Understanding Autism

A picture containing text, pool ball, sport, pool table

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Publication details

Originally published: 5 August 2015

Last updated on: 9 September 2022

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# How to use this guide

This app has been developed to help provide guidance to people who want to have a basic understanding of autism. You may find this particularly useful if you do not work in a setting that provides specialised services for people with autism.

Please note that this is intended to be used for basic awareness only and you are encouraged to use the links to get further information. You should also relate the content to the policies and procedures of your own organisation.

We would like to thank Joanna Panese from Scottish Autism, Christine Collingwood from Autism Network Scotland, and Frank Slokan and David Breslin from the Richmond Fellowship Scotland for generously giving their time to write the content. We would also like to thank Alison Johnson from Scottish Autism and Neil Barbour from Autism Network Scotland for their contributions to the videos within this resource.

# What makes a good support worker:

## Values

Values which determine and influence practice can be:

• Personal values.

• Workplace values.

Personal values are a set of principles that guide what a person believes to be right or wrong. Many factors can influence these personal values and they can change over time. Factors and experiences which might influence our values can. include things like, culture, health, gender, family size and make up. What we value is important to us and can influence our attitudes and behaviour.

Workplace values help to set the internal culture. They ensure that everyone in the workplace is supporting a consistent approach and gives purpose to what they do. Without workplace values staff would not have guidance of right or wrong in their practice. Although workplace values may not always align with personal values, staff embracing and understanding workplace values as a code of practice ensures staff are striving for the same outcomes for the same reasons.

## What is my role?

The basis of the role of the support worker is in the values and guidance set out in systems of professional practice like the Health and Social Care Standards. The role is no longer about a person who merely cares for those they support. The role is guided by practice that focuses not only on what supports that person's everyday needs but takes a person-centred approach by striving to enable the person using services to live an independent, fulfilling and meaningful life.

This might include supporting them to take part in activities, help them maintain their home, support personal care and advocate on their behalf to make sure they can fully take part in their community.

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The practitioner themselves should evolve as the role has. A support worker should embrace the process of reflection on practice and continuous development and learning. This ethos is motivated in the support worker by striving to improve and learn from practice but also the principle that I can learn as much from this person as they can from me. Central to the role of support worker is having a sound sense of values and practice driven by:

* Values.
* Principles.
* Ethics.

## The reflective practitioner

Reflective practice drives improvement in providing support and you yourself. Being reflective enhances the support you are able to offer. Ask yourself why am I doing this, what does it mean for the person I am supporting, how can I be better?

To be a reflective practitioner is to be involved in the practice of continuous learning and development through review of your own practice and experiences. The sole focus is to use personal development to improve your practice for the people you support.

The reflective practitioner should

be thinking more deeply and

critically about:

* What has driven their practice.
* If their practice aligns with workplace values.
* What areas of practice require development.
* Whether they would change support to be different in the future.

A support worker's approach should be centred on growth and progression designed in partnership with the person using services. This foundation, based on a mutual exchange, should be mindful of the aspirations, goals and what the person using services values.

## Support styles

As a support worker you should be continuously reflecting on your practice and making sure the person you are supporting is at the centre of your support style. Take time to get to know them, what are their interests? What do they like to do? Who are the important people in their lives?

Consider how you can find out more about them; work collaboratively with everyone involved in their care and support, learn more about how they prefer to communicate and use this to promote their voice and choice. Everyone you support will have a support plan, use this as a source of information to help inform your support style and accept that what the autistic person needs at the time should define your approach.

Your relationship with the people you support will evolve and grow over time and will be as much about what you can give to them as what they can give to you.

# Recognising strengths:

## Medicalisation of autism

When searching for information about autism, most resources focus on negative, overly medicalised aspects. These are often presented as coming from experts and professionals, who have spent their lives researching autism. The emphasis is often on the things autistic people cannot do. This idea of autism being a condition, which means the person is not able to do a wide range of things, is what often follows an individual throughout their life.

## Shifting the emphasis

Recently there has been a shift in focus, with autistic people highlighting the positive aspects of autism, moving away from the negative picture often created. Many autistic people have skills that often go unnoticed, due to our focus on difficulties. Positive characteristics may include things such as good memory and visual thinking skills, being genuine and honest, paying attention to detail and a high motivation to work.

