

# Sensory Processing Issues

## are real.

Some people are much more — or much less — sensitive than others to what they hear, see, smell, taste, or touch. Sensory processing issues can also affect balance and movement.

## can be overwhelming.

Things like bright lights and loud noises can trigger meltdowns beyond a person's control. These difficulties can lead people to seek out sensations, too — like wanting to be hugged.

## are misunderstood.

Trouble with sensory processing doesn't mean a person is "difficult" or "overreacting." When provided with the right strategies, people can thrive.



**Sensory processing issues aren't caused by a lack of discipline or toughness.**

## Trouble areas

- Melting down from sensory overload
- Not reacting to pain, heat, or cold as expected
- Handling changes in routines
- Coordination and balance
- Invading personal space or playing too roughly
- Trying new foods
- Managing emotions

## Ways to help

1. Strategies like removing clothing tags, dimming the lights, or using noise-canceling headphones
2. Fidgets or chewing gum to help sensory seekers maintain a "just right" state
3. Quiet spaces and advance warning about changes in routine or loud noises, like fire alarms

A practical approach to early support for  
young children with autism at home



# Autism at home

A guide for parents, carers and professionals





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# Understanding Autistic Spectrum Disorder and the Importance of Creating a Supportive Environment

When we talk about Autism, we refer to it as a spectrum. What this means is that each child will be different, that is “no one size fits all”. Some children will have very mild symptoms and some moderate or more severe.

Nottinghamshire County Multi Agency Pathway to support children and young people with concerning behaviours ([www.nottinghamshire.gov/concerningbehaviourspathway](http://www.nottinghamshire.gov/concerningbehaviourspathway)) focuses on supporting professionals and families to plan the right support, at the right time and at the right place - with an emphasis on early support strategies rather than diagnosis.

This booklet provides some ideas and strategies for you to consider. Please note, that the term ‘secure’ is referred to throughout the booklet e.g. secure touch. By secure we stress that it is important not to cause discomfort, pain or injury..

People with Autism Spectrum Disorder are part of a distinctive group with common characteristics. In order to assist individuals to learn and develop, it is crucial that those around them understand Autistic Spectrum Disorder and assist the individual to develop by providing structured teaching. This includes organising the physical environment and developing schedules and work systems which incorporate the use of visual material to make expectations clear and explicit.



With regard to the physical environment, people with Autistic Spectrum Disorder perceive the world differently and many have difficulties making sense out of a lot of details.

People with Autistic Spectrum Disorder first of all see detail, and then try to get meaning. It is therefore necessary to adapt the environment to suit each individual, to ensure that everything abstract (vague or theoretical e.g. the concept of time) is made concrete and to ensure that structured support is carried out in the appropriate context.

If too much stimulation (something that produces a reaction/response) is available, people with Autistic Spectrum Disorder are unable to grasp the meaning, particularly if stimuli change all the time. Consistency in the environment, approaches and positive routines may assist the young person to cope with daily living.

When adapting the environment, it is important to clear work areas/ rooms of any unnecessary stimuli in order to allow the individual to understand the task and focus on what is expected of them.

To help you understand and put support in place, it may help to carry out a simple functional analysis. This means thinking about how a child is behaving and asking some key questions;

### **When did this start?**

- Was there anything that triggered it?
- Is it associated with anything? (time, meal, activity, environment, other)
- Is there anything that makes it better or worse?
- Is there something sensory going on?
- Can I “unpick” what is causing this behaviour?
- What can I do to address this issue?
- Has this happened before? Consider keeping a record or diary to see if a pattern emerges?

### **Don't be afraid to go back to basics and consider facts like;**

- Is it too hot or too cold?
- Is the child hungry or thirsty?
- Is it too noisy?
- Is the child in pain? (e.g. toothache/headache/temperature)



## **Children who are on the Autistic Spectrum (with or without diagnosis) may:**

- Have a need for consistency of approach and for environment and routines to remain unchanged.
- Need flexibility to be specifically introduced; gradually and with planning.
- Need visual supportive environment encouraged at a limit the child/ young person is comfortable with.
- Have difficulty knowing how to spend time if it's unstructured.
- Need to have time alone, especially after busy periods such as school.
- Have difficulty understanding the need for social interaction.
- Find it difficult to play imaginatively, e.g. use toys as objects.
- Exhibit unusual or repetitive behaviours, such as spinning and head banging.
- Have sensory processing difficulties which lead to an extremely high or low tolerance to heat and/or pain.
- Be over sensitive and become overwhelmed by the noises of equipment or other people, smells and visual stimulation.
- Not be aware of the consequences of actions or of danger.
- Dislike being in a car - adaptive equipment may need to be considered in order to keep the child safe.
- Have gross or fine motor difficulties e.g. find it difficult to manipulate objects.



