



Social care

Assessment of need for adults with an autism spectrum disorder

By Mari Saeki and Andrew Powell

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Introduction

Without the support that an accurate assessment can lead to, many adults with an autism spectrum disorder (ASD) may become socially isolated, drop out of college, employment or day services, and suffer mental health problems or psychological breakdown.

To inform our *I Exist* campaign, we spoke to adults with an ASD, their families and carers, who told us that they struggle to access services that meet their needs.

Sixty-three percent of adults with an ASD say that they do not have enough support to meet their needs. Many parents and carers do not get support from their statutory agencies and have not received a carer's assessment.

This booklet is intended for use by health and social care staff involved in assessment and care planning for adults with an ASD. It will also be useful for any other person who supports someone with an ASD across a variety of settings, such as housing support staff, community psychiatric nurses, occupational therapists or psychologists.

There is very little guidance for professionals who carry out assessments of need,¹ and it is not always easy to identify the needs of an adult with an ASD. Many have communication difficulties, and may – unintentionally – misrepresent their support needs. This booklet will give you some ideas and references for developing your knowledge of ASDs and how they affect each person differently.

¹ Professionals may carry out an assessment of need under the following Acts: the *NHS and Community Care Act 1990*; the *Mental Health (Care and Treatment) Act 2003*; the *Social Work (Scotland) Act 1968*; the *Mental Health Act 1983* or the *Mental Health (Care and Treatment) Act 2003*.

With greater understanding, social workers and other assessors can make sure that support and resources are directed in the most cost-effective and appropriate way. There is evidence that a relatively low level of ongoing support for adults with an ASD can prevent anxiety and distress, and negate the need for more expensive crisis support later.²

We hope that this booklet will help you feel better prepared to identify and meet the needs of people with an ASD.

The legal context

It is essential that people with an ASD approaching their statutory agency are offered an assessment of need, and that agencies establish a clear route for families to request an assessment.

It is the legal duty of a statutory agency to undertake an assessment regardless of whether the agency believes a person will be eligible for support. In fact, this is a proactive duty and **not** dependent on someone asking for support.

A diagnosis of an ASD (which may include autism; high-functioning autism; and Asperger syndrome) does not mean that someone will meet eligibility criteria for services.³ However, an assessment of need will nearly always be required to establish whether the individual's particular difficulties make them eligible.

² The National Autistic Society (2008). *I Exist: the message from adults with autism*. Editions published in England, Northern Ireland, Scotland and Wales.

³ In England this is the Department of Health's Local Authority Circular (2002). *13: Fair access to care services: guidance on eligibility criteria for adults in social care*. In Wales, Welsh Assembly Government (2002). *Health and social care for adults: creating a unified and fair system for assessing and managing care: guidelines for local authorities and health services*.

Each statutory agency has a statutory duty to assess where it appears that any person for whom they may provide or arrange community care services may be in need of any such services. The agency should carry out an assessment of needs for those services and have regard to the results of that assessment when deciding if the person's needs call for the provision by them of services.⁴

Government guidance also makes the need for assessment clear.⁵

Mental health legislation

The *Mental Health Act 1983* (*Mental Health (Care and Treatment) Act 2003* in Scotland) defines those who may receive care and control due to a mental disorder.

While ASD is not a mental disorder, there may be times when a social or health care professional is called upon to assess someone with an ASD and an additional mental health disorder. Sometimes the behaviour of someone with an ASD looks like a mental health problem, when it isn't. Conversely we know that many people with an ASD have an additional mental health difficulty which is not recognised, because behaviour which indicates a possible psychiatric difficulty may be dismissed as 'just being part of their ASD'.

We hope therefore that the guidance in this booklet will be of use to professionals providing assessment where there may be mental health difficulties involved.

⁴ This duty is quoted, with minor variations, in *The NHS and Community Care Act 1990* s.47 (1)(a) and the *Social Work (Scotland) Act 1968*, further amended by the *Health and Community Care (Scotland) Act 2002*.

⁵ Practice guidance (2003) to Local Authority Circular (2002) (13); and Welsh Assembly Government (2008). *Autistic spectrum disorder (ASD) strategic action plan*.

The Mental Capacity Act 2005

This Act, which applies in England and Wales, establishes that every adult has the capacity to make their own decisions until it is shown that they can't. It also states that the emphasis must be on assisting adults who have some capacity to understand the decisions they are able to make by giving them support, information and advocacy. You will need to consider the implications of this Act, remembering that people may have capacity in some areas but not others. For example, a person with an ASD may have the capacity to consent to basic medical treatment, but not to manage their financial affairs. It is important to be aware of people's general level of understanding and ability, and how they communicate their feelings and wishes.

The five principles of the *Mental Capacity Act 2005* are as follows.

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.



What are autism spectrum disorders (ASDs)?

Autism spectrum disorders are lifelong developmental disabilities. The word 'spectrum' is used because, while all people with different diagnoses (such as autism, Asperger syndrome or high-functioning autism) share three main areas of difficulty, their condition will affect them in very different ways. Some are able to live relatively 'everyday' lives; others will require a lifetime of specialist support.

ASDs can affect people of different intellectual ability. You may find that you are assessing people with severe learning disabilities, as well as those who are of average or above average intelligence.

It is important that professionals do not make assumptions about a person's level of need based on their intellect. For example, a person may have an academic degree, a good vocabulary, and appear to be very able and not in particular need of support. In actual fact, they could struggle on a daily basis to understand social situations and manage their personal care and independent living needs.

