

# **Autism Spectrum Disorder**

## **Your Child; Your Family**

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# 1 Introduction

Your child has just been given a diagnosis of Autism Spectrum Disorder (ASD). Although this may leave you with mixed feelings, it will allow you and your family/ friends to better understand and help your child.

This booklet is aimed to try and help you and your family understand your child, their diagnosis and how it may affect them in daily life. It covers a wide range of difficulties, strategies and further information or support, to help you and others in your child's life to understand them better.

## What is autism?

The term ASD covers both autism and Asperger's Syndrome, which previously were diagnosed separately. Autism is a lifelong developmental condition often referred to as ASD. Sometimes 'condition' is used rather than 'disorder' as some people on the autism spectrum say they may be different but do not have a disorder.

ASD affects each person individually. Many adults live independently but others need support.

Some people with ASD also have Learning Disability and need specialist support throughout their lives. Others have average or above average intelligence (high functioning autism). Whether your child also has a learning disability or more high functioning autism, the core difficulties in autism will remain the same. People with ASD tend to have problems with:

*Social interaction and communications*; such as the need for conversation to be two-way and also understanding what someone else may be thinking or feeling, including using and understanding non-verbal communication (e.g. facial expression, body language, tone of voice etc.).

Those with ASD may have *repetitive or restrictive routines* which can be inhibiting and distressing for them and their family and friends. The stress of daily life may impact on the emotional wellbeing of people with ASD and those close to them.

ASD can be a hidden condition. Those not familiar with or understanding of its effects on the daily life of the person, can raise barriers and cause extra stress and discrimination without meaning to

## **How common is Autism?**

ASD is thought to be at least three times more common in males than in females, although recent diagnosis rates may change this ratio. A rate of around 90 in 10,000 people is the best current estimate. Of the 4,563,326 people living in Scotland, around 47,231 are thought to have ASD.

## **Understanding a diagnosis of ASD**

No matter how well prepared you were for a possible diagnosis of an ASD, when it becomes a reality you may feel upset and distressed. This is perfectly natural. But remember that your child is still the same child. The only difference is that you now have a name for their quirky, idiosyncratic ways.

In the period after diagnosis, parents/ carers often concentrate on finding information and learning as much as they can to help the child. This is understandable as you want to do the very best for your child. Having to grasp what this diagnosis means for your family, as well as meeting various professionals and learning 'their language', can be very daunting.

Families react in all sorts of ways, and take varying lengths of time to come to terms with the diagnosis, and it is essential to help and support each other through this period. Sometimes talking to others is helpful; sometimes parents/ carers may just wish to retreat to their own family home and shut out the world for a while. All these attitudes are normal.

Grandparents, close family and friends can often help and support you at this time, particularly if you have other children who need life to go on as before. However, depending on their age, your other children will probably be aware that something has happened and do need some explanation.

There are a number of helpful books written for brothers and sisters that will explain ASD in terms they can understand. You'll find a short list in the Helpful Resources section of this booklet.

Many parents/ carers have said that meeting other parents/ carers who have gone through a similar experience can be very helpful. As well as giving emotional and practical support, they will be able to tell you about local activities.

With the growth of the internet, numerous online support groups can be found. However, as with all resources and information on the Web, the quality varies from excellent to poor.

Online support and information can be really helpful for various reasons, including ease of access, speed of finding information and keeping in contact. Families living in remote and rural areas may get particular benefit from internet access.

*Source: NHS Scotland "Information for parents and carers with a child or young person recently diagnosed with an Autism Spectrum Disorder."*

## 2 Specific Difficulties & Helpful Strategies

The majority of children with ASD experience the world in a very different way to others.

Your child may have some specific behavioural difficulties, which may be related to their understanding of particular types of communication and skills. The best way to reduce behavioural difficulties is by understanding the condition and difficulties associated with it, understanding also increases confidence, once you understand the condition, the behavioural difficulties make a lot more sense. People with ASD usually have what is called a 'triad of impairments'. This section aims to offer an insight into the difficulties you may have noticed in your child from the triad as well as secondary factors (e.g. environment), as well as offering strategies that may be helpful in addressing these. The examples given here are not concrete, and will vary in importance between children; your child may have some, all, or very few of these traits.

### Language and communication

One of the biggest difficulties of children and young people with ASD is with language and communication. It may seem like they understand everything we say, but this may be because of a lot of other signals and clues, such as:

- What usually happens at that time of day?
- Your use of gesture.
- What other people are doing?
- Cues in the environment (e.g. a swimming bag).

This can be likened to when we go abroad to a country whose language we do not know well – we rely on lots of extra cues. So it is important to try to keep your language clear and unambiguous, even if a child seems like they understand. Avoid sarcasm and be positive when giving instructions; tell the child what they should do, not what they shouldn't do, and say things in the order that they will happen.

Problems with communication can involve difficulties communicating with others (expressive), and understanding others (receptive). For example this relates to using words and language flexibly and appropriately to the context or situation. It also means being able to understand other people's use of language, both verbal and non-verbal.

Your child may have difficulties in social communication, such as:

- Have difficulty understanding and using gestures, facial expressions or tone of voice appropriately E.g. they may use their tone of voice in an unusual way or find it more difficult to use non-verbal communication such as eye contact.
- Find it difficult to respond to questions and instructions, particularly longer instructions or questions.

- Have difficulty in starting and maintaining a conversation or engaging with ‘chit-chat’.
- May understand things in a very concrete or literal way, which can make it difficult to “read between the lines” with regard to understand proverbs, jokes and common sayings.
- Repeating words or phrases others have just said (“Echolalia”).
- Use complex words, but not understand their meaning.
- Talk about a special interest they have, not noticing that others do not share this interest.
- Difficulty understanding different viewpoints, new ideas and broad concepts.

If a child has difficulties communicating, they are less able to communicate their needs. Challenging behaviour can be used as a way of trying to get his/her needs across to someone else. It may be a way for them to show they are confused, anxious, or upset about the situation. See more on this in the behaviour section of this booklet.

### **Helpful Approaches:**

- Get the attention of your child before starting a conversation (for example, tap on their shoulder or say their name).
- Reduce your language and use key words; reduce fillers (unnecessary words). Especially when they are upset.
- Speak clearly and keep your sentences short.
- Allow time for them to process what you have said as there may be a delay in them making sense of what you have said. Try not to keep rephrasing your request during this time as this can cause them to become overwhelmed with copious amounts of information.
- Say things in the order they will happen. Use "then" consistently to help him/her understand the sequence of events.
- Tell him/her what to do – NOT- what not to do; “walk!” rather than “no running!”.
- Use pictures, symbols, gestures and actions to back up what you say verbally. Do not assume he/she has understood what you have said.
- Pick up on their own use of language and look past the actual meaning of the words and think about what he/she may be trying to communicate to you e.g. is he/she anxious, worried, uncertain, or annoyed about something?

- Try not to use humour or sarcasm unless you are sure that he/she understands or is in the right mood to accept this.
- Be aware that your child may misinterpret or misunderstand the verbal information. Be aware of your child's specific difficulties and how this may make them feel anxious or worried, confused, scared or frustrated.
- Become a detective in working out what the verbal and non-verbal behaviour (e.g. body language) means to him and how he/she uses it within interactions to communicate.

## **Social Interactions**

Everyone with ASD will have problems engaging with others in a two-way social situation and changing in social relationship. This relates to making sense of the social world we live in and understanding subtle social rules that we assume everyone is aware of e.g. what to do if someone says hello to you. They may not look for social interaction or contact, or know how to take themes in a conversation. They may get social interactions wrong and break implicit 'social rules'.

Social interactions also involve having an awareness of the needs of others, recognising and responding to others feelings and being able to empathise with others - putting yourself in their shoes and understanding how they may feel. This is difficult for people with ASD and they may often get this wrong. This may make social situations very stressful because they do not know what to expect or how to interact with others, and can lead to inappropriate social behaviour.

Having difficulties in making sense of the complexities of social interactions can result in challenges to developing and maintaining relationships. These difficulties may include:

- Finds it difficult to understand other people's emotions and feelings.
- Finds it difficult to express their emotions and feelings in a socially acceptable manner.
- Wants to interact with other people, but does not know how to do it, especially in new or complex social situations e.g. in high school.
- Finds it difficult to build relationships and friendships with others.
- Not sure or does not understand the 'social rules' for different settings and struggles to adapt accordingly.
- Unsure how to or does not want to share activities with others.
- Unsure how to or does not like meeting other people, especially new people or new situations.
- Finds it difficult to recognise other people's emotions, likes, and interests.

- Unsure how to, or does not seek comfort from others.

As your child will struggle to learn and understand complex social situations, they will need you to explain and teach these rules, expectations and appropriate behaviours.

### **Helpful Approaches:**

- Try to make your feelings clear. If you feel happy, look and say that you are happy – teach him/her facial expressions.
- Explain the boundaries and rules for a social situation and refer to them if needed (e.g. social expectations; saying hello to someone on the street).
- Encourage the person to interact with others, for example, if they like computers, could they join a computer club?
- Over time, help the person to develop social interaction skills, perhaps by practising situations at home or in school. A social worker, teacher or other professional may be able to help.
- Help the person to understand and explain their feelings. For example, give your child his/her favourite toy and say, "This makes you happy."
- Use social stories as a way to explain appropriate ways of responding in certain situations.
- Understand that some of his/her behaviours are a form of communication and are a way that he/she makes sense of the world.
- Encourage his/her understanding of situations by giving clear explanations about the reasons for people's actions.
- Accept that the person may need some time alone.

Due to these difficulties, social situations can often be overwhelming and stressful for young people with ASD, especially as social rules become more complex. This can often lead to avoidance and behavioural reactions to this stress and anxiety.

## **Flexibility of Thinking and Imagination**

Children with these difficulties may have problems in everyday life - sorting out what to do when things change or coping when things go wrong. They may also have problems with attention, memory and organisation. Organising themselves and their environment will be difficult. As a consequence of the difficulties they have, their behaviour may be challenging when they are faced with a situation they cannot cope with.

Some of the challenges that your child may face, or issues you may have noticed in this area include:

- Enjoys or requires structure and routine – becomes upset if routine is disrupted.
- Finds change difficult, especially without prior warning.
- Finds it difficult to guess what other people are thinking, or often gets this wrong.
- Has limited interests.
- Tries to impose routines on others, and becomes frustrated if these are not followed.
- Believing that others know what they know, or cannot imagine what others may be thinking – referred to as “mindblindness”.
- Thinking in concrete and literal ways.
- Skills learnt in one situation may not be easily transferred or generalised to another context.
- Limited concept of time.
- Difficulty with sequences.
- Difficulty linking events or actions - problems understanding cause and effect, for example – does not link behaviour with consequences.
- Problems shifting attention from one task to another.
- Repetitive behaviour. This can result from a need for sameness and makes the world more predictable and so reduces a person's anxiety.
- Preference for sameness.
- Difficulties planning, setting goals and working out how to get a task started and how long it may take to complete.
- Difficulties reflecting on past experiences to plan for the future e.g. making the same mistakes over and over.
- Difficulties communicating details in an organised and sequential manner.

- Overlooking important details, or, alternatively, become fixated on specific details and failing to appreciate the big picture.
- Difficulties initiating activities or generating ideas independently.
- Difficulties retaining information while doing something e.g. remembering a phone number while dialling.
- Difficulties picking up on social cues.
- Weakness with “working memory” (or “seeing in your mind’s eye”), which is an important tool in guiding ones actions.

Rehearse scenarios using different behaviours and assess outcomes.

Behavioural reactions may happen when these difficulties impact your child in a situation that leads to increased anxiety e.g. sudden and unpredictable change.

### **Helpful approaches:**

- Try to use repetitive behaviours constructively and incorporate the enjoyment of repeating the same action into everyday activities.
- Structure the person's day using a visual timetable, perhaps by using real photographs, pictures or a written/ visual timetable. These can be used to help explain changes and to work towards introducing flexibility and choices.
- Prepare him for new or future events by making things concrete and clear e.g. photographs, symbols, social stories and visual sequences of what is likely to happen. Build in options for change and what the plan is if something can't work e.g. if it is raining what are you going to do? How can you prepare him/her for this?
- Go over things in the order they will happen to help him/her organise this in his/her mind.
- Provide clear and consistent boundaries e.g. only responding to repetitive questions 3 times. For example, explain and warn him/her of this and on the 4th time divert or distract his/her attention from this fixation and do not respond. This must be consistent.
- He/she will benefit from everyone working with him/her in the same way. This will reduce his/her levels of anxiety, as he/she knows what to expect.
- Provide time when they can do their favourite activities.
- Prepare the person for change by telling them about it in advance.
- Make gradual changes.

- Encourage the person to broaden their interests. For example, if your child collects chocolate wrappers, see if you can interest him/her in locating the countries where they are produced. This may lead to him/her learning more about the people and customs of different countries.
- Help in developing these interests into hobbies, if possible. For example, if your child likes tearing paper, you could try teaching him/her paper folding or origami.
- Provide opportunities to develop new or different interests. For example, if your teenage child likes water play, encourage him/her to learn swimming.
- Tell them what to do or provide fixed choice – option a or option b, as they may struggle to problem solve alone.

