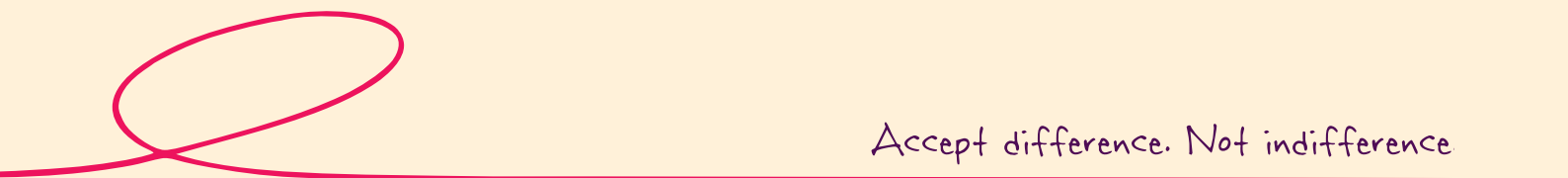
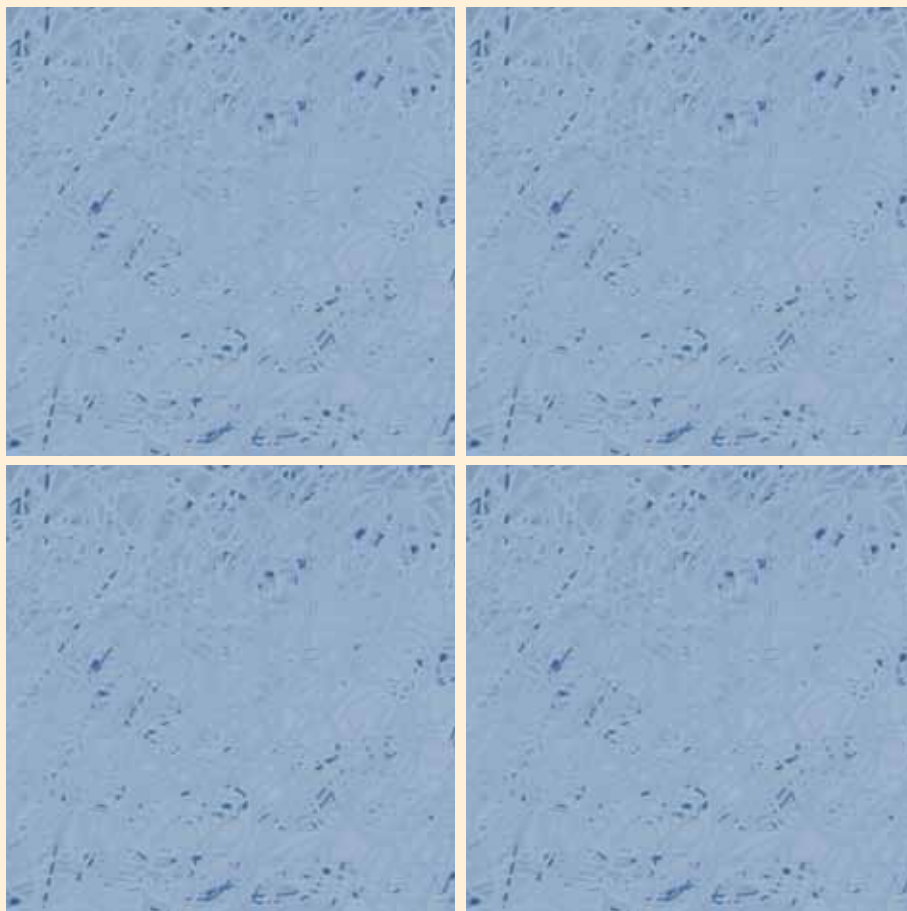


# Self-advocacy booklet

for adults on the autism spectrum



Accept difference. Not indifference

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Photo: Steve Hickey Front cover: illustration by Ema-Sayuru Nyx

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# Introduction

This self-advocacy booklet was developed by a group of adults on the autism spectrum.

The booklet is for you to complete by yourself or with a person of your choosing.