Furthermore, because of the communication difficulties they experience, people with an ASD may mis- or under-represent their own needs and it is important for professionals to be aware of this.

Many people are diagnosed early in life, but others may not receive a diagnosis until they are adults. There is no 'cure' for an ASD but with the right support, people can develop greater independence and reach their full potential.

The three main areas of difficulty which all people with an ASD share are sometimes known as the 'triad of impairments'. They are:

- > difficulty with social interaction
- > difficulty with social communication
- > difficulty with social imagination.

Social interaction

People with an ASD often have difficulty recognising or understanding other people's emotions, feelings and needs, and expressing their own. This can make it more difficult to fit in socially and, potentially, to explain their needs to a professional.

Common social interaction difficulties include:

- > problems building relationships or maintaining them
- > finding it hard to work out what other people think or feel (eg, not understanding why you want to ask them questions)
- > difficulties picking up the unwritten 'rules' of social behaviour (eg, how close to stand to other people when talking to them)
- > fewer social skills.

Because of these interaction difficulties some may prefer to spend time alone rather than seeking out the company of other people, while others are keen to talk to other people and make friends, but may be unsure how to go about this.

Difficulties with social interaction can make it hard for a person with an ASD to explain what support they want, or need. Or the person may not wish to engage with you, or understand how to take part in an assessment.

Social communication

People with an ASD have difficulties with both verbal and non-verbal language, that is, using and understanding words and body language in order to communicate with other people. Many will need extra time to process what has been said to them.

Common social communication difficulties include:

- › a lack of spoken language
- › problems understanding the 'gist' of what people are saying, or the spirit in which it is said (for example, recognising jokes or sarcasm)
- › having a literal understanding of language and thinking people always mean exactly what they say
- › difficulty making or maintaining eye contact
- › difficulty reading other people's facial expressions and body language.

Social communication difficulties mean people with an ASD can misunderstand or misinterpret what has been said to them. They may find it difficult to express, or accurately represent, their own needs during assessment. A person may also struggle to understand your questions and intentions, unless you make them absolutely clear and unambiguous.

Social imagination

The world can seem a very unpredictable and confusing place to people with an ASD, who often prefer to have a structured routine so that they know what is expected of them, and what is going to happen every day. This means that meeting you may feel like quite a daunting prospect, because it is a break from what is familiar.

Common social imagination difficulties include:

- › problems with predicting what will happen next, or what *could* happen next
- › finding it hard to self-organise and plan (for example, cannot structure their day without support)
- › less ability to transfer skills learnt in one situation to another
- › not understanding the concept of danger (for example, that running on to a busy road poses a threat)
- › fear of change and planning for the future (eg a person might initially reject all discussions about going somewhere new or unfamiliar).

Because of these difficulties it is hard for people with an ASD to understand their own needs and wants or imagine what alternatives there may be to their current situation. They may not have the insight to realise what information you need to get during an assessment.

For each person you assess it will be important to understand how difficulties with social interaction, social communication and social imagination affect them, and to adjust your approach accordingly. Preparation is key: see page 11.

Other related characteristics

Sensory issues

People with an ASD may experience some form of sensory sensitivity. This can occur in one or more senses – sight, sound, smell, touch, taste, balance and body awareness. People can be over-sensitive (hyper-sensitive) or under-sensitive (hypo-sensitive), although their level of sensitivity can vary over time and between the different senses.

For example, a person with an ASD may find certain background sounds, which other people ignore or block out, unbearably loud or distracting. This can cause anxiety or even physical pain.

It is important to record people's sensory differences when assessing their support needs or deciding on placements.

Stress and anxiety

Because the world and people in it seem so unpredictable, many people with an ASD experience stress and anxiety. This can have a huge impact on the three main social difficulties they experience, as well as sensory tolerances. When under stress, the ability to communicate, interact socially and to think flexibly is likely to be further reduced.

Other difficulties

People with an ASD sometimes have additional difficulties, such as learning disabilities; or specific learning difficulties like dyslexia or dyspraxia; or related conditions such as attention deficit hyperactivity disorder (ADHD).

It is not uncommon for people with an ASD to have problems with sleep, or a very restricted diet. Some develop mental health problems. All associated difficulties need to be treated in their own right, but within the context of the person's primary diagnosis.

The impact on the family

People with an ASD bring many positive qualities to their family's daily life. However, they may have high support needs and these can be a cause of stress for family carers.

All staff involved in assessing or supporting a person with an ASD should think about the impact on people's families and immediate carers, especially when the person with an ASD is living at home. It is good practice to carry out a carer's assessment. Make sure that family members and carers know they are entitled to an assessment, and that they can speak to you alone and in confidence if necessary.

It is important to include a person's family and wider support networks in the assessment process and to take time to get to know people with an ASD, to build a full picture of their support needs.

Preparing for the assessment

It is good practice to have a clear idea of how to engage with the person you are assessing and their ways of communicating and understanding **before you start**. Without this, the person may not engage with you, and you risk making them feel anxious or more isolated.

For many people with an ASD, face-to-face contact with new people is often stressful. It may take a while before they feel comfortable with a professional and are able to start expressing their needs. You may find that when you first meet a person with an ASD, it is not a very long meeting. However, it is important to try and make it a positive one.

Wherever possible, speak to the referrer (if the person is not self-referred), the person's family and carers to find out how they prefer to communicate, to what extent they can describe their needs, and what their level of understanding is. Would it help to have a supporter or an advocate present?