## Strength-based approach

It is important that we get to know autistic people well and look for their preferences and interests. Focusing on strengths and achievements can be a good way to approach the support for autistic people on a day-to-day basis. It is important to understand that autistic people need to trust the individuals supporting them and that the emphasis is on achieving and highlighting what they are good at, rather than focusing on areas of difficulty they may experience.

## Positive approach to support

As mentioned earlier, autistic people have many positive aspects that are important to understand and engage with when supporting them. As their support worker you should find out what they like about themselves and what they think their own gifts and skills are. Think about having a note of their positive qualities, strengths and talents. It is often helpful to ask them, their friends and family, what they like and admire about themselves. Once you've established a good sense of who the person is and how they see themselves, it will allow you to work with them, using their resources and building strong relationships to engage in natural support.

## Working with the person

Be interested and enthusiastic about their passions and interests and see where the conversation leads. If the autistic person has had few opportunities to express themselves or experience the world, you may need to start small and plan opportunities to offer new experiences. This will help them build their own understanding of what they love. Remember autistic people, just like everyone else, have something to offer.

# Environments and senses

## Sensory perception

Our senses enable us to interpret our world. They assess an action or an environment and determine if it is safe or threatening and dangerous. Autistic people experience sensory processing disorder. Their brains have difficulty organising the information from their senses. They are either hypersensitive and may have extreme reactions to external stimuli or they may be hyposensitive and under-responsive.

## Responding to the environment

Working in groups can stress an autistic person because too much unfiltered noise can be painful. Problems can result from noisy radiators, flickering lights, strong smells or tastes, the texture of clothes or unintended body contact. These may get a stronger than expected response and should be seen as triggers when an autistic person's mood changes.

## Supporting coping strategies

An autistic person often adopts tried and tested routines. Familiar territory is more comforting. Obsessive compulsive disorders (OCDs) may also be a stress-reducing response. It is important to try to get inside the autistic person's reality. It is not the one offering help who is having the difficulties, so it is very important to do a lot of listening before offering advice. You should observe, record, consult others and try to devise strategies designed to desensitise.

## Understanding autistic experience

In general, the passage through life is a lot more precarious for an autistic person than for a neuro-typical person. Understanding why is the starting point for helping that person. Their sensitivities, if understood, may not be completely overcome but they can be accommodated. There is logic in their behaviour. So if a person on the autistic spectrum is coping in a situation in their own way and it is safe and serving a purpose for them, allow it to proceed rather than insisting on change.

## Respecting preferences

There is a reason behind unusual social behaviour so avoid being judgemental. For instance, if isolation allows an autistic person to avoid distraction and process information you should respected that. Denying them that choice is denying them a coping strategy. In fact they can be helped to cope by identifying quiet corners or safe spaces. Respecting their choices reduces stress. The route taken, where to sit there and how long to stay are important decisions. Allowing some down time on a liked, familiar task at the end of a day's activity can reinforce positive earlier experiences or reduce the stress of a negative one.

# Supporting transitions:

## What does a transition mean?

In its simplest form it is the passage of change from one situation to another.

Transitions are inevitable and a natural part of life and can be challenging and cause anxiety. For an autistic person the challenges can be greater and anxiety heightened.

## Types of transition

**Vertical Transitions**

These are transitions across the lifespan.

### Examples of vertical transitions

• Pre-school/primary/secondary

• Starting and ending relationships

• College/University

• Into work/change of job

• Moving from home to residential care

• Marriage

• Pregnancy and parenting

• Retirement

• Bereavement

**Horizontal Transitions**

Also known as micro-transitions, these are day-to-day transitions.

### Examples of horizontal transitions

Both types are important!

'Autistic people may often need support with small day-to-day transitions. It is just as important to get the bigger transitions right. Establishing the best way to support smaller transitions can often help the bigger ones go more smoothly. ' (The Autism Supplement to the Principle of Good Transitions 3)

## Planning

When planning, the autistic person is at the centre and their well-being is paramount. They should be listened to and their thoughts, wishes, needs and ambitions respected.

There should be a key person who will lead and coordinate the transition process, who knows the autistic person well.

• Start the process early, as appropriate to

the autistic person.

• Communicate clearly, giving time to process. Ensure context and meaning are understood.

• Listen to those closest to the person.

• Advocate for the autistic person.

• Use personal profiles/social stories/timetables.

• Consider sensory needs.

• Pre-visits to a new environment.

• The autistic person has their calming/favourite item with them.

• Use visual aids, videos, cartoons, photographs - these enhance transitions.

• Contact key people and meet/have further meetings.