Children who have an Autistic Spectrum Disorder may not be able to adapt to their environment, therefore changes may have to be made for them to maximise their potential.

These changes will be applicable at home, in nursery, school and any other environment in which the child spends a substantial period of time.

Always use, simple clear communication. Face the child when communicating. Don't expect eye contact. Use familiar language each time and ask other people for ideas and suggestions about communicating effectively by using their name, and give one instruction at a time.

The following are suggestions of possible strategies and are split into sensory and general strategies. Each child is an individual and the strategy which works for one may not work for another. Parents often know 'at a glance' which strategies will work for their child.

A close-up of a green, round character with large, expressive blue eyes and a thick black, fuzzy hair-like border around the top of its head. The character has a simple, slightly downturned mouth.

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## Activities of Daily Living

### Dressing

#### **Sensory/suggestions**

- Use comfortable clothes - consider type of fabric and length of sleeves.
- If the child cannot tolerate labels, cut them out.
- If the child 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.
- Try writing down or noting the order/sequence of dressing to share with others.

#### **Sensory/suggestions**

- Practice dressing skills at home when there is plenty of time to complete the activity.
- Choose shoes with Velcro, or add Velcro to button backs and zips.
- Organise drawers and put a picture label, if necessary, in front to enable the child to choose their own clothes.
- If the child has balance difficulties, try dressing sitting down.
- Play with dolls or teddy bears that require dressing to practise skills.
- Grade the activity so that the parent does some and the child does some.
- A dressing chart with pictures may assist to sequence the activity.

### Personal Hygiene

#### **Sensory:**

- Use non-perfumed soap.
- Be aware of bathroom lighting levels and minimise any noises, e.g. run the bath prior to entering the bathroom.
- Be aware of pressure when shampooing or drying with a towel.



- Before bath time, do activities that provide consistent, secure, deep touch input, for example, resting your hands on your child's shoulders and applying moderate pressure.
- Make the transition from undressing and getting into the bath as quick and as smoothly as possible, or in a planned and ordered sequence - Be prepared to be flexible
- If the child dislikes having their face or body washed, encourage them to wash themselves.  
Self-initiated touch produces a less defensive reaction.
- Use a large sponge or loofah. Consider using a consistent secure rubbing action to decrease defensiveness, but always allow the child or young person to determine the pressure they are comfortable with.
- If the child is showering, use a hand held shower nozzle. Let the child control the direction and force of the water.
- Use a large towel, and quickly and securely wrap the child in it. Avoid exposure of the wet skin to the air: the light touch may trigger a defensive reaction.
- Provide secure-touch using a towel to the head, hands and feet to decrease defensiveness. If the child will tolerate it, provide a firm massage, using lotion to avoid skin irritation.

### **General:**

- Where the choice is available, allow your child to choose a bath or a shower. (A larger showerhead is often more acceptable to the child, as it distributes the water more evenly)
- Try to incorporate bathing into a play activity, for example use floating toys and bubbles.
- Talk to your child 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 child 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.



## Hair Grooming, Cutting, Washing

- Work closely with your child/ young person and be confident about the level of pressure they prefer and are most comfortable with.
- Seat the child securely on your knee and squeeze the child firmly between your knees or apply a little less pressure to ensure comfort.
- You may place your hands on top of your child's head and exert gently but constant, secure, gentle pressure down, or you may need to apply as little pressure as is possible to ensure comfort.
- Count or have the child count as you comb, wash, rinse or cut the hair.
- Give definite time limits to the task e.g. let's count down to 10, then we will stop cutting your hair, provide light, secure or no 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.

## Toileting

### **Sensory:**

- The child may be sensitive to toilet tissue, try using moist toilet roll.
- Consider visual and auditory stimulation around and keep it to a minimum.