### **Teach problem solving strategies:**

- Help the child to identify what is the important goal.
- Help them identify alternative ways to behave and when to use these.
- Help them identify appropriate coping strategies.
- Help them recognise when to seek different behaviours and coping strategies.
- Use flow charts and “planning paths” to map out how to reach their goals.

### **Use memory aids:**

- Prepare visual schedules e.g. checklists, and review them throughout the day.
- Make use of visual clues as reminders of events or steps that are needed e.g. visual prompts on school books as a reminder to check for spelling, use of full stops and capital letters. Coding schoolbooks by topic e.g. by colour or with stickers, can also help in organising what to take to school.
- Use cues or strategies that help you remember the sequence of steps. For example, mnemonics are an example of a strategy or cue for example, “my very entertaining mother just sent us nine pizzas” as a reminder as to the order of the planets. If you can teach them a general strategy that whenever they have a multi-step task, they could try to develop a mnemonic, you will be teaching them a lifelong strategy.

## **Sensory Issues**

Our life is full of sensory experience. We respond to sensory information automatically often without realising that we are doing so; we touch, move, see, hear, taste and smell. We intuitively respond and interact with our environment. Sometimes we seek sensory information to make ourselves feel better (e.g. seek a cuddle).

Sometimes we retreat from sensory information if it makes us feel uncomfortable (e.g. very loud noises).

We all have different likes and dislikes when it comes to sensory experiences.

People on the autism spectrum can often experience sensory stimuli differently to people without ASD. It appears that they tend to process sensory information more slowly and this can lead to them finding some sensory stimuli very challenging and sometimes, overwhelming. People with ASD may be over or under-sensitive, or have very strong reactions to sensory stimuli. This may then present in their behaviour as extreme agitation or distress in dealing with discomfort.

By understanding an individual's sensory preferences better we can help to support them to manage situations that may be challenging for them. Preparing in advance for / or reducing exposure to a disliked or upsetting sensory experience may help the young person with the sensory issue to feel calmer and be able to take part in daily tasks. It is important to recognise that difficulties interpreting sensory information can have an impact on how we feel, how we think and how we behave or respond. If the sensory information is not processed efficiently, this can cause us problems.

## **Reading the Signs: Sensory Strategies for Daily Activities**

Becoming a detective can help you to better understand your child's sensory preferences and how he/she responds to different sensory stimuli. This can then help you to support your child better when they have to be in environments that they find challenging.

Understanding your child's sensory profile can also help you to choose the strategies that are likely to be the most effective in helping your child to regulate the amount of sensory information they need so that they can remain calm and do what they need to do in situations that may be challenging to them.

People know about the five senses but there are two other senses that help us make sense of all the information we receive. These are our sense of movement and body awareness.

<b>Hearing</b>	<b>Highly sensitive</b>	<b>Low sensitivity</b>
	<ul style="list-style-type: none"> <li>• Noise levels feel magnified</li> <li>• Dislikes like loud noise</li> <li>• Is easily startled</li> <li>• Likes to 'chew' to damp down noises</li> <li>• Is anxious before expected noise (e.g. school bell)</li> <li>• Talks loudly.</li> </ul>	<ul style="list-style-type: none"> <li>• Enjoys really loud noise</li> <li>• Fails to pick up expected cues.</li> </ul>

<b>Vision</b>	<b>Overly sensitive vision</b>	<b>Not sensitive enough or under-sensitive vision</b>
	<ul style="list-style-type: none"> <li>• Dislikes bright lighting;</li> <li>• Prefers dark environment;</li> <li>• Is distracted by visual information.</li> </ul>	<ul style="list-style-type: none"> <li>• Takes more visual information to react;</li> <li>• Likes bright environment, reflective or spinning light.</li> </ul>

<b>Taste/ smell</b>	<b>Overly sensitive</b>	<b>Not sensitive enough or under-sensitive</b>
	<ul style="list-style-type: none"> <li>• Dislikes strong tastes</li> <li>• Likes only bland tastes</li> <li>• Tastes or smells objects, clothes etc.</li> <li>• Smells people</li> <li>• Likes consistent temperature of food or really cold or really hot</li> <li>• Can't cope with certain textures i.e. small pieces of fruit in yogurt</li> <li>• Over-reacts to new smells</li> <li>• Gags easily.</li> </ul>	<ul style="list-style-type: none"> <li>• Eats non-food items</li> <li>• Has lots of hard, crunchy food in diet</li> <li>• Craves strong tastes</li> <li>• Under-reacts to strong, bad or good smell.</li> </ul>

**Touch**

<b>Overly sensitive</b>	<b>Not sensitive enough or under-sensitive</b>
<ul style="list-style-type: none"><li>• Avoids other children</li><li>• Dislikes hugs</li><li>• Fussy about clothes</li><li>• Dislikes messy play</li><li>• Dislikes getting hair cut or nails cut</li><li>• Reacts aggressively to being touched</li><li>• Avoids going barefoot</li><li>• Feels pain and is very sensitive to temperature.</li></ul>	<ul style="list-style-type: none"><li>• Seeks frequent hugs</li><li>• Touches people or objects</li><li>• doesn't seem to notice when face or hands are messy</li><li>• Mouths objects</li><li>• Has difficulty responding to pain/temperature.</li></ul>

**Movement**

<b>Overly sensitive</b>	<b>Not sensitive enough</b>
<ul style="list-style-type: none"><li>• Avoids playground equipment</li><li>• Becomes dizzy easily</li><li>• Avoids having feet off ground (e.g. swings)</li><li>• Doesn't like tipping head back i.e. in bath</li><li>• Cautious when going down stairs or stepping off a kerb</li></ul>	<ul style="list-style-type: none"><li>• Is always on the go</li><li>• Has difficulty sitting still</li><li>• Is constantly fidgeting/tapping</li><li>• Runs rather than walks</li><li>• Takes risks</li><li>• Can twirl self throughout the day</li><li>• Rocks on chair</li><li>• Does not seem to get dizzy when others would</li></ul>

Body Awareness	Overly sensitive	Not sensitive enough
	<ul style="list-style-type: none"> <li>• Doesn't like others being too close</li> <li>• Removes self from crowds (e.g. Crowded shops/busy queues).</li> </ul>	<ul style="list-style-type: none"> <li>• Bumps into or trips over things/people</li> <li>• Stands close to/ leans on others</li> <li>• Puts self in too small spaces or pushes against corners of the room</li> <li>• Loves rough and tumble play</li> <li>• Trips/ falls frequently</li> <li>• Holds objects so loosely they drop</li> <li>• Walks on tip toes</li> </ul>

### Calming Strategies

When the young person is over-stimulated and feeling anxious these activities/strategies may help them feel calmer.

#### Quick fix:

- Sitting under a big, heavy blanket.
- Hands on head and pressing down.
- Tucking legs up and squeezing.
- Deep pressure massage.
- Slow rocking e.g. rocking chair.
- Giving themselves a hug.
- Calming aromas like vanilla or cinnamon
- Squeezing and relaxing a small fidget toy, face and/or hands.
- Snuggling into a small space.
- Sucking a sweet.
- Sucking yoghurt/thick milkshake through straw.
- Bear hug.

## **Longer lasting ideas:**

Long term routine calming activities may be part of the day.

- Walk after coming home from school (with heavy/ weighted backpack on).
- Press ups or chair press ups regularly through the day e.g. before school, lunch time, after school.
- Allow chill out time, prior to homework in a daily routine.
- Help with moving furniture e.g. pushing sofa – relocating plant pots, hovering, bringing in shopping bags.
- Help with heavy manual tasks in the garden e.g. digging.
- Swimming.
- Put on a heavy coat or heavy blanket over the shoulders as part of chill out time.
- Have a corner with favourite sensory activities to go to at any time.
- Squeeze/rock against gym ball.
- Access to a tactile feely bag

Your child may have sensory difficulties relating to their:

- Hearing (auditory seeking or avoiding)
- Smell (seeking or avoiding)
- Touch ((seeking or avoiding)
- Sensation or tactile (seeking or avoiding)
- Taste (seeking or avoiding)
- Sight (visual seeking or avoiding)
- Movement (vestibular seeking or avoiding)
- Position (proprioception – knowing where your body is or being “all legs and elbows”)

## **Alerting Strategies**

When the young person is not alert enough to pay attention to a task, these activities / strategies may help.

### **Quick fix:**

- Up/down movements, i.e. trampoline, jogging/running, fast movement (for short periods only).
- Jumping, jumping jacks.
- Clapping activities.
- Making faces e.g. open mouth wide.
- Stamping on spot.
- Sucking sour sweet.

- Eating crunchy food.
- Drinking cold drinks.

#### **Longer lasting ideas:**

- Regular routine of jumping/chair push ups.
- Timetable the 'Quick Fix' that works into regular routine, immediately before.

### **Sensory strategies for daily activities**

Sensory sensitivity can lead to difficulties with young people being independent in daily life skills. The following strategies may help in personal tasks.

#### **Dressing**

- Use comfortable clothes; consider type of fabric and length of sleeves.
- If the young person cannot tolerate labels, cut them out.
- If the young person cannot tolerate seams, undergarments can be worn to reduce friction.
- Try washing and drying clothes in unscented products.
- Dressing can be done in front of a mirror so as to provide visual cues to assist with sequencing, motor planning and body awareness.
- Be aware of other visual or auditory noises in the room which may be off-putting.

#### **Personal hygiene**

- Use non-perfumed soap.
- Be aware of bathroom lighting levels and minimise any noises, e.g. run the bath prior to entering the bathroom.
- Use deeper touch pressure when shampooing or drying with a towel.
- Before bath time, do activities that provide deep touch input, e.g. rest your hands on your young person's shoulders and apply moderate pressure.
- Make the transition from undressing and getting into the bath as quick and smooth as possible.
- If the young person dislikes having his face or body washed, encourage him/her to wash himself. Self-initiated touch produces a less defensive reaction.
- Use a large sponge or loofah sponge. Rub firmly to decrease defensiveness.
- If the young person is showering, use a hand held shower nozzle. Let the young person control the direction and force of the water
- Use a large towel, and quickly and firmly wrap the young person in it.
- Avoid exposure of the wet skin to the air as the light touch may trigger a defensive reaction.

- Provide deep-touch using a towel to the head, hands and feet to decrease defensiveness. If the young person will tolerate it, provide a firm massage, using lotion to avoid skin irritation.

## **General**

Some non-sensory strategies can also help:

- Where the choice is available, allow your young person to choose a bath or a shower. A larger showerhead is often more acceptable to the young person, as it distributes the water more evenly.
- Try to incorporate bathing into a play activity, for example, use floating toys and bubbles and/or coloured floating soap.
- Talk to your young person and explain every step, particularly when you are going to touch them with soap or a towel.
- Visual aids can be used in order to help your young person understand the activity.
- Consider adaptive equipment that may make the task easier, for example a grab rail may offer more support getting in/out the bath.

## **Haircare**

- Seat the young person firmly on your knee and squeeze the young person firmly between your knees (deep pressure).
- Place your hands on top of your young person's head and exert gentle but constant pressure down.
- Use a firm stroke or pressure as you comb or wash your young person's hair.
- Count or have the young person count as you comb, wash, rinse or cut the hair.
- Give definite time limits to the task e.g. let's count to 10, then we will stop cutting your hair, provide deep pressure immediately after (see above).
- Break the task into small steps and eliminate any unnecessary steps or stages. Practise each step in isolation in a stress-free environment.
- Gradually combine these steps and perform the task in the natural environment. Practise without scissors, lifting up sections of hair and tugging very slightly to mimic the feel of cutting.

## **Toileting**

- The young person may be sensitive to toilet tissue, try using moist toilet roll.
- Consider visual and auditory stimulation around and keep it to a minimum.
- The young person may not like how the toilet seat feels.
- The young person may feel unsafe with their feet off the ground and sitting (consider small padded seat insert and stepping stool).

Many children have particular sensory needs. There are low cost solutions to meet these needs in children, for example:

### **Shiny things**

- Sheets of silvered foam, sold to fix behind radiators to reflect the heat into the room (DIY stores).
- Pan scrubbers (soft ones).
- Survival blanket
- Mirror balls.
- Sequined material.
- Old CDs.
- Tinsel tied to a scarf.
- Acrylic tubes filled with sequins and glitter.

### **General Calming strategies**

Anxious behaviour with a sensory basis is like any other anxious, sensitive response. Here are some calming suggestions.