## Why are transitions challenging?

• Result of a crisis when you cannot plan.

• Scary, producing heightened anxiety.

• Unknown outcome/ending.

• Resistance to change.

• Some autistic people prefer routine.

• Sensory and environmental factors.

• Affects the rest of the family.

• Often unable to predict the future.

• Unable to refer to a previous experience

• Forming new relationships - can be difficult to build trust.

## Examples of transitions

Crisis transition example

A member of the family has been taken to

hospital.

• Consider who should tell the autistic person if they are to be told.

• Consider how much information should be given at one time/what they need to know.

• Consider using visuals which describe a hospital setting.

• Be clear with information in a way the person can understand.

• Be prepared for raised anxiety or no reaction at all.

• Tell them when they may visit if appropriate and who will take them and how.

• Consider the timing of a visit and the impact.

• Consider the new sensory/environmental experiences.

• Consider who else it would be helpful to speak to - who can you get help from?

Planned Transition Example

Leaving school

Planning should start about a year ahead, including the autistic person as early as appropriate. Go at their pace and communicate in the most appropriate way for them

The person's ambitions, views and thoughts should be considered.

What are their skills/strengths and options:

* Further education.
* Into work/apprenticeship.
* Voluntary employment with an organisation.
* Consider with the individual/carers what else is available if needs are greater.

If someone has the welfare guardianship of an autistic person ensure they are up to date with the requirements as per Adults with Incapacity Act (Scotland) 2000.

Who else should be involved in this transition - education staff, other professionals already involved, career/'into work' agencies

Use visuals/social stories.

Share the person's needs, skills and capabilities with those involved.

Meet staff, arrange advice visits to familiarise and learn about the future environment

Engage support networks.

Organise group support.

Possible adjustments made in the new environment.

Training with regard to travel.

Negotiate a phased induction as appropriate.

## Possible support systems

In your role as support worker being a constant person.

The possible support systems depend on the transition:

* Parents/Carers
* Siblings
* Friends/Colleagues
* Mentors/Buddy
* Advocacy
* Key professionals e.g. social work, education, speech and language, other
* health professionals, residential care, other local authority departments, non-statutory organisations and anyone else deemed essential.

## Forms of advocacy

* Self-advocacy - Most importantly whenever possible allow autistic individuals to self-advocate.
* One-to-one - Support an individual to speak for themselves, or represent the view of the individual if they are unable to do so.
* Peer - is also individual advocacy as the peer empathies with the individual, shares experiences and builds self-awareness and confidence.
* Collective/Group - Peer group and the wider community, the collective voice can be more effective.

What "Forms of Advocacy" means to an autistic individual:

* Someone to speak on their behalf.
* Someone who acts in their best interests.
* Someone who informs them about their options.
* Someone who speaks for them when they lack the capacity to do so.
* Someone who doesn't give legal advice.
* Someone who helps ensure their rights and entitlements.
* Someone who advises them on what to do.

## Reflection

Think of a good transition you experienced.

* What made it good?
* Think of a transition which was not as good.
* Why was this?
* Who could have helped to make this better?
* What planning/actions would have helped?

The focus should always be what will work for the person you support. As a support worker you should be a very positive enabler in the process.

## Stress and coping:

What is stress?

'Stress is the feeling of being under too much mental or emotional pressure. Pressure turns into stress when you feel unable to cope. People have different ways with coping with stress, so a situation that feels stressful to one person may be motivating to another.' (Source: NHS)

Some stress is good for us all; it helps keep us motivated and safe. However how we react to stressful situations and the impact stress chemicals in our brain have on our bodies can have a very significant impact on our wellbeing. Stress becomes a problem when it prevents you from carrying out your normal daily routine or stops us from being able to complete a task.

How do we deal with the stress if it's different for all of us?

Our brains cannot differentiate between psychological or physical stress so will behave in the same way. This reaction triggers the flight or fight mechanism in our brains.

As a support worker, you can look after your own stress and that of the people you work with and support by looking out for the signs of stress. These might include:

* • Feeling irritable, aggressive, wound up or impatient.
* • Over burdened.
* • Anxious, nervous.
* • Unable to enjoy activities you once enjoyed.
* • Disrupted sleep patterns.
* • Uninterested in life.
* • Self-injurious behaviour, alcohol or substance abuse.

Autism and stress

Anxiety in new and stressful situations can be limited by prior planning, clear communication of what will happen and what is expected of the autistic person.