The aim of this booklet is to help you communicate your wishes and needs to the people you meet by filling in a particular section(s) of this booklet and taking it with you to the relevant meeting. For example, if you had a meeting with someone to discuss your welfare or disability benefits you would complete the section on welfare and disability benefits found on page 22 and then give this to the person or people that you have the meeting with. Please look at the contents page of the booklet to see which sections might be relevant to you.

There is also a general section about you to complete to make the person that you are meeting aware of your requirements. For example you may want the person to know that you require a 'distraction-free' room to meet in. Or you may need information written down for you in plain English rather than being given lots of information orally.

I am giving you this booklet as I am on the autism spectrum. Please take the time to read this brief explanation of what this means so that you are able to understand my wishes and needs.


### What is autism?

This section tells you what to expect when you meet a person with autism. Autism is a spectrum disability, which means that, while all people with autism share certain difficulties, their disability will affect them in different ways. There are three main areas of difficulty: communication, social interaction and social imagination. These are described opposite.

People on the autism spectrum may also experience over-sensitivity or under-sensitivity to sound, touch, tastes, smells, light or colours. They may also have difficulties with balance and body awareness. You can find more information on sensory issues in Appendix one.

Asperger syndrome is a form of autism.

Autism is often described as an 'invisible' disability, which means you can't always tell that someone has it. People on the autism spectrum are prone to anxiety and often develop coping strategies which hide their disability.



## **Difficulties with communication**

- May have difficulty understanding facial expressions, gestures, body language and tone of voice.
- May have difficulty in understanding what topic to talk about and understanding when or how to start or end a conversation.
- Might be very literal in their understanding, and jokes, irony and sarcasm can be difficult to understand. Phrases like 'it's raining cats and dogs' or 'pull your socks up' can be taken literally.

## **Difficulties with social interaction**

- May find it difficult to make and maintain friendships.
- May not be able to understand 'unwritten rules' that others seem to pick up naturally, like standing too close to people or being inappropriately honest, eg if somebody has body odour.
- May find other people confusing and unpredictable.
- May appear withdrawn or uninterested in other people (eg not making eye contact), which can create an impression of aloofness, or may be over-friendly (eg staring inappropriately).
- May behave in an inappropriate manner or appear tactless, eg laughing if a person is hurt.

## **Difficulties with social imagination**

- May find it hard to predict what may happen next. This may cause anxiety which affects the way a person behaves.
- May find change and coping with uncertainty difficult and stressful.
- May not be able to interpret other people's thoughts feelings or actions. Body language and facial expressions are often missed.
- May have a limited range of imaginative activities, so may prefer things rooted in logic and fact, such as mathematics. This doesn't mean that people on the autism spectrum can't be artistic.
- Some people might be very trusting and believe everything that people say to them. This might make them vulnerable and put them at risk.

Some people on the autism spectrum have a need for personal routines and sameness, and changes to routine may cause a lot of anxiety.

Some people on the autism spectrum may have a passionate interest in a particular object or subject.

## **Difficulties with planning, organising and doing**

Because of difficulties with 'executive functioning' – the mental processes that allow us to think, act and problem-solve – some people with autism find it hard to plan ahead, organise themselves, multi-task or change from one activity to another. They may need 'prompting' even with familiar everyday tasks.

# Some ways to help and support people on the autism spectrum

- Ask the person what they want and how they would like to communicate.
- Remember that everyone is an individual.
- Talk slowly, precisely and clearly but do not patronise.
- Discuss one idea at a time.
- Because somebody is very articulate do not assume that they have understood you.
- People may take a little while to process a question – please leave several seconds before asking the question again. Six seconds is a good guideline but this will vary. Do not rephrase the question (unless asked).
- Use correct language, avoiding slang, irony, metaphors or sarcasm.
- Do not force eye contact as this can be quite threatening or painful for some people.
- Make graded or staged changes rather than sudden changes.
- Use closed questions, eg “do you understand this form?”