- **Routines-** Make a list or organising a specific routine always helps to make us feel calmer. In particular after school or bed time routines will help to calm. Include one or two of the calming quick fixes in the routine. Organise the environment and establish routines e.g. establish consistent routines around getting ready for school and having specific places where important items are kept such as school bags. The more frequently you use a routine the more likely it is to become habit.
- **Visual Supports-** When the young person cannot hear what others are saying or cannot focus, a visual timetable or written list of what to do may help as a reference.
- **Environmental Checklist-** Try to consider the young person's environment and what could be done to reduce possible trigger stressors and help positive experiences. Home, leisure activities, colleges, clubs etc., times alone and with others need to be investigated. Think about this carefully and it may make a positive difference. Be a detective to look at the environment in the light of sensitivities and preferences of young person.
- **Challenging Environments-** The young person may be stimulated positively or negatively just by the environment around them. For all of us the light can be too bright, the room too noisy, the glare of the sun too dazzling, affecting how we feel.
- **Inside the home-** Developing a routine and a consistent way of doing things is really helpful and can reduce the impact of over-reacting. Organisation can give the young person a sense of control over how they plan their day.

### **Daily Sensory Routines**

- Provide a place where the young person can take themselves for time out, for example a small tent or cabin bed. Young people affected by sensory sensitivity often find dark and enclosed spaces calming.
- Avoid visual and auditory stimulation that is not necessary.
- If the young person has a positive response to movement, try a rocking horse or chair swing.
- Paint the young person's room soft, pastel colours and put dark blinds or lined curtains on windows to prevent light distracting the young person.
- If possible, situate the young person's room in a quiet corner of your house.
- Give your young person "heavy work" tasks around the house, for example carrying the shopping, arranging tins on shelves. This may have a calming and organising effect.
- Give "movement breaks" to help relieve tension e.g. collect the pens in class.

### **Outside the home**

Playground equipment can be used at home and school or in the local park or leisure centre to provide an area where a young person can play and have time out. Accessing local facilities may be more suitable at less popular times to reduce noise levels and distractions.

The following pieces of equipment can help the young person to have sensory experiences:-

- Swing, therapy balls, mini-trampoline or space hoppers for movement.
- Sand and water pits for tactile experiences.
- Play house or tent to provide a safe and calming area.
- Small sheds in the garden to give a less distracting environment.
- Soft play centres, ask staff when quietest time is.

### **Noisy, Busy Environments**

- Whenever possible, consider additional planning for special events such as firework displays, birthday parties, football matches. Is there a quick exit route if the young person becomes stressed? Is there a special toy/routine/contact that can be used to calm the young person?
- Reflect on when to carry out everyday activities. Is there a quieter supermarket, off-peak time or on-line shopping? Is there a quiet space available e.g. dining booth?
- Consider the wearing of snug clothing such as Lycra undergarments.
- It may be useful to use earplugs or a music player with headphones, allowing the young person to listen to favourite songs/music. This may help to drown out environmental noises and help the young person stay focused on an activity.
- A small toy to fidget with can help distract from other sensory input.

- Pre warn him/her of noises you know he/she does not like and encourage helpful coping strategies e.g. cover his/her ears when there is a vacuum on.
- Minimise clutter. Organisation tasks can quickly overwhelm people with executive function difficulties which often co-occur in ASD.
- Be aware that they may have difficulty coping with being overloaded with sensory information when outside and you will need to plan for this.

Source; Falkirk NHS; Making Sense of sensory behaviour & Lothian CAMHS Occupational Therapy Service

## **Strengths**

Your child may be particularly aware and receptive to the environment, which can lead your child displaying a number of strengths:

- Likely to be a strong visual learner. As such the use of real objects, pictures, demonstrations and written material can all help with their understanding.
- A good eye for detail and accuracy.
- Once learned, information, routine or processes are likely to be retained.
- Some can focus on their special interest for a long time and may choose to study or work in related areas
- Sticking to routine can make individuals with ASD reliable employees in an organised, structured environment.

# 3

## General Strategies

### Strategies to help children around bedtime

Anyone who feels wound up around bedtime might struggle to sleep. Children might have many worries around bedtime (e.g. being alone, niggles of the day).

- Reassure them that you are downstairs/in the house. Sometimes a picture map showing this can help.
- Explain how different family members have different bedtimes.
- Have time before bed when the child can talk over any worries.
- Certain oils. E.g. lavender added to bath water or bedcovers may aid relaxation
- Relaxation exercises, gentle massages and music tapes can also help.

Children typically respond well to routine and structures, they become familiar with the routine and can predict what happens next. It is important to consider timing when starting a new bedtime routine (e.g. not just before a family holiday when routines are likely to change). Bedtime routines are normally along the lines of teatime, followed by quiet play, bath and story and then being settled into bed with a goodnight phrase so the child understands that it is time to sleep. Bedtime routines need to be fairly simple with enough flexibility for all family members.

### Sleep

#### *Sleep diaries*

A sleep diary can be useful to help parents find out what triggers poor sleep behaviour and what seems to help. Sleep diaries can also be useful to help professionals understand the severity of a child's sleep behaviour. Sleep diaries can also act as a visual incentive so the child can be rewarded if they stay in bed and try to sleep.

Create a relaxing and comfortable place:

- Make a child's bedroom a safe, calm and pleasant place to relax.
- Do not use it as a place to send your child when they have been naughty.
- Try to separate out play and sleep areas.
- Some children are sensitive to light; black out blinds can make it dark. Others are afraid of the dark – a night light can help.
- Some children are sensitive to noise. Place the bed as far away from noise as possible. Other children might find gentle relaxing music helps them settle.
- For children sensitive to touch consider the type of fabric for sleepwear and bed covers.
- Ensure that they are warm enough but not too hot.

- Avoid too many stimulating toys and games e.g. video games, TV in the background.

It helps to:

- Keep a regular bedtime for the child and wake them at the same time each morning.
- Limit day time naps.
- Make sure that they are not hungry at bedtime.
- To reduce the chance of the child falling asleep in the wrong place e.g. sofa it can help to keep them upstairs after bath time.
- Avoid stimulating drinks and food high in sugar and additives.
- Avoid TV and computer screens, including tablets, phones or devices for up to two hours before bedtime, as the light from the screen can disrupt a child's normal sleep rhythm.
- Do not stay with the child in the bedroom until they are asleep, this way the child learns to settle themselves.
- Some children take time to settle themselves. Soft favourite toys can help offer the child comfort.

It is important to remember that it may take several weeks for a new routine to alter a child's sleep patterns!

### **Helping children settle to sleep:**

#### *Managing crying*

Sometimes children cry because they don't want to go to sleep. It is important to know whether they are distressed or just avoiding going to sleep. It is important that, if it is to avoid sleep, that this behaviour is not encouraged. If you think it is because they are struggling to settle and they are not distressed then:

- Do not take the child out of bed.
- Do not put on the light.
- Make the child comfortable, gently and calmly.
- Say 2-3 comforting words and/or stroke the child 2-3 times.
- Leave the room.

Wait for a few minutes and then repeat the above steps. Gradually increase the interval before you go in to them. Continue until they settle to sleep. If they come out of the bedroom take them back immediately without eye contact or talk and gently but firmly resettle them.

## The Disappearing Chair

Some children get upset when you leave the room:

- Start by sitting on the bed.
- Avoid getting into bed or cuddling them once the settling routine is done.
- Try to avoid eye contact or conversation. Pretending to read a book can help.
- Each night move nearer the bedroom door until you are outside the door.

*Persevere!* - Changing bedtime habits can take a while. The child's behaviour may get worse before it gets better. If you persevere and stick to the routine their behaviour will start to improve.

*Reward good behaviour* - If a behaviour is rewarded it is more likely to happen again. Star charts are useful.

Source: Leicestershire Partnership NHS Trust

## Managing feelings

Children with ASD do not always find it easy to manage their feelings. They can become overwhelmed and feel unable to cope. An important skill to learn is the ability to monitor and manage their own emotions and behaviour, so that they can identify and respond appropriately to situations, which in turn increases independence and confidence. Possible strategies include:

- **Learning to identify feelings** – Many people with ASD have difficulty understanding their own and others emotions. Emotions training can help by teaching an individual to read and respond to the cue that represents particular emotions, such as facial expressions and body language in other people and bodily sensations in themselves.
- **Relaxation** – Relaxation approaches such as deep breathing, thinking positively, redirection to pleasant, calming activities such as taking a bath, listening to relaxing music, playing on a computer, having a swing or jumping on a trampoline can start to help someone manage their anxiety.
- **Anger management** – Some children with ASD may have difficulty managing emotions such as stress, anxiety and frustration, which can sometimes be expressed as outbursts of anger or aggression. It can help to identify the physical sensations that show they are becoming agitated and then to develop a range of alternative, more appropriate activities to help them calm down. These can include breathing exercises, counting exercises, going for a walk, listening to music, walking away from the scene or asking for help. The child should also be supported to develop the communication skills needed to show distress and ask for help.

## Coping with demands

Children who are demand avoidant typically feel the need to dominate in social interactions, and to ensure that everything is done on their own terms, and can often come across as overbearing.

- It is important to remember that children who are demand avoidant often have deep anxiety about the demands that they fear will be made of them, and a need to control their environment to prevent this.

They will avoid the ordinary everyday demands placed on them, which is not normal laziness or timidity. They may do this by distraction attempts, or by refusing to speak or trying to drown out your voice with speech or singing.

Children who are demand avoidant may withdraw from situations or become disruptive. They usually know how others expect them to behave. It is important to remember that these children **do not choose** to behave in these ways. Their inability to cope with what they perceive as the stress of everyday demands results in them being unable to meet others expectations.

Children who are demand avoidant may sometimes appear compliant but might actually be “switching off”, that is they pretend to be attentive because then fewer demands are made of them. The child who learns that fewer demands will be made if they just “act” attentive needs to have this strategy recognised and countered before it becomes habitual.

## Strategies

- Be very firm and **consistent** with rules and boundaries.
- Distinguish between “essential” rules for the child and “important” rules.
- Having rules written down so they can be referred to can help older children.
- Prioritise issues you wish to work on and which you can let go i.e. pick your battles.
- Disguise the perceived pressure of a new tasks using the positive relationship you have with the child (e.g. “I bet you can’t...!”).
- Make requests indirectly (e.g. “I wonder if you know how to...?”).
- Let the child think that they have come up with the idea (of what you want them to do).
- Use chatty language to disguise requests (e.g. “I wonder how you do this; I can’t seem to work it out!”).
- Use props, e.g. phones, puppets, dolls and distance demands through them e.g. holding a puppet or phone and saying “I have a lot of things to do today, where shall I start?”.
- Try not to rely on telling the child not to do something in the hope that they will. Whilst this may sometimes work it is not a helpful lesson.
- Present requests such as everyday chores in a positive way, making use of play, making use of surprise and novelty can help empower the child by giving them choices (where the easiest choice is the one you want them to do).

- Always keep calm and level in your emotions.
- Avoid confrontation as far as possible.
- Use humour to diffuse situations.
- Focus on helping the child see that cooperation is no big deal.
- Ignore unwanted behaviour where possible.
- Try not to take a child's reaction personally when disciplining them.
- Use the child's interest in adult roles, allowing them at times to teach you things.
- If a child is using distraction to avoid an activity it is important to pay attention to the distracting behaviour but to remain focused on the task at hand.
- It is important to regularly monitor and check what the child has taken in. It will help to go over this information a number of times and in different ways to ensure the child has fully understood it.
- Remember that many unwanted behaviours are a result of anxiety rather than aggression and benefit from reassurance.
- Take time out *before* the child has reached their tolerance limit.
- A specific strategy is likely to work one day and not the next, and so it is helpful to accept this and draw on a variety of approaches rather than just sticking to one.
- It helps to be very truthful with children who are demand avoidant as they can be suspicious and become obsessive about "deviousness".

Source: Leicestershire Partnership NHS Trust

## Support in Education

Education is always uppermost in the minds of parents/ carers and this is especially true when your child has special or additional needs. The type of education provided depends on local authority policy and where you live. Children with a diagnosis of ASD may attend a mainstream school or possibly a specialist unit attached to a mainstream school. Some children will attend a special school for children with Learning Disabilities.

Whichever type of school your child attends, it is important that everyone involved with them has basic knowledge, understanding and awareness of the implications of ASD and how best to deal with it.

It is crucial that the links between the family, the school, and all professionals involved with the family are strong. Communication, collaboration and respect are important for the child progress and success.

The Education (Additional Support for Learning) (Scotland) Act 2004 (as amended) is the main legislation which supports children with additional support needs.

It places a legal duty on Local Authorities to identify, provide for and review the additional support needs of their pupils. Additional support may be required for a number of reasons, such as disability or Autism. Under this Act, Local Authorities also have a duty to provide a Co-Ordinated Support Plan (CSP). This is a plan which supports children and young people who require significant additional support with their education, particularly support from other services, such as health and social work. A CSP outlines the child's additional support needs, sets objectives for them to achieve and describes how they will be supported to achieve these. It also helps to co-ordinate education with other services your child might use, such as social work, educational psychologists or speech and language therapy. Only a small number of children will require a CSP, usually those with more complex needs.

If your child needs support in Education, there are other provisions which can help:

#### Individualised educational program (IEP)

An individualised educational program is a written plan that is used to plan specific aspects of education if your child needs some or all of their curriculum to be individualised. Your child's needs will be assessed and the plan will outline some targets for them. These targets will be short and long term, and will be based on your child's particular needs. The plan will also describe how your child will be helped to reach them. The targets should be regularly revised and updated. Where possible, you should be involved in updating the targets. Many children with a diagnosis of ASD may benefit from an IEP. It is important to note that this is not a statutory document, which means that your Local Authority does not have a legal duty to provide one or to follow the support outlined in them, although many schools do use IEPs in practice.

