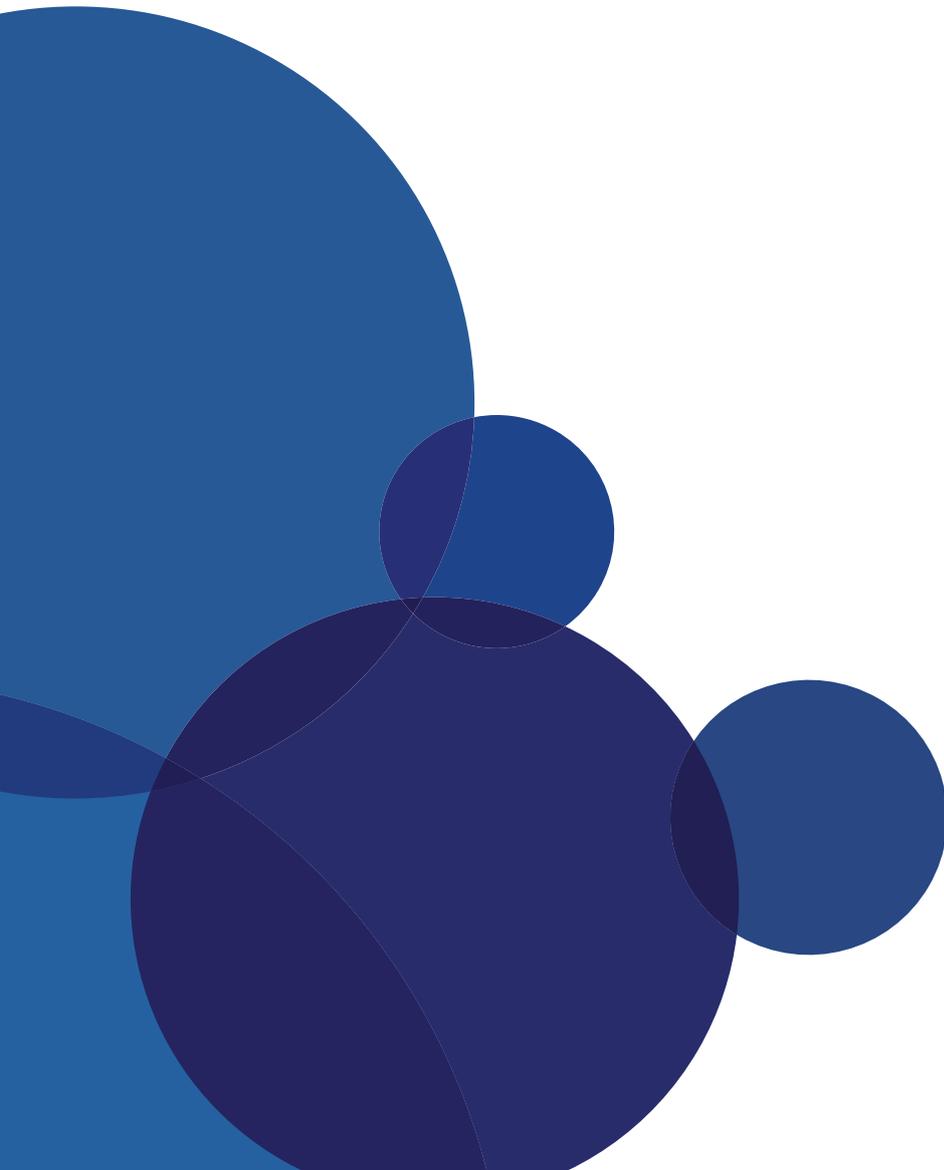


Guidelines for assessing adults with autism for self directed support (SDS)



Contents

- 1) Introduction
- 2) Setting the Scene
- why should adults with autism be given special consideration?
- 3) Autism - a definition and common characteristics
- 4) How the common characteristics of autism might affect the assessment process
- 5) Additional considerations when preparing to assess
- 6) Summary
- 7) More information

1) Introduction

This booklet has been developed for the intended use of health and social care staff involved in the assessment and care planning for adults with autism.

The principle aims of the booklet are:

- > to produce accessible information to increase the assessors' awareness and knowledge of autism
- > to provide practical advice to help facilitate the accurate assessment of adults and appropriate provision of care services
- > to minimise possible stress and anxiety for adults with autism during the process of assessment and care planning

Thereby making the Self-Directed Support SDS process as positive and supportive as possible for people with autism and minimising avoidable difficulties.