* Use the autistic person's preferred method of communication wherever possible. This may be pictures, written words, sign language, or simply clear speech. Try to be mindful that they may take what you are saying or communicating literally. Do not force eye contact.
* Allow extra processing time for communication and changes to plans/routine
* Respect the autistic person's personal space; ask before touching.
* Sensory sensitivities are common. Sensory overload can be prevented by use of personal support, such as sunglasses, ear defenders/headphones, comfortable clothing, altering the environment to limit its sensory impact and/or allowing regular breaks from sensory stimulating environments.
* If an autistic person becomes distressed, stay calm, reassure them, try to work out the cause of their distress and allow or support them to leave the stressful situation if appropriate. They may have reduced ability to process communication and respond appropriately while distressed.
* You should use person-centred care and personally tailored support plans designed collaboratively, as far as possible, with the autistic person you are supporting as everyone with autism has their own individual needs and preferences.

Transactional stress

Stress is a dynamic result of your relationship with your environment and other people around you. Your attitude and behaviour affect those around you, no matter if you are feeling positive or in a bad mood. Those around you interpret and absorb some of how you are feeling and this affects how they feel. For example, if you have had a bad journey into work this morning and arrive flustered and in a bad mood, this affects the people around you and the way they in turn behave towards you and the environment. They may experience feelings of stress and anxiety.

This is a stress transaction.

When supporting someone that may be experiencing a high level of stress and anxiety it is natural that you might feel your own stress levels building. This may be a result of not feeling able to support the individual to reduce their stress or feeling like you cannot cope. As a support worker it's important to recognise your own stress and develop your own coping strategies to help manage it. This could be using mindfulness techniques or something as simple as taking time out. Making sure you have all the information and training needed to support the person effectively can also help you feel like you are able to cope.

Stress and mindfulness

We all have stress signatures, these individual responses to stress help others identify that we are stressed and they are also useful to help others reflect on their own stress.

Stress signatures can take any form and they make up the early warning system that stress might be becoming a problem. For example, you may look very tense or speak faster than usual, experience butterflies or shaking, appear rushed or frozen, unable to move on. You may be more emotionally sensitive and experience extremes of emotion disproportionate to what is happening around you. You may not be able to think clearly and make decisions.

As a support worker it's vital you take some time to reflect on what your own stress signature might look like. Once you understand what your own stress looks like you will be able to develop coping strategies to help you deal with it.

We all develop coping strategies that help us deal with everyday stress, these might include going for a walk, taking time out, speaking to someone or removing yourself from the source of the stress. However at work that might not always be possible.

Being mindful or in the moment can be useful in dealing with stress. For example, if we daydream about being on holiday when at work and then while on holiday worry about work we are not 'in the moment'. We will often miss out on key points or focus on things that either did or didn't happen, preventing us from dealing with what's in front of us.

When faced with a difficult situation it is important support workers take time to make sure they are mentally ready to deal with the situation in front of them.

Stress and the environment

Environments play an important role in how we behave and how we cope. Low stress environments can help support positive participation in a particular task or activity. However how we respond in our environment is deeply personal and experiences can vary significantly from person to person.

Some autistic people may experience sensory difficulties in particular environments and this can affect one or more of the senses resulting in hypo (underdeveloped) or hyper (overdeveloped) sensitivity to environmental factors.

For example someone who is hyposensitive may not experience pain in the same way as others do and be unable to manage their own risk within the environment. A hypersensitive person may find background noise extremely painful or it prevents them from being able concentrate on a task; the purr of fridge may sound the same as a jet plane in the room to some people.

As practitioners it is important that we understand how someone's sensory profile may affect their ability to function in a particular environment.

Managing restrictive repetitive behaviours

Flow is a state of mind; a mental state that people experience when they are absorbed in an activity or interest that gives them a sense of focus. That can help them zone out and create a sense of escapism.

For an autistic person, being in a flow state could mean engaging in a repetitive or restrictive activity to help reduce their stress and anxiety and help them regain control. They use it as a coping strategy.

Engaging in a familiar activity of choice can be an important part of a person's daily routine. Trying to stop the activity can lead to heightened anxiety and perhaps behaviours that can be challenging to those around them. If the activity is problematic or inappropriate, rules may be helpful, for example, planned, specific times before, during or after periods of stress.