### **General:**

- Visual aids can be used to explain task.
- Consider adaptive equipment, would an extra rail or infant chair be beneficial.



## Eating

### **Sensory:**

- Certain textures may be avoided by the child.
- Weighted cutlery may give an increase in sensory feedback so as to make the child more aware of the appropriate movement.
- Give the child a personal stereo to wear with calming music, this may make it more tolerable for them to sit at the table.
- Before meal times, it may help to provide secure touch and total body exercises to decrease touch defensiveness.
- Try to make mealtimes a relaxed, pleasurable experience. It may not be useful to introduce new challenges at meal times.
- Try to limit the number of new foods introduced at any one time.
- Set aside a separate time for graded feeding programmes to resolve the underlying problem.

### **General:**

- Try cutlery that is in a particular colour or theme to create interest.
- Try plates and cutlery with words on them to associate to task.
- Try playing with foodstuffs at separate times, e.g. cheese building blocks, vegetable monsters, but be sensitive to a child's fears.





## Oral Challenges

Eating non-foodstuffs, biting hands, chewing and/or regurgitating and similar behaviours are often encountered. There may be a sensory element contributing to the development of these behaviours in this case the following strategies may be helpful: (See also touch challenges, social and emotional environment)

- Redirect the need to bite to more positive sensory activity i.e. chewy toys, crunchy foodstuffs.
- Be aware of choking hazards
- Substitute another item for the hand that is readily available e.g. wristband of suitable robust material.
- Provide a range of oral experiences throughout the day e.g. hot, sour, sweet, salty, cold, different textures.
- Try electric toothbrushes in a tooth brushing routine.
- Include some sensory toys as part of daily routine e.g. shuddering snake.

## Sleeping

### **Sensory:**

- Develop a calming routine before bedtime. Encourage quiet activities.
- Use a heavy/weighted blanket or flannel sheets to provide secure-pressure and a calming environment, but always make sure whatever method you use is comfortable to the child and is safe.
- Use older fashioned layers of blankets rather than duvets.
- Try using a sleeping bag making sure the child is comfortable and safe.
- Check visually all bed spreads, walls/paintwork for too much detail or colour.
- Check all bed linen for texture and smell i.e. conditioners, washing powder etc. that may irritate.



## Hand Function

Many young people with Autistic Spectrum Disorder have difficulties with hand function. The following may be useful to carry out at home:

### Fine hand-play activities

#### **When a child only uses finger tips:**

- Before activities consider, providing secure pressure into the palms of the hands, such as firm clapping or full press-ups or half press-ups.
- Grade activities by using the fingertips then moving to use the whole hand. If the child will tolerate it, provide secure-touch input over the hand and writing tool, i.e. hand over hand.

#### **When a child avoids getting hands dirty:**

- Encourage less messy activities.
- Use tools to manipulate the supplies whenever possible (for example, a paintbrush rather than finger paint).
- Use messy materials that provide resistance, such as putties or dough mixtures.
- Lucky Dips – hiding items in different dried goods



## Adapting Environments

Developing a routine and a consistent way of doing things can reduce the impact of their difficulty with language or attention. Organisation can give the child a sense of control in how they plan their day.

### Inside

#### Sensory:

- Provide a place where the child can take themselves for time out, for example a small tent or cabin bed. Children with an Autistic Spectrum Disorder may find low, ambient lighting and enclosed spaces calming. Ensure these spaces are safe and easily accessible and that the child can be observed.
- Try to minimise visual and auditory stimulation.
- If the child has a positive response to movement, try a rocking horse or chair swing.
- Paint the child's room soft, pastel colours and put dark blinds or lined curtains on windows to prevent light distracting the child.
- If possible, situate the child's room in a quiet corner of your house, although give thought to their room being close to yours to prevent anxiety.
- Perhaps try to give your child appropriate simple, physical tasks around the house, for example carrying the shopping, arranging tins on shelves. This may have a calming and organising effect.
- Provide a three sided work station in order to reduce distractions. The child can do homework or other activities in this area.
- Activities such as vacuuming may be better kept for when the child is not around.