## **For more information:**

National Autistic Society Autism Helpline

Tel: 0845 070 4004 (Mon-Fri, 10-4)

Email: [autismhelpline@nas.org.uk](mailto:autismhelpline@nas.org.uk)

National Autistic Society Website: [www.autism.org.uk](http://www.autism.org.uk)

# Contents page

Personal information .....	1
How autism affects me.....	2
Financial needs .....	13
Welfare and disability benefits needs.....	13
Education .....	14
Training .....	14
Employment .....	15
Housing needs .....	15
Daytime activities .....	16
Evening activities.....	16
Health care needs .....	17
Spiritual/Cultural needs .....	17
Transportation needs.....	18
Contact with the criminal justice system .....	18
Other issues .....	19
Appendix one: Sensory issues.....	23
Appendix two: Information for criminal justice professionals .....	27

# Self-advocacy booklet

## Personal information

**My name:**

My preferred method of communication is:

Address:

Phone number:

Email:

**Next of kin/Preferred contact:**

**Contact details:**

**People who support me**

**Name:**

**Role:**


**Contact details:**

**People who support me**

**Name:**

**Role:**

**Contact details:**



## **How autism affects me**

(Please use the space below to write how being on the autism spectrum can affect you.)

**Communication difficulties:**

**The things that help me are:**

**Social interaction difficulties:**

**The things that help me are:**



**Social imagination difficulties:**

**The things that help me are:**

## Sensory issues

**Hearing:**

**The things that help me are:**




**Sight:**

**The things that help me are:**

**Smell:**

**The things that help me are:**



**Taste:**

**The things that help me are:**

**Touch:**

**The things that help me are:**




**Balance:**

**The things that help me are:**

**Where my body is in space:**

**The things that help me are:**



**Other issues are:**

**The things that help me are:**

## Financial needs

These are: (eg 'someone to help me budget')

To meet these I would need: (eg 'a support person to help me plan meals so I buy only what I need')

Extra information: (eg 'I'm unable to cook complicated meals for myself and need things that can be produced quickly and easily, like omelettes')

## Welfare and disability benefit needs

These are: (eg 'I need Disability Living Allowance')

Please take into consideration: (eg 'I find form filling very difficult and do not always respond to letters')

Extra information: (eg 'I need attendance allowance as I find it hard to organise myself to go out and require assistance dealing with formal communication')



## Education

I would like to: (eg 'to go to university')

To do this I would need: (eg 'support to attend lectures and a safe place to live')

Extra information: (eg 'I have 4 A-levels at grade C and above')

## Training needs

These are: (eg 'access to autism-friendly training software and courses')

To meet these I would need: (eg 'help finding a suitable course')

Extra information: (eg 'I might have to change courses to find something that suits my needs, I may need a support person to attend the training with me')

## Employment

I would like: (eg 'help to find a job')

To do this I would need: (eg 'someone who understands my skills and needs to help me complete an application form')


Extra information: (eg 'Interviews are very stressful for me and it would help me to have a support person present who can rephrase the interview questions if necessary')

## Housing needs

These are: (eg 'help with chores around the house')

To meet need these I would need: (eg 'help planning in my diary when to wash laundry or put out rubbish and recycling')

Extra information: (eg 'I am unable to read instructions and need a diagram of how to wash clothes')



## Daytime activities

I would like to: (eg 'to meet with other people to have coffee and lunch')

To do this I would need: (eg 'help to get there and someone safe to meet')

Extra information: ('I used to go to a Resource Centre that I really liked')

## Evening activities

I would like: (eg 'to attend an NAS social group')

To do this I would need: (eg 'details of times and places of activities and buses so I can attend')

Extra information: (eg 'I get lost and confused in places I don't know so would need someone to attend with me so I can familiarise myself with the route')

## Health care needs

These are: (eg 'help eating regularly, taking medication, brushing my teeth and showering')

To meet these I would need: (eg 'a timetable so I know when to eat, take medication, brush my teeth and shower')

Extra information: (eg 'I'm unable to follow a timetable without someone to prompt me')

## Spiritual/Cultural needs

These are: (eg 'help with the cultural/spiritual texts, help with choosing a place of worship, help with attending a chosen place of worship')

