



Mental Health Interventions for Rough Sleepers: Autistic Spectrum Disorders - Appendix 1

Supporting someone to make a decision and considering their mental capacity

About this appendix

This appendix supports The Mental Capacity Act Guidance and the Mental Capacity Screening Tool in The Mental Health Service Interventions for People Sleeping Rough: www.pathway.org.uk/services/mental-health-guidance-advice

It is designed to help people who are not mental health professionals, but who are concerned that someone they are supporting may lack capacity to make a particular decision, and that this is because of known or suspected autism.

Completing the Mental Capacity Screening Tool will help you to follow the principles of the law and should help you to make a better judgement about someone's ability to make a decision. The completed tool can also act as evidence of your concerns to help mental health professionals carry out additional assessments where needed.

What are autistic spectrum disorders

Autism and autistic spectrum disorders (sometimes referred to as ASD or being 'on the spectrum') are lifelong developmental disabilities that affect how a person communicates and relates to others. They also affect how a person makes sense of the world around them. The level of disability can range from mild to severe. People may also have learning disabilities and mental health difficulties.

The core difficulties people with autism face are:

- problems with communication,
- difficulties with social interaction,
- repetitive patterns of behaviour,
- restricted interests.

Many people with autism are hypersensitive to some sensory stimuli.

The prevalence of autistic spectrum disorders amongst people who are homeless

In the general population current prevalence estimates vary between 1 in 100 and 1 in 58, but there has been very little research into the prevalence of autism spectrum disorders amongst people who are homeless. It is possible that levels may be higher, as the core difficulties associated with autism can lead to social isolation, poor employment prospects, and difficulty and reluctance when needing to access support, all of which are risk factors for homelessness.

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Communicating with a person who may have an autistic spectrum disorder

- Generally, the fewer people involved in meetings the better.
- Try and involve people who know the person well.
- Use direct, unambiguous language.
- Avoid using jargon and acronyms.
- Decide on the minimum key information which should be given to the person to avoid over complication.
- Provide a low stimulus environment.
- Experiment by using visual aids with people when communicating e.g. sketches and flow charts.
- Set an agenda for the meeting and share this with the person beforehand where possible.
- Provide written summaries.
- Adapt your timescales someone on the spectrum may take much longer to adjust and accommodate your presence, allow more time for the person to warm up to you and the process.

Using the Guidance to the Mental Capacity Act Questions

The text below refers to particular factors that may be relevant to people who may have an Autistic Spectrum Disorder. The numbers next to each of these points reference "Guidance regarding the Mental Capacity Act" on page 26-27 of the Mental Health Interventions for Rough Sleepers – Tools and Guidance book.

- 1. What is the decision the person you are concerned about needs to make, and why do they need to make this decision now?

 Is this an immediate decision, or is there time to experiment with different ways of communicating this? Bearing in mind the behavioural and cognitive rigidity of people on the spectrum, are you able to defer the decision to give the person time (and support) to accept the nature of the decision and the consequences?
- 2. Is there reason to believe that the person may lack mental capacity due to a known/suspected mental health problem, learning disability, brain injury, dementia or intoxication?

With regards to identifying autism spectrum disorders: is there a history of social avoidance and isolation? Does their communication have any markedly unusual features consistent with autism? Is there prior diagnosis or suspicion of autism? Is the person known to be extremely rigid in their behaviour, or have any marked sensory sensitivities? If you are not sure, consider referring to a specialist for consultation - you would need to have reasonable grounds of suspecting a person has ASD before using this as the sole cause of lack of capacity.

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3. Has sufficient information been given to the person to help them understand the decision?

Steps you can take to ensure this might include:

- Providing written back-up to verbal communication or using visual aids to support what is being said e.g. flow charts.
- Trying to avoid references to complicated bureaucratic processes, and to health or social care systems. Reduce information to the minimum sufficient and necessary.
- Using plain English.
- Allowing the person time to digest the information, and checking their understanding over a couple of meetings, some people with autistic spectrum disorders can significantly misunderstand information without this being apparent.