#### **Additional Information**

Education is a complex and important area for a family with a child on the autism spectrum, and there are many sources of information to explore. It is important that you and your child have their say in decisions which affect them. You may find it useful to make a list of questions you would like to ask at meetings or to write down useful information.

If you feel that you or your child need support to have your views heard or to ask questions, you could consider taking a trusted friend, relative or person who is knowledgeable about ASD to important meetings to support you and give you confidence. This person is called an advocate. You can also get help from someone called an Independent Advocate, who will support you to make informed choices and decisions.

Your education authority must have a contact person to give you information and advice about additional support needs. You should find their contact detail by either telephoning your authority or looking on its website. Please check the resources section for further information.

*Source: NHS Scotland "Information for parents and carers with a child or young person recently diagnosed with an Autism Spectrum Disorder."*

## Homework

Children and young people with ASD may have difficulties completing their homework. This may be because:

- They have difficulty with processing instructions and may not have been able to record their homework correctly in class or have it recorded for them – it may be unclear what work needs to be done when they get home.
- They have a very rigid thought process and are unable to adapt to the change in working environment.
- The homework that has been set is too difficult or they may forget a concept that has been taught in school – this can lead to frustration and anger when trying to complete this work at home.
- The homework that has been set is too easy or repeats what the teacher has already covered in class – a child or young person with ASD may not see the point in completing this homework and will lack motivation to complete it.

Source: National Autistic Society

# 4 Understanding and Managing Behaviour

## Understanding and coping with challenging behaviour

This section provides information about why children with ASD might engage in difficult behaviour that challenges other people, sometimes referred to as 'challenging behaviour'. It is important to first understand what is behind behaviour so that you can respond appropriately. Often this behaviour is your child's way of communicating something to you, such as asking for attention, refusing something, expressing a need or feeling. It may appear that your child behaves inappropriately, however these behaviours may be because:

- They are trying to communicate; behaviours are functional and have developed helpfully or unhelpfully to meet a need.
- They do not understand the social rules.
- They are feeling anxious, scared or frustrated as a result of difficulties understanding the situation, or experiencing sensory overload.
- They enjoy a particular activity but do not understand its consequences. For example, a person may enjoy the sound of breaking glass but does not realise it is not safe or acceptable to break glass in public.

However you may not know why your child is behaving in a particular way. People may assume that a child is naughty or the parents are not controlling the child, simply because they appear the same as everyone else, and forget that there may be other causes for this behaviour. A psychologist, doctor or a specialist teacher may be able to help you manage these.

### Helpful approaches:

- Work with your child to develop clearer means of communication (e.g. use visual support).
- Channel the behaviour into socially acceptable forms. For example, if the person likes clapping their hands loudly, encourage them to play an instrument like drums.
- Anxiety management and behaviour management go hand in hand. If the person is anxious or upset, find a quiet place where they can calm down.
- If you know there is an object that will help the child to calm down, such as a favourite toy, keep this to hand.
- Provide alternatives where possible. For example, if the person does not like loud noises, give them earphones to wear when they are out and about.
- Seek a doctor's advice if you think that there may be a medical problem

- Slowly expose them to some of the situations that they are finding difficult.

Provide time for them to do their favourite activity in a safe and containing environment

Working out the function of a type of behaviour will help to understand what your child is trying to communicate. You need to enter your child's world and try to see the world as they do. The function of a type of behaviour might include:

- Confusion or fear produced by unfamiliar events and situations.
- Interference with daily routine or repetitive activities.
- Inability to understand explanations or instructions.
- Lack of knowledge about how to behave appropriately.
- Inability to communicate needs and feelings.
- Over-sensitivities.
- Specific fears of situations or objects.
- Pressure to do tasks that are too difficult.

Functional analysis is a way of analysing and understanding your child's behaviour, so that you have a clear idea about what is triggering the behaviour and keeping it going/ it can help to think about the function of behaviour as an iceberg. We are often able to see the behaviour, but need to think a bit deeper to work out what it means, rather like the iceberg, most of which is out of sight.

Once we have worked out why a type of behaviour is happening, we can work out if there are patterns. The best and most accurate way of doing this is to keep records using a chart, which is discussed in the next section. Keeping accurate records and spending time assessing the pattern of behaviour makes it more likely that any changes you try to bring about will work.

### **Starting to make changes**

Strategies for responding to and coping with different behaviours are provided, based on what we have found works. However the best way to minimise the chance of difficult behaviour occurring is to anticipate it happening and take steps to avoid it if this is possible. Looking for any patterns in behaviour can often be useful to spot triggers and things that seem to help. When thinking about dealing with a behavioural problem, it is worth focussing on one or two areas to change. Usually this is the type of behaviour that is most concerning or having the greatest impact on daily life. Some parents find it helps to select something that may not be too difficult to start with so that you can feel more confident in tackling

other problem areas. Narrowing the behaviours down can help to understand why a particular type of behaviour is occurring so that you can work out ways of changing or managing it. Trying to tackle several areas at once can make it difficult to achieve any positive changes in any area, which can affect your confidence greatly.

### **Consider the setting**

Think about what else is going on. Children with ASD often find it harder to listen well when there are lots of other things going on. Think how hard you would find it if, say a pneumatic drill were running outside your door all day. This is one of the reasons why **giving information visuals** can help. Keeping the environment around the child calm with low amounts of stimulation can avoid anxiety. Paying attention is often also a problem area for children with an autism spectrum disorder as social interaction may not be enjoyable for them.

### **Use minimal language**

When a child is distressed, try to reduce the amount of language you use and the rate of your speech. It is likely that they will find it harder to take-in and process verbal information at these times. Think about using concrete visual cues, objects, gestures or signs to back up what you say.

Think about what you want the child to do and communicate this in clear, short phrases. Try not to give choices until they are calm. Think of choices and questions as demands that create pressure for them as they need to think things through and make a decision.

### **Moving on from difficult behaviour**

Try to give them a 'way out' of the behaviour. A countdown can be helpful in encouraging someone to calm e.g. 'from 10 to 1, when you reach 1 you will feel calmer and then we will do...'. Pick something that is safe with few demands. Repetitive type activities can be calming and often do not require any conversation or social interaction which might be stressful. Distract them on to another task and praise them when they begin to participate.

### **Managing physical arousal**

When there has been an outburst, children will have a high level of physical arousal. It is well established that it takes anything up to 90 minutes to 'cool off' after episodes like these. The best tactic is to talk in a calm, reassuring manner, without trying to get them to explain why they acted in a certain way. They probably cannot put it into words.

A first step to helping children think about what and how they feel is to build in opportunities during the day for them to experience a range of physical sensations, such as

warmth, cold, sticky, smooth etc. Later on you might ask them to notice how their tummy feels when on a swing, or something familiar and label it. You might then be able to use those words to help children talk about how they feel when they are angry or upset. This helps them to develop words and an alternative way of telling you how they feel, rather than using their behaviour.

### **Reflecting on what has happened**

Following a difficult situation, try to be a detective and identify the reasons why your child may have become anxious or angry. You can use STAR behaviour diaries (*see next page*) to look at some of the reasons why they become upset and to understand their behaviour in the context of ASD.

If you are able to do this at the time, your response may vary depending on what you think the underlying reason is e.g. if they are anxious about a new place, you may try to give them concrete information such as photos, maps or drawings to help them visualise what to expect.

### **Increasing desirable behaviours**

There are several ways to encourage the development of new skills by the way we respond to the child with ASD. The following are a number of approaches that have been proven to be helpful:

- **Positive reinforcement** – This refers to a strengthening of a particular behaviour by following it with something desirable such as favourite activities, treats or objects (tangibles e.g. favourite toy), praise or social reinforcement or sensory-based reinforcement such as a tickle. Food may be used as a positive reinforcement, however this should only be used very rarely and not relied on to avoid fixation on food and possible weight issues. For any of these to lead to an increase in desired behaviour, it is essential that the child and their particular likes, interests and level of ability are taken into account. If they are not motivated or do not enjoy what has been chosen to reinforce the preferred behaviour, it will have little impact. The thing chosen to reinforce preferred behaviour also needs to be ‘novel’ that is, an activity or object that is not readily available. It also needs to be changed as often as necessary to make sure your child does not get bored or tired of it. You will need to plan ahead and have a variety of items to use as reinforcement, but remember to take your own resources into account. It is far better to offer something small and manageable and to be able to continue to offer this each time. Reinforcement works best when it is provided immediately after the desired behaviour has occurred and when it is given every time the child behaves in the desired way. It can gradually be

faded out over time, but not too quickly. Then the item used for reinforcement should be given alongside verbal praise that clearly describes the behaviour you are praising, such as “That’s nice sharing, Jack!”

- Rewards charts are an excellent way of demonstrating how well someone is doing, and reminding them what they’re working towards, a reward. For example:

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
AM	🏆	🏆		🏆	🏆		
PM			🏆	🏆			

🏆x10 = 30 minutes extra listening  to your music

- **Token systems** – For some children, using token systems is a very useful way of increasing the number of times preferred behaviour happens. Token systems are a type of positive reinforcement that involve your child collecting points, ticks, stars, stickers, small objects or symbols that might not be enough to reinforce behaviour on their own, but which can eventually be swapped for a larger item to reinforce preferred behaviour. So, for instance, three stars might mean that your child gets to play their favourite game for five minutes. Token systems usually work best for ‘higher functioning’ children who are able to wait for their reward and understand visual symbols. Verbal praise and encouragement should still be provided as your child achieves each token.
- **Prompting** – This is a technique that can help your child learn new skills by providing the level of assistance needed to finish a task or activity. Prompting is paired with reinforcement to strengthen each stage of learning a particular skill. The ultimate goal is for your child to complete a task on their own without prompts.
- **Shaping** – This refers to the process by which you gradually reinforce preferred behaviour that have been broken down into steps and start to put them together until you are able to create the desired response. An example of shaping may be a child eating independently. Initially, reinforcement might be needed for the child to reach for the spoon, then once this stage is mastered, reinforcement would then be held back until the child is spooning the food into his or her mouth. An alternative example might be the process of greeting someone and starting to have a conversation.

## **Using Behaviour to Communicate (STAR)**

Many of the symptoms associated with ASD lead to behavioural difficulties. It is important to have a clear idea about how your child is affected by each of these symptoms when considering each area of behaviour.

A STAR analysis is a helpful way of assessing what happens before, during and after an episode of unacceptable behaviour. The STAR framework was set up by the National Autistic Society to reduce the behavioural problems that so many parents of children with ASD face. The STAR approach focuses on those with ASD rather than children with general behavioural difficulties, although it can still be helpful for this group. The basis of the STAR approach is that all episodes of problem behaviour need to be seen as actions with a purpose to receive a specific response.

**STAR** stands for:  
**Setting Trigger Action Response**

### **Setting**

This is something critical but often underestimated. These are the contexts in which the unacceptable behaviour takes place. Considering, and if needed, adjusting the setting where the behaviour takes place is important, and can also work as a way of preventing particular behavioural difficulties.

### **Trigger**

These are the signals or stimuli that 'set off' a specific action, occurring immediately before the episode of unacceptable behaviour. Reasons that trigger sets of the behaviour may include:

- Expressing a need - for example, smelling dinner cooking might signal food to a hungry child.
- Expressing something the child does not want – for example; seeing a spider triggers a wish to avoid it, or wearing a particular outfit could trigger the need to avoid something the child finds too difficult, such as a family gathering or somewhere new.
- Emotional overload – something relatively insignificant triggers the feeling that this is 'the last straw' and can lead to a 'meltdown'.

### **Action**

Action is the behaviour that actually happens and is a very important part of the chart.

### **Response**

These are the events that follow an action, and are often the part of the process that can be controlled. Response to an action can indicate the appropriateness of an action and influence the likelihood that the child will do the same thing at some point in the future. A basic STAR recording chart is included on the next page, which you can photocopy and use as your own record. We have also included a list of questions for you to use to help

understand the function of a particular type of behaviour.

Great Ormond Street Hospital NHS Trust

**STAR Recording Chart**

Date and Time	Setting	Trigger	Action	Response
<b>Example</b>				
21/06/2016 7.30pm	On the computer	Asked to go to speak to granny on the phone	Shouting Yelling Refusing to come to the phone	Carried on with computer

Great Ormond Street Hospital NHS Trust

## Questions to establish the function of a type of behaviour

1. What happens during the behavioural incident? What does the behaviour 'look like'?
2. How often does the behaviour occur? Several times each day, daily, weekly?
3. How long does the behaviour last?
4. How severe is the behaviour?
5. What time of day is the behaviour most likely to occur?
6. Where, or in what environments, is the behaviour most likely to occur?
7. With whom are the behaviours more likely to occur?
8. What activity is most likely to produce the behaviour?
9. Are there any other events or situations that can trigger the behaviour (such as particular demands, delays or transitions between activities)?
10. What does your child gain by engaging in the behaviour? What is the consequence or outcome for your child?
11. What is avoided by engaging in the behaviour?
12. Is your child experiencing any medical issues that may be affecting their behaviour, such as toothache, earache, infections, colds, flu, allergies, rashes or seizures?
13. Is your child experiencing difficulty with sleeping or eating?
14. How predictable is your child's daily routine? To what extent does he or she know what is happening throughout the day and when?
15. Have there been any recent changes to routine?
16. How does your child communicate the following:
  - Yes, no or stop
  - Indicate physical pain
  - Request help
  - Request attention
  - Request preferred food, objects or activities
  - Request a break
17. What objects, activities or events does your child enjoy?
18. What skills or behaviours does your child have that may be alternative ways of achieving the same function as the behaviour of concern?

