



Autism skills and knowledge list, for workers in generic social care and health services

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



Introduction

Every health or social care service should be ready to provide services to people with autism, or to their families or others who care for them. This *Autism skills and knowledge list* has been developed to help improve awareness of autism and skills among workers in generic health and social care services. There is some introductory information about autism in the appendix to this document.

The list is intended to enable individual workers, or services and teams, to work out whether they have the knowledge and skills needed to provide a good service to people who have autism. It can be used as a checklist. If this shows that you or some of the people in your team need to develop your skills and knowledge further then you can use the list in several ways to gain those skills and knowledge.

The list will also be useful for people who are arranging or providing training to workers. This may include people with no knowledge and experience of autism, as well as those with existing knowledge about autism including lived personal experience of having autism or being a family carer to a person with autism. Professionals in the training field may also find an accompanying document, ***Implementing the 'autism skills and knowledge list' through staff training and development***, useful.

The list was developed by the National Autistic Society and Skills for Care and Skills for Health. They developed the list by consulting with hundreds of people who work in services or who have autism or who are family carers of people with autism.

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)..."

Fulfilling and rewarding lives: the strategy for adults with autism in England (2010) DH, 3 March 2010

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

The *Autism skills and knowledge list* is not an exhaustive list of the skills and knowledge that need to be developed, as that must vary according to the particular needs of people being supported, but it is the foundation on which education and staff development resources should be based.

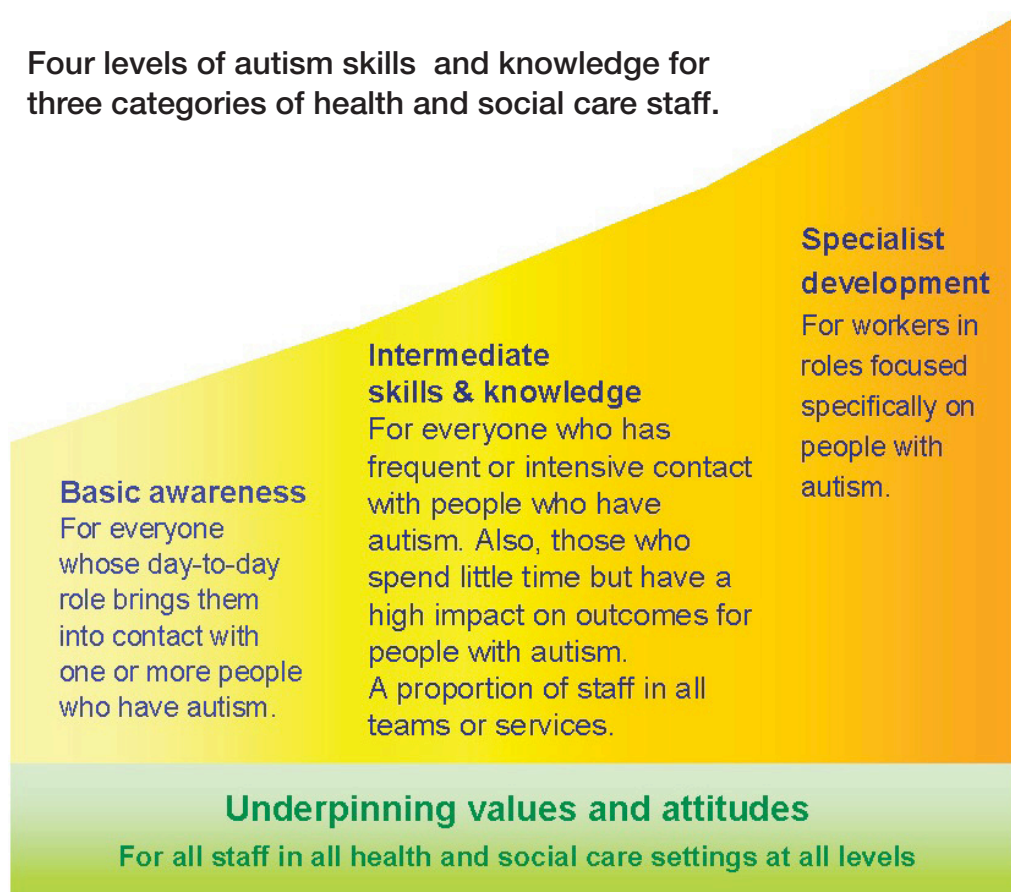
The skills and knowledge list is overleaf, and we have also presented it as a checklist.



