

People with autism frequently don't receive the services and support that they need and they are usually excluded from the planning and development of services and policies. This needs to change. This guide is a tool to help you think differently about autism and involve people with autism in your work.



The National
Autistic Society

The National Autistic Society is the UK's leading charity for people affected by autism.

Over 500,000 people in the UK have autism. Together with their families they make up over two million people whose lives are touched by autism every single day.

Despite this, autism is still relatively unknown and misunderstood. Which means that many of these two million people get nothing like the level of help, support and understanding they need.

Together, we are going to change this.

The National Autistic Society is a company limited by guarantee

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Involving people with autism: a guide for public authorities

It's time to
think differently
about autism.

Involving people with autism: a guide for public authorities

People with autism frequently don't receive the services and support that they need and they are usually excluded from the planning and development of services and policies. This needs to change. This guide is a tool to help you think differently about autism and involve people with autism in your work.



What is autism?

There are over half a million people in the UK with autism – that's around 1 in 100. Autism (including Asperger syndrome) is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.

Autism is a spectrum condition, which means that, while all people with autism share three main areas of difficulty, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support.



The three main areas of difficulty (sometimes known as the 'triad of impairments') are:

> **difficulty with social interaction**

This includes recognising and understanding other people's feelings and managing their own. Not understanding how to interact with other people can make it hard to form friendships.

> **difficulty with social communication**

This includes using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice.

> **difficulty with social imagination**

This includes the ability to understand and predict other people's intentions and behaviour and to imagine situations outside of their own routine. This can be accompanied by a narrow repetitive range of activities. Coping with change can also be difficult.

People with autism may also experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours.

Some people with autism also have an accompanying learning disability.

Ensuring people with autism are involved in your work

The first step is to actually make sure you are involving people with autism from across the spectrum – including those with the most complex needs. In order to do this, the following suggestions may be useful.

Find people who want to be involved

- As a public authority, you could begin by contacting existing service user groups, representative organisations and local support networks for people with autism. Local support organisations and social groups for people with autism can be found at www.autism.org.uk/directory

Set clear expectations

- Be clear about what being involved will mean for the person with autism and what will be expected of them. Incorrect or vague information can be extremely stressful.
- Make it clear that consultation or involvement will not result in an immediate change in their circumstances. Providing people with autism with a clear understanding of the purpose of the work enables them to decide whether they want to take part and helps to manage their expectations when they do.
- Show people an ‘autism-friendly’ document (see page 8) explaining what you are aiming to achieve, what the process is and why they have been asked to be involved.

- Explain what will happen after they have shared their experiences and views.

Establish a clear point of contact

- People with autism often find it easier to have just one point of contact to give them the information they want. Be specific about who they should contact and what will happen if that person is unavailable.





How to involve people with autism

Here are some tips for involving people with autism, regardless of the format of the involvement.

- ✓ Give people plenty of notice to prepare themselves, whether it's for a meeting or a request for information.
- ✓ Once you have told people what is expected of them and/or made an arrangement, do not change this without good reason.
- ✓ If you do have to change an arrangement, give as much advance warning as possible.
- ✓ Use clear and accessible language - do not use complicated words, abbreviations, or jargon. Avoid non-literal language.
- ✓ Use images or pictures to support spoken or written language.
- ✓ Provide people with access to advocates or support workers who are skilled in their preferred methods of communication, eg communication aids or symbols.
- ✗ Avoid abstract concepts – use concrete questions and, for people with more complex needs, base discussions on their experience and current circumstances.

How to produce 'autism-friendly' documents

All information for people with autism should be accessible to them. Here are some suggestions for how to produce 'autism-friendly' documents:

- ✓ use visual prompts – words followed by a simple illustration, as used in easy-read documents (see further resources on page 18)
- ✓ use short sentences
- ✓ use bullet points
- ✓ use an uncluttered layout
- ✓ be mindful of the colours you use; people with autism can be sensitive to some colours
- ✓ give concrete questions for people to respond to
- ✓ advise of deadlines and how and where to respond
- ✓ give people adequate time to read documents and to discuss the content with others before responding
- ✓ let people know who they should contact with queries or for more information and what to do if that person is unavailable
- ✗ avoid jargon or abbreviations
- ✗ avoid non-literal language such as metaphors (eg 'working in silos'), euphemisms (eg 'gone to sleep' instead of 'died') or idioms (eg 'over the moon'); because of their literal understanding, people with autism are unlikely to comprehend such phrases
- ✗ don't rely on something being inferred through language - be explicit.