As mentioned on page 38, people with an ASD may not want you to consult their family, so if they are still living in their family home, consider gaining additional information from a carer's assessment. If there is background information about the person on file, read it.

Reasons why assessment may be difficult

It's possible that people with an ASD may not engage with you initially because of fear, anxiety or an inability to understand why you are there – or just because they do not wish to be seen as 'different'.

People with an ASD may also mis- or under-represent their own needs.

The following are some of the reasons why you will need to prepare carefully and be creative with your assessment techniques. The person may:

- › have limited communication skills and understanding
- › feel uncomfortable having a conversation with a stranger
- › not understand who you are and what you want
- › not be able to define what their own needs are
- › not be able to talk about or explain their needs very easily, and so risk misrepresenting them
- › be able to speak fluently, but this may mask difficulties with actual understanding
- › try to say the 'right' thing in response to your questions rather than stating what their actual needs are
- › find it hard to plan for the future or to think about change, and be uncomfortable talking about support that involves changes to an established routine or a move to a different service
- › not understand what you are asking and take things very literally, so if you ask 'Are you able to wash yourself on your own?' a person might say 'yes' – when in fact they can only do it with verbal prompting at every stage.

As well as this, some people with an ASD may not particularly **want** to engage with professionals, have an assessment or receive services, despite the fact that they could benefit from this. There are several reasons why this might happen. They may:

- › feel belittled by the suggestion that they need assessment or support
- › not be able to understand the link between having an assessment and getting the support they do actually want and need (meaning it may not have been well explained before)
- › be wary of social workers and other professionals who may have caused anxiety in the past
- › have ‘social anxiety’ or depression
- › be concerned that they won’t be able to process all the information that professionals could give them, so refuse to talk to you.

Do not take lack of engagement during your early meetings as failure to consent to an assessment. Prepare, take your time and try to get to know the person first. Involve people’s families and wider support networks in the assessment process, to build a full picture of their support needs.

Build a relationship with the person you are assessing

People with an ASD often say that they respond well to certain personal qualities in others. If you can show these qualities, it can help you to build a relationship with the person you are assessing and promote their self-esteem.

Patience

It will often take some time and patience to understand a person with an ASD. His or her needs can be complex, and they may also:

- › have difficulty recognising, or expressing, their needs and wishes

- › have a short attention span and be easily distracted
- › prefer to talk about a favourite topic, rather than the issue you are asking them about
- › not always display social niceties
- › fail to remember appointments
- › have additional learning disabilities which make spoken communication difficult
- › display challenging behaviour
- › take time to process information and respond.

It really helps if you can take the time to understand a person’s particular needs and be supportive and patient during the assessment. This will reduce any anxiety the person may be feeling and reassure them that you are there for them.

Sensitivity, kindness and straightforwardness

People with an ASD can find the world a confusing place. Other people often don’t say what they mean and it can be difficult to understand their behaviour or motives. The world can also be unkind: many people with an ASD have been the victims of bullying.

You should provide clear, unambiguous information in a sensitive, kind way.

Consistency, calmness and reliability

People with an ASD often benefit from structure and routine: it is a way to cope in a confusing and unpredictable world. They need people around them who are calm, who take a consistent approach,

and who can be relied upon. Simple things like arriving on time, having the necessary paperwork and not making promises unless you are sure they can be kept, will help the person to develop trust in you. Inconsistent and unreliable support can be worse than no support at all.

Acceptance

Many people with an ASD have told us that they value their differences and would like people to accept them for who they are. Many will be averse to a 'make me normal' approach or talk of a cure for autism. Being positive about ASD can help to make the assessment process a success.

Use person-centred planning

Person-centred planning (PCP) is described as 'the collective term for a variety of techniques used to get to know a person, develop an understanding of that person's hopes for the present and the future, and to set priorities for change'.⁶

PCP is often seen as a less formal way of working, giving more control to people and their families, and so may be a less stressful way to assess and plan. It is also about looking at the whole person, not solely concentrating on their difficulties, so it is a positive way of working.

Person-centred planning helps us to understand and respond to people, and to get a balance between what is important to someone (for example, their individuality and lifestyle) and what is important for them (what keeps them healthy and safe). Person-

centred planning can also clarify the roles and responsibilities of people who are paid to support a person with an ASD, and make sure that the person (and their specific support needs) is known to everyone who will be supporting them. It is vital to record people's needs in detail – especially as the needs of a person with an ASD may not be immediately obvious, even to professional care staff. Failure to respond to these needs properly can cause support plans to fail.

There are a number of person-centred planning 'tools' that can help you to record information about the support people are receiving and their needs and wishes. What's working? What isn't? What are the person's learning and support needs? What do they want to achieve, and how do they want to be supported? All in all, you will be able to carry out a much more thorough assessment, or create a tailored support and care plan for a person with an ASD if you use a person-centred approach.

Some PCP tools identify immediate action and short-term targets. These might typically involve questions about a person's important routines and specific needs so their day goes well.

Other tools consider more abstract concepts and long-term goals. The key is to use tools which suit an individual's temperament, understanding, interests and current circumstances.

We recommend that person-centred planning should be used by all social care professionals, whenever possible. For more information, see www.autism.org.uk/pcp

⁶ Kennedy, J., Sanderson, H., and Wilson, H. (2002). *Friendship and community*. Helen Sanderson Associates

Information to gather before the assessment

The more information you can gather before meeting the person, the better. Here are some useful questions to ask. Your answers will inform the assessment process.

