences for people with autism. Surgeries or treatment and meeting facilities may have too many sensory distractions, may be too noisy (talking, bells, chairs scraping the floor), lots of visual stimuli (people, pictures on the wall). Staff can help to create an ‘autism friendly’ space by having a quiet room available, or use furniture in the room to create an area free from distraction.

Structure and routine help people with autism to feel safe and comfortable, and function better. Whenever there is going to be a change to the scheduled meeting or appointment, it is important to make sure the person is prepared about it well in advance. Also while visiting a new place, the person can be sent pictures; and the plans for the day can be discussed so that he or she is able to be prepared.

“My mum can do this”

“Send a letter telling me the details and what will happen – it would also be helpful if people wrote in my journal what had happened and what needs to happen next”
4.14.4 Staff attitudes

‘Success’ should not just be about clinical, medical or service placement outcomes but about the individual's experience as well. Staff need to be allowed to spend adequate time with people and they need the right support to enable them to provide compassionate care. This applies not only to doctors, nurses, social workers, managers, support workers and allied health and social care workers, but also to receptionists, porters, restaurant staff, volunteers and others outside of clinical, medical or social care interventions. Everyone can play a part.

A key message coming out of the focus groups is that it is very important for health and social care workers to have the right attitudes and values. [This is reflected in the Autism Skills & Knowledge List focus on describing the attitudes and values required.]

Group members felt that while the training that is provided to those working full-time with people with autism is generally OK, there is a need for training across the wider health and social care sector to ensure that people with autism receive the right services and treatment at the right time. Too many health and social care workers have no basic autism training while many need support to adapt treatments and approaches for children and adults with autism.

“Yes …it would help a lot if people understood my stress and anxiety … and what causes me to become stressed and anxious”

“I don’t like things being forced on me”

Individual group members each worked on their own ‘top ten’ of the good and bad things that can happen in health and social care services. Below is the cumulative top ten.
<table>
<thead>
<tr>
<th>Good things that can happen in health and social care services</th>
<th>Bad things that can happen in health and social care services</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. On time – if my appointment is at 10 o’clock, see me then or explain that you can’t.</td>
<td>1. Don’t listen to us or take time to get to know us.</td>
</tr>
<tr>
<td>2. Look after me and my health, keep me well and give me medication when I need it.</td>
<td>2. When they are bad to you – sometimes people are rude or ignore you, or they don’t let you do what you want to do… like go out for lunch.</td>
</tr>
<tr>
<td>3. Doctor’s receptionist has more time to talk to me.</td>
<td>3. Not doing their job properly – if they don’t or can’t do their job – get them out of it.</td>
</tr>
<tr>
<td>4. I would like to be able to go into a quiet room.</td>
<td>4. Not listening to me – the annoying thing is for professionals to talk to people that are with you and not talk to you.</td>
</tr>
<tr>
<td>5. Distracter music – when having procedures done like an injection, or now there are televisions in waiting rooms instead of the standard hospital TV programme. An example may be to let a person take their own DVD to watch whilst waiting in the waiting room on the TV – it may need to be edited so that it meets the anticipated time frame.</td>
<td>5. It would be bad for professionals to plan something behind your back.</td>
</tr>
<tr>
<td>6. Understand that I become anxious at waiting for an appointment when professionals are late for a meeting – do not let that happen.</td>
<td>6. Doctors do not believe all I say – and do not always check me physically. They believe NAS staff if they say something differently from me, they listen to other people instead of me.</td>
</tr>
<tr>
<td>7. Do not cut the budget.</td>
<td>7. Don’t complicate things, explain things clearly.</td>
</tr>
<tr>
<td>9. No smoking, don’t smell of smoke.</td>
<td>9. Take more care not to make mistakes: I arrived at the hospital for a check-up with my neurologist (epilepsy), but reception had sent my patient files to the wrong place. I walked a long way to get there, just to find it was the wrong place. By the time I arrived at the right department, there was a huge wait because all appointments were delayed and so there was a major backlog. I became very stressed and the staff didn’t understand.</td>
</tr>
<tr>
<td>10. Make me feel better.</td>
<td>10. Seeing different people – you just get used to someone and then you have to see someone else.</td>
</tr>
</tbody>
</table>
4.15 Summary of conclusions