Examples of repetitive and restrictive

activities:

* Body movements - rocking, spinning, twiddling, hand flapping, finger flicking, jumping
* Objects - flicking a rubber band, twisting a piece of string or chewing parts of clothing
* Special interests - collecting things, researching and gathering information on specific topics, fascination with numbers, trains, Lego, Minecraft
* Other - repetitive speech, watching a film over and over again, acting out parts in films, fixation on a character or person.
* Reasons autistic people use restrictive and repetitive activities can be:
* To distract, self-soothe and reduce stress/ anxiety when over stimulated by the sensory environment.
* At times of uncertainty, change and to support transitions.
* To provide stimulation when under stimulated, that is jumping, spinning.
* For enjoyment, creating a sense of security and control as external factors in the world can be so unpredictable.

Without understanding the underlying reasons for restrictive and repetitive behaviours, onlookers may find this quite disturbing and not understand the benefits to the autistic person.

As a support worker it's important to try to understand why the person engages in the activity and the individual benefits. If there is a risk, can an alternative or substitute be offered?

# Communication

## Introduction

Autistic people receive information in different ways and at different levels. Respecting and understanding them as a person and being open to their own characteristics, abilities, challenges, and not approaching them with preconceived ideas, will help you in your role as a support worker.

Ask them how they'd like to communicate. If that's difficult ask the person they are closest to.

A special interest can be a way to engage; do some research to assist how you engage.

Remember you may not always get it right; this is not a reason to stop trying.

## Verbal Communication

• Call them by their name.

• Be mindful of your tone of voice.

• Keep dialogue simple.

• Speak in short, active sentences and use specifics.

• Use understandable instructions and phrases.

• Avoid metaphors, sarcasm, and figurative speech.

• Speak slowly and clearly.

• Give longer to respond

• Check they understand.

## Non-Verbal Communication

### Pecs (Picture Exchange Communication System)

A picture containing graphical user interface

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Symbols can:

* Be single words.
* Help to make requests.
* Form sentences.

### Talking Mats

A picture containing text

Description automatically generated

A communications symbols tool, to help autistic people express themselves and their opinions.

### Boardmaker

Boardmaker has an enormous range of picture symbols, this was originally in book form. Now, with Boardmaker online, you can produce your own stories and games.

You can create images of a person's routine and of their feelings/mood, which can then be downloaded for the autistic person to use. (Boardmaker is in a few libraries in Scotland)

### Makaton

A picture containing necklet

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A picture containing text, clipart

Description automatically generated

• Signs and symbols to support spoken language.

• It may be required throughout life or an individual may drop signs and symbols naturally as they develop speech.

### Social Stories

Text

Description automatically generated with medium confidence

Carol Gray developed Social Stories in 1990.

These aid understanding and explanation of:

• Tasks

• Positive feedback

• Key events

• Coping strategies.

### One Page Profiles

Treemap chart

Description automatically generated

Example personal information:

• Personality.

• Things which are important.

• how to support the individual.

### Communications Passports

Diagram

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Provides information on:

• How to communicate.

• Particular views.

• Personality.

• Who they are.

## What can affect communication?

• What is said is taken literally.

• Difficulty in understanding social cues and body language.

• Inappropriate responses.

• Misunderstandings.

• Heightened anxiety.

• Sensory issues.

• Environmental issues.

### Echolalia

Echolalia is when words, part of words, phrases which have been heard before are repeated; it is a unique form of speech.

This can be meaningful and it is important to try to understand what the individual may be trying to communicate when they do not have developed speech.

However, the aim should always be to develop speech.

### Challenging Behaviour

When an individual's appearance or movement is an indicator of heightened anxiety or approaching a 'meltdown', consider stopping what you are doing and allow them time to calm down.

Safety is paramount when challenging behavior becomes heightened; be careful of touching an individual as this may be a trigger for them, allow them space.

Read as much as you can on this subject and consider appropriate strategies in relation to the individual you are supporting.

## Who can help?

• Family - parents/carers.

• Siblings (who may be the carer).

• Other people close to the person.

• Key professional - eg. speech and language therapist.

• Occupational therapist and other professionals already involved with an understanding.

• What is said is taken literally.

• Difficulty in understanding social cues and body language.

• Inappropriate responses.

• Misunderstandings.

• Heightened anxiety.

• Sensory issues.

• Environmental issues.

## Hints and tips

• Be patient.

• Communication can raise anxiety.

• Do not shout.

• Do not expect eye contact.

• Provide reassurance.

• Respect social space, touch can be very difficult.

• Emotions may not be obvious.

• Responses can be different to what you might expect.

• An autistic person may take your hand to take you to what they want.