## General:

- Label cupboards in the kitchen or bathroom with pictures so that the child knows where to find things.
- Minimise clutter.
- Try using a diary or photo book with familiar pictures, such as school buildings, family members, to ease the transition to different situations.
- Sharing a bedroom with a sibling can be difficult. Clear boundaries maybe helpful.
- Try to structure the child's time and consider introducing an 'activity schedule'.
- Provide a range of favourite toys that can be played with independently for short times, e.g. jigsaws, trains, cars.
- Store toys/equipment in closed containers which can be moved to a designated area when it is time to move to another environment/ activity e.g. from playtime to bath time.
- Consider clearly marking a work area at nursery/school.

## Outside

Playground equipment can be used at home, school, in the local park or a leisure centre to provide an area where a child can play and have time out. Accessing local facilities may be more suitable at less popular times to reduce noise levels and distractions. Play areas that have clearly defined boundaries may be preferable.

The following pieces of equipment can help the child to interpret sensory information and make it more meaningful:

- 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.
- Play houses.



## Noisy Public 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?
- Consider when to carry out everyday activities. Is there a less busy supermarket, or off-peak time? Is there a quiet space available e.g. dining booth?
- Consider having the child wear snug clothing e.g. lycra undergarments.
- Consider having the child wear ear defences.
- Consider using a music player with headphones, allowing the child to listen to favourite songs/music. This may help to drown out environmental noises and help the child stay focused on an activity.

## Walking

- Consider trying providing secure pressure on the bottom of the feet, before commencing. Again consider seating your child firmly on your lap facing a wall and possibly placing the child's feet flat against the wall and placing pressure directly through the knees into the feet. Have your child help push.
- Have a clear route that can be described, or use pictures of your route.
- Have a clear timescale – e.g. we are going on a 10 minute walk round the pond.
- Consider if a buggy is required for longer distances.
- Consider taking a toy along in your/their pocket.

## Garden Activity

The garden may provide a positive experience to give a young person calming times, time alone or with friends. Time to 'let off steam' is essential to all young people but especially people with Autistic Spectrum Disorder. It can be planned to meet individual needs unique to the child and their family.help push.



### **Some of the following may be helpful to consider with close supervision:**

- Creating sensory areas - small safe hidden areas or use of play houses with suitable toys can create a calming experience.
- Always make sure spaces are secure, safe and that the child can be observed.
- Large climbing frames, trampolines, chutes and swings may give the young person the experiences of movement they need.
- The dislikes, likes, motivations and pleasures can be carefully looked at to give a unique experience which a young person can have in their garden environment which is vital to family life and support at home.
- Night lighting, gazebos and sheds allow the experiences not to be curtailed by weather or the dark.
- Small water features can be extremely calming or give something to distract when things are difficult for a child. Likewise, small wind chimes, musical chimes, light reflector toys or spinning toys may be both aesthetic and enjoyable.
- Also consider that a child may find these activities difficult.

The garden may be an area where, as a family, a shared experience with a young person can take place or simply be pleasurable for the rest of the family as a calm, quiet area.

## Functional Communication to Access the Environment

Young people will benefit from visual schedules for the day. These may be pictorial, symbolic or object reference based. Sometimes a sensory element to this can be helpful, particularly if the young person has an accompanying severe learning disability. This is crucial in the home or other environment. The child in school should be using this.



### **It may:**

- Help the young people predict what will happen.
- Support spoken instruction regarding transitions.
- Provide a constant reminder.
- Support their understanding of the sequence of events.
- Introduce new activities in the context of familiar activities.
- Introduce planned change to their daily/weekly routines.
- Support the young person's independence.
- Provide security of routine and planned changes

### **It should be used when:**

- The young person needs structure.
- The young person struggles to self-occupy.
- The young person has limited sense of his/her day.
- The young person needs help to predict or organise their day.
- The young person needs to know what is expected of them.

### **It can be carried out simply in the home by:**

- Choosing the visual system e.g. concrete objects, photographs, symbols, written word - this can be with advice from the Speech & Language Therapist.
- Organising and sequencing timetables, before the start of the day/evening.
- Keeping the timetable in a recognisable place for each young person.
- Keeping the timetable portable. When the young person makes any physical transitions, help them retrieve their timetable.
- Reviewing the daily timetable at the start of each day/evening, with each young person.
- Employing 'Point-Say-Do' principle for each activity on the timetable.
- Actively showing and reinforcing when each activity is finished by turning over the symbol/ticking the word/putting the object in the 'finished' box.
- Gradually fading your physical/gestural prompting, allowing them to develop their responsibility to use and learn from their timetable.



