

So your next patient has autism and/or a learning disability

A guide for staff new to working with people
with autism and/or learning disabilities



A learning disability is a significant, lifelong condition that started before adulthood, that affected the person's development and which means they need help to understand new or complex information, learn new skills and cope independently.*

*The Same as You, 2000; Valuing People, 2001

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people including difficulties with understanding and processing language. It also affects how they make sense of the world around them. Asperger syndrome is a form of autism. *

* The National Autistic Society

The majority of people with autism and/or a learning disability can successfully access mainstream services when reasonable adjustments are made.

Planning and preparation for your appointment

A person with autism and/or a learning disability has individual needs like everyone else, however, the following suggestions may be helpful when preparing for your appointment.

Try to find out in advance

- Relevant medical history - they might not be able to remember or explain all the details you need.
- Information relating to the particular condition or syndrome they may have.
- If the person has a Health Action Plan, Health Passport or Communication Passport and request a copy.
- If the person has specific likes or dislikes, which may affect the appointment.
- Some people are under or over sensitive to sound, touch, smell, lights or colours.

Appointment planning

- If possible consider the location of the appointment, and where the person is most likely to be relaxed and comfortable. For community visits try to choose a location which limits disruption to the person's routine. In a clinic setting choose a separate quiet room to reduce distractions.
- Provide longer appointments so that you can take your time with the person and avoid rushing them. Alternatively, if you are aware that someone has a short attention span, it may be better to offer several short appointments and let people know how long appointments will be.
- Some people may be unable to read. Consider arranging appointments via telephone and back this up with a letter, using an accessible format.
- Where appropriate ask for a carer who knows the person well to attend with them.
- Check whether the person needs specialist equipment for the appointment (e.g. hoist or Loop system communication tool).
- If your location is difficult to find offer to meet them at the front door.
- Make sure signage is clear and easy to follow.
- Let people know who else will be attending the appointment and why. If possible your letter should have a photo of the building and person they are coming to see.

Don't forget about consent!

Many people with autism and/or learning disabilities are able to give consent to treatment, however, some may not. Assume a person has capacity to give consent until an assessment indicates otherwise.

Remember

- A capacity assessment is not a blanket decision, it relates to a specified task/activity.
- A person can have capacity for one decision and not for an other.
- Capacity can vary – it may be necessary to review the decision or wait until capacity returns.
- You might need to do some work to increase a person's capacity.

Where someone is unable to give informed consent, you will need to adhere to the Mental Capacity Act 2005. You should also refer to Northumberland, Tyne and Wear NHS Foundation policies for further guidance.



How to get the best outcome from your appointment

Time

Start your appointment on time. Many people don't understand the concept of waiting and may find waiting areas stressful.

Environment

Consider the environment. Minimise sensory stimulation; bright lights, noisy computers, street noise etc. Limit the likelihood of interruption and remove unnecessary equipment. Enclosed and noisy waiting rooms, and the smell of clinical environments may be unsettling for some people. A number of short pre-visits might help them relax.

Communication

- Check if the person has any hearing or visual impairment which may impact on their communication.
- Think about how you will speak to the person. Use short sentences, avoid using abstract ideas and jargon. Using words the person is familiar with can help to get ideas across more effectively.
- Always talk directly to the person using their chosen name, even if they are unable to answer. Include the carer in the discussion to confirm information and advice. A good balance of involving both is needed.
- Allow time for the person to understand what you are saying.
- Ask if the person has any communication tools that would help them understand and participate.

Flexibility

Be prepared to work from the person's perspective. A flexible and relaxed approach is essential. Encourage the person to look at and touch equipment, as appropriate eg physio equipment, blood pressure checks.

Assessment

Think about your assessment from a practical point of view. Plan the order of your assessment to minimise frequent topic changes. Think about where to start, given you might not be able to do everything you hope to. You may need several appointments rather than just one.

Functional

- Use imitation and role modelling; asking them to copy you or including their carer in demonstrations can be a good strategy.
- If you want to observe their movement ask the person to perform functional activities that make sense, or make the task relevant to their interests and fun. Be creative! Dance, music, iPads, puzzles are just a few examples that could be effective.

Making communication work

Use visual aids to explain what you want the person to do and what will happen. Pictures, photographs, symbols and video can be helpful. If you need to give them information to take home try to make it accessible, and refer to their communication passport if available.

Difficult behaviour

Difficult behaviour can often be someone's way of communicating information. Use your assessment, carers advice and specialist tools, such as DisDAT, to rule out potential physical causes before assuming these are behavioural issues.

Lack of success

If your appointment isn't going to plan don't despair, just stop the session and schedule a follow up. Continuing with a negative experience may make future sessions more difficult. Discuss this with the person and/or carer and talk to them about alternative approaches you could use next time.

Also speak to your local learning disability team as they have further information or look at the resource links at the end of this booklet.

Useful contacts

The National Autistic Society
www.autism.org.uk

<http://www.autism.org.uk/about-autism/autism-and-asperger-syndrome-an-introduction/what-is-autism.aspx>.

British Institute of Learning Disabilities
<http://www.bild.org.uk/>



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