4. Have all practicable steps been taken to support the person to make the decision?

See the steps for help in presenting information. Make sure you have allowed sufficient time. Has a trusted person been identified? Consider using prompts such as written pros and cons lists.

Consider whether the person may have been anxious or distressed when making the decision. Distress might give the impression that the person lacks capacity, but in a less intense and over-stimulating situation they may be much more able to communicate and reflect.

5. Is it felt that the person is free from external pressures to make their decision?

People with autism may not have the social awareness to judge whether they are being coerced or manipulated, so endeavour to obtain information from a number of informants regarding this question.

6. Can the person understand, in simple language, the information involved in making the decision?

Be aware that some people with autism may have learning difficulties.

- 7. Can they retain the information long enough to make the decision? Support short-term memory with written notes.
- 8. Can the person use or weigh up the information to make the decision? Ensure that the person has enough time to weigh up information and that the decision is not impacted by their routine e.g. I can't go to hospital because I haven't had my 11 o'clock cup of tea yet.

A person's ability to weigh up information might be affected by poor knowledge of the social consequences of their actions or inactions e.g. not phoning up the Department of Work and Pensions might lead to a cancellation of benefits, which might take months to re-instate.

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9. Can the person communicate their decision (whether by talking, using sign language or any other means)?

Some people who are autistic may find it difficult to answer questions directly, or may not be able to formulate a response to the question. This can be the case even where they are able to understand, retain, and weigh up the information relevant to making a particular decision. Some people are "echolalic" and might echo your speech, rather than creating their own flexible response. You can check if this is happening by offering the person opposing choices to see if they echo those too.

10. The decision: does the person on the balance of probabilities have the capacity to make the specific decision at this particular time?

Bear in mind the person may have rigid behaviour and lack of awareness of social consequences. It may seem as if someone is making a "poor judgement" (which is not indicative of lack of capacity) rather than making a choice as a consequence of autistic rigid thinking. In acute cases you may need to give this due consideration.

11. How did you decide what was in the person's best interests? Indicate here how you followed the best interests 'checklist'.

The best interests of someone on the spectrum may be different to others e.g. living in a busy and noisy hostel may be threatening and debilitating for the person, in some cases it may be worse than living on the street. Similar comments might also apply when involving people in complicated assessments e.g. for benefits. Group therapy on a ward might be threatening. There are no ASD specific treatments (i.e. medicines, psychotherapy) that can be given on a psychiatric ward, so being explicit about the treatment rationale is important.

12. What action should be taken in the person's best interests?

There is no set answer to this, as it depends on the question being asked. Good quality of life for an autistic person might be quite different, for example, minimal social engagement, and a limited or repetitive range of activities might be good outcomes for some people on the spectrum.

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Further help and advice

The location of specialist knowledge around autism varies in different local authority areas. Sometimes it may be located within Adult Social Services and sometimes in Adult Mental Health Services.

National Autistic Society

NAS offer information, advice, training and accreditation for professionals supporting people affected by autism. They also provide support and advice for people living with autism, their family and friends, through a network of local branches across the UK.

Web: www.autism.org.uk Telephone: 020 7833 2299 Email: nas@nas.org.uk

Advice for London charities

Pathway offers an advice line for homelessness outreach workers in London seeking advice on the use of the guidance with complex clients on the streets. The helpline can:

- Support workers from housing and mental health services in London with expert advice.
- Give guidance to workers in the homeless sector around considering whether someone has mental capacity to make a particular decision.
- Help health workers understand how services for homeless people operate.
- Help apply mental health and housing legislation in specific situations.

Advice line: 020 3291 4184 (24-hour answerphone)

Email: mentalhealthenguiries@pathway.org.uk

All messages will be answered within 24 hours by an Approved Mental Health Professional with expertise in homelessness and mental health. The service is open to any professional or organisation working with people sleeping rough, or who have had a homeless person who is sleeping rough referred to them. Please remember to leave contact details and a brief outline of the issue.

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