



How to do a great

**assessment for someone
who has autism**

How to do a great assessment for someone who has autism

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Bibliographic reference data for Harvard-style author/date referencing system:

Short reference: Skills for Care & Skills for Health [or SfC&SfH] 2015

Long reference: Skills for Care & Skills for Health, How to do a great assessment for someone who has autism (Leeds, 2015) www.skillsforcare.org.uk
www.skillsforhealth.org.uk

Having any form of assessment can be an ordeal for someone with autism...



I spend a lot of my time feeling like a failure, don't make this experience more of the same...



Skills for Care and Skills for Health were asked by the Department of Health to work with people who have autism and their families to co-produce a guide for people who carry out assessments – for example; social workers, community care assessors, speech and language therapists, occupational therapists and others, including those who assess people for benefit claims.

The guide is intended for people who already know how to carry out professional assessments but want to know more about autism so they can make reasonable adjustments to their practice to ensure a client or patient with autism gets the best intervention possible.

To accompany this guide we have produced resources two additional guides called 'how to be a great personal assistant for someone with autism' and 'how to be a great autistic individual employer', as well as two videos called 'important things to remember as a personal assistant for someone with autism' and 'important things to remember when doing any type of assessment with someone with autism'. These resources can be found online at www.skillsforcare.org.uk/autism.

Detailed guides for some specialist autism related assessments are available on the National Autistic Society website, e.g. Social Care. Assessment of need for adults with an autism spectrum disorder.

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them and often autistic people will have sensory differences. Some people with autism will not have any social care or special health care needs – others might need a little or a lot.

It is a condition that covers a wide spectrum of differences, sometimes including a learning disability, which means that while many people with autism share certain difficulties, autism will affect each person in very different ways.



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Things to think about when doing any assessment for someone with autism

In order to conduct a fair and accurate assessment effectively it is essential that you are able to minimise the ways in which facets of autism might affect the process or outcome. These include sensory differences, difference between verbal and actual abilities, difficulty with social communication, social imagination and social interaction and anxiety.

Planning the assessment:

- ✓ Try to be flexible about the day, time, duration and location of the assessment. For some people it might be good to make the appointment the first or last of the day when waiting areas are quieter.
- ✓ Ensure the place where the assessment will take place is as calm as possible as this will help alleviate anxiety.
- ✓ Help people prepare for the journey to the assessment – information about travel, how much time is needed to find the room, parking, which floor the room is on and how to find the right room or who to approach on arrival will usually be very useful.
- ✓ Try not to send out unnecessary or irrelevant information.
- ✓ Be flexible if an appointment is cancelled, don't assume the person doesn't want the assessment: find out why – you may need to adapt your approach.
- ✓ Allow extra time for the assessment.
- ✓ If the person needs more than one assessment, try to link up with other professionals to keep stress and anxiety down.

Being aware of sensory differences:

- ✓ Try to find out about any sensory differences that the person has which may impact on the assessment, and make reasonable adjustments.
- ✓ Try to understand any potential triggers that could make the assessment difficult such as specific words, topics, colours or smells.



Adapting your communication:

- ✓ **Speak to the person who made the referral or someone who knows the person well. Ask them about the best way to communicate and what support they might need.**
- ✓ **Remember people with autism may use non-verbal communication as well as verbal. Some autistic people find using pictures, diagrams, social stories or written or audio helpful.**
- ✓ **It might help to give people an idea about what needs to be discussed in advance so they can prepare.**
- ✓ **Find out whether there are any particular phrases or words that the person uses that will help you. For example, for one young man “Maybe, I’m not sure....” actually means “No!”**
- ✓ **Make sure your language is not ambiguous. Use clear and direct questions that are easy to understand.**
- ✓ **Don’t use words with double meaning or humour, as people with autism often take things literally. Or if you do, then offer to explain it – people with autism can learn what these things mean and enjoy the humour in them.**
- ✓ **Be careful about using metaphors or examples – the person may answer your question only in relation to the example you have given. For example, if you ask them if they can get safely to the shops the literal answer might be yes, but you can’t assume this means they can also get to the bus stop across the road or to work or to other places at other times of the day.**





Consider the person with autism's communication methods:

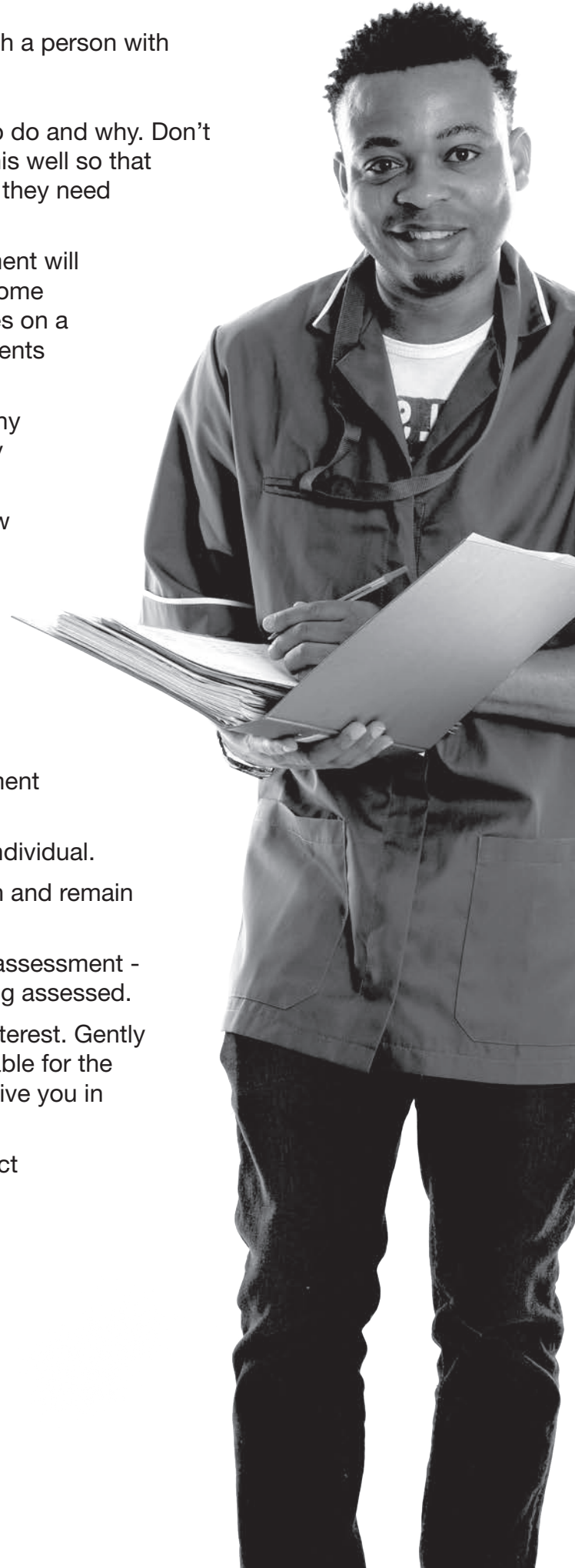
- ✓ Allow for processing delays – it may take more than one appointment for the person to consider their response to a specific question.
- ✓ People with autism may use non-verbal communication as well as verbal. Invite them to give you information in the way that suits them best.
- ✓ Some people are very articulate with a more extensive vocabulary than you but still won't be able to articulate their needs, feelings and emotions verbally – having a chance to communicate in writing (maybe in advance or after an appointment by a letter or email) or pictorially might be more effective.
- ✓ Some people can describe how they would do something – this does not mean that they are able to do it.
- ✓ Repetitive behaviours may be a coping mechanism, so should be respected.
- ✓ Allow extra time for the assessment.
- ✓ Behavioural changes, however challenging, are often a way of communicating. It would be helpful to find out what the communication is indicating. Perhaps offer to take a short break.