- There is evidence of the need to improve services in order to improve the health and well-being of people with autism and their carers.
- There is evidence to support the need to improve services to reduce costs for service providers.
- Training is part of the solution but there are also wider solutions within the infrastructure of services.
- The majority of staff at all levels in health and social care do not know the prevalence of autism in the general population (it is currently estimated to be approximately one per cent). Without this knowledge, planning and provision may be flawed.
- There are many varied areas of difficulty within service provision and they all need attention.
- There is a mismatch between workers who see carers as mainly very helpful when accompanying people to access services, but the carers do not feel valued by those workers.
- There is a need for specialist services and/or expertise for generic service providers to call on or refer to. Working in multi-disciplinary teams was seen as highly beneficial.
- Autonomy and flexibility is reasonably high. This needs maintaining and increasing.
- The list of knowledge, skills and attitudes that people need to learn is extensive.
- The topic that was seen to make the biggest difference to service provision was staff attitudes. The required attitudes are not widely demonstrated across social care and health, despite efforts by employers.
- There are several suggested and acceptable methods of education delivery. The need to use ICT learning is increasing for practical and cost reasons.
- Learning directly from people with autism and their carers was seen to be highly desirable by all groups.
- People with autism and their carers could support workers to offer a better service by providing written guidance about their needs, but this would need to be kept brief to ensure workers have time to read it.
5. The Autism Skills and Knowledge List and its implementation

The Autism Skills and Knowledge List has been published separately alongside this report. It is based on four levels of skills and knowledge targeted at three types of worker involvement with people with autism, as represented below.

Figure 1

5.1 Overview of content

Figure 1 above illustrates that practice in health and social care should be built upon underpinning values and attitudes. This was emphasised by all categories of respondents. It is therefore essential that these values and attitudes are highlighted as being important and integral to the work being carried out by workers in providing services to people with autism.

Having identified underpinning values and attitudes, the next step is that basic autism awareness training should be included within general equality and diversity training programmes across all public services. However, the specific needs of people with autism must not be subsumed by general issues. Extending equality and diversity programmes in this way is not just good practice; it reflects the continuing ‘disability equality duty’ under the Disability Discrimination Act and the subsequent requirements of the Equalities Act 2010.

Beyond basic autism awareness, there is a need for some staff in generic services to have intermediate skills and knowledge, and beyond those are the skills and knowledge
required by workers in specialist autism-specific services.

5.2 Underpinning values and attitudes

The following underpinning values and attitudes should be given high priority. It is not the intention that they replace any other statements about values created by the many professional bodies supporting those employed in the health and social care sectors, in fact, they should mainly mirror the guidance that already exists. For example, the values cited here match closely the ‘social care values’ in Skills for Care’s Common Induction Standards.

However, it is worth highlighting that these factors were seen to be critical by the respondents to the survey. It would therefore appear that current systems and learning are not sufficiently making a positive impact on the experiences of people accessing services.

People with autism should be given the same opportunities as the rest of the population. This should include but is not restricted to, the right to:

- be independent
- be regarded and treated as individuals
- make choices for themselves
- be treated in an equal and fair way
- be treated with respect, dignity and confidentiality
- access specialist support to realise potential
- receive compassionate and non-judgemental support, and to give it in their own roles as parents, carers, workers or volunteers.

In any human relationship it is understood that errors will be made in connecting with and fully understanding an individual. To do well in establishing relationships with individuals, employees in both sectors must have the skills and value base to want to succeed. In relation to autism, one must also understand the difference in the way of being and thinking of that person. People with autism, their families and workers commented that this is essential for anyone who serves a person with autism professionally. One respondent felt that if workers are not willing to explore that difference and respond accordingly they shouldn’t be allowed to work with people with autism.

This project has made clear that it is important to have a culture which is based on appropriate attitudes and values. These can be used in managing all aspects of human resource development, from informing recruitment and selection practices to underpinning staff induction, and they can be used as a source for identifying staff’s personal development needs.