## Behaviour Strategies

As well as introducing positive behavioural strategies, it is sometimes necessary to have a range of strategies available to respond to a behavioural incident or outburst. None of the following should ever be implemented on its own. If you need to use any of the following strategies, then you should also start to use the range of positive strategies on a regular basis at the same time.

We all use experience to work out how we are going to behave, if we find that we do something that brings about a good outcome, we will do it again, and we are more likely to behave that way in the future. This is human nature and it happens all the time. Similarly, if we find out that something we do does not bring about a favourable outcome, we are less likely to do it again. This principle gives us helpful ways of managing undesirable behaviour, one easy way of remembering this is:

### IGNORE → DISTRACT → REDIRECT

These are best applied in the following ways:

- **Ignore.** Extinction or planned ignoring refers to the strategy where **undesirable behaviour is ignored rather than ignoring the child doing it.** This is because responses provided by others, such as attention or providing an object or activity, may be maintaining the unwanted type of behaviour, even without you realising it. Planned ignoring involves providing no response behaviour, including verbal comments, body language, facial expression or eye contact. But remember; not to ignore your child.

This need to be coupled with other strategies such as positive reinforcement to give your child opportunities to learn alternative ways of achieving what they want. In other words, for this to work, you need to be ready to respond to and reinforce your child's appropriate behaviour as well as not responding to inappropriate behaviour.

When thinking about planned ignoring, it is important to be consistent. When you first try the strategy, your child's inappropriate behaviour will increase before it decreases. **You may well think that everything is getting worse, but it is important not to give up.** This increase in undesirable behaviour is called an 'extinction burst' and can be seen as your child saying "This has worked for me before. Maybe I need to try harder to get the usual response." Consistency is very important at this point, otherwise your child will learn that increasing the wrong behaviour will bring about the desired response and he or she may escalate to the same point the next time as well.

Planned ignoring can be used with a number of behavioural difficulties but it should never be used when there is risk of harm to the individual or others.

- **Redirection.** Redirecting your child's attention to a preferred topic of conversation or activity can be an extremely effective way of preventing a situation getting worse or diffusing a difficult situation. It can be helpful to have a range of calming and distracting strategies lined up to use if your child starts to get agitated. You can start to predict these and use redirection. Relaxation strategies and anger management techniques can be used to redirect and refocus your child when distressed. It can be helpful for your child and others to be aware of other triggers, which, although they

vary from person to person, could include swearing, pacing, hand biting and talk to themselves, and to be ready to redirect your child's attention to a calming activity as soon as they are noticed.

Alternative approaches to managing behaviour include:

- **Time out** – This approach involves time out from positive reinforcement that may or may not include physically removing your child from the area. When carried out appropriately, time out can provide your child with the opportunity to calm down by limiting external stimulation. They need to be informed why time out is being used, and this information can be backed up with visual cues, such as picture symbols or social stories if necessary. You can draw up what is sometimes called a 'behavioural contract' to explain clearly what is going to happen and why.

If a time out area is used, it is very important that this be an identified uninteresting but safe space where there is no risk of your child harming him or herself and he/she can be observed unseen to protect them. Time out should never be longer than a few minutes and any reductions in agitation should be encouraged. Following time out, your child should be redirected to a calming neutral activity and reinforcement provided for the first occurrence of appropriate behaviour.

- **Punishment** – This involves the use of an unpleasant response to reduce an undesirable behaviour and can include smacking, shouting or physical restraint. Lots of research has shown that this strategy **does not work**. It is not an effective way of promoting learning. It is not effective because it does not address the root cause of the behaviour. It may reduce it in the short term, but often it will quickly be replaced by another undesirable behaviour because the cause has not been addressed. The only thing this teaches is that it is alright to be aggressive and can also lead to aggression in response to the person administering it. It also leads to a child feeling bad about themselves and angry inside, which can then worsen their behaviour.  
**Punishment is not a viable way of changing behaviour.**

**Useful tips to remember:**

- **Consistency** - One of the most important things to remember when carrying out any behavioural strategy or intervention is the need for a consistent approach. Without the support and commitment of those surrounding the child, for instance, family, school and friends, lasting changes will be harder to make. If a strategy is proving too difficult to implement consistently, then it is worth going back to review the strategy and make any necessary adjustments.
- **Generalisation** – Generalising new skills that have been learnt in a particular situation can be an area that presents special challenges to children with ASD. It is

therefore essential that special care be taken to assist your child to apply new skills and coping strategies to a variety of situations.

- **Maintenance** – From time to time, it may be necessary to go back and revisit a particular strategy or approach if your child is experiencing difficulties. This will make sure that new skills are kept up over time. This may particularly be the case around times of illness, stress or change.
- **Fading out prompts and reinforcement** – Our ultimate goal for any behavioural intervention should always be to increase your child's independence, quality of life and self- efficacy .To this end, it is important that any prompts or reinforcements, with the exception of verbal praise, be very gradually reduced to as low a level as possible while continuing the desired change in behaviour.

### **Take a break**

Dealing with challenging behaviour can be highly demanding for parents and carers. All parents need a break from caring for their children from time to time – this is normal and healthy. Making sure that you have the energy to respond appropriately and to support an individual with challenging behaviours is one of the most important aspects of any intervention. Thinking about your own needs means that you will be better equipped to provide the best support possible to your child or family member with ASD.

### **Managing Behaviour – golden rules and tips for success**

#### **Structure**

- Too much choice causes anxiety.
- Environment must be structured, organised and predictable – this includes them knowing:
  - Where am I to be?
  - What am I doing?
  - How much do I have to do?
  - When will I know if I am finished?
  - What will I do next?
- Offer clear breaks in between activities to unwind and relax.

#### **Clear rules and consistency**

- Have they understood?
- Be consistent – make sure you follow through with what you say.
- No surprises – always let them know ahead if there have been changes to plans.
- Use language that is clear and concrete.
- Give plenty of warning.

### **Do not rely on verbal communication**

- Put it in writing.
- Use plans and timetables, photos and pictures.

### **Recognise stress**

- Do not crowd or overload with information.
- Allow personal space.

### **Teaching skills**

- Make sure you have their attention.
- Allow extra time for processing information.
- Break the skills down into achievable steps to ensure success.
- Use prompts to teach alternative behaviours.
- Use their interest to teach a skill.
- Reward success regularly and explicitly.
- Short and brief verbal instructions.
- Lots of praise.

### **Behaviour**

- Find ways of coping with aspects of the environment that cause distress, such as noise level.
- Try to prevent a behaviour from taking place – if it cannot be prevented it should not be rewarded as it will get stronger.
- Consistently observe the behaviour and your responses, and then think about change.
- Monitor changes through recording systematically – only adjust method after trying it for a sustained period.
- Behaviour that is rewarded is more likely to be repeated – reward any appropriate behaviour immediately.
- Try to reward a different and more appropriate activity to replace the inappropriate behaviour.
- Inconsistency tends to make the behaviour worse.
- Your child is complex and it will take time to understand him or her – you will need to be patient and persevere and remember that results take time.

### **General**

- Regular physical exercise tends to diminish aggressive behaviour and repetitive activities.

- Changes need to be planned and introduced slowly and gradually – let your child know in advance.
- Adapt methods of communication so that they can understand what is wanted.
- Be aware of sensory needs and have sensory type play as a part of daily routine (see sensory section)

Avoid putting pressure on them to perform above their ability.

# 5 Skills, Learning, and Development

## Transition and change

Many people with ASD dislike change and rely on routine. It is important for people with ASD to know when an activity or event starts and finishes, particularly when it finishes. Without this knowledge, it may be difficult and confusing for people to move on to another activity. Visual supports can be a good way of introducing changes, helping during periods of transition and perhaps helping people to become more open to the idea of change.

## Visual Supports

A visual support refers to using a picture or other visual item to communicate with a child who has difficulty understanding or using language. They are adaptable, portable and can be used in most situations. Visual supports can be photographs, drawings, objects, written words, or lists. Research has shown that visual supports work well as a way to communicate. We see and use visual prompts every day, for example road signs, maps and shopping lists. They help us to function, to understand the world around us, and provide us with valuable information.

Visual supports are used with children with ASD for two main purposes. They help parents communicate better with their child, and they help their child communicate better with others. Many people with ASD are thought to be visual learners, so presenting information in a visual way can help to encourage and support their communication, language, development and ability to process information. It can also promote independence, build confidence and raise self-esteem.

All people with ASD can potentially benefit from using visual support, regardless of their age or ability. It's an opportunity to communicate without complications.

Whichever visual support you decide to use, make sure it is appropriate to the person with ASD and in line with their needs and current stage of development. Visual supports are very personal and what works for one person may not work for another. Once you choose a type of visual representation (for example, line drawings), use it consistently so that the person with ASD becomes used to it.

Children with ASD may not understand social cues as they interact with others in daily activities. They may not grasp social expectation, for example how to start a conversation, how to respond when others make social approaches, or how to changes their behaviour based on unspoken social rules. Visual supports can help teach social skills and help children with ASD use them on their own in social situations. For example, visual (or written) supports can help better explain how a person is feeling at different times of the day or in different situations. Illustrating the "rules" of social interaction can help a person with ASD to understand the concept.

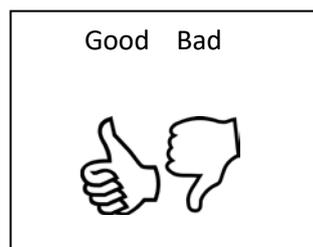
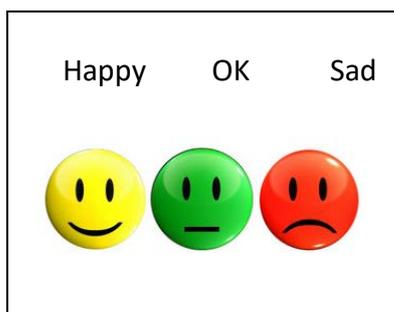
Example of a basic written scale:

On a scale of 1 to 10, 1= very happy / relaxed; 10 = very unhappy/ anxious	
Registration:	4
English:	6
Lunch	2
Science:	5
Art:	8
Home:	3

Children with ASD often find it difficult to understand and follow spoken instructions. They may not be able to express well what they want or need. Visuals can help parents communicate what they expect. This decreases frustration and may help decrease problem behaviours that result from difficulty communicating. Visuals can promote appropriate, positive ways to communicate.

Some children with ASD are anxious or act out when their routines change or they are in unfamiliar situations. Visuals can help them understand what to expect and will happen next and also reduce anxiety. Visuals can help them pay attention to important details and help them cope with change.

### Basic visual symbols:



In addition, visual supports can be used to help illustrate a conversation or review an incident. See the “Comic Strip Conversations” (*number 4 on “Types of Visual Supports”*) section.

### Types of visual supports

Introduce visual supports gradually; it is best to start off with one symbol and then build up

a collection. You may find that it's best to use more than one type of visual support (see below) which again, should be introduced gradually.

- Real objects
- Tactile symbols / objects of reference, for example swimming trunks, packaging, food labels (though some children with ASD can have difficulties in generalising e.g. they may not realise that a Hula Hoop packet symbolises **all** crisps)
- Photographs
- Miniatures of real objects
- Coloured pictures
- Line drawings
- Written words
- Symbol Systems (see resources at the back of this booklet)

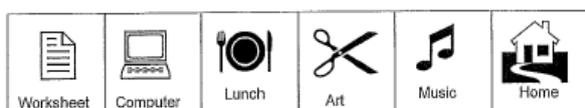
Areas where the use of visual support may help people with ASD are:

- Timetables/ schedules
- Helping with sequencing
- Transition and change
- Starting and finishing activities
- Introduction of new activities or situations – general knowledge, curriculum subjects, news
- Instructions / reminders
- Choice
- Understanding emotions and expressions
- Behaviour strategies
- Social skills

Below are some examples of using visual supports.

### **1. Timetables / Schedules – daily weekly, monthly**

Timetables and schedules are a good way of helping to create structure and routine, reducing uncertainty and helping to make daily life more predictable for people with ASD. When producing a timetable or schedule, it can be a good idea to place an activity that someone enjoys doing after a work-based activity



## First-Then Boards

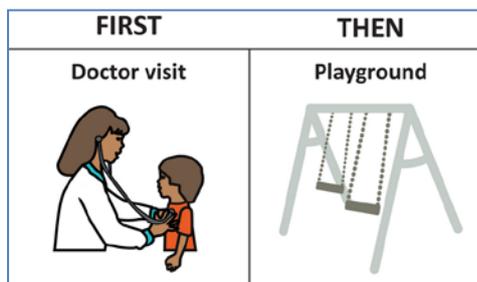
### *What is it?*

A First-Then Board is a visual display of something your child prefers that will happen after completing a task that is less preferred.