The assessment

To get an accurate outcome of any assessment with a person with autism, it's necessary that you:

- Explain who you are and what you are going to do and why. Don't assume they will already know. Plan to pace this well so that you don't rush and don't give more detail than they need or use jargon.
- Give the person an idea how long the assessment will take and what the process or stages will be. Some people with autism find it helps to have pictures on a timeline/schedule strip to show the order of events and help to alleviate anxiety.
- Make sure you inform the person if there are any delays as the person may become increasingly anxious.
- Don't take offence if the person does not follow social norms or says something that you are not expecting or seems rude or abrupt.
- Ask if the person would like a break during the assessment, plan this at the start and agree a way they can ask for a break if they need it.
- Make a point of appreciating positive engagement during the assessment.
- Make no assumptions - treat everyone as an individual.
- Make sure you are consistent in your approach and remain calm whatever the person's response is.
- Try to be flexible in the way you complete the assessment - consider what is preferable for the person being assessed.
- The person may wish to talk about a special interest. Gently help them make the best use of the time available for the assessment and consider how this topic can give you in sight into what matters to them.
- Recognise how cultural beliefs and values affect behaviours.



What attitudes, knowledge and skills are required to carry out effective assessments with people who have autism?

Below are examples of the attitudes, knowledge and actions that people with autism and their families felt were important from any professional doing an assessment of someone who has autism.

Attitudes	Knowledge	Actions
<ul style="list-style-type: none"> ■ People with autism have feelings. ■ Be concerned with the long term of someones life, not just the minimum they need to survive right now. ■ Be positive about autism – see the good things as well as the difficulties. Show this with your language and body language. ■ Accept how the person sees their autism – as an asset and/or a disability. ■ Accept and embrace the persons (and their family’s) individuality – work with them not against them. ■ Believe that all (autistic) people can and do communicate. ■ Be supporting and non-judgemental. 	<ul style="list-style-type: none"> ■ Understand what ‘neuro-typical bias’ is. ■ It’s hard for non-autistic people to imagine all the ways autism can affect someone. This makes it hard for them to assess properly. ■ Know the person as an individual including: <ul style="list-style-type: none"> ■ their background ■ how autism affects them ■ their aspirations and future plans ■ their wishes, preferences, hobbies and interests. ■ Understand what the person’s sensory differences actually are. ■ Know behaviour is communication, even challenging behaviour. ■ Know that autism is not curable. ■ You need to consider all my needs not just the one your team covers. 	<ul style="list-style-type: none"> ■ Ask for, and read, the person’s ‘one page profile’ or ask them to send you some brief information about what’s important to them. ■ Explain what you are doing and the process you’ll follow – consider using diagrams or timetables to show the stages of a process and the time available. ■ Use the most familiar method of communication and find the right tools. ■ Use familiar language not medical jargon. ■ Spend time finding out how it feels – ‘walk a mile in our shoes’. ■ Use ‘adult’ language with adults and accurate language with children. ■ Do a holistic assessment of the ‘whole person’(and where relevant their family) – considering their wellbeing and hopes and fears for the future expect their values and beliefs. ■ Be creative – bypass managerial (and budgetary) constraints. ■ Practice personalisation in its true sense.

Attitudes	Knowledge	Actions
<ul style="list-style-type: none"> ■ Remember the struggles. individuals and families may have had and why they may be frightened, wary or impatient – ‘auties’ are survivors! ■ Trust – trust the person and be someone they can trust. ■ Accept that things may have been unfair. ■ Understand trauma – past experience and other causes of anxiety. ■ If someone has asked for an assessment they must really need something – they might have a hard time figuring out or explaining what. ■ Believe there is always a solution. ■ Respect the things that matter to the person – especially if they seem childish or trivial. ■ Understand that people may feel ashamed of their difficulties or special interests. 	<ul style="list-style-type: none"> ■ Try to be aware of any other conditions the individual might have e.g. learning disabilities, anxiety, communication difficulties, ADHD. ■ It’s okay to admit you don’t know everything. ■ Non-verbal doesn’t equal stupid; long words don’t equal clever. ■ You should have observational skills, observing both environment and behaviour. ■ There’s more to getting employment right than just the environment. ■ Be aware of the network of professionals that the individual may already have contact with. ■ Understand professional boundaries. ■ Repetitive behaviours can be a useful tool to aid communication for a person with autism. ■ The importance of funding for training for care staff. ■ Be aware of ways that caring for someone with autism can impact on family members (e.g. health, relationships and employability). ■ Know how to sensitively ask the right question. ■ A diagnosis is a big thing that takes huge efforts and resources; respect it. 	<ul style="list-style-type: none"> ■ Stick to agreed arrangements – don’t change things last minute or, if you have to, then let people know as soon as you can, apologise and understand the effect on them. ■ Practice compassion. ■ Have a good work life balance – for yourself and the people you are assessing. ■ Adapt, adjust, learn skills and use them, always have an open mind and be willing to learn. ■ Share knowledge. ■ Offer support emotionally and physically. ■ Accommodate individuals’ needs. ■ Apply the Autism Act 2009 – be prepared to make reasonable adjustments! ■ Recognise when someone with autistic spectrum disorder (ASD) is finding a situation stressful and be able to alleviate it. ■ Adapt the environment to the individual – don’t expect them to adapt to the environment. ■ Allow people time to process information – find out what works best for that person. ■ Respect routines that matter to that person. ■ Prioritise continuity and consistency. ■ Share information and involve the person in responsible decision making. ■ Talk to the individual not their family member or support worker – if you need their viewpoint then get permission and make it clear you are asking for their views at that point.