5.3 Basic autism awareness

The generic health and social care sectors need to improve the level of basic awareness of autism across all people who may come into contact with those who have autism. This would include ancillary and support services employees including receptionists or those who may be a point of contact for those accessing services. This level of awareness would also be required by all frontline staff, managers, employers and commissioners. The section on learning and development methods shows that this can be provided in a number of ways. It should be noted that this area of development should vary in intensity; for example, if it was delivered as a taught session then a few hours to half a day would be sufficient for ancillary and support services employees.
Basic autism awareness should include:

- The notion of autism as a spectrum, including the fact that it is a life-long condition.
- A brief synopsis of the theoretical models developed by Kanner and Asperger in identifying autism.
- Key characteristics – understanding the main differences found in people with autism (often referred to as the ‘triad of impairments’).
- Common sensory differences experienced by people who have autism.
- Common co-occurring conditions.
- Basic understanding of the complexity surrounding diagnosis, which includes:
  - getting a formal diagnosis
  - lots of different diagnoses within the ‘autistic spectrum’
  - reasons for avoiding, or barriers to, diagnosis.
- Prevalence of autism in the general population.

5.4 Intermediate knowledge and skills development

Both responses to the questions asked and the additional information supplied by respondents have highlighted the need for further development of knowledge and skills across both sectors. This list of areas that require development should be the next step beyond basic awareness and should be appropriate for frontline staff, managers, employers and commissioners. It is particularly recommended that staff who have frequent or intensive contact with people with autism and those members of staff who may spend little time with, but have nonetheless a high impact on the outcomes for, people with autism would need this level of development.

To enable people with autism to have fair and equal access to the right services, the following areas of knowledge and skills should be developed further.

- Use appropriate communication skills when supporting a person with autism.
- Support families and friends and make best use of their expert knowledge of the person.
- Recognise when a person with autism is experiencing stress and anxiety and support them with this.
- Recognise sensory needs and differences of a person with autism and support them with this.
- Support the development of social interaction skills.
- Provide support with transitions and significant life events.
- Understand the issues which arise from co-occurrence of mental ill health and autism.
- Support people with autism to gain and maintain employment (where appropriate).

However, this is in no way a definitive list of the skills and knowledge that need to be developed. Professional development is the responsibility of individuals with support from their employers and individual line managers. In planning for professional development, workers should:

- read at least the Autism Skills and Knowledge List and the accompanying Implementation Guide
- consider the service they provide
- consider what skills and knowledge teams or individuals will need to develop.
The *Autism Skills and Knowledge List* includes a self-assessment checklist to help this process.

5.5 Specialist development

The government strategy for adults with autism in England, *Fulfilling and Rewarding Lives* (DH 2010), highlights the need for developing a “clear consistent pathway for diagnosis of autism”.

According to the strategy, staff in health and social care “can be highly influential in determining the kind of support adults with autism receive, both through needs assessment processes and in terms of the actual care and treatment prescribed or provided”. To this end, those who require specialist training to help improve the services of people with autism should consider the following areas if appropriate to their professional role:

- diagnosis
- assessment skills
- sensory profiling
- strategic planning of services.

Professional development in these areas will require input from specialist providers. The National Autistic Society’s *Autism Services Directory* ([www.autism.org.uk/directory.aspx](http://www.autism.org.uk/directory.aspx)) is a good source of information on autism services including training.

5.6 Learning & development methods

The purpose of this section is to highlight areas requiring development. There are lots of different ways in which that development can be delivered. To demonstrate the different possibilities, we have chosen some of the most commonly used methods and provided some detail below.

Profession-related qualifications

As the *Autism skills and knowledge list* was being developed, it became clear that many of the professionals questioned wanted to see autism training delivered as part of qualifications. Some of the elements of knowledge and skills identified in the list could be:

- subjects or units within existing professional qualifications
- accessed via post-graduate or post-qualifying or higher education certificate level qualifications that stand alone as autism-specific modules.

There are already examples of autism units being available as options in nationally accredited qualifications, as noted in the mapping above. The same knowledge units are also available in the smaller level 2 and 3 awards and certificates in Supporting Individuals with Learning Disabilities.