### *When is it helpful?*

A First-Then Board is helpful in teaching children with ASD to follow directions and learn new skills. A First-Then Board motivates them to do activities that they do not like and clarifies when they can do what they like. A First-Then Board lays the language foundation needed to complete multi-step directions and activities and to use more complex visual systems.

Sequencing is important to people with ASD. It may help to relieve anxiety and reassure them about what is going to happen next.



### *How do I teach it and use it?*

Decide what task you want your child to complete first (what goes in the “first” box) and the preferred item or activity (what goes in the “then” box) that your child can have immediately after the “first” task is done. This preferred item/activity should be motivating enough to increase the likelihood that your child will follow your direction.

Put the visuals on the board (e.g. photos, drawings, written words) that represent the activity you identified. Present the board to the child with brief, verbal instruction. Try to use the least amount of words possible. For example, before beginning the “first” task, say, “first put on shoes, then swing” when your child is almost done.

When the “first” task is completed, refer back to the board. For example, say “all done putting on shoes, now swing!” and immediately provide the preferred, reinforcing item or activity.

In order to teach children with ASD the value of the First- Then Board, you must give them the reinforcing activity or item after they complete the “first” task. Otherwise, your child may not trust the board the next time you use it.

## Visual Schedule

### *What is it?*

A visual schedule is a visual representation of what is going to happen throughout the day or within a task or activity.

### *When is it helpful?*

A visual schedule is helpful for breaking down a task that has multiple steps to ensure the teaching and compliance of those steps. It is also helpful in decreasing anxiety and rigidity surrounding transitions by communicating when certain activities will occur throughout the day or part of the day.

### *How do I teach it and use it?*

After your child understands the concept of sequencing activities through the use of a First-Then Board, you can develop a more complex schedule for a series of activities during the day.

Decide the activities that you will picture in the schedule. Choose activities that really will happen in that particular order. Try to mix in preferred activities with non-preferred ones.

Put the visuals that show the activities that you have identified on the schedule (e.g. photos, drawings, written words). The schedule can be portable, for example, on a binder or clipboard, or it can be fixed to a permanent place, like a refrigerator or wall. Your child should be able to see the schedule before beginning the first activity on the schedule. It should continue to be visible to your child during the rest of the activities.

When it is time for an activity on the schedule to occur, cue your child with brief, verbal instruction. For example, say "Check the schedule". This helps your child pay attention as the next activity begins. At first, you may need to physically guide your child to check the schedule (e.g., gently guide by shoulders and prompt your child to point the next activity on the schedule). You can gradually decrease physical prompts as your child begins to use the schedule more independently.

When a task is completed, cue your child to check the schedule again, using the procedure described above, and transition to the next activity.

Provide praise and/or other positive reinforcement to your child for following the schedule and for transitioning to and completing activities on the schedule. It may be helpful to use a timer that your child can hear to make transition times clear to your child.

Mix variability into the schedule by introducing a symbol that represents an unknown activity (e.g., "oops" or "surprise activity"). Begin to teach this concept by pairing this with a positive activity or surprise. Gradually use this for unexpected changes in the schedule.

### *What if challenging behaviours occur?*

If challenging behaviours occur, continue by physically prompting your child to complete the

task that is occurring. Keep your focus on the task rather than on the challenging behaviour. Then transition to the next activity as communicated by the schedule and still provide the reinforcing item or activities indicated on the schedule, since the focus of the schedule is on completing the tasks, and not on addressing challenging behaviours.

If you think challenging behaviours may happen, begin by introducing the visual schedule during tasks that your child usually completes willingly and successfully. If challenging behaviours become more difficult to control, it may be appropriate to consider behavioural consultation with a professional to address these behaviours directly.

## **2. Picture Exchange Communication System (PECS)**

This approach is widely used, often alongside behaviour-based interventions. PECS encourages a person to communicate their needs, wants and desires by exchanging a picture card for a desired item or activity. In time, the type and number of picture cards used by the person increases.

## **3. Signalong**

Signalong is a sign-supported communication, based on British Sign Language, and designed to help children and adults with communication difficulties, mostly associated with learning disabilities, autism and other special needs.

## **4. Comic strip conversations**

Developed by Carol Gray, comic strip conversations are a way for people to exchange information and express themselves during a conversation. Colour, symbols, drawings and written words are used, alongside speech, to help people understand the ideas and emotions being expressed. Comic strip conversations can also help people to understand past incidents or conversations.

## **Social Skills development**

Difficulties with social interaction can also be a major cause of difficulty and distress for people with ASD. Not knowing how to behave or what is expected can lead to anxiety and behavioural difficulties. Possible strategies that can be useful in starting to develop social understanding and skills include:

### **Social Skills Training**

This approach involves teaching a child the skills necessary to cope with social situations directly. It may include instruction around a variety of areas depending on the child's needs. Some of these could be eye contact, appropriate topics for conversation and how to start and finish a conversation. There are a number of good books and resources available to help people with ASD to develop social skills (for details see the reading list in the *Resources* section). The important thing is that social skills are used in a variety of contexts so that the

person is able to start transferring their skills to various environments, that than in just one setting where they may have learnt the skill. All the evidence indicates that this is most likely to provide long-lasting change.

## **Social stories**

Introduced by Carol Gray in the early 1990s, social stories are short (written) descriptions of a particular situation, event or activity, to help those with an autistic spectrum disorder to develop their understanding of relevant social cues and learn appropriate responses. They include specific information about what to expect in that situation and why so as to relieve some of the anxiety of social situations. They can provide a person with an ASD with structure and guidelines for expected behaviour, and an idea of how others might behave in a particular situation. They can also introduce a new social skill. Social stories can be strengthened by using visual supports, such as symbols or illustrations.

Social expectations or the proper way to respond when interacting with others are typically learned by example. Social stories are meant to help children and young people understand social situations, expectations, social cues, new activities, and/or social rules. They are brief descriptive stories that provide accurate information regarding a social situation. Parents, teachers, and caregivers can use these simple stories as a tool to prepare the child for a new situation, to address problem behaviour, or even to teach new skills in conjunction with reinforcing responses.

## **How to write a social story**

**Picture the Goal:** Consider the social story's purpose. For example, the goal may be to teach a child to cover their mouth when coughing.

Now think about what the child needs to understand to achieve this goal. For example they need to understand why covering their mouth when coughing is important. E.g. it stops germs from being spread which may make other people sick.

**Gather information:** The next stage is to gather information about the person including their age, interests, attention span, level of ability and understanding.

As well as this, collect information about the situation you want to describe in your social story. For example where does the situation occur, who is it with, how does it begin and end, how long does it last, what actually happens in the situation and why?

**Tailor the text:** A social story is made up of several different types of sentences that are presented in a particular combination.

- 1 Descriptive sentences: objectively define anticipated events where a situation occurs, who is involved, what they are doing, and why (e.g. when people are inside, they walk

- 2 Perspective sentences: describe the internal status of the person or persons involved, their thoughts, feelings or moods (e.g. Running inside could hurt me or other people)
- 3 Directive sentences: are individualised statements of desired responses stated in a positive manner. They may begin “I can try...” or “I will work on...” Try to avoid sentences with “do not” or definitive statements (e.g. I will try to walk inside).

A social story should have 3 to 5 descriptive and perspective sentences for each directive sentence. Avoid using too many directive sentences. They will be lost without adequate contextualisation.

Write in first person and on the child’s developmental skill level. Also remember to use pictures that fit within the child’s developmental skill level to supplement text.

Additional points to consider:

- Social stories need to have an introduction, body and conclusion and should use positive language (i.e. where possible, describe what should happen, rather than what should not).
- Stories need to be as accurate as possible and should include words like “sometimes” and “usually” for situations where a particular outcome is not guaranteed.
- Stories should appeal to the interests of the person for whom they are written. Avoid using words that may cause the person anxiety or distress.
- The content and presentation of social stories should be appropriate to the person’s age and levels of understanding. *Example of a social story:*

	<b>People sleep</b>		<b>Jane will stay in bed until Jane is asleep</b>
	<b>Because people need to rest</b>		<b>When the curtains are closed it is night Jane will stay in bed</b>
	<b>Jane needs to rest too</b>		<b>When the curtains are open it is time to get up</b>

Source:  
Haringey NHS  
and Haringey  
Council

# 6

## External Supports

### General Support

#### Getting it right for every child (GIRFEC)

GIRFEC is the national approach in Scotland to improving outcomes and supporting the wellbeing of our children and young people. The aim of the approach is to support families by making sure children and young people can receive the right help, at the right time, from the right people. The goal is to help them to grow up feeling loved, safe and respected so that they can realise their full potential.

The GIRFEC approach is child-focused, ensuring that children and families are at the heart of the decision-making process. Children and young people generally get the help and support they need from their family and community, but sometimes, perhaps unexpectedly, they may need a bit of extra help. Getting it right for every child helps families to access this additional support easily and without stigma. The approach supports families and practitioners to work together to identify and address needs early when they emerge. For more information, please check the Scottish Government GIRFEC webpage, available here: <https://www.gov.scot/policies/girfec/>

#### Wellbeing

SHANARRI is an acronym based on the 8 wellbeing indicators, which support children to grow up feeling lived, safe and respected.

These are: Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible and Included.

Thinking about these eight different indicators of wellbeing help make it easier for children and families and the people working with them to discuss how a child or young person is getting on at a point in time and if there are any needs or opportunities to promote wellbeing. Wellbeing must be considered within the wider context of the child's life and what is or may affect their wellbeing.

#### Child Plan

Planning for children is part of everyday practice for practitioners, when needs emerge then this planning will step up to provide the framework for coordinated support. As part of local GIRFEC policy, Child Planning Meetings (CPMs) may be available for children to help develop and review a Child's Plan. These meetings provide a forum where practitioners and families can meet to discuss needs and plan coordinated support.

A Child's Plan may include information about the child's wellbeing needs and what an improvement in wellbeing would look like, highlight services that can provide support, agree details of actions to be taken, and when the plan should be reviewed. It will also record details of the Lead Professional, who acts as coordinator for the plan.

The child and parents will generally know what information is being shared, with whom and for what purpose, and their views will be taken into account. This may not happen in exceptional cases, such as where there is a concern for the safety of a child or someone else.

### Help With Travel

People with Autism can sometimes find travel or using public transport stressful or difficult, for example due to sensory issues or unexpected changes to routine, such as a bus being late.

Travel providers can provide free support to disabled people, including people with Autism. This help can be things like:

- The bus driver telling you which stop to get off at
- Having someone meet you and accompany you to or from your train
- Someone accompanying you to your ferry and keeping you updated on the journey
- Extra support to get through airport security

In some cases, you'll need to book this in advance. To find out more, you should contact the provider you're travelling with (for example, ScotRail, FirstBus or Lothian Buses). You can also visit the following website:

<https://www.mygov.scot/transport-help/>

Your child may be eligible for a Blue Badge if, because of their autism, they lack awareness of danger from traffic and therefore might risk the safety of themselves or others. Having a Blue Badge might also mean that you can get free transport on other services. Contact your local council for the full eligibility criteria and details of how to apply.

## **Social Support**

Support from partners, family, friends or neighbours can be extremely important. However, help can sometimes also be requested from other services.

Social care involves different forms of personal care and other practical assistance for children, young people and adults who need extra support. Local Authorities have a legal duty to provide certain services to disabled people, which may include help with things like personal care. You should contact your local authority if you think that you or your child

need support in this way. Any support you receive will be based on an assessment of your family's needs and should take account of your wishes and preferences.

Families of disabled children, including parents, siblings and the wider family, might need access to practical and emotional support in their own right. If you care for a child or young person with autism, you may be entitled to support as an unpaid carer. Unpaid carers are eligible for support in their own right under the Carers (Scotland) Act 2016. This includes:

- the right for every carer to an adult carer support plan or a young carer statement which focuses on what is important to them;
- the right to statutory support to meet their eligible needs, as detailed in their plan or statement; and
- the right to be involved in assessing the needs of the cared-for person and in decisions about discharging the cared-for person from hospital.

## **Financial Support**

Sometimes families can receive extra financial support or funding to help support their child with ASD. Families can be eligible for a number of national benefits and tax credits, particularly if they are on low or single incomes.

In 2018, a Bill was passed through the Scottish Parliament. This Bill sets out a framework for the new Scottish Social Security System. The Bill also helps to transfer the eleven existing social security benefits, such as Disability Living Allowance and Personal Independence Payments, from the UK Government to the Scottish Government.