To meet these I would need: (eg 'someone willing to be asked difficult questions about my chosen cultural/spiritual text, a church directory to choose the church I want to attend, someone to accompany me to the place of worship to help me understand the rituals')

Extra information: (eg 'As cultural/spiritual texts are very abstract, please be as literal and concrete as you can. Recommending an easy-read version of my cultural/spiritual text will aid me with this')

## Transportation needs

These are: (eg 'finding the right timetable for buses/trains/trams, getting to the stop or platform on time, changing trains or buses, applying for a railcard')

To meet these I would need: (eg 'directions to get to the information office so I can ask about timetables, help with booking a train, help with filling in a railcard application')

Extra information: (eg 'I'm unable to read or change trains in the dark, I need help photocopying and scanning documents for my railcard, I panic when I miss my train and cannot speak')

## Contact with the criminal justice system

My needs are: (eg 'not to keep eye contact when talking to people')

To meet these I would need: (eg 'for people not to try to keep eye contact with me – ideally the person will sit next to me not opposite me')


Extra information: (eg 'direct eye contact hurts me and makes me feel anxious. When I am anxious I rock quite hard and some people find it threatening')

## Other issues

I would like:

To do this I would need:

Extra information:



I would like:

To do this I would need:

Extra information:


## Self-advocacy booklet

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I would like:

To do this I would need:

Extra information:



I would like:

To do this I would need:

Extra information:

## Appendix one: Sensory issues

Some people on the autism spectrum might be hyposensitive (under sensitive) or hypersensitive (highly sensitive) in one or all of their senses. Hypersensitivity and hyposensitivity can be combined or even change from one to the other.

### Tactile (Touch)

#### Hypersensitivity

- May find certain materials cause pain or discomfort.
- May feel certain types of clothes feel uncomfortable, eg cuffs and collars.
- May find certain types of touch (often light) causes pain.
- May find certain textures comforting and others distressing.

#### Hyposensitivity

- May not respond/notice light touch.
- May not notice getting a scrape or bruise.
- May wear tight clothes.
- May bite or pinch themselves in order to gain sensory sensation.
- May not respond to pain in a conventional way.

### Vestibular (Balance)

#### Hypersensitivity

- May find sports and games difficult.
- May find aspects of getting dressed difficult, eg putting on trousers whilst standing up.
- May find holding one position for any length of time difficult and uncomfortable.
- May find balancing whilst standing up on moving transport difficult.

#### Hyposensitivity

- May rock backwards and forwards.
- May move around a lot even when sitting, eg 'wiggling' their legs.
- May constantly lean back in a chair using two rather than four legs.
- May enjoy swings and roundabouts.

## Auditory (Hearing)

### Hypersensitivity

- May find loud/sudden noises distressing or painful, eg thunderstorms
- May find certain tones are quite painful, such as emergency sirens, alarms and dogs barking.
- May find the noise of certain material very distracting, eg pen on paper or clothing rubbing together.
- May find some noises feel amplified, eg a clock ticking.
- May find it difficult filtering background noise.

### Hyposensitivity

- May not respond if they are addressed, unless by name.
- May not be aware of conversations taking place around them.
- May enjoy noisy places.
- May enjoy making noise, eg banging objects such as toilet seats.
- May like vibrations.

**Proprioception** (gives us our sense of body awareness and informs us where our body parts are and how they are moving).

### Hypersensitivity

- May have difficulty with fine motor skills, eg doing up buttons.
- May move their whole body to look at something.
- May place their bodies in strange positions.

### Hyposensitivity

- May have poor muscle tone.
- May be prone to tripping on uneven surfaces.
- May have poor body posture so may slump or lean on people/furniture.
- May bump into people/furniture.
- May drop or break objects.
- May not be aware of their body sensations so may not know when they are thirsty.

## Visual (Sight)

### Hypersensitivity

- May find bright lights or bright days painful on the eyes.
- May dislike the dark
- May see things that other people do not, such as dust particles.

### Hyposensitivity

- May have difficulty finding a particular object that they are looking for.
- May have poor depth perception so things seem closer or further away than they are.
- Some may concentrate on peripheral vision as central vision appears blurred (and some may find the opposite the case).

