

# Safeguarding Practice with Autistic People A Brief Guide

bullying pinching

withholding coercion intimidation

hitting isolating

restraint emotional abuse

misusing medication shaking

scalding teasing sexual abuse

leaving on own blaming

stealing money or benefits neglect

### 1. Introduction

This guide is intended to provide professionals with an introduction to autism, and to support them in exploring how they can ensure autistic people are involved in safeguarding enquiries about them.

Please consider the information shared in the following sections, but remember, none of it is as important as getting to know the individual.

# 2. Autism

For autistic people, it is often not their autism that causes difficulties as such, but the expectations and responses they have from other people. In particular, the expectation to act, respond and learn in the same way that more typically developing peers do.

Autism is a term used to describe a neurological difference in brain development that has a marked effect on how a person develops. Autism is experienced differently by individuals, but <u>The Autism Education Trust</u> recognises 4 main areas of difference in autistic people:

- Differences in their communication and interaction Differences in understanding and expressing communication and language, with skills ranging from individuals who are highly articulate, to others who may be non-verbal. Good language skills may mask a deep level of misunderstanding.
- Differences in their social understanding Differences in understanding social behaviour and the feelings of others, which informs the development of friendships and relationships
- Differences in their interests and information processing Differences in perception, planning, understanding concepts, generalising, predicting, managing transitions, passions for interests and ability to absorb auditory or spoken information.
- Differences in their sensory processing Differences in perceiving sensory information. Hypo (low sensitivity), hyper (high sensitivity), touch, sight, hearing, smell, taste, vestibular inner ear (balance), proprioceptive (body awareness).

These four areas of difference create high levels of stress and anxiety, and this can have a profound impact on an individual's performance and behaviour.

Autism is often diagnosed alongside other conditions. It's important to support people with more than one condition in a way that meets all their needs, while understanding that the needs that arise from being autistic are distinct. Associated conditions include, but are not limited to:

- <u>Epilepsy</u> autistic people are more likely to develop epilepsy than those who are not autistic.
- Eating issues can include restricted eating habits, food aversions and <u>eating</u> disorders
- <u>Disrupted sleep</u> many autistic people have disrupted sleep patterns, which can be difficult for them and their carers
- Attention-deficit/hyperactivity disorder (ADHD) Most people with ADHD experience both inattentiveness and hyperactivity-impulsivity that interferes with daily life.
- Anxiety can affect a person psychologically and physically and impact quality of life for autistic people and their families

- <u>Depression</u> a mental health condition that results in persistent feelings of sadness and/or hopelessness
- Obsessive Compulsive Disorder (OCD) a mental health condition where a person feels driven to perform certain behaviours to reduce great distress or anxiety
- <u>Bipolar Disorder</u> a mental health condition that usually means a person experiences episodes of mania (high energy, excitable) and depression (low energy and mood).
- Learning disabilities Some autistic people with learning disabilities will be able to live fairly independently - although they may need a degree of support to achieve this - while others may require lifelong, specialist support
- Dyslexia a lifelong specific learning difficulty, mainly affecting the development of literacy and language related skills.

<u>The National Autistic Society</u> has further advice and guidance on autism and related physical and mental health conditions.

## 3. Autistic Women and Girls

The National Autistic Society reports that more men and boys are currently diagnosed as autistic than women and girls although this is changing slowly as more women and girls are being diagnosed. Dr Judith Gould - Lead Associate Consultant at the National Autistic Society Lorna Wing Centre for Autism has written numerous articles and given many talks on how it is only in recent years that research has begun to focus on gender differences in autistic males and females.

Much of the research on best practice when working with autistic people (and therefore much of this guidance) is based on the experiences of autistic men and and boys. So for balance, here are a few things you should know about autistic women and girls, remembering of course that everyone is different and these pointers will not be true for everyone:

- It's common for autistic women and girls to mask their difficulties, leading to their autism being missed
- Autistic women and girls are commonly described as very shy, anxious and/or quiet
- Autistic women and girls may have a lot of difficulty maintaining friendships, even if they
  are friendly and people like them
- Autistic girls may develop fairly typically when they are young, but their difficulties become more severe during the teenage years
- Autistic women and girls may have "normal" interests but to a much greater intensity than other people
- Autistic women and girls might be more likely to experience depression and anxiety
- Autistic women and girls may be quite passive and are likely to just go along with things and agree to things
- Autistic women and girls are likely to be very sensitive and have very strong emotions
- Some autistic women and girls are very sociable, chatty and loud

 Not recognising their autism can mean many women and girls not only struggle to manage their problems, but may not fully appreciate their strengths and uniqueness

# 4. Making Safeguarding Personal

Making Safeguarding Personal (MSP) is the approach that should be taken to all safeguarding work. The key principle of MSP is to support and empower each adult to make choices and have control about how they want to live their own life.