Taught courses

There are a variety of providers in the UK who can deliver training based on the units in the Autism skills and knowledge list. Training will vary in respect of the specific outcomes and length of each course. Further information of providers of autism training can be found in the *Autism Services Directory* on the National Autistic Society’s website – [www.autism.org.uk](http://www.autism.org.uk)

The consultation that led to the *Autism skills and knowledge list* showed that many people found it useful to hear personal accounts from people with autism and their families and carers included in their learning about autism. However, due to the very individual nature of autism, it is essential that this method should include or be used alongside other more theoretical and general information about
autism and the ways that people with autism are different from each other. The *Autism skills and knowledge list* is intended to help people delivering this kind of training to make sure that their training covers all the essential values, skills and knowledge that the learners need.

**E-learning**

A number of providers can provide autism training as e-learning. This can be accessed via the internet or CD-Rom. Essentially, the learner sits at a computer and engages in learning that is often self-paced and flexible to suit time constraints, personal commitments and work-life balance. E-learning therefore suits people who can use a computer and lack the time to be away from the workplace. E-learning can also be used by small groups of people. Some programmes include interactive discussions to simulate the conversations that usually happen as part of a taught course. People with autism and their families may find it easier to develop a video or audio or animation to get their message across rather than having to deliver training to groups of people face-to-face.

It is worth bearing in mind that e-learning is not always suitable for all learning or all learners. It may provide good opportunities to learn about theory but be less able to provide practical insights and experiences. It may not always give the best opportunities for learners to engage effectively with other participants or a course facilitator.

A blended approach which uses e-learning to deliver facts and information to learners, linked with face-to-face or interactive methods to answer questions, encourage debate, share experiences and challenge beliefs and attitudes, would seem to be a sensible approach.

The following quote comes from *Skills for life – a practical guide for employers*:

“Skills for Care recommends that social care employers encourage the use of e-learning for their staff wherever possible. This helps to develop ICT skills as well as vocational skills and subject knowledge.” (SfC 2009)

**Shadowing, coaching and mentoring**

The use of work shadowing, mentoring and coaching can support a broader culture of learning in the workplace. These are methods which are often used in health and social care settings to provide individually-tailored staff development.

If properly planned, designed, delivered and evaluated, this is a reliable method of providing on-the-job training, learning and development and should be seen as an integral part of the whole process used by an organisation for its staff.

**Written materials**

There are many resources available, including books, journals, toolkits, resource kits and guidelines, published in print or electronically. These can be used to enhance knowledge and skills in the health and social care sectors, but they should not be seen as a complete solution to staff development needs.

The information collected from workers, suggests that the preferred method for learning about autism is the implementation of suitable and clear guidelines for providing individual support. With an increase in knowledge and skills about autism and sensitivity to the impact on individuals receiving the service, the development of effective guidelines will enhance the experiences of people with autism. However, we would suggest that this method alone
would not reliably make the desired difference. The appropriate staff attitudes, knowledge and skills are all essential for the implementation of any guidelines and without this the guidance will have far less impact and may even become a meaningless piece of paper.

Supporting a culture of learning and development
It is essential that the development of awareness, knowledge and skills is something that is supported by employers, managers and commissioners if it is to be taken seriously by the rest of the workforce. The creation of clear development plans should be encouraged and the implementation supported across the sector.

Consideration should be given to how awareness, knowledge and skills are developed and supported as part of an ongoing process. Developing skills to provide better services to people with autism should be viewed as essential as part of the continuing professional development (CPD) process in organisations. Members of the workforce should also be able to use this document to help them create an effective personal CPD strategy. Responsibility for development should always be with both the employee and the employer.

5.7 How the QCF supports learning and development around autism
The Qualifications and Credit Framework (QCF) is a new way of recognising skills and qualifications, by awarding credit for qualifications and units (small steps of learning). It enables people to gain qualifications at their own pace along flexible routes.

The QCF is designed to make sure that future qualifications allow a flexible, ‘mix and match’ approach to meeting the different development needs of the workforce. Every unit and qualification in the framework has both a ‘credit value’ and a ‘level’. One credit represents 10 hours of average learning time and so the credit value shows how much time it takes to complete. The level shows how difficult the unit or qualification is on as scale of ‘Entry’ then levels 1–8.

There are three sizes of qualification in the QCF:
- awards (1–12 credits)
- certificates (13–36 credits)
- diplomas (above 36 credits).

(QCF diplomas are not the same as the ‘14-19 Diploma’.)