- To what extent can the person with an ASD, or their family, lead the work to identify their own needs?
- How much does the person themselves, and their family, understand about the assessment? Do they know about the referral and why it has been made? Does the person understand the concept of assessment? If not, how will you explain this at your first meeting with them?
- Is the person with an ASD able to meet face-to-face, or is there a better way of getting information about their needs? A person with an ASD may be reluctant to talk about themselves to a stranger, or not very confident about communicating verbally.
- Would the person with an ASD like another person to be present when you meet, for example a parent, sibling or advocate?
- How articulate is the person, and what is their understanding of spoken language? Do they use alternative or additional means of communication, for example visual symbols, sign language or a 'talking mat'? Do they prefer indirect communication to begin with, such as a phone call or an email?
- How long can the person concentrate? For some people with an ASD, a five-minute exchange would be considered quite a lengthy conversation.
- Are there any words or subjects that you need to avoid? (Some people have certain 'trigger words' or topics that make them upset; others have special interests and it may be difficult to end a conversation about them.)
- Do they have any dislikes, fears or phobias? Might you need to avoid talking about these completely, especially in the early stages of assessment?
- Does the person have any special interests? Can you use these to put them at ease or to engage them in the assessment process?
- Is it best to meet at home or in another place the person is familiar or comfortable with, for example, a public park or a café where you can find some privacy?
- Are they comfortable with eye contact, handshakes and other people being close to them?
- What is the best time to meet and how long should the meeting be? (For example, at a time of day when the person is not coming from, or going to, another activity. They may feel anxious if they think a routine is going to be interrupted.)

Assessment

Every person with an ASD is an individual. It is important to remember that while each shares three main areas of difficulty, they will experience life very differently. Knowing that someone has a diagnosis of an ASD is only your starting point. A thorough assessment of each individual's personality, abilities, difficulties, aspirations and support needs takes time.

Creative approaches to assessment

If you are working with people with an ASD, you will find that often, just going to someone's home and trying to conduct an assessment will not work. Consider the best way to engage with each person you are assessing; for some, this may mean thinking about alternative ways of conducting the assessment. Here are some suggestions, but remember they are only suggestions: the important thing is to make each person feel comfortable and tailor the assessment to fit with their ways of thinking.

- Some people may prefer to speak to you via email, instant messaging, phone call or text first. This avoids the difficulties they can experience with social interaction and communication, such as not being able to 'read' other people's expressions or body language; or understand the gist of what someone is saying. Do be aware however that some people also find phone conversations stressful.
- See if the person wants to organise their own meeting to discuss what they want and need. They might like to send out invitations. The person may wish to hold the meeting in a place where they feel more at ease, for example their own home may be a more autism-friendly environment than your workplace.

- A multiple-choice questionnaire may be a good way to elicit information before your first meeting. If they are able to write, many people with an ASD can express themselves eloquently and may offer more information this way.
- Some people may prefer to write their needs down rather than face the social demands of a face-to-face meeting. If so, give the person a list of clear and unambiguous questions to answer.
- Sometimes a more formal approach, such as making the assessment a written exercise, can help as it shifts the focus away from direct interaction. Or you might leave the assessment form with the person, and family if relevant, to complete.
- However, others may not like an overly formal assessment. Some might find it easier to talk while they're out for a walk; others might prefer to go for a drive and talk, so that they don't need to make eye contact.
- You might ask the person if, when they close their eyes, it helps them to think more clearly. Suggest they do this during the assessment if it's helpful. Or people could answer you by drawing the pictures they have in their mind, or the things they think are most important.
- Consider ways to make the process more meaningful. You might use people's special interests as a theme; or write information in their favourite colour.
- Visual supports can help the assessment process. Firstly, they can help set out what you are going to talk about and in what order. Secondly, they can help some people to understand what you're saying. Thirdly, visual supports can help someone to express

choices and preferences, for example using photos of different workplaces might help you to identify what aspects of that environment people feel most comfortable with. Some of these visual supports include Mind Maps™, flowcharts, Talking Mats, 1 to 10 scales, timetables and illustrative diagrams. Some, like Talking Mats, are specifically designed for people who have communication difficulties.

- › Some people with an ASD who are able to appreciate the difference between words and thoughts may find the use of simple stick-figure drawings helps them visualise their own or others' thoughts. This can be an easy way to help people understand the differences between their thoughts and words, and to accurately represent their thoughts to you. For example you could draw a stick person (make it clear that this represents the person with an ASD) and ask them to write in various thought bubbles what makes them feel happy. You can also do this to show the person how other people, for example their family, may be feeling.
- › Word association may be useful to see how people understand concepts such as 'home', 'employment' or 'friendship'.

Altering how you communicate

It is important to communicate clearly, in a way that suits the person and elicits the information you need to make a fair and thorough assessment of need.

The following tips will help you to communicate with people with an ASD during an assessment. Not all of these tips will apply to all the people you assess, some of whom will have average or above average IQs, others profound learning disabilities.

Verbal communication

Some people with autism are very articulate, while others may not speak at all. However, all may struggle to understand what you are saying. There are a number of reasons for this, and a number of ways in which you can help.

Make sure you get the person's attention before communicating, for example say their name then pause briefly before carrying on.

