

Bristol Autism Spectrum Service

Guide for social care staff supporting adults with
autism

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Social care staff are always welcome to contact us for consultation, joint visits and advice. The Bristol Autism Spectrum Service covers Bristol, South Glos and North Somerset and is available on 01275 796 204 or awp.bass@nhs.net

If people with autism want to use informal support through the Bristol Autism Spectrum Service they can attend our weekly advice services in venues across Bristol, South Glos and North Somerset. The services are slightly different in the different localities. We run groups on understanding autism, anxiety management, mindfulness, relationships, problem solving through peer support.

The Bristol Autism Spectrum Service also offer bookable one to one appointments for people with autism to get information, support and advice with one of our Bristol Autism Spectrum Service staff. The Bristol Autism Spectrum Service is available on 01275 796 204 or awp.bass@nhs.net

It is also worth knowing that we have uploaded a number of free resources on local social activities and social groups called 'Stuff to do' <http://www.awp.nhs.uk/media/756970/stuff-to-do-guide.pdf>

There are also Guides to college, university, benefits, money, social care and housing, driving, bus passes and more: www.awp.nhs.uk/bass

Preparation for working with people who have autism

The following are reminders for social care staff when communicating with people who are autistic, especially those who are in the average (or higher) range of intelligence. People with autism:

- have difficulties with both expressing and understanding some verbal information and may struggle to answer questions unless given space and time to process your words. Some may need alternative formats to express their thoughts and feelings; you may need to allow more time for the assessment.
- usually suffer from anxiety and sometimes depression – it is important to think about ways to reduce their worries in meeting/talking with you. Also, do not take a missed appointment as evidence the person has no interest in getting help. They may just be fearful of meeting /talking to new people or have executive functioning difficulties that make time management very problematic.
- often have sensory processing differences such as inability to filter out noise or dislike of bright lights so meetings need to take account of sensory needs.

- are likely to have weak central coherence – not to see the bigger picture re what the assessment is for and what they need to express; unless you ask the exact question ‘are you lonely?’ ‘do you ever feel depressed?’ they may not think to volunteer important social care information.
- may have difficulties processing their own emotional and physical state; lack of insight into their own needs and be unable to articulate their needs independently; ensure you fully involve carers/partner/family.
- especially those with higher IQs may feel embarrassed asking for help and tell you they are more independent than is evidenced in their actual lifestyle. They may also say whatever answer they think will end the conversation with you, if they are feeling defensive/ashamed/stressed/confused.
- may process spoken language differently to the average person. Drill down into the specifics of what you are asking. For example, do not ask ‘can you maintain your own home’ and leave it at that. Ask specific questions. So, rather than asking, ‘can you cook?’, ask ‘can you tell me what meals you are able to cook?... do you cook a hot meal every day?...’what did you cook yesterday/today?’
- have executive functioning difficulties – self organisation, short term memory, prioritising, planning, and executing actions are all affected. This often affects daily living tasks completion so washing, dressing, eating can all require prompts.
- sometimes have excellent language skills but be aware that the ability to talk about something is often quite separated from the ability to do it.
- may be feeling isolated yet talk about many friends and informal networks they rely on. However, these networks may not always exist beyond occasional Facebook ‘like’. Or they have a potential network but are too anxious to use it.

Top tips for assessment and working with people with autism

- Involve and talk to people who know the person if given consent eg parents, partner
- Read the file! What is their conversational ability?
- Do not be put off if a person has an unusual or even 'difficult' personality
- Person may have excellent language skills but be aware that the ability to talk about something is often quite separated from the ability to do it.
- Be careful and don't jump to conclusions - it can take a long time to begin to understand someone with autism
- Sensitively check daily living functional skills – self report may be unreliable
- Be a punctual, consistent, dependable, patient, calming presence
- AS = Autism spectrum = Anxiety and Stress – find out what helps to reduce this
- Be very specific in pointing out positives you see eg in personality or abilities
- Be clear and precise (think before you speak - words can easily be misunderstood)
- Be open, upfront and sensitive (*"is it ok if I am completely honest?"*)
- Structure the conversation - tell them what you are going to talk about them; talk; then sum up and agree actions in written form
- Make things visual – eg written letters, questionnaires, action assessments and plans
- Allow processing time; suggest breaks and longer assessments (being with people is tiring)
- Consider sensory needs in terms of where it is best to meet, how your physical presence impacts on someone with autism and in planning appropriate services
- Provide reassurance after meetings eg email to say *'thank you everything you said was helpful and has given me a better understanding of your needs'*
- Make sure you tell the person what will happen next and timescales
- Link people into existing services – Bristol Autism Spectrum Service www.awp.nhs.uk/bass
- Autism assessment and finding appropriate services can be complex - get advice from Bristol Autism Spectrum Service 01275 796 204 awp.bass@nhs.net

What makes a good autism service?

Planning the service around the person

A plan should show evidence of person centred planning. For each person the following should be documented and known by staff:

- Things I am good at
- My special interests and hobbies
- Things I like doing and things I don't like doing
- Who knows me best
- Causes of anxiety/stress triggers and techniques for calming.
- How I relax and prefer to use my leisure time
- What I like about myself and what others say they like about me
- What my important daily routines are
- What sort of people (including support staff) do I like spending time with

When reviewing a service consider whether the person using the service say 'yes' to each of these statements:

- I make everyday choices
- I make important decisions about my life
- I take part in everyday activities
- People treat me with respect
- I have friendships and relationships
- I am part of my local community
- I get the chance to work
- I am safe from bullying and abuse
- I get help to stay healthy
- People listen to my family's views

Planning the service around the person

These are the questions that National Autistic Society (NAS) Accreditation ask of a service when assessing whether they are autism friendly:

Does the organisation provide evidence that it has a specialised knowledge and understanding of autism?