Methods of involvement

There is no single preferred method of involvement for people with autism - it will depend on the preferences of each individual. There is a tendency for public bodies to use meetings as a mechanism for involving people. However, many people with autism find meetings difficult. Some people would be happy to use the telephone, while others will never use the telephone but might frequently use email. It is vital, therefore, that you find out the communication preferences of the person in advance of their involvement.

Email

Many people with autism prefer communicating through the written word rather than face-to-face or over the telephone. This is because:

- › communicating by email does not require the person with autism to read non-verbal clues such as facial expressions or hand movements
- › they are not distracted by sensory overload (noises that are peripheral but that they are not able to ignore)
- › they can concentrate on what they would like to say rather than on the social interaction itself.



Email could be used to:

- communicate one-to-one with someone
- target a number of people with a survey asking a range of questions
- establish an email forum. This would allow a number of people to be involved and to share ideas. Any forum would need to be moderated to protect those using it.

The tips above on producing autism-friendly documents also apply to writing emails.

One-to-one work

One-to-one work may be most suitable for those people with autism who have a severe learning disability or very complex needs.

- › Tailor it specifically to a person's individual communication needs.
- › Ideally, one-to-one work should be undertaken by a person who the individual knows well and who understands their means of communication. For example, where the person with autism does not use speech it is essential that whoever is carrying out the one-to-one work is skilled in using alternative methods of communication, for example, symbols.
- › If the person carrying out the one-to-one work does not already know the individual with autism it is important for them to take the time to get to know them and to be trained in their methods of communication.

Group work

As people with autism generally have difficulty with social interaction and communication, group work may be difficult for them. However, this type of interaction will usually be feasible for people with verbal skills and those who have Asperger syndrome or high-functioning autism. Consider the following information when involving people with autism in group work.

(A) **Terms of reference:** having terms of reference is especially important for people with autism. The terms of reference should be clear and state:

- > the purpose of the committee
- > who is on the committee
- > how often the committee meets
- > who organises the administration
- > what topics or issues the committee covers
- > what sort of decisions or action the committee can take.

It is always useful to add visuals to these, eg a photograph of the people on the committee.

(B) **Rules:** it is important that the rules of the meeting are made explicit, and are then adhered to. The rules may need to be repeated at every meeting. Meeting rules may include:

- > no interrupting
- > confidentiality

- > speaking through the chairperson
- > keeping to the agenda
- > keeping to the topic.





If possible, the meeting rules should be visible throughout the meeting – on a board/flipchart or personal copies, if people prefer this.

(C) **Agenda:** an agenda is often essential for people with autism as it reduces anxiety brought about from not knowing what is going to happen next. The agenda should be as explicit as possible, with the item, timing, reason for its inclusion and possibly an explanation given. It may help to make the agenda visual, ie by using pictures as well as writing to describe activities. It is also a good idea to group agenda items into categories, such as: items for information/discussion; items for decisions; and items for review (see sample agenda on next page).





Sample agenda

	Time	Item	Description	Documents
1	Approximately  3PM	Introductions	The chairperson introduces everyone	
2	Approximately  3:15PM	Minutes from last meeting	Information	✓
3	Approximately  3:30PM	Matters arising from last meeting	Discussion	
4	Approximately  3:45PM	Evaluation of summer play scheme	Review	✓

(D) **Written information sent ahead of the meeting:** any written information sent in advance of the meeting should be ‘autism-friendly’.

- Be clear about what you want people to do with the documentation, eg “Before coming to this meeting, please read through the enclosed minutes and write down any comments or suggestions about them. This should take about an hour. Bring these comments or suggestions about the minutes to the meeting.” The time this requires will depend on the individual.
- All documentation should be clearly marked with the corresponding agenda item and title.
- Some people may find paperwork difficult to manage. It may be helpful to take a laptop into the meeting with the paperwork already loaded in agenda order.
- A person with autism may find it hard to wait until an appropriate time to make comments. They may therefore find it helpful to make notes on their laptop or paper until it is their turn to contribute.
- A person with autism may wish for an opportunity to talk through the agenda in advance of the meeting. Two phone calls may be required for some people - one to talk and ask questions with a further one a couple of days later once they have thought through what they would like to say.