Slow down your overall approach and allow time for processing. It may help to count to about six seconds in your head after saying something, before expecting a response. Some people need this amount of time (or more) to process what you have said. If the person does not respond at all, repeat what you have said and wait again. If there is still no response, try re-phrasing.

Reduce the number of words you use, especially in your first few meetings. Fewer, well-chosen words are always better than talking too much. It may help to rehearse what you are going to say in your head before you speak and to consider how it is likely to be interpreted. Any written and/or visual material should be easy to understand and well spaced out. Use boxes and clear headings.

Use unambiguous language. People with an ASD can easily misunderstand your meaning or intentions. For example, 'This looks like the sort of college that would suit you' may be taken to mean 'This is the college you will go to'.

Try to avoid vague language. For example, 'maybe' and 'perhaps' are difficult words for some people with an ASD. Better to say 'I do not know', or 'Ask me again next week, I will try and find out for you'.

Avoid metaphors and expressions which could be taken literally. For example, 'It sounds as if you've had a nightmare just recently' might lead the person to believe you are privy to their dreams. Be careful introducing jokes; these may not be understood.

Use a calm voice and rely upon your actual words to communicate effectively. Lots of gesturing or being over-animated will confuse the person.

Ask straightforward questions which the person can understand and answer. For example, some people may require closed questions ('Would you like to study at college next year?' rather than 'What are your future plans?'). You could also ask which of two choices they prefer.

Use visual aids as appropriate, for example pictures, photos, symbols and written cues. In order to find out what someone likes, you might use a choice board. It will take time to understand people with severe learning disabilities and what their opinions are.

Body language and gestures

People with an ASD may not be able to 'read' your body language and gestures, so try not to impart important information this way. State information clearly in a way that the person understands, whether by saying it, writing it down or using visual aids.

Remember that making or maintaining eye contact can be difficult for some people with an ASD. It may be helpful, until you get to know the person, to reduce the amount of time you maintain direct eye contact. Not sitting face to face will help.

Keep body language non-threatening. Do not crowd the person or use lots of gestures. Keep your movements and body language clear

and predictable. Do not speak too quickly and try to keep your tone of voice even and measured.

Check the person's understanding

People with an ASD can appear to be very able, and it would be easy to make the assumption that they have understood everything you've discussed, and made informed choices. Always check people's understanding. For example, a person with an ASD may say they can manage an aspect of self-care when in fact they can only do so with verbal prompting at every stage. The person would feel they are answering honestly because they see it in concrete terms.

Sometimes a letter to follow up a conversation may help to clarify what has been said and agreed. If the person is quite anxious, a short, follow-up email, text or letter that thanks them for their useful contribution to the meeting and clearly explains what will happen next is a good idea. Include visual symbols or pictures as well as text if people need this.

Do not assume that if you are talking to another person in the room, people with an ASD will necessarily remain interested, be listening, or understand how this other conversation is also relevant to them. Recapping from time to time can be useful.

Be aware that the person may struggle to identify what they want or make choices based on limited information. They may, for example, choose a placement based on the lunch menu in the canteen.

Plan the assessment around the person

There are some simple ways to plan assessments so that you get the information you need, and the person you are assessing fully understands and engages in the process.

For example, you might ask the person to write out questions they want to ask you. Use these to draw up an agenda together and try to stick to it. Tackle one topic at a time if possible, to avoid confusion. The person may need a gentle reminder to keep them on track in conversations.

People who do not read should receive information in a format they can understand, for example use pictures or symbols to describe the assessment and planning process.

Take care when sharing assessments and plans with the person: avoid over-lengthy verbal explanations which could be confusing and again, use pictures or symbols if necessary. Note that some may react badly to written words which they perceive to be negative. Your assessment or plan will need to be written in an unambiguous and positive way.

Be clear about your role

It is helpful to be clear about what your role is from the very beginning: what do you want to achieve for the person? How much help can you realistically offer? How long will you be involved?

Depending on a person's understanding, try to explain why you are meeting them, what your job is and the reason you want to know certain things about them. It would be helpful if you could prepare some information about your role and the assessment process and, if appropriate, to leave that with the person and any supporter or carer. Someone who has a severe learning disability may need this information in photos or symbols as well as words. Tailor any explanation to individual need. 'My job is to find out what things you like' may be enough as a starting point for some people. Be clear about what you can or cannot offer.

Help the person understand what will happen next, so that they know there is a logical order to your meetings.

If you are only involved for a short time, make sure that the person understands why, knows when you are withdrawing, who you have referred them to and how to get in touch with services again, should they need to.

Practicalities

People with an ASD will benefit if they meet with professionals who understand their condition, communicate clearly, keep them informed about progress and can establish some sort of routine around assessment meetings.

Too often people with an ASD find that others are embarrassed to mention their condition. If the person knows they have an ASD and accepts that, be positive (in a realistic way) about their strengths and special interests. Read about ASD before you meet the person, because someone who understands ASDs will be most likely to help people develop a better sense of self-worth.

Communication with new people is often quite tiring for people with an ASD: it helps if you allow time for breaks and avoid asking too many questions.

People with an ASD need to be kept informed about the assessment process. It is usually best to write to let them (and parents, carers or other significant people) know the likely waiting time before assessment; what happens during assessment and the eligibility criteria for services. If you anticipate any delays in the process, explain these from the outset. Make sure that you tailor the amount and type of information you provide to each person's needs.