The principle of SDS in allowing people to choose how their support is provided is entirely compatible with the often unique and individual needs of a person with autism. The challenges arise from developing an accurate and shared understanding of the person's needs and how their autism impacts on those needs.

The Autism Self Direct project aims to support people with autism and their families and professionals working with them to use and get the best from the SDS process.

For more information about the project please contact:

Tel: 01506 434670

The website contains case studies of where SDS has been used by people with autism and their families including the challenges they have faced and how they were overcome.

www.autismselfdirect.org

2) Setting the Scene

why should adults with autism be given special consideration?

Assessing adults with autism can prove complex. The three overarching reasons behind this complexity are:

- > The person may have communication difficulties
- > The person may unknowingly misrepresent their needs and desires due to lack of self-insight/ understanding
- > It is easy to make assumptions that you have a shared understanding with the person with autism

This is compounded by the fact that an assessor may not be familiar with people with autism and the individual. Awareness and understanding is therefore needed to help ensure that individuals with autism are accurately assessed and that the support services more closely meet their personal life outcomes.

3) Autism - a definition and common characteristics

Autism (sometimes referred to as 'Autism Spectrum Disorder' or 'Autism Spectrum Condition') is the name used for a wide range of developmental conditions on the 'Autism spectrum', including 'Asperger syndrome'. A person with autism will usually have some difficulty or difference in the areas of communication, social interaction, flexible thinking and in sensory sensitivity. However, the way in which autism impacts on each individual is unique. No two people are exactly the same.

The exact causes of autism are still unknown but it is likely that there are several factors affecting brain development that result in the differences of autism. There may be some genetic links, meaning that more than one person in a family may be affected.

How to help a person with autism

It is essential to understand that a person with autism may think about, perceive and therefore understand others and the world around them differently.

A holistic, person-centred approach to understanding and supporting the person is essential which includes understanding what the person with autism understands, how they communicate, what motivates them, what they expect and what they experience through their senses. All these may be very different from our non-autism perspective and it is essential to avoid assumptions about what the person thinks, feels and wants.

'Spectrum' is used to describe the variation in the way in which the condition affects different individuals. Their intellectual ability ranges from profound learning disabilities to above average intelligence. Levels of everyday functioning do not however always correlate with intellect. For example, a highly intelligent person with academic qualifications could struggle with personal care tasks and understanding certain social situations.

Key facts

- > Current research suggests that over 1 in 100 people may be on the Autism Spectrum and it is more common in males than females
- > It is a lifelong condition and there is no 'cure' but people with autism can and do continue to learn throughout their lives
- > A formal diagnosis of autism is given following medical assessment

4) How the common characteristics of autism might affect the assessment process and what to do

Social Communication (i.e. Use of verbal and non-verbal language)

Common autism characteristics	What you may notice	Helpful hints
Language processing	<ul style="list-style-type: none"> > Not answering question, appearing not to be paying attention or being seemingly uncooperative 	<ul style="list-style-type: none"> > Provide more time to process information > Emphasise key words in question to facilitate better understanding > Break question down into smaller chunks
Varying speech abilities	<ul style="list-style-type: none"> > Difficulty in accurately communicating their own needs > May speak with an unusual accent or limited expression (e.g. monotone) 	<ul style="list-style-type: none"> > Use other modes of communication (e.g. pictures and writing) and gentle probing to help clarify any ambiguities > Avoid interpreting tone of voice as disinterest
Understanding language	<ul style="list-style-type: none"> > Literal interpretation of language (e.g. not understanding jokes and sarcasm) 	<ul style="list-style-type: none"> > Carefully word questions and give fixed options for answers whenever possible > Avoid common non-literal phrases, sayings and jokes (e.g. it's raining cats and dogs) > Simplify language by using shorter sentences
Using and understanding appropriate facial expressions, eye contact and body language	<ul style="list-style-type: none"> > Using unusual patterns of eye contact, ranging from complete avoidance to extremely intense 	<ul style="list-style-type: none"> > Enquire about what level of eye contact the individual is comfortable with and act accordingly > Do not demand or try too hard to establish eye contact

A simple approach when talking to a person with autism is:

- 1. Listen** - show that you are 'actively' listening, being 'present in the moment'.
- 2. Acknowledge** - let the person know you have understood by reporting back/summarising what you think was said.
- 3. Respond** - to show the person you want to communicate with them further.
- 4. Check** - reflect to ensure you and the person share an understanding of what has been said.