To find out more about the changes to Scotland's social security system visit:

<https://www.socialsecurity.gov.scot/>

To find out more about existing benefits and grants visit: <https://www.mygov.scot/benefits/>

Benefits also exist at local level to help with Council Tax, housing and health costs. Local Councils have Benefits Offices where individuals can visit or call to discuss their specific circumstances. You can find details of these on your local council's website or visit the links in the Resources section at the back.

The Citizen's Advice Bureau can also help you to find out what financial support you're entitled to. Visit: <https://www.citizensadvice.org.uk/scotland/>

When you are applying for benefits, it is helpful to make a copy of any completed application forms before sending them. This allows you to refer back to exactly what was written if there is a query.

As well as benefits, there are many other types of financial support you may be entitled to:

- Your child may be entitled to a National Entitlement card, which is a national scheme that helps them to access various public services and facilities. It includes things like concessionary travel, access to leisure and library services and various discounts.
- You can apply for a CEA card (forms can be obtained from the cinema) which allows a companion to accompany someone with ASD to the cinema for free and is accepted at 90% of cinemas nationwide (requires proof of certain benefits).
- Take A Break Scotland provides grants for short breaks for families and carers of disabled children and young people.
- The Family Fund also provides grants for low income families
- The Independent Living Fund (ILF) provides a Transition Fund to support young people aged 16-21 to enhance their independence.
- Contact can provide advice on benefits and financial support, including help with applying. You can call them on: **08088083555** or visit their website
- Turn2Us can provide advice and support about benefits

For links to the websites mentioned and for more information about where to find support, please see the Resources section at the back of this document.

# 7

## Parents top tips for everyday

1. Plan ahead. Use pictures in advance and explain what will happen to your child. Repeat! Once is not enough. A telephone call to an airport, restaurant or cinema to explain your circumstances might mean extra understanding and help for you.
2. Use phrases: "First-Then", and "Finish". Use their likes and dislikes to your advantage. "Nappy first, then Thomas DVD".
3. Give time warnings, so that the child is not suddenly expected to stop an activity. 2 minutes, 1 minutes, then counting up or down from 10, say "to finish" or just "Finish".
4. Use basic language with pictures and symbols to give a visual clue.
5. Use calendars, visual timetables or sequence a task, using pictures and symbols as well as words. Put symbol reminders on display e.g. in the bathroom you could put a wash hands symbol.
6. Use strategies and routines and tell friends, family and people who work with your child to use them too.
7. Sometimes you won't be able to, but sometimes you can work out what has triggered unwanted behaviour. Smell? Sound? Touch? Sensation? Change? This may mean you can prepare your child or make changes to the environment for the future.
8. If a tantrum happens use distraction! Bubbles, music, a favourite toy, blowing a top windmill. It might just give your breathing space to leave the situation.
9. Keep trying! A strategy might work well for a while and then need a change. Or it might not work at all now but may do in the future.
10. Give and take. Decide what is most important. Work on the things that really matter, that have the most impact on your family life. Leave the rest for now!
11. Use books and DVDs to explain. Point out things in the pictures – you don't have to read the story. Use them to describe what is happening e.g. "kicking ball" or "snowing". How someone is feeling e.g. "happy", "sad" and "hungry".
12. Remember that words can be confusing. Someone who reacts badly to injury might not like the thought of having their hair "cut"/ But they might not mind having it "trimmed" or "tidied up".
13. Think of a different way. Finger nails can be clipped when a child is asleep. Hair being "trimmed" when wet in the bath means it is less scratchy and can be rinsed off the skin with each snip!
14. Limit choices. It is good practice making choices, but between two things is enough at first. A whole shop is too much!
15. Join a support group. Some people like to just listen to others, while some people want to discuss their problems and successes with the strategies they use. But the

best part is the realisation that you are with people who simply understand, because they live with ASD too.

## 8 Resources

There is a wealth of information available on ASD, including books, videos and of course the internet. At times parents/carers can feel overwhelmed by it all and at a loss where to start, so the list will give a starting point for good-quality information.

### Research and Guidelines

#### **Sign Guideline 145**

*This guideline provides recommendations based on the assessment, diagnosis and interventions for children, young people, adults and older adults with ASD.*

<https://www.sign.ac.uk/assets/sign145.pdf>

#### **Autism Research Website**

*Research Autism is a UK charity dedicated to research into interventions in autism. They carry out independent research into new and existing health, education, social and other interventions.*

<http://researchautism.net>

#### **The Scottish Strategy for Autism**

Scottish Government strategy for improving access to services and diagnosis for people with ASD, as well as research and training for people around them.

Web: <http://www.autismstrategyscotland.org.uk/>

### Education

#### **Enquire**

[www.enquire.org.uk](http://www.enquire.org.uk)

Helpline **0345 123 2303**

#### **Parentzone**

[www.parentzonescotland.gov.uk](http://www.parentzonescotland.gov.uk)

#### **Reach Scotland**

*Website run by Enquire to support young people with any issues they may be facing in education:*

<https://reach.scot/>

### **My Rights, My Say:**

*Service run by Enquire to help support children and young people to understand their rights in education and to challenge things if they feel their rights aren't being upheld:*

<https://enquire.org.uk/myrightsmysay/>

## **Communication**

### **CALL Scotland**

*Scottish Organisation who provide support and information about technology and communication aids:*

<https://www.callscotland.org.uk>

ASD-specific information: <https://www.callscotland.org.uk/information/autism-spectrum-disorder/>

### **Inclusive Communication**

*Website which provides information and signposting about inclusive communication:*

<http://inclusivecommunication.scot/>

### **Symbol Systems:**

*Below is a list of free symbol systems which you may find useful:*

<https://mulberrysymbols.org/>

<http://www.tomorraccessibility.co.uk/bss.htm>

*This site has some free resources available:*

<https://www.widgit.com/resources/index.htm>

## **Financial Support:**

### **Information on all benefits for disabled people:**

Web: <https://www.disabilityrightsuk.org/>

### **Dial UK – Information and advice for people with disabilities:**

Tel: **0808 800 3333**

Email: [helpline@scope.org.uk](mailto:helpline@scope.org.uk)

Web: [www.scope.org.uk/support/disabled-people/local-advice/](http://www.scope.org.uk/support/disabled-people/local-advice/)

### **DLA applications and Carers Allowance:**

Contact your local Benefits Agency or Benefits Enquiry Line

Tel: **0800 121 4600**

### **Family Fund Trust:**

*UK-wide charity who provide grants and funds to families with a disabled or seriously ill child or young person:*

Web: [www.familyfund.org.uk](http://www.familyfund.org.uk)

Tel: **01904 550055**

**National Entitlement Card:**

<https://www.entitlementcard.org.uk/what-nec>

**ILF Transition Fund:**

<https://ilf.scot/transition-fund/>

**Take a Break Scotland:**

<http://takeabreakscotland.org.uk/>

**Contact:**

Web: <https://contact.org.uk/>

Tel: **08088083555**

**Turn2Us**

<https://www.turn2us.org.uk/>

**Local Council Benefits Offices:**

City of Edinburgh: [http://www.edinburgh.gov.uk/info/20127/benefits\\_and\\_grants](http://www.edinburgh.gov.uk/info/20127/benefits_and_grants)

East Lothian: [https://www.eastlothian.gov.uk/info/210559/council\\_tax\\_and\\_benefits](https://www.eastlothian.gov.uk/info/210559/council_tax_and_benefits)

Midlothian: [https://www.midlothian.gov.uk/info/612/benefits\\_and\\_grants](https://www.midlothian.gov.uk/info/612/benefits_and_grants)

West Lothian: <https://www.westlothian.gov.uk/council-tax-and-benefits>

## **Advocacy**

**Scottish Independent Advocacy Alliance (SIAA)**

*Organisation which provides information about advocacy, as well as a database to help you find advocacy support in your local area:*

Web: <https://www.siaa.org.uk/>

Tel: **0131 524 1975**

**Scottish Government Guidance on Advocating for Your Child**

Webpage providing you with information to help you understand advocacy and some tips to help you advocate for your child or young person:

<https://www.gov.scot/publications/childrens-advocacy-guidance/>

## Carers

### **CareInfo Scotland**

Organisation providing advice and support to carers:

Web: <https://careinfoscotland.scot/>

Tel: 0800 011 3200

### **Coalition for Carers Scotland**

<http://www.carersnet.org/>

### **Shared Care Scotland**

National organisation providing support and information to carers. They also manage the Short Breaks Fund, which works to support unpaid carers to take a break from their caring role:

<https://www.sharedcarescotland.org.uk/>

### **Carer's Scotland**

<https://www.carersuk.org/scotland>

### **Minority Ethnic Carers of People Project**

<https://www.mecopp.org.uk/>

### **Carer's Trust Scotland**

<https://carers.org/country/carers-trust-scotland>

### **Scottish Government Carer's Charter**

<https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2018/03/carers-charter/documents/00533199-pdf/00533199-pdf/govscot%3Adocument/00533199.pdf>

## Groups, Contacts and resources in Lothian

### **Aspire (a part of Transition Team run by Edinburgh Council):**

Transition team support for school leavers with high functioning autism.

Tel: **0131 663 4444**

### **Autism Initiatives**

*Helps individuals and families learn methods to cope with Autism through skill development and personal growth.*

Web: <http://www.autisminitiatives.org>

Tel: **0131 551 7260**

### **Into Work:**

*A specialised employment support service*

Web: <https://www.intowork.org.uk>

Email: [enquiries@intowork.org.uk](mailto:enquiries@intowork.org.uk)

Tel: **0131 475 2600**

### **Lothian Autistic Society**

*Charity designed to improve the social opportunities for individuals with ASD.*

Web: <http://lothianautistic.org/>

Tel: **0131 661 3834**

### **Number 6**

*The one-stop shop for adults with high functioning Autism and Asperger's syndrome. Based in Edinburgh*

Tel: **0131 220 1075**

### **Signpost**

*Good service to direct families to other services in the area. Based in West Lothian.*

Web: [www.signpost-online.co.uk](http://www.signpost-online.co.uk)

Tel: **01506 431 123**

Email: [enquiries@signpost-online.co.uk](mailto:enquiries@signpost-online.co.uk)

### **TaylorEd**

*Charity designed to teach daily living skills to children with autism. Based in Edinburgh. Offers Early Years Service and Target Specific Service to those with a referral and Social Supports open to the entire Autism community.*

Web: [www.tailoredfoundation.co.uk](http://www.tailoredfoundation.co.uk)

Tel: **0131 624 8970**

### **The Yard**

*Social groups for children and siblings aged 2-25 years. Based in Edinburgh.*

Web: [www.theyardscotland.org.uk](http://www.theyardscotland.org.uk)

Tel: **0131 476 4506**

## Scotland-based sources of support

### **Supporting Disabled Children, Young People and Their Families Guidance**

The Scottish Government has put together some guidance for families which contains national information about a variety of topics like financial support and where to find support in your community:

<https://www.gov.scot/publications/supporting-disabled-children-young-people-and-their-families/pages/introduction/>

### **Autism Initiatives Scotland**

11 Granton Square, Edinburgh EH5 1HX

Tel: **0131 551 7260**

### **National Autistic Society – Scotland**

Central Chambers, 109 Hope Street,  
Glasgow, G2 6LL

Tel: **0141 221 8090**

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

### **Number 6:**

Number 6, 24 Hill Street, Edinburgh, EH2 3JZ

Email: [number6@aiscotland.org.uk](mailto:number6@aiscotland.org.uk)

Tel: **0131 220 1075**

Web: [www.number6.org.uk](http://www.number6.org.uk)

### **Scottish Autism**

Hilton House, Alloa Business Park,  
Whins Road, Alloa, FK10 3SA.

Tel: **01259 720044**

Web: [www.scottishautism.org](http://www.scottishautism.org)

Email: [autism@scottishautism.org](mailto:autism@scottishautism.org)

### **Contact Scotland**

*Scottish branch of a UK-wide charity which provides all sorts of information and advice to families with disabled children and young people:*

<https://contact.org.uk/scotland>

## Local Groups

### **ALISS: A Local Information System for Scotland**

*A national database which allows you to search for up-to-date information about groups and services in your local area, including advocacy, youth clubs, activity groups and advice and support services:*

<https://www.aliss.org/>

Examples of local supports shared by parents which are up to date at the time of going to press:

**Edinburgh Leisure**

*Offers accessible swimming lessons and activities for children with additional needs.*

Web: <https://www.edinburghleisure.co.uk/activities/disability>

**Dobbie's "little seedlings"**

*Gardening classes.*

**EarlyBird**

*The National Autistic Society's training programme for parents of pre-school children with ASDs.*

Web: [www.nas.org.uk/earlybird](http://www.nas.org.uk/earlybird)

**Edinburgh International Airport**

*Can accommodate children with ASD and ease the check-in and security-check process.*

Web: [www.edinburghairport.com/prepare/special-assistance](http://www.edinburghairport.com/prepare/special-assistance)

**Future Horizons Inc.**

*A good website for resources about ASD for families and professionals.*

Web: [www.fhautism.com](http://www.fhautism.com)

**Hearts F. C.**

*Season tickets available for individuals with ASD either at a discounted rate or allowing a carer to attend for free.*

Tel: **0333 043 1874**

**National Museums Scotland**

*Events and resources for autistic children and young people.*

Web: <https://www.nms.ac.uk/national-museum-of-scotland/plan-your-visit/events-and-resources-for-autistic-people/>

**Odeon**

*ASD friendly screenings. Odeon also run monthly showings for young people with ASD.*

Web: [www.odeon.co.uk/accessibility/autism-friendly-cinema-screenings/](http://www.odeon.co.uk/accessibility/autism-friendly-cinema-screenings/)

### **Young Archaeologists Club**

*A muddy ten-week course held once a year. Book early as this is a popular group!*

Email: [edinburghyac@gmail.com](mailto:edinburghyac@gmail.com)

Web: <http://www.yac-uk.org/clubs/edinburgh>

## **Societies**

### **British Psychological Society (BPS)**

St Andrews House, 48 Princess Road East, Leicester, LE1 7DR.