Attitudes	Knowledge	Actions
<ul style="list-style-type: none"> ■ Accept ‘stimming’ activities, routines of actions or language and that ‘paying attention’ might look like ‘not paying attention’. ■ Be enabling and encouraging – people can grow and develop throughout their lives. ■ People can contribute to training. ■ Some people want to be part of an autistic community – some don’t. ■ All services can always be improved. ■ Equality of opportunity means doing things differently for people. ■ Know your limits and signpost to others or get advice if you can’t help. ■ Don’t finish my sentences. ■ Don’t make assumptions about me. 	<ul style="list-style-type: none"> ■ People are not less able to do a job because of weaknesses in other areas; e.g. communication difficulties when a job is to fix computers alone. ■ It can be a big problem being able to do some activities when everything around me is ok, but then I can’t do them when it is needed. ■ Eligibility criteria do not take into account variable difficulties so find ways to compensate. ■ It’s ok to ask questions – and explore them. ■ Understand that my attention will be depleted if things are changed at the last minute or not what I expected. ■ Know about Deprivation of Liberties Safeguards (DoLS). ■ Once you have met one person with autism – you have met one person with autism. ■ People can be greatly affected and still make eye contact! ■ Be aware of family history – parents/ carers attending the appointment may also have autism. ■ Regular medication reviews are needed. 	<ul style="list-style-type: none"> ■ If the person has not got mental capacity, seek the opinion of people who know the person best - this includes deputies, family members, experienced carers and professionals working directly with the person and who are familiar with the person’s history, preferences and choices. ■ Make any demands realistic and low pressure. ■ Probe respectfully, ask open questions and ask people to describe how things are for them – understand that literal answers may not give a picture of a person’s difficulties. ■ Be sensitive and constructive if you need to ask someone to ‘stick to the point’ or limit the time spent on one topic. ■ Be open to signs of other conditions such as anxiety / depression and physical health conditions – don’t put everything down to autism.

Attitudes

Think about how your attitude affects the person you are assessing and the outcome of the assessment.

The best assessors think about how I might feel and react to something that they say, even if it isn't meant to sound bad.

The best workers...	The worst workers...
<ul style="list-style-type: none">■ are a real ally who will stand up for what people need■ are interested, non-judgemental, respectful, empowering and empathetic.■ value freedom of choice, independence and taking risks.■ act with honesty for the person they are supporting.■ speak to the point.■ are caring.■ value me and my family's experiences.■ are proactive.■ are passionate about getting things right for me.■ value the person's cultural or religious diversity and sexual orientation.■ ask – 'how does your autism affect you?' or 'What has changed?'	<ul style="list-style-type: none">■ don't practice what they preach.■ are too controlling, e.g. speaking for me or interrupt me.■ think they know a lot about autism and make assumptions about me.■ are opinionated and don't realise they are biased and making wrong assumptions.■ start by considering budgets and resource constraints before my needs and hopes.■ disbelieve my circumstances, difficulties, diagnosis or sensory differences.■ are judgemental, blaming or criticising me and my family for my difficulties.■ are bullies.■ think in an institutionalised way.■ let their personal life affect their professional life.



Knowledge



The best workers know that autism can affect someone differently in different situations and environments.