Social Interaction

Common autism characteristics	What you may notice	Helpful hints
Working out other people's thoughts, emotions and expectations	<ul style="list-style-type: none"> > Confusion over why you are meeting him/her > Might misrepresent their needs by giving a disproportionate number of positive' answers (could be due to their misinterpretation of what is expected of them or they may not want to get an answer 'wrong') > Might have difficulty understanding questions that don't use the main question words (e.g. how, what, where, when, why) 	<ul style="list-style-type: none"> > Provide a clear explanation as to who you are, why you are doing the assessment and what to expect (You might want to put this in writing detailing date/time and include a photograph of yourself). > Ask the same questions using different phrases to check consistency of response > Use unambiguous language > Avoid implied or indirect questions where possible
Picking up on unwritten social rules	<ul style="list-style-type: none"> > Personal space - may stand/sit too close or too far away > May not want, or know how, to initiate an interaction 	<ul style="list-style-type: none"> > Ask explicitly for a more appropriate physical distance > If possible, use a table and sit opposite > Explain that you will take turns question / answer > You could use cue cards to indicate who has a turn
Social skills	<ul style="list-style-type: none"> > Reluctance to engage - may place him/herself in the periphery or refuse to take part in assessment process > Not bothered by long periods of silence 	<ul style="list-style-type: none"> > Do not interpret negative behaviours or indifference personally > Initiate interaction using known favoured interests
Building Relationships	<ul style="list-style-type: none"> > Can take a long time to build up familiarity and acceptance in order to form relationships 	<ul style="list-style-type: none"> > Be prepared to do assessment over several visits. A time line could help (e.g. four visits each lasting 1 hour date and time of each)

Social Imagination/Flexibility of Thought

Common autism characteristics	What you may notice	Helpful hints
Need for structure and routine	<ul style="list-style-type: none"> > Anxiety and/or confusion about what's happening next > May seem like he/she has not welcomed or accepted you during initial visits 	<ul style="list-style-type: none"> > Prepare well by providing a structure and rough timescale. Refer to this to comfort and ease anxiety > Avoid tendency to be too task-oriented - accept that it'll take time to build up familiarity and for person to feel comfortable with you
Self-organisation, the concept of time and planning ahead	<ul style="list-style-type: none"> > Might think something will happen now or soon if it is not stated otherwise > Might not fully understand discussion around planning for the future and its consequences 	<ul style="list-style-type: none"> > Be specific and follow through on promises when referring to time (i.e. say "10 minutes" rather than "soon" or "shortly"). Using a buzzer or timer could help here > Break down questions about future events (short or long-term) into smaller steps > Limit the use of open-ended questions. Instead, use forced-choice options (using the spoken words, pictures, written word or video) to guide the answers. Includes discussion about relevant services.
Fear of change	<ul style="list-style-type: none"> > Resistance to suggestion about a change of routine, a new activity or a new service > Negative behaviour if they feel coerced or forced into doing something 	<ul style="list-style-type: none"> > Be patient > Where possible, use visual material (e.g. pictures or video) to help them 'imagine' what it would be like > Don't argue or pursue conflict - when excitable or stressed, the ability to reason may be impaired. If available, look at risk assessments for the individual.
Transferring skills from one situation to another	<ul style="list-style-type: none"> > You might make assumptions about certain abilities 	<ul style="list-style-type: none"> > Do not presume a level of functioning based on intellect or previous conversations