Does the organisation provide evidence that its knowledge and understanding of autism consistently informs:

- the organisation, the resources and management?
- the individual assessment and support plan for all people with autism?
- all aspects of practice?

Check internal audit/quality (has the service been accredited by a recognised body such as NAS Accreditation? They may have their own internal quality assurance check if this is sufficient)

Check if the service uses a well-known approach such as TEACCH or SPELL (look these up on www.autism.org.uk for more information)

Care plans etc should mention how the person's autism (unless person refuses to use that term) affects them and how to best support the needs arising from their autism

Staff have regular, quality autism training – who by? Some autism training is not very practical. Is the training done by internal staff only? – often better if service go on external courses as well

Ask to see CQC regulation reports about the service

Are there autism training resources/library accessible to staff within the service?

Ask if they have worked with people with autism before – what did they do differently and why?

Speak to the management of the service – if they understand autism it is a good sign as they will influence staff (what is their professional background?)

What are the qualifications of the manager and staff?

What is the experience of the manager and staff with individuals with autism?

Is there clear structure?

If someone with autism is in a service whether it is residential, shared housing or community support a sign of a good service is that the person usually know:

- What they are doing
- How to do it (may need task/activity broken down into understandable steps)
- How long the task/activity will last for
- When happens next (and the rest of the day/week)

If they know the answer to all the above (even if they cannot always articulate it) it will make their life easier and probably lead to lower anxiety and fewer behaviour difficulties

Observation checklist

A service does not have to be expensive 'autism specific', it just needs to be autism aware and autism friendly. Here are a few pointers to look for:

- How they talk and behave around people
- Staff engage with people using the service
- Not overcrowding the person
- Lack of exciting décor may not be bad sign
- If sharing who with? Check compatibility
- If in shared accommodation block check neighbours' compatibility
- Accommodation for sensory needs is in evidence
- Does the service provide a low arousal environment?
- Lack of clutter
- Clean clear layout
- Clear evidence of visual supports and structure? e.g. which staff are on duty
- People know what is happening, when, for how long etc. e.g. timetables
- Privacy, need for time away
- Routines are respected
- Change introduced carefully
- Evidence of visual communication

Appropriate level of staffing; sensible ratio

Incident reports – can you see these? Do they get sent to you?

Is there a clear autism-specific physical intervention policy in place? Hands off is usually best default approach

Do staff receive regular training on physical intervention? Is this by a recognised organisation?

Incidents books tell you a lot about how staff are approaching challenging behaviour

Have they had people they could not maintain within the service and why?

Does everyone who requires it have a behaviour support plan?

Are behaviour support plans clear and known to all staff and simple enough to use?

Behaviour support plans should include details of baseline behaviour, triggers and causes of stress/anxiety/anger; signs of stress/anxiety/anger and strategies for staff to use and encourage person to employ when in a state of stress/anxiety/anger

Does each service user have a clear plan of support within the service that all staff refer to and use?

Is there evidence that each person is developing independent living and relationship skills? Who provides this and how are carers/partners/parents communicated with and involved? what form does this take?

Is there evidence of progression in terms of community – employment, college courses, voluntary work?

Ask if there is a consistent level of staffing with not too much reliance on agency staffing? (how are holidays and sickness covered?) Staff turnover, use of agency staff. This is one of the major difficulties for people being supported by a stable staff team (or individual) so trying to get this right from the start is important

Are keyworkers used?

Appropriate staff ratio for the person and within the service generally?

Gender balance?

Hand over meetings?

Communication book used by staff to record incidents and ensure smooth change over between staff

Home link books – how does the service communicate with important people in the individual's life (as appropriate)?

Physical exercise and health catered for

- people with autism often have very specific needs around their diet eg where they eat, what they eat, who they eat with

Check what support the person has for their physical health eg routine check-ups with GP, dentist, optician, chiropodist

What access does the service offer each individual psychology, psychiatry, occupational therapy, physiotherapy, behavioural optometrist, speech and language therapy etc.? This may be especially an issue for out of area placements/treatments.

Mental health support? Regular medication reviews from autism knowledgeable specialists?

Are policies easily accessible? Do staff and people using the service understand them?

How are people with autism involved in quality monitoring? And any carers/partners/parents?

How are people who use the service able to voice concerns or complaints? Does the service encourage use of advocates?

Has the service had any autism related deprivation of liberty situations – what for?

Has the service had many safeguarding and autism issues recently – what about?

Useful contacts

- Bristol Autism Spectrum Service Advice services operate in Bristol, South Glos, North Somerset and BaNES. These offer support to people with autism 01275 796 204 or awp.bass@nhs.net
- National Autistic Society helpline 0808 800 4104, www.autism.org.uk
- National Autistic Society Autism Accreditation, 0117 974 8420 (0117 974 8400) accreditation@nas.org.uk
- National Autistic Society Autism Services Directory www.autism.org.uk/directory - details of autism providers in Bristol, Avon and the UK.
- See also Guide to housing and social care in Bristol <http://www.awp.nhs.uk/media/890220/Guide-to-Housing-and-social-care.pdf>
- For assistance with any social care case work call or email: awp.bass@nhs.net
- Bristol Asperger Social Group – hello@bristolaspergersocialgroup.org.uk (network for adults with Asperger syndrome and autism to meet and do social activities)

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NHS Bristol Autism Spectrum Service
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(Tuesdays and Fridays)