MSP is about having conversations with people about how responses to safeguarding situations can be made in a way that enhances their involvement, choice and control as well as improving their quality of life, well-being, and safety. It is about seeing people as experts in their own lives and working alongside them to identify the outcomes they want.

MSP focuses on achieving meaningful improvements to people's lives to prevent abuse and neglect occurring in the future, including ways for them to protect themselves. People are individuals with a variety of different preferences, histories, circumstances, and lifestyles; so safeguarding arrangements should not prescribe a process that must be followed whenever a concern is raised, but instead take a more personalised approach.

# 5. Strengths Based Practice

Strengths-based practice is all about the relationship between those who are supported by services and those who provide that support. It means working in collaboration with the person to support them to develop solutions, enabling them to achieve the outcomes which are important to them. In a world of experts they are the experts on what is important to them.

Focusing on strengths does not mean ignoring challenges and addressing these accordingly. Strengths-based approaches are not prescriptive; there is no one-size fits-all model. The strength based approach requires a focus upon the individual's personal strengths and abilities.

With this in mind, here are some of the positive things about autism:

- Autistic people are usually highly dedicated to, and interested in, their interests
- Autistic people are likely to be very straightforward and direct
- Autistic people may have very good attention to detail. Their work is likely to be thorough and accurate
- Autistic people might be more likely to feel content (calm and stability are more important than new things and excitement)
- Autistic people are likely to be very reliable and committed they will stick to plans and follow through with things
- Autistic people may have exceptionally good awareness of themselves and of others
- Autistic people may be very sensitive to sound, smell, light etc. as well as their own and other people's feelings
- Autistic people are likely to think about the facts they care about what/when/why/who/where/how

- Autistic people are likely to be more accepting and welcoming to difference and may challenge norms
- Autistic people have a different way of thinking about things which can lead to creative ideas and innovative solutions

# 6. Safeguarding Enquiries

As a reminder, the objectives of an enquiry into abuse or neglect are to:

- establish facts
- ascertain the adult's views and wishes
- assess the needs of the adult for protection, support, and redress, and how they might be met
- protect the adult from the abuse and neglect in accordance with their wishes
- make decisions as to what follow-up action should be taken with regard to the person or organisation responsible for the abuse or neglect
- enable the adult to achieve resolution and recovery.

# 7. Undertaking a Safeguarding Enquiry with an autistic person

Local Authorities have a duty under sections 67 and 68 of the Care Act 2014 to provide independent advocacy to an individual who would experience substantial difficulty in being involved in a safeguarding enquiry, though this role might be carried out by a family member or friend if appropriate.

Undertaking an enquiry with an autistic person might require a different approach because autistic people:

- may express their needs in unconventional ways making it difficult for practitioners unfamiliar with these ways to understand
- may require the purpose of an enquiry etc. made explicit in an accessible way before engaging
- may have needs unrelated to their level of intellect, or masked by fluent language skills
- may not understand the questions, because they are asked ambiguously or unclearly

   the question 'Can you access the community by yourself?' may be answered 'Yes',
   even if the person has to be prompted at every stage of the process
- may not like the attention, or the focus on their needs may cause them anxiety, so their answers may reflect their desire to finish quickly
- may have been let down by services in the past
- may have spent a great deal of time and effort developing ways to cloak their difficulties

- may have family members/carers who mediate the outside world and compensate for their difficulties
- may experience sporadic changes of mood from one appointment to the next and within the duration of one appointment

Please remember, it is very rare you will meet someone who displays all these characteristics, and nothing is as important as getting to know the individual.

### Tips for best practice

While some of the following examples are of specific relevance to autistic people, others are simply good practice in any interaction. You may be working with someone who presents like they are autistic, but they have no diagnosis – possibly because it was never sought due to cultural understandings about the benefit or otherwise of having one. Adopting these good practice tips will not do someone who hasn't got a diagnosis, or indeed isn't autistic, any harm – it just makes things more explicit and accessible for all.