5) Additional considerations when preparing to assess an adult with autism

Common autism characteristics	What you may notice	Helpful hints
Perceiving the world and other people differently	<ul style="list-style-type: none"> > Misunderstandings in the motivations of other people > Unusual opinions > Inaccurate beliefs in their skills and abilities (or lack of) > They may assume that you know what they know 	<ul style="list-style-type: none"> > Check on the person's understanding > Don't rely on just what the person or other people are saying > Don't assume that the person with autism is motivated by what you would expect them to be
Stress and anxiety (not necessarily a mental health diagnosis)	<ul style="list-style-type: none"> > Increased vocalisations, social withdrawal, physical behaviours or other behaviours specific to the individual > Discussion with family/ carers and information within communication passports may inform you of the individual's presentation of stress 	<ul style="list-style-type: none"> > Ask before visits about possible mental health problems, potential triggers for becoming upset and what tends to help the situation > Be aware that stress and anxiety can negatively affect the ability to communicate, concentration and to think clearly
Over- or under-sensitivity to noise, lights, textures or tastes	<ul style="list-style-type: none"> > Blocking out of sensory stimuli > Seeking out comfort from repetitive motions (e.g. tapping) on him/herself or others > Focus on one sensory input at a time > Showing signs of distress caused by loud or unexpected noises 	<ul style="list-style-type: none"> > Arrange visits in a familiar setting for the individual > Ask before visit about his/her sensory profile > Continually assess the environment for things that seem to effect the person > Be aware that sensory sensitivities can change
Co-morbidity of additional difficulties	<ul style="list-style-type: none"> > Individual may present with characteristics of other difficulties/diagnoses such as ADHD, dyslexia, dyspraxia, depression, anxiety, eating conditions 	<ul style="list-style-type: none"> > Assess for additional difficulties/ diagnosis
Carer Assessment	<ul style="list-style-type: none"> > Identified or suspected problems (financial or practical) associated with carrying out the care and support 	<ul style="list-style-type: none"> > Carry out a carer's assessment
Setting specific ability	<ul style="list-style-type: none"> > Individual may not easily transfer skills from one setting to (what might appear to be) another similar setting 	<ul style="list-style-type: none"> > Check on skills and confidence in different settings > Don't assume anything

6) Summary

5 key points to consider when assessing an individual with autism.

- 1. Prepare, prepare, prepare** - gather detailed information from as many key people in the individual's life before carrying out the assessment.
- 2. Use unambiguous language** - use meaningful words and a straightforward manner.
- 3. Allow time** - an assessment with an individual with autism is likely to take longer than other client groups. It'll take time to increase familiarity, ease anxiety, and overcome problems of concentration and attention.
- 4. Break questions down** - make them more understandable and meaningful (e.g. Do you have a bath or shower every day? Do you have any help? Who helps you? What do they do?)
- 5. Don't make assumptions** - the way autism affects people is unique to each individual therefore it is essential that assumptions are avoided when carrying out an assessment
- 6. Environment** - make sure that the environment is suitable and takes account of any sensory issues. Remember you are part of the environment and you may have to adapt to suit their need.
- 7. Anxiety** - look out for signs of anxiety as this may be difficult for them to express. Each individual expresses anxiety in a different way and some people may even appear calm but could be unpredictable and escalate to show anger, fear or frustration very quickly. Awareness of de-escalation techniques appropriate to them would be advised.

When other people are contributing to the assessment and your understanding of the person with autism, be aware that:

- > They may only know the individual in one specific setting or context
- > Everyone has their own views on what a 'good outcome' is for someone else - the person with autism can often have unique aspirations and desires

7) More Information

These are a few recommended sources for further information about autism.

- > Saeki, M. & Powell, A. (2008). Social Care: Assessment of need for adults with Autism Spectrum Condition. The National Autistic Society.

<http://www.autism.org.uk/working-with/social-care-and-support.aspx>

- > Valios, N. (2012). Help for social workers in assessing adults with Autism. Communitycare.co.uk.

<http://www.communitycare.co.uk/articles/10/09/2012/118466/help-for-social-workers-in-assessing-adults-with-autism.htm>

Further Reading

- > Howlin, P. (2004). Autism and Asperger Syndrome: preparing for adulthood. Oxford: Routledge
- > Powell, A. (2002). Taking Responsibility: good practice guidelines for services for adults with Asperger Syndrome. London. The National Autistic Society
- > Wing, L. (2002). The autistic spectrum: a guide for parents and professionals. London: Constable and Robinson

Useful Video

- > Social Care Institute for Excellence. Social Care TV: Working with people with Autism: the professionals
<http://www.scie.org.uk/socialcaretv/video-player.asp?guid=11ba2edb-cc2e-4a4a-9f88-68f9a0817c01>

Alternatively please contact the Autism Self Direct project:

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The Autism Self Direct project is funded by the Scottish Government and delivered as a partnership project between Autism Initiatives, The National Autistic Society Scotland and Scottish Autism.

It provides information about autism and Self Directed Support to people with autism, their families and those involved in the SDS process.