When you meet with a person with an ASD, explain how long the meeting will be first. Make sure the person has not got another meeting or appointment straight after yours and try to arrange meetings to avoid breaking into people's routines too much. For example, a person with an ASD might need to have lunch at 12.30pm in order to feel comfortable. If a social worker made an appointment for 12.15pm, it could cause great anxiety and curtail the interview.

Always forewarn people about changes to the routine you've established, for example different meeting times, venues or staff in attendance. Unexpected changes will cause anxiety.

How does the person interact and communicate?

Your assessment needs to consider how communication, interaction, flexibility of thought and other difficulties affect the person on a day-to-day basis.

Before you first meet a person with an ASD you should find out about their preferred way of communicating and what their level of communication skills is. As you get to know the person better, you will wish to record more detailed information.

You should record the level of a person's communication skills by looking at:

- › how they use spoken language, eg single words; three to five-word phrases; they have echolalia (repeating what other people have just said)
- › whether they use other communication systems, eg sign language, symbols, PECS, augmentative devices

- › how much they understand of what other people say, eg they can understand most simple, unambiguous conversation, but avoid lengthy discussion and small talk
- › whether they have any communication-specific difficulties, eg mutism, a stutter, or trouble regulating voice tone or volume.

Communication and interaction skills should also be assessed. These include the person's ability in the following areas.

- › Expressing yes or no. People may understand a concept, but sometimes say 'no' as a default answer. When offering an item to someone, check by physically offering it and then ask again.
- › Making choices. For example, some people can only make common, non-abstract choices, such as choosing food from a menu or picking an activity from a short list of no more than three choices.
- › Initiating communication. Will people start a conversation themselves, or will they do it when given verbal or visual prompts?
- › Expressing feelings. People might understand common 'emotion words' like angry, happy, OK or sad and be able to express these emotions. However, they may not know other words for emotions or ways to express these.
- › General social outlook and integration. For example, a person might try to appear outgoing (while not naturally being so), or may want to develop more social relationships. Perhaps they can talk about general interest topics and/or make small talk, but dislike doing so.

- › Asking for assistance. Can the person ask for help if they need it? Will they tend to phone parents and need a reminder to contact their support worker instead? Would they know who to ask for help in public places?
- › Discussing daily events. Some people may only rarely discuss their day without prompting. They might also respond better to closed questions, eg 'How many lengths did you swim this afternoon?' rather than 'Have fun at the pool?'.
- › Holding a conversation. Can the person return greetings and occasionally ask a follow-up question? Do they remember personal information and use this in conversation? Will they benefit from prompts such as 'Can we go back to what we were talking about?'.
- › Preferred ways of interacting. Does the person like to talk one-to-one, rather than in groups or unstructured social situations? How much conversation can they cope with at any one time - five minutes; ten minutes or longer?
- › Relationships. For example, the person has one good friend and several acquaintances.

In summary, you should try to record how a person communicates ideas and thoughts, makes choices, expresses wishes and feelings, and builds relationships. Use this to inform your assessment.

What is important to the person?

It helps to make sure that an assessment is as much about the skills and abilities people have and the things they enjoy, as it is about the difficulties they have and the things they dislike.

As part of the assessment, you should consider all the factors that can help you to understand someone's personality. The following are some examples of headings for an assessment, under which to gather details about a person's life:

- › things I am good at
- › my special interests and hobbies
- › things I like doing
- › things I don't like doing
- › who my family, friends, acquaintances and other relationships are
- › who knows me best
- › who can cheer me up; who I like to be around
- › things that cause me anxiety and stress
- › who can help me if I am stressed out – what do they need to do?
- › how I relax and prefer to use my leisure time
- › who I spend most of my day with
- › the sort of person I like best as a friend
- › the sort of person who is best at giving me support
- › what I like about myself
- › what others say they like about me
- › what my important daily routines are.

This sort of information is about focusing on what a person can do, rather than their difficulties and limitations. It is a vital part of any assessment – looking at what a person can do and building their self-esteem. It also gives you a much better idea of a person's routines, preferences and qualities, meaning that their needs are less likely to be missed.

It is important to observe the detail of someone's life and their personal preferences. What others might see as minutiae may be more important to the person than anything else. It will explain what motivates a person to do or avoid certain things. For example, if a person is frightened of dogs and you suggest a walk in the local park, it is quite likely they will refuse to go. You can win someone's trust by respecting these choices. Failure to recognise the importance of detail could jeopardise any support which is put in place.

Assessing people's sensory needs

As mentioned on page 9, many people with an ASD have sensory sensitivities. People may seek out certain sensory experiences, or try to avoid them. This is an important area to consider during assessment as it affects the way in which people cope with the environment around them.

If a person does appear to have sensory needs, an occupational therapist with an understanding of sensory issues in people with an ASD should carry out an assessment.

As well as including a person's day-to-day sensory needs in your assessment report, you can work to make the assessment as comfortable as possible for them. For example, some people prefer natural daylight to artificial strip lighting in a meeting room.

People with an ASD may have sensory sensitivity in any or all of the following senses. The degree of sensitivity may vary from day to day, and be affected by factors such as stress, environment or physical tiredness.

Sight

People with an ASD may:

- › be more comfortable using peripheral vision (looking out of the corner of their eyes)
- › notice (and sometimes fixate upon) fine details, such as the very slight movement of an object in a room
- › find it hard to track movement
- › like to wear a peaked baseball cap or sunglasses to reduce glare, because of hypersensitivity to light
- › not like changes in floor patterns (and so feel nervous about walking between different areas or rooms).