## Gustatory (Taste)

### Hypersensitivity

- May not be able to tolerate certain textures, eg some people may only eat smooth food.
- May only be able to cope with bland food as other food tastes too strong.
- May be a poor eater.
- May gag or be sick easily.
- May find new tastes and foods difficult.

### Hyposensitivity

- May like very spicy food.
- May regurgitate their food.
- May eat anything, eg grass, soil, paper.

## Olfactory (Smell)

### Hypersensitivity

- Some smells may be overpowering and distressing, such as perfumes or detergents.
- Some people may find smells a way of recognising a person, eg they will associate a shampoo with a certain person.

### Hyposensitivity

- May get close to people in order to smell them.
- May have a very poor sense of smell and are unable to notice strong odours.
- Individuals may lick objects in order to compensate for not being able to smell them.
- May seek strong odours.
- May smear faeces.

Sensory overload may cause people to go into 'meltdown'. This is when a person reacts in 'flight-or-fight' mode to an environment or situation. Others may become unable to communicate – this is known as 'shutdown'.

## Appendix two: Information for criminal justice professionals

Autism is listed under the Mental Health Act 1983, and therefore the Codes of Practice for PACE and YJCE relevant to vulnerable persons and Disability Equality Duty are applicable.

Autism specialists are generally agreed that people with autism are far more likely to become involved in criminality as victims than as perpetrators and are particularly vulnerable to abuse due to their social naivety. Experts, however, have identified four main reasons why a small minority of people with autism might be suspected of involvement in criminality:

- exploitation by others
- interruptions to routines leading to disruptive behaviour
- difficulties understanding social norms
- special – often ‘obsessive’ – interests.

### **Difficulties in social communication, social interaction and social imagination in police settings**

People with autism are likely to describe events differently to other witnesses, because they perceive and contextualise things differently to most people.

- Take care to consider responses in a context appropriate to the individual and, in particular, explore any apparent contradictions fully so that you can identify unanticipated perspectives.

### **People with autism all struggle to ‘tell their own story’.**

- Adopt a structured interview approach, breaking down the topic for discussion into clearly defined elements and using direct questions, where possible.
- Use diagrams, drawings and other visual aids, and maximise summarising techniques, to aid understanding.
- Provide plenty of breaks
- Two or more interviews are likely to be more useful than a single one.

People with autism find intentions and needs, including their own, very confusing unless these are made explicit. Their understanding of the emotional and social aspects of situations tends to lag far behind their own literal understanding of the facts.

- Use of an Appropriate Adult and Special Measures is recommended (bearing in mind that vulnerability is likely to be relatively greater at the hearing stage than at police interview)

People with autism are more reliant on detail than most people when making sense of situations and find it difficult to recognise what is or isn’t relevant. This means that it takes them significantly longer than most people to express themselves, and that they tend not to draw the same inferences as most people from conversations or instructions.

- Allow extra time for interview preparation as well as for the interview itself.

- Provide clear guidance and instructions, in advance of the interview and again at the beginning of the interview, about how the interview will be conducted.

A person's level of functioning is highly dependant upon the predictability of the environment in which they find themselves and their own mental state. Reactions to any changes may be seen as disproportionate by most people.

- Establish contact with somebody well known to the person at the earliest possible stage in any police engagement.

## **Sensory difficulties in police settings**

The degree of physical contact during arrest and the unfamiliarity of police custody suites are likely to cause considerable distress to people with autism. In some cases the lighting and noise levels may cause them discomfort or even pain.

- Be mindful that people with autism often experience sensory overload, and adjust the environment in which you detain them accordingly.

Further information can be found in 'Autism: a guide for criminal justice professionals', published by The National Autistic Society. Available from [www.autism.org.uk/shop](http://www.autism.org.uk/shop) or [www.autism.org.uk/cjs](http://www.autism.org.uk/cjs)



### **The National Autistic Society**

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### **[www.autism.org.uk](http://www.autism.org.uk)**

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**NAS code 930**

**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.***