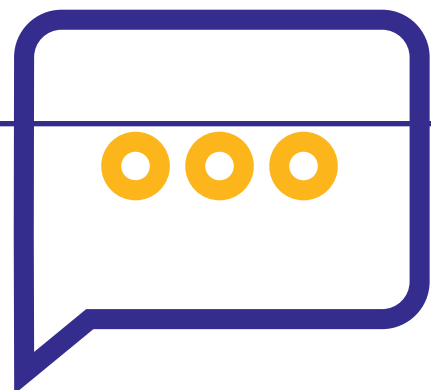


The best workers...

- understand about autism not just in an intellectual way but in a feeling and experiential way.
- understand that autism can be very different for different individuals.
- understand the individual and what's important to them.
- respect my lifestyle and home.
- understand my specific needs, e.g. memory, communication, sensory and behaviour differences, etc..
- understand somebody with autism can be very skilled in some aspects of their life but desperately struggling in others – and may feel ashamed of this.
- know about a range of tools and resources that might help e.g. tools to help with communication and ways to help sensory differences.
- have knowledge of the individual's cultural and religious or similar needs and background.
- if they don't know, ask, or go and find out!
- are aware of the individual's health needs.

The worst workers...

- don't know anything about autism and are not prepared to learn.
- think IQ or verbal skills equals life skills and competence.
- don't understand the real pain and distress that sensory differences cause.
- record literal answers to questions in a superficial way.
- think they are experts in what they do just because they have been working with people with autism for a long time.
- make assumptions.
- treats somebody like a child.



Actions



Do exactly what they say they are going to do! (or honestly explain any differences)



The best workers...	The worst workers...
<ul style="list-style-type: none">■ listen attentively■ build a rapport to create a trusting relationship■ share information and signposting■ make reasonable adjustment for my needs■ accept the individual's language■ don't leave me waiting■ agree time scales■ be patient■ go at my pace■ give me time to regulate sensory problems■ believe me■ get other people involved when needed (with my permission, involve my family)■ look for solutions, addressing access and communication needs■ have a holistic approach & think about my family■ are person-centred and help me plan for the future■ find the answer■ are available and responsive■ work flexibly■ accept and admit mistakes – correct errors in records quickly■ accept the person's presentation■ are friendly and approachable■ find out what makes me angry and upset■ value my cultural and diversity needs■ show patience	<ul style="list-style-type: none">■ disrespect my style or home (different for each person).■ hand pick people who are easy to work with and avoid people with complex needs.■ let their personal life affect the way they work.■ shy away from dealing with anything to do with sexual health and sexual relationships.■ record things incorrectly, e.g. minutes that don't reflect the conversation or inaccurate information copied from other sources.■ lie – for whatever reason.■ are vague about what I can expect.■ leave me hanging, unsure what to do next.■ tell me I lack empathy or imagination.■ joke and tease.■ tell me to ignore sensory differences.■ are rude or dehumanising, using language to describe traits or diagnostic criteria that is hurtful.■ keep information from me.■ don't consult and check information with my family.■ are confrontational, passive aggressive, dismissive or insincere.■ do not read background information before meetings.

Who has contributed to the development of this guide?

In June and July 2015 a group of people worked together with Skills for Care and Skills for Health to think about what really makes a great personal assistant for someone with autism.

The group included:

- people with autism
- carers and family
- advocates
- personal assistants
- direct employers
- health and social care professionals with a specific interest in autism.

Useful links and references

The autism skills and knowledge list, Skills for Care/Skills for Health, 2011.
www.skillsforcare.org.uk/autism

The National Autistic Society has detailed guides, training and resources for a range of professionals. www.autism.org.uk

Acknowledgements

Autism guides development group (which included individuals and groups representing people with autism, family carers and professionals working in social care, health and the police)

Autism guides wider consultation group

Leeds Asperger Adults - www.leedsaspergerblog.wordpress.com

Leeds Autism AIM - www.autismleeds.org.uk

The National Autistic Society - www.autism.org.uk

Insight Autism Consultancy - www.insightautism.co.uk

Department of Health - www.gov.uk/government/organisations/department-of-health

Skills for Care - www.skillsforcare.org.uk

Skills for Health - www.skillsforhealth.org.uk

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