The qualification type – award, certificate or diploma – represents the ‘size’ of a qualification, not how difficult it is, therefore there are awards available at various levels up to 8 within the framework.

It is important to note that existing NVQs, already completed or that workers have already registered for but not yet completed, continue to be valid qualifications in health and social care. The QCF is designed to make sure qualifications allow a flexible, ‘mix and match’ approach to meeting the different development needs of the workforce. So those people who already hold a generic health or social care NVQ or professional qualification may choose to undertake units specifically about autism to complement their existing qualification.
The QCF Diplomas in Health & Social Care
The Health and Social Care (HSC) NVQs at levels 2 and 3 were replaced by QCF Diplomas in Health and Social Care (HSC) at levels 2 and 3 in January 2011.

The diplomas offer opportunities to take a generic HSC diploma or a diploma with a specialist pathway in either dementia or learning disability pathway, so learners can tailor their learning to their job role.

The diplomas are made up of nine mandatory units and a range of ‘optional’ units. The mandatory units are very closely aligned to the refreshed Common Induction Standards for adult social care, and the aim is for learners from any area of work to complete these and then contextualise their learning to their job role or service, including support for people with autism, by selecting relevant optional units.

QCF units specifically about autism
There are currently three QCF knowledge units specifically about autism, at levels 2, 3 and 5:

- LD 210 – Introductory awareness of Autistic Spectrum Conditions
  (level 2, credit value 2, ref: M/601/5316)
- LD 310 – Understand how to support individuals with autistic spectrum conditions
  (level 3, credit value 3, ref: T/601/5317)
- LD 510 – Promote good practice in the support of individuals with autistic spectrum conditions
  (level 5, credit value 7, ref: A/601/5318).

These are complemented by other units such as ‘Support Individuals Undergoing Healthcare Activities’, ‘Contribute to supporting individuals with a learning disability to access healthcare’ and ‘Working in partnership with family carers’.

All the units are available to view at www.skillsforcare.org.uk/qcf.

Collectively, the units within the Diplomas in Health and Social Care cover many of the areas identified in the Autism skill and knowledge list as essential underpinning values and attitudes, basic autism awareness and knowledge and skills. This is shown in detail in the mapping below. Work is currently underway to develop further specialist QCF competence units about autism.

Sample list of relevant QCF units
This list shows several units that may be relevant for workers supporting people with Autism, however there are many more. We recommend the individual workers tailors their qualification to their job role and the people they support and therefore there are many different possibilities in using the units and in structuring qualifications.

SHC 23 – Introduction to equality and inclusion in health, social care or children’s and young people’s settings (level 2, credit value 2, ref: R/601/5471)
PWCS 23 – Principles of diversity, equality and inclusion in adult social care settings (level 2, credit value 2, ref: H/602/3039)
SHC 33 – Promote equality and inclusion in health, social care or children’s and young people’s settings (level 3, credit value 2, ref: Y/601/1437)
PWCS 33 – Principles of diversity, equality and inclusion in adult social care settings (level 3, credit value 2, ref: M/602/3044)
SHC 53 – Champion equality, diversity and inclusion (level 5, credit value 4, ref: Y/602/3183)

HSC 25 – The role of the health and social care worker (level 2, credit value 2, ref: J/601/8576)

HSC 26 – Implement person centred approaches in health and social care (level 2, credit value 5, ref: A/601/8140)

HSC 36 – Promote person centred approaches in health and social care (level 3, credit value 6, ref:)

LD 208C – Contribute to supporting individuals with a learning disability to access healthcare (level 2, credit value 3, ref: J/602/0036)

HSC 2025 – Support individuals undergoing healthcare activities (level 2, credit value 3, ref: L/601/8725)

HSC 3038 – Work in partnership with families to support individuals (level 3, credit value 4, ref: H/601/8147)

HSC 3057 – Work with families, carers and individuals during times of crisis (level 4, credit value 5, ref: F/601/9029)

HSC 3065 – Implement the Positive Behavioural Support model (level 4, credit value 8, ref: T/601/9738)

LD 311K – Principles of supporting young people with a disability to make the transition into adulthood (level 3, credit value 3, ref: M/601/7227)

LD 311C – Support young people with a disability to make the transition into adulthood (level 3, credit value 5, ref: F/602/0049)

SS OP 3.7 – Support individuals to access education, training or employment (level 4, credit value 4, ref: H/601/3546)

ACT 307 – Equality and diversity in activity provision (level 3, credit value 3, ref: Y/502/7577)
6. The self-assessment checklist

This checklist has also been published in the Autism Skills & Knowledge List.