# **Planning**

Preparing in advance and flexibility towards the person may help the discussion capture the right information. Be open minded and be prepared for something completely different from what is expected. If you are conducting an enquiry:

- be clear about your role from the start
- consider sending a photograph of yourself in advance or develop a one page profile
  of yourself this is me, this is my job, this is what that means, contact details.
  Leaving something tangible with someone allows processing time and, hopefully
  understanding and acceptance
- accept that you may need more than one or two meetings; people with autism can
  often only manage short conversations
- be flexible about how information is recorded; use formats that the person with autism can understand
- find out what would help the person feel in control of the meeting
- where appropriate, find out from the person's family or carers how they best communicate
- read about the person on their file, without fixing your views on the basis of what you learn there
- ensure that you are punctual as lateness can cause anxiety
- focus on the person's strengths and achievements.
- be clear about the purpose, length and likely outcomes of any activity or meeting (and, if appropriate, back up the outcomes of a meeting in writing later).

You might also want to ask yourself:

- Does the person have special interests I could use to foster a good relationship?
- Does the person have sensory sensitivities; should I, for example, not wear perfume or aftershave?
- Are there things that might trigger anxiety for the person?
- Do I have to do the meeting face to face, or could it be done by email, for example?
- Can I send an 'agenda' in advance providing enough structure to reduce anxiety and sufficient flexibility to adapt as needed:
- Time of visit
- What we will talk about first
- What we will talk about next
- Any questions you want to ask
- Summary Finish/Action Points
- Email address/Tel number (plus acceptable times to contact)
- Does the person need extra time to answer questions?
- Have I been asking them questions while asking them to read something or fill out a form?
- Does the person want a friend, family member or advocate with them?
- Is there a time of day that would suit the person well?
- Would the person prefer to be met with while walking, for example, so that eye contact need not be made so often?
- How does the person like to interact with others? For example through touch, or by looking in your mouth, touching hair, wanting to be squeezed or not making eye contact at all
- Is there an informal carer and do they require any support? A separate carer's assessment should be offered. In order to lessen anxiety for the carer, this could be offered or arranged at the same time

### Communication

- Be conscious of the environment in which you are communicating. Lights, sounds, smells, animals, or crowds can all be distracting.
- Use very clear, literal language, and consider any possible alternative interpretations
  of what you say. Avoid metaphor, sarcasm, and jokes.
- Reduce language to key information

- Allow the person time to process what you've said, and don't repeat it, or say something else, too quickly. Pauses in conversation may be awkward for you, but may mean the autistic person is still processing what has been said and what response is required.
- Check for understanding on key points and concepts.
- Be consistent: across your own communication, with other staff, and between staff and the person's family and friends.
- Photographs or objects can help lessen ambiguity and alleviate anxiety for some people or be a way of offering choices.
- The person's comprehension might not be as good as their verbal expression. A person might just be echoing what you say, rather than answering a question.
- Facial expressions or body language are unlikely to be understood and may be misconstrued entirely.
- Sit to someone's side if they are uncomfortable with eye contact.
- Use the person's name often.
- Be calm and still, with no large gesticulations.
- Communicating well in advance of an appointment will help some people mentally prepare for it. For others, it may be better to discuss something just before it's going to happen. This can help avoid unnecessary distress.
- Not all autistic people use spoken language to communicate. Several tools are used to assist the communication of people with autism, many involving visual devices.
- Find out how the person communicates that they would like an interaction to end. Autistic people can sometimes be violent to other people, or more likely themselves, if they are scared or uncomfortable. This is not intended to perpetrate the myth that all autistic people are aggressive but this is something that professionals should be aware of. It is crucial that appointments are ended before the autistic person becomes distressed and soft signs of agitation should be recognised.

### **Further information**

Fulfilling and rewarding lives (2010)

Think Autism: fulfilling and rewarding lives, the strategy for adults with autism in England: an update (2014)

Statutory guidance for local authorities and NHS organisations to support implementation of the Adult Autism Strategy (2015)

This brief guide has been developed with reference to the information, guidance, advice and resources available on the <u>Social Care Institute for Excellence website</u>, the curly hair project, <u>The National Autistic</u>
<u>Society</u> and <u>The Autism Education Trust</u>

With thanks to Experts by Experience Solihull Community Interest Company who provided valuable contributions to this guide.