Tel: 0116 254 9568

Web: [www.bps.org.uk](http://www.bps.org.uk)

Email: [enquiry@bps.org.uk](mailto:enquiry@bps.org.uk)

### **British Association for Counselling and Psychotherapy**

(BACP)

Monday-Friday, 8.45am – 5pm

BACP House, 35-37 Albert Street, Rugby, CV21 2SG.

Web: [www.bacp.co.uk](http://www.bacp.co.uk)

Email: [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

### **Autism Services Directory**

*This is an online ASD-specific searchable data-base of autism services across the UK*

Web: <https://www.autism.org.uk/services/helplines/directory.aspx>

## **Self-Help**

The resources in this section offer information on developing life-tools to cope with stress, anxiety and low mood.

### **Lothian based resources:**

[www.edspace.org.uk](http://www.edspace.org.uk)

[www.westspace.org.uk](http://www.westspace.org.uk)

### ***Helplines***

#### **Samaritans:**

*Open 24-hours per day, to offer emotional support if you want to talk to someone.*

Tel: 0131 221 9999

Web: [www.samaritans.org](http://www.samaritans.org)

### **Breathing Space:**

*Confidential phone line to help with worry.*

Tel: **0800 83 85 87**

Web: <https://breathingspace.scot/>

### ***Self-referral Services***

#### **Living Life**

*An NHS telephone service, offering support self-help and CBT.*

Tel: **0800 328 9655**

Web: <https://breathingspace.scot/living-life/>

#### **“Living Life to the Full” classes**

*A life skills course based on CBT techniques*

<https://lltff.com/>

## **9 Further Reading**

### **General**

- *A Mind Apart: Understanding Children With Autism And Asperger Syndrome.* P Szatmar (2004)
- *Cant Eat, Wont Eat: Dietary Difficulties And Autistic Spectrum Disorders.* B Legge (2001)
- *Emergence Labelled Autistic.* T. Gradin (1986)
- *Explaining The Enigma.* U. Frith (2004)
- *Sensory Perceptual Issues In Autism And Asperger Syndrome.* O. Bogdashina (2003)
- *Sleep Better! A Guide To Improving Sleep For Children With Special Needs.* V. M. Durand. (1998)
- *Through The Eyes Of Aliens: A Book About Autistic People.* J. L. O’Neil (1999)

### **Personal experiences**

- *Eating an Artichoke.* E. Fling (2000)

- *George and Sam*. C. Moore (2004)
- *Martian in The Playground*. C. Sainsbury (2000)
- *Pretending To Be Normal*. L. Holliday-Willey (1999)
- *Autism And Me*. R. Hoy  
DVD: 20 minutes. An 18-year old with autism explains what it's like to have Autism.
- *Rosie's Story*.  
DVD: 23 minutes. A young boy narrates the story of his young sister, Rosie, who has ASD. This DVD shows what life is like – its ups and downs- living with ASD.

#### **For Parents and Carers**

- *A Parent's Guide to Asperger Syndrome and High Functioning Autism*. S. Ozonoff, G. Dawson & J. McPartland (2002)
- *A Treasure Chest Of Behavioural Strategies For Individuals With Autism*. Fouse, B. And Wheeler, M (1997)
- *Asperger Syndrome: A Guide For Parents And Professionals*. T. Attwood, (1997)
- *Autism: The Facts*, S. Baron-Cohen & P. And Bolton (1993)
- *Autism Spectrum Disorders: The Complete Guide*. Sicile-Kira, C. And Grandin, T. (2003).
- *Asperger Syndrome and Adolescence: Helping Preteens and Teens Get Ready For The Real World*. T. Bolick (2004)
- *Behavioural Concerns and Autism Spectrum Disorders: Explanations And Strategies For Change*. Clements, John, and Zarkowska, Eva (2000).
- *Calm Kids*. Lorraine E Murray
- *Caring For a Child with Autism*. Ives, M And Munro, N (2002)
- *Children with Autism and Asperger Syndrome: A Guide For Practitioners And Carers*. Howlin, P. (1998).
- *Encouraging Appropriate Behaviour for Children On The Autism Spectrum: Frequently Asked Questions*. Richman, S (2006)
- *Freaks, Geeks & Aspergers Syndrome*. Luke Jackson
- *How to Live With Autism and Asperger Syndrome: Practical Strategies For Parents And Professionals*. Williams, C. Wright, B. (2004).
- *Parenting A Child With Asperger Syndrome: 200 Tips And Strategies*. Boyd, B (2003).
- *Ten Things Every Child With Autism Wishes You Knew*. E Notbohm (2005)
- *Transition Toolkit: A Framework For Amazing Change and Successful Transition Planning For Children And Young People With ASD*. K. Boderick & T. Mason-Williams (2005)

- *The Autistic Spectrum: A Guide For Parents An Professionals* Wing Constable (1996)
- *The Complete Guide To Asperger Syndrome* T. Attwood, (2006)
- *The Optimistic Child*. M. E. Seligman (1996)
- *Toilet Training For Individuals With Autism And Related Disorders: A Comprehensive Guide For Parents And Teachers*. M. Wheeler (1999)
- *Topics in Autism. Siblings Of Children With Autism. A Guide for Families*. Harris, S. L. (1994)
- *Understanding And Working With The Spectrum Of Autism*. W. Lawson (2001)

**For siblings understanding ASD:**

***Siblings aged 0 – 7 years***

- *A book about what autism can be like*. S. Adams (2009)
- *Children with Autism: A booklet for Brothers and Sisters* Davies J. (1993).
- *Ian's Walk: A Story about Autism*. Lears, L. (1998)
- *My Brother Sammy*. Edwards, B. And Armitage, D. (1999)
- *My Brother is Different*. Gorrod, L. (1997)
- *My family is different* C. Brook (2006)
- *My friend Sam: introducing a child with autism to a nursery school*. L. Hannah (2007).
- *My sister is different*. S. T. Hunter (2006)
- *Russell is Extra Special: A booklet for Children*. Amenta, C. (1993)
- *Since we're friends: an autism picture book*. C Shally (2007)
- *Understanding Sam and Asperger Syndrome*. C. Van Niekerk & L. Venter (2006)

**Siblings understanding ASD:**

***Siblings aged 7-13 years***

- *Adams Alternative Sports Day*. J. Welton (2004)
- *Asperger Syndrome, the Swan and The Burglar*. B. Boyd (2007)
- *Asperger Syndrome, the Universe and Everything*. K. Hall (2001)
- *Blue Bottle Mystery: An Asperger Adventure*. Hoopman, K. (2000)
- *Buster and The Amazing Daisy: Adventures With Asperger Sundrome*. N. Ogaz (2002)

- *Can I Tell You About Asperger Syndrome? A Guide for Friends And Family.* Welton, J. And Telford, J. (2003)
- *Dannie's Dilemma.* C. Haldane & K. Jones (2008)
- *Everybody Is Different: A Book For Young People Who Have Brothers Or Sisters With Autism.* Bleach, F. (2001)
- *Friends Learn About Tobin.* Murrell, D (2002)
- *My Brother Has Autism.* Campbell, K. (2000)
- *The London Eye Mystery.* S. Dowd (2008)
- *Thomas Has Autism* J. Powell (2006)
- *Topics in Autism. Siblings Of Children With Autism: A Guide For Families.* Harris, S. L. (1994)
- *What Does It Mean To Have Autism?* Spilsbury, L. (20002)

#### **For siblings ages 13+**

- *I'm A Teenager, Get Me Out Of Here!: A Survival Guide For Teenage Siblings Of Young People With Autism.* C. Brock (2010)
- *Hangman.* J. Jarman (2003)
- *Haze.* K. Hoopmann (2004)
- *The Curious Incident of The Dog In The Night-Time.* M. Haddon (2004).
- *Truth or Dare.* C. Rees (2000)

#### **For young people with ASD**

- *Asperger Syndrome, The Universe And Everything.* Hall, K. (2001)
- *Baj and The Word Launcher: Space Age Asperger Adventure In Communication.* P. Viktor (2006)
- *Caring For Myself: A Social Skills Storybook.* C. Gast and J Krug (2008)
- *Different Like Me.* J Elder (2005)
- *Everybody Is Different.* Bleach, F. (2002)
- *Finding Out About Asperger Syndrome, High Functioning Autism And PDD.* G Gerland (1997)
- *Freaks, Geeks and Asperger Syndrome: A User Guide To Adolescence.* Jackson, L. (2002)
- *How To Be Yourself In A World That's Different: An Asperger Syndrome Guide For Adolescents.* Y. Yoshida (2007)

- *I Am Special: Introducing Children And Young People To Their Autistic Spectrum Disorders.* Vermeulen (2001)
- *I Have Autism – What’s That?* K. Doherty, P. McNally & E. Sherrad (2000)
- *Middle School: The Stuff Nobody Tells You About. A Teenage Girl With High-Functioning Autism Shares Her Experiences.* H. Moss (2010)
- *Of Mice and Aliens: An Asperger Adventure.* Hoopman, K. (2001)
- *The OASIS Guide t*
- *o Asperger Syndrome: Advice, Support, Insight, And Inspiration.* Romanowski, B., Bashe, P. R., Kirby, B. L. And Attwood, T. (2001)
- *The Red Beast: Controlling Anger In Children With Aspergers Syndrome.* K. I. Al-Ghani (2008)
- *The Survival Guide For Kids With Autism Spectrum Disorders (And Their Parents).* E Verdick & E Reeve (2012)
- *Tobin Learns To Make Friends.* D. Murrell (2001)
- *What Is Asperger Syndrome And How Will It Affect Me?* National Autistic Society (2001)
- *When My Autism Gets Too Big! A Relaxation Book For Children With Autism Spectrum Disorders.* K. D. Buron (2003)

#### **For Children: Emotions and Facial Expressions**

- *Alfie Gives A Hand.* Hughes, S. (1983)
- *Big Brother, Little Brother.* Dale, P (1999)
- *I’ll Always Love You.* Lewis, P. (2001)
- *Not Now Bernard.* Mckee, D. (1996)
- Oxford Reading Tree Books From Oxford University Press, [www.oup.co.uk/literacy/oxed/primary/ort](http://www.oup.co.uk/literacy/oxed/primary/ort)
- *The Mr Men And Little Miss Books* By Roger Hargreaves.
- *Where The Wild Things Are.* Sendak, M. (1998)
- *Tuesday.* Weisner, D. (1991)

## **Software and CDs**

### *Software*

- Let's Face It! A program consisting of a series of engaging games designed to improve facial recognition abilities. Web (free download):  
<http://web.uvic.ca/~letsface/letsfaceit/?q=node/5>
- Mind Reading Emotions Library: The Interactive Guide to Emotions (CD-ROM), Baron-Cohen, S. (2004).

### *Websites*

- Scottish Autism 'Right Click' online courses for parents of children with ASD  
[www.scottishautism.org/services-support/support-families/online-support-right-click](http://www.scottishautism.org/services-support/support-families/online-support-right-click)

### *Videos*

- ICAN  
*Children's communication charity offering advice and guidance for parents with concerns and questions about their child's speech and language development.*  
31 Angel Gate (Gate 5), Goswell Road, London, EC1V 2PT  
Tel: 020 7843 2544  
Web: [www.ican.org.uk](http://www.ican.org.uk)

## **Other Helpful Websites**

### **The National Autistic**

Society is the largest UK organisation for people with autism and their carer.  
[www.NAS.org.uk](http://www.NAS.org.uk)

### **Sibs**

UK based organisation which supports siblings of disabled people  
<https://www.sibs.org.uk/>

### **Autism Network Scotland**

<http://www.autismnetworkscotland.org.uk/>

### **Resources for Autism**

[www.resourcesforautism.org.uk](http://www.resourcesforautism.org.uk)  
Practical support for children and adults with autism

### **The Curly Hair Project**

A social enterprise supporting people on the autistic spectrum and people around them.  
<https://thegirlwiththecurlyhair.co.uk/>

**Tony Attwood**

Covers Asperger Syndrome and social skills:  
[www.tonyattwood.com.au](http://www.tonyattwood.com.au)

*\*Disclaimer. The groups, supports and contact details entered within this booklet are correct and accurate at the date of 27th March 2019. Since this date some information and groups mentioned may have changed.*

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