(E) **Environment:** many people with autism report a different way of sensing the world around them. Therefore things which people without autism may hardly be aware of may interfere with the person with autism's ability to concentrate on the meeting.

- The room should be quiet and spacious. It may be helpful to offer the opportunity for an individual with autism to visit the room prior to the group work.
- Things which may distract, such as loud air conditioning, strip lighting, highly patterned blinds and noisy rooms next to the meeting room, should be avoided.
- Name badges or place names on the table in front of each person are a useful aid to identifying and remembering who people are. It may be helpful to have a diagram of where people are sitting, and for them to sit in the same place at each meeting.

(F) **Introductions:** people with autism may have particular difficulties in mixing with other committee members. This is especially likely if the person is new to the group or if the place where the meeting is held is new.

- A person with autism should be explicitly introduced and welcomed. The chairperson should speak to the individual prior to the meeting to ask how they would like to be introduced and whether they would like others to be made aware of their condition.
- In the introduction, the chairperson should explain what is going to happen in the meeting, when the breaks will be and when the meeting is likely to finish.

(G) **Time management:** people with autism may find the meeting confusing unless it is managed very tightly.

- It should be made clear when each agenda item is finished and the next item is about to begin.
- Avoid spontaneously changing the order of agenda items as this may cause anxiety.

(H) **Communication:** try to keep the language you use clear and simple and avoid non-literal language.

- Write up complex points on a flipchart or whiteboard to help people concentrate and focus.
- Use visual stimuli such as symbols, photos and objects to supplement what you are saying.
- Avoid open questions.
- Remember that people with autism may not communicate in a way you are used to, eg they may avoid eye contact but this does not mean that they do not have something to say.
- Remember that people with autism may not recognise non-verbal cues such as body language and facial expression, nor the assumptions people make from these cues.
- The chairperson should summarise from time to time. Do not assume that people with autism will understand a point because it has been implied; make it explicit.



(I) Decisions

- Provide clear choices when asking for input. Specified options are easier than open choices for people with autism.
- Whenever possible, it needs to be made obvious when a decision has been made, and what that decision is. At the end of the meeting, repeat in clear terms what has been decided and how it will be taken forward.

(J) **Closing the meeting:** it needs to be made very clear when the meeting is finished and what will happen next.

(K) **Feedback:** do not presume that, just because someone sits through the meeting, they feel that they have participated and contributed. It is worth spending time with the person with autism at a time that is appropriate for them to find out what they thought about the meeting and to agree strategies that include them at future meetings; their perceptions may surprise you.

People with autism often provide a unique perspective. Involving people with autism may change the way you see things. *think differently - act positively.*

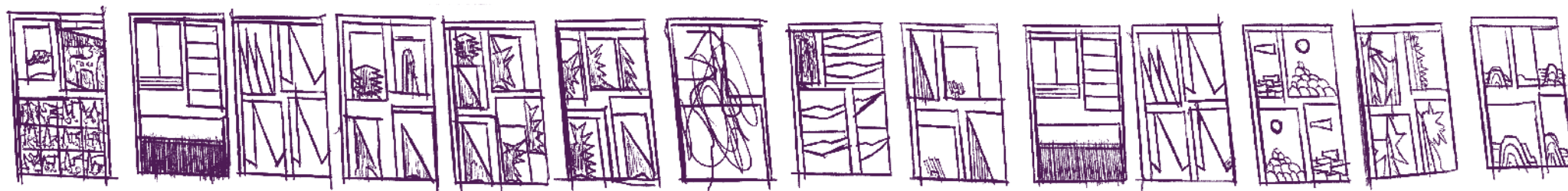
Further resources:

www.autism.org.uk

Our own website contains a wealth of information on autism and autism-related services and support. Our information centre (0845 070 4004, info@nas.org.uk) welcomes enquiries from professionals.

www.mencap.org.uk

The Mencap website has advice and resources to help you produce accessible, 'easy-read' documents. It also has links to other organisations that can assist you in making information accessible.



Artwork by Mike, a man with autism.
Mike is non-verbal and his drawings record the things he has seen or done during the day.