Hearing

People with an ASD may:

- › be uncomfortable with certain noises, for example a hand-dryer, a vacuum cleaner, or busy roads
- › find it difficult to ignore quiet or faraway sounds that other people simply block out; therefore, it can be difficult for them to concentrate on the subject at hand – for example, the person who is talking to them
- › not like the sound certain foods make in the mouth

- › use noise to block out other sounds – they may hum to themselves, or have a fan on in order to go to sleep at night.

Taste

People with an ASD may:

- › be especially sensitive to certain food textures or tastes
- › follow a restricted diet
- › have pica (eating non-edible substances)
- › hate the taste of something like toothpaste, therefore dislike brushing their teeth
- › wish to try new foods and crave spicy food.

Smell

People with an ASD may:

- › be very sensitive to certain smells and get distracted by things like perfume, particular foods or cigarette smoke
- › like, or not notice, his or her own body odour and not wish to change clothes
- › have certain favourite smells
- › only be able to use neutral soaps and deodorants
- › not want to eat with others because of the smell of their food.

Touch

People with an ASD may:

- › find another person's light touch uncomfortable or even painful
- › not wish to shake hands
- › find that certain weather feels unpleasant on their skin
- › not like having their hair brushed, cut or washed
- › not notice or respond to physical pain
- › enjoy the sensation of firm pressure on their skin.

Body awareness system

This tells us where the different parts of our body are and how they are moving. People with an ASD can have reduced body awareness and may:

- › appear to be clumsy or accident prone
- › find co-ordinating their movements difficult
- › prefer easy-to-negotiate surroundings, eg clutter-free rooms
- › feel calm and able to concentrate after a deep pressure massage
- › enjoy firm physical contact and being 'squashed'.

Balance (vestibular system)

This lets us know where our body is in space and whether we, or our surroundings, are moving. People with an ASD may:

- › get travel sick easily, even by climbing stairs
- › enjoy activities that involve spinning or jumping, eg fairground rides or trampolining

- › have difficulty with activities requiring balance, eg cycling
- › have difficulty navigating through a room and avoiding obstacles like furniture or other people.

When considering housing and daily occupational needs, make sure that the person with an ASD is in an environment that takes account of their sensory differences. Typically, people will prefer spaces with less clutter, neutral décor, low lighting, plenty of space, clear signage, fewer people and less intrusive sound, such as traffic or noisy plumbing. Noisy neighbours are often a source of difficulty for people with an ASD. People with an ASD may prefer it if you, and other people who work with them, avoid strong perfumes, brightly coloured clothing or jangling jewellery.

See page 42 for recommended reading about sensory issues and autism.

Associated difficulties

Health services need to be involved in identifying if any of the following difficulties, which are associated with ASD, are experienced by the person you're assessing:

- › learning disability
- › specific learning difficulty, eg dyslexia
- › movement difficulties, eg dyspraxia
- › sleep difficulties
- › bowel difficulties
- › tics

- › epilepsy/seizures
- › allergies or dietary sensitivities, eg to gluten or casein
- › hearing or visual impairments
- › under- or over-sensitivity to pain, eg not feeling pain, therefore not being able to tell people that anything is wrong
- › response to temperature, eg doesn't seem to experience extremes of hot or cold in the same way as other people
- › ADHD/ADD.

For any of the associated difficulties, note details and how they are currently managed.

In addition to this, many people with an ASD have mental health difficulties. Most commonly, these include depression, or anxiety-based problems such as obsessive compulsive difficulties, panic attacks, paranoia or phobias. It is vital to check this as part of your assessment. If you think someone has a mental health difficulty, consult a psychologist or a psychiatrist. Note how any mental health difficulty is currently managed and any treatment plans.

Behaviour

Your assessment should also look at the person's behaviour, as this will help you to plan any future support. For example:

- › obsessions and rituals that prevent daily functioning
- › over- or under-eating, or other dietary difficulties
- › social isolation (eg refusing to leave the house)

- › self-neglect
- › running away
- › lack of a sense of danger (eg not understanding that running onto a busy road poses a threat)
- › social naïvety and personal safety outside their home (eg gives money and personal items to strangers)
- › verbal abuse
- › problems with personal care or grooming
- › inappropriate sexual behaviour
- › self-harm
- › physical aggression towards other people
- › damaging property.

Work with parents and other significant people

Many people with an ASD rely on their family for support and still live at home. Others who live independently are often only able to because of a high degree of support from family members. It is likely that it will be a parent or carer who makes the initial request for an assessment.

Family carers must be told about their right to a carer's assessment. Sometimes support services can be offered under carers legislation⁷ if a person with an ASD has refused to accept help in their own right.

Occasionally, parents and siblings feel left out of the assessment and planning process because they are told that their son or daughter is the client, not them. There may also be some tension between parents' beliefs and lifestyle (and how they would like these to be reflected in services), and those of their child. However, in general families will bring long-term commitment, care, understanding and detailed knowledge about the person you are assessing.

It is sometimes beneficial to arrange a separate meeting to talk to those who support the person, and get their views. Sometimes, this information may form part of the carer's assessment you offer. Meeting with a person's family or carers requires sensitivity and a positive approach. For example, you might tell the person with an ASD, 'So that I can provide you with the best service I can, I need to speak to all those who support you in some way'. If the person feels strongly that they do not want anyone else to be contacted, you will need to respect that.