There are four sections to the list:

- The *underpinning values and attitudes*, which should be given a high priority to meet the needs of people with autism. These do not replace values statements that already exist, but complement and work alongside them.
- *Basic awareness*—the basic knowledge and skills required for all non-specialist staff whose day-to-day roles may bring them into contact with those who have autism—remembering that this is for all social care and health services, and includes non-care and non-clinical workers such as administrators and receptionists, drivers, catering staff, etc.
- The *intermediate knowledge and skills* following on from the basic level and aimed at staff who have frequent or intensive contact with people with autism, and those members of staff who may spend little time but have a high impact on the outcomes for people with autism. This level is also appropriate for a proportion of workers in all generic services.
- *Specialist development*—skills for specialist workers or workers in specialist services. This section of this list is brief since at the time of publication further work is needed about these specialist skills.

Four levels of autism skills and knowledge for three categories of health and social care staff.





The autism skills and knowledge list

1. Underpinning values and attitudes needed to enable workers to provide people with autism with a service which values their 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.

2. 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.



3. Intermediate knowledge and skills. The worker will be able to:

- 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).

4. Skills for specialist workers

- Diagnosis
- Assessment skills
- Sensory profiling
- Strategic planning of services

Further work is intended on how to develop specialist skills for those whose work is focused specifically on people with autism.

This is one of three publications from Skills for Health and Skills for Care that form the 'Better social care and health outcomes for people with autism' series.

The others are:

- 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'.

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.



The self-assessment checklist for workers and services

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.

1. Underpinning values and attitudes	The first and second sections should be completed by all staff and volunteers.
2. Basic 'autism awareness'	
3. Intermediate knowledge and skills	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. In large teams it may be helpful to have a proportion of workers who have this intermediate level of skills and knowledge.
4. Specialist development	Skills for those working in autism-specific services or for 'autism specialists' within more generic teams.



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 and www.skillsforhealth.org.uk



Criteria	Meet	Some areas to improve	Don't meet	Action needed (What action is planned? By when? Person/people responsible.)
1. Underpinning values and attitudes. People with autism using our service have a 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				



Criteria	Meet	Some areas to improve	Don't meet	Action needed (What action is planned? By when? Person/people responsible.)
2. 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.				



Criteria	Meet	Some areas to improve	Don't meet	Action needed (What action is planned? By when? Person/people responsible.)
3. Intermediate knowledge and skills				
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).				



Criteria	Meet	Some areas to improve	Don't meet	Action needed (What action is planned? By when? Person/people responsible.)
4. Specialist development				
Diagnosis				
Assessment skills				
Sensory profiling				
Strategic planning of services				



Appendix – some introductory information about autism

This publication is not a training resource in itself. However, the following brief information should help explain why there is particular concern about the quality of health and social care services experienced by people with autism.

A) What is autism

“...a lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. The three main areas of difficulty, which all people with autism share, are known as the ‘triad of impairments’. They are difficulties with:

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

Many people with autism may experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours. People with autism often prefer to have a fixed routine and can find change incredibly difficult to cope with. Many people with autism may also have other conditions such as attention deficit hyperactivity disorder (ADHD), a learning disability or dyspraxia.

Autism is known as a spectrum condition, both because of the range of difficulties that affect adults with autism, and the way that these present in different people. For example, Asperger syndrome is a form of autism. People with Asperger syndrome typically have fewer problems with speaking than others on the autism spectrum, but they do still have significant difficulties with communication that can be masked by their ability to speak fluently. They are also often of average or above average intelligence.”

From Fulfilling and rewarding lives: the strategy for adults with autism in England (2010), p.10

DH 3 March 2010, www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

B) What people with autism said about social care and health services

The comments below emerged from a focus group of people with autism that was part of the research leading to the *Autism skills and knowledge list*. Some of the concerns will be held in common with other people using health and social care services; the point is that they can have a much greater effect on a person with autism, affecting the quality of their care and the running of the service.



Good things that can happen in health and social care services



1. On time – if my appointment is at 10 o'clock, see me then or explain that you can't.

2. Look after me and my health, keep me well and give me medication when I need it.

3. Doctor's receptionist has more time to talk to me.

4. I would like to be able to go into a quiet room.

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.

6. Understand that I become anxious at waiting for an appointment when professionals are late for a meeting – do not let that happen.

7. Do not cut the budget.

8. Learning to communicate with people on the autism spectrum.

9. No smoking, don't smell of smoke.

10. Make me feel better.

Bad things that can happen in health and social care services



1. Don't listen to us or take time to get to know us.

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.

3. Not doing their job properly – if they don't or can't do their job – get them out of it.

4. Not listening to me – the annoying thing is for professionals to talk to people that are with you and not talk to you.

5. It would be bad for professionals to plan something behind your back.

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.

7. Don't complicate things, explain things clearly

8. Not communicating in the right way.

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.

10. Seeing different people – you just get used to someone and then you have to see someone else.



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