The purpose of this checklist is to help workers who provide health and social care services to people with autism to assess their current skills, knowledge and behaviours and to inform an action plan for development, where necessary. It can also be used to audit and improve the readiness of teams and departments to provide ‘autism friendly’ services, drawing on the requirements of the Autism Act 2009 and the Equalities Act 2010. There is some introductory information about autism in the appendix to this document.

The checklist is divided into the same four sections for three different types of workers noted above. You should consider how it applies to your specific team or service.

<table>
<thead>
<tr>
<th>1. Underpinning values and attitudes</th>
<th>The first and second sections should be completed by all staff and volunteers.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Basic ‘autism awareness’</td>
<td>This section is aimed at those staff or volunteers who have high level of contact with or “high impact” on people who are on the autism spectrum. Examples include GP and hospital receptionists and non-specialist nurses and doctors. Some professionals may also need enhanced strategy workshops; for example, sensory training for dentists and physiotherapists.</td>
</tr>
<tr>
<td>3. Intermediate knowledge and skills</td>
<td>In large teams it may be helpful to have a proportion of workers who have this intermediate level of skills and knowledge.</td>
</tr>
<tr>
<td>4. Specialist development</td>
<td>Skills for those working in autism-specific services or for ‘autism specialists’ within more generic teams.</td>
</tr>
</tbody>
</table>
When completing the checklist as an individual, please consider the support you provide to people on the autism spectrum and assess your current confidence levels. Then agree an action plan with your line manager for your personal development needs.

When using this checklist as a team, ask yourselves the question “How well do we…?” for each of the criteria and then plan for necessary changes, which may include changes to policies, systems, processes and/or individual development needs, etc.

The checklist should help you focus on the specific way your service might impact particularly on a person with autism; for example, highlighting how information could be provided more clearly or how a sensory issue in the service may be adding to people’s anxieties, such as those cited in the appendix.

**What to do after completing the checklist**

It is envisaged that almost all social care and health services will find that the checklist shows they require some development among at least some of their workers in order to provide high quality care to people with autism.

To help with this, an accompanying document in the ‘Better social care and health outcomes for people with autism’ series is *Implementing the ‘autism skills and knowledge list’ through staff training and development*. It shows where in the health and social care training and education framework to look for relevant skills development. If you are responsible for your service’s workforce development you may need to use that document yourself, or if you are in a larger organisation with HR or training staff, you might need to discuss it with them.

All the documents in the series are available in the autism sections of [www.skillsforcare.org.uk](http://www.skillsforcare.org.uk) and [www.skillsforhealth.org.uk](http://www.skillsforhealth.org.uk)
<table>
<thead>
<tr>
<th>Criteria</th>
<th>Meet</th>
<th>Some areas to improve</th>
<th>Don’t meet</th>
<th>Action needed (What action is planned? By when? Person/people responsible.)</th>
</tr>
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<tbody>
<tr>
<td>Be independent</td>
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<td>Be regarded and treated as individuals</td>
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<td>2. Basic autism awareness should include:</td>
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<td>Diagnosis</td>
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<td>Sensory profiling</td>
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References

MacKay & Dunlop 2004

DH 2010

(This draws on the findings of the National Audit Office report, *Supporting adults with autism through adulthood* (2009), and the recommendations from the Public Accounts Committee.

King’s Fund 2010

SfC 2009
Bibliography


National Autistic Society (2010) *You Need to Know*

Equality Act 2010 and Equality Duty in the Disability Discrimination Act (DDA)

SQA Higher National Unit Specification

Qualifications & Credit Framework (QCF) units, Skills for Care

Other resources

Please search on ‘autism’ at either [www.skillsforcare.org.uk](http://www.skillsforcare.org.uk) or [www.skillsforhealth.org.uk](http://www.skillsforhealth.org.uk) for links to a range of further useful resources on supporting people with autism.