The following are common issues for families affected by ASDs.

- › Many people with an ASD have difficulty with sleep. This often means that the main carers are also sleep-deprived and may have been so for many years.
- › People may have specific dietary needs. This means that family or carers have to cook two separate meals and shop separately for the person with an ASD. It is also often a cause of great concern to people's carers.
- › Some people with an ASD can be very controlling at home. This can be difficult for family and carers.

⁷ Carers and Disabled Children Act 2000; Health and Community Care (Scotland) Act 2008.

- › People with an ASD may commandeer a lot of their parents' or carers' attention, which can create resentment from other people, such as siblings. Parents may feel guilty.
- › Sometimes, people with an ASD display challenging behaviour such as physical or verbal aggression. This is often caused by frustration, but nonetheless people's families or carers may not receive support or advice on how to cope with it.
- › Some people with an ASD suffer from depression and anxiety, which places stress on family members.
- › ASD is an invisible disability. Families are often worn out by the almost constant battles they have to fight in order to secure any sort of support. Public attitudes to ASD are often not sympathetic. This can take its toll on family resources – emotional, social, physical and financial.
- › Families and carers worry about the future. Some adults with an ASD do not wish to be assessed. Others may not have received services that meet their needs, as they don't fit the criteria for either learning disability or mental health services.
- › There is thought to be genetic element to ASD, and occasionally parents will also have some degree of social communication difficulty. This needs a sensitive approach and you may use similar communication techniques to those you employ with their son or daughter.

The skill of the professional is in keeping the person's best interests at heart and making these the focus of support and intervention.

Summary: top tips

Here are our top tips for preparing for, and carrying out, an assessment of needs for people with an ASD.

- › Prepare: think in particular about how best to communicate and engage with a person with an ASD. It may not be easy and new ways of working will sometimes need to be found. Speak to the person's family and carers.
- › Allow plenty of time for the assessment. It is likely to take longer for people with an ASD than for others.
- › Be aware that some people will resist support. Do not take lack of initial engagement as evidence of lack of needs.
- › People with an ASD may mis- or under-represent their own needs – sometimes because they don't know how to express these needs themselves. It is important for professionals to be aware of this. Involve people's wider support networks in the assessment process and help the person find ways to express their needs.
- › Use person-centred planning – as well as the person themselves, involve parents, carers and other natural support networks in your assessing and planning.
- › Make sure you spend time finding out what the person's skills, strengths and abilities are, and what makes them tick. Understanding what is important to the person (for example, what makes them happy) will make for a more successful assessment. It will also boost people's self-esteem as they see that their interests and concerns are being considered.

- Notice and record details that are important to a person's well-being. Paying attention to these things – even if they appear to be small or idiosyncratic to you – can be very important to those with an ASD.
- Use visual methods of communicating if these will help the person you're assessing. Consider reinforcing spoken information with written and pictorial information. This may vary from visual schedules to the use of a calendar or diary.
- Learn to identify the signs of stress in the person with an ASD and have agreed strategies to deal with this. Discuss this in a calm moment with the person themselves (if they are able), as well as with their family or those who know them best.
- Remember that people with an ASD may have additional needs that should be assessed: they may experience anxiety or depression, have sensory sensitivities, or co-morbid conditions such as ADHD or dyspraxia.
- Always be aware of sensory issues. People with an ASD may not be able to tell you what is causing them stress; sometimes, you may need to be a detective and try to imagine what could be causing it. For example, it could be a noise that is so low that you have not registered it.
- Tailor assessment (and service planning) to people's individual needs. Record people's strengths and abilities as well as their support needs.
- Understand autism, understand the person and develop a positive relationship – out of this comes good assessment.

Further reading and useful contacts

Further reading

Attwood, T. (2006). *The complete guide to Asperger syndrome*. London: Jessica Kingsley Publishers

Howlin, P (1997; updated 2004). *Autism and Asperger syndrome; preparing for adulthood*. Oxford: Routledge

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Wing, L. (2002). *The autistic spectrum: a guide for parents and professionals*. London: Constable and Robinson

Sensory issues

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Wilkes, K. (2005). *The sensory world of the autistic spectrum: a greater understanding*. London: The National Autistic Society

Yack, E., Aquilla, P., and Humphries, S. (2002). *Building bridges through sensory integration*. Arlington, Texas: Future Horizons



Useful contacts

NAS Training and Consultancy has ten years' experience delivering training in ASDs to professionals throughout the UK. We offer training on subjects including autism; Asperger syndrome; sensory issues; ways of supporting social communication and interaction; challenging behaviour; and effective partnerships with parents and carers. Visit www.autism.org.uk/training to find out more.

Autism spectrum disorders (ASDs) are lifelong developmental disabilities. Some people with an ASD are able to live relatively 'everyday' lives; others will require a lifetime of specialist support. Most will benefit from services based around their individual needs, but it may not always be easy for social care staff to identify what these needs are.

This booklet is for professionals who are involved in assessment and care planning for adults with an ASD. With greater understanding of the way ASD affects each person differently, assessors can make sure that support and resources are directed in the most cost-effective and appropriate way.

The National Autistic Society is the UK's leading charity for people affected by autism.

Over 500,000 people in the UK have autism. Together with their families they make up over two million people whose lives are touched by autism every single day.

Despite this, autism is still relatively unknown and misunderstood. Which means that many of these two million people get nothing like the level of help, support and understanding they need.

Together, we are going to change this.

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