- Using the timetable to emphasise clear beginnings and ends to activities.
- Using an hour glass or other form of time keeper to help structure time. An hour glass is visual and available in different sizes/times e.g. 10 mins, 15 mins, 30 mins.

## Play in the Home

Playing at home is something all children do as part of growing up. Sometimes this play is done alone, sometimes with siblings, friends, relatives or parents. It can be planned or spontaneous. It can involve the whole family. Play is often the occupation of children at home. It happens so spontaneously families do not notice it or how it happens.

Children with Autistic Spectrum Disorder need help to learn to play. Often for them it is a skill to learn, as are other skills such as dressing. Often families need to understand play from their child's world.

### **Children with Autistic Spectrum Disorder may:**

- Need their play time structured.
- Need a routine to play similar to other daily task routines.
- Need to be taught the rules in detail.
- Enjoy playing in different ways, which families need to understand and value.
- Need someone playing alongside if they are to begin to notice another person.
- Be distracted by a lot of detail or sensory difficulties.
- Need encouraged to extend from only one activity or occupation by introducing a second play experience for short periods, over time.
- Need only one sensory channel to attend to at a time e.g. something to see only or something to listen to or something to smell etc.
- Need communication in play at an appropriate level.
- Need no more than a few toys presented at a time.
- Need play to be in manageable time frames, which can be amended to the child's needs.



Play for most children regularly includes toys. Children with Autistic Spectrum Disorder often have difficulty playing appropriately with toys.

**Children with Autistic Spectrum Disorder may:**

- Have set ways of playing with a toy which needs help to change.
- Not be motivated by toys.
- Become overloaded with too many toys (consider putting some away when not in use and bringing out in a structured way).
- Have difficulty jointly playing with toys with another person.
- Easily break toys when first interest has gone.
- Have difficulty with imagination playing with toys.
- Require toys to be limited in detail i.e. plain, not patterns.
- Require toys which are easily built or have few small parts due to co-ordination challenges.
- Prefer toys most like real items i.e. pan or phone like a real one.
- Need adults to value motivating “toys” even if they do not seem like a toy to the adult e.g. flapping a ribbon or ripping paper.

## Play Environment

Play, both indoors and in the garden, needs to be an environment with careful safety checks on toys and location. Any possible sensory overload needs to be looked at in the environment. Play in the garden needs times when an adult supports. This encourages joint play but also stops a young person becoming too isolated or withdrawn. Play needs to motivate a child. Often motivation is the challenge to young people on the Autistic Spectrum. Familiar layouts need to be available to relax a young person enough to engage in the serious business of play.



## Play challenges you may encounter, with ideas for you to consider:

Play Challenges	Ideas
Only play with one activity again and again	Try introducing a second one before it for only 1-2 seconds then on the next occasion increase the time. Try introducing something else at the same time then gradually do it on its own first e.g. music with rough and tumble play.
Does not play with any toys	Box them up and only leave out one or two which they will play with. Get two of them and play alongside with the child in the routine they do with the toy e.g. spinning the car wheels. If it is only self-play, do the thing too e.g. flicking fingers or flapping. See the item they like do as "toys" e.g. ribbon.
Only notices part of toy	Consider borrowing or if possible buying a second one and you do the action then vary it slightly to include another part.
Times when they are not able to focus on any toy	Consider keeping a box of motivating favourite toys separate for this time e.g. wind chimes, windmills, light vibrating toys etc in a box.
Only likes one piece of music	Try introducing new music at a different time/place i.e. in bath time routine or on a different CD player.
Hates table top Games	Keep it to only a few seconds. Consider a visual schedule with favourite activity straight after.
New toys are played with rigidly one way	Don't give a new toy to be explored until you play with the toy and the young person in a structured session.



## Creating a Social family Environment

### **The Social and Emotional Environment**

Research shows that a child with Autistic Spectrum Disorder can cause a great deal of extra stress in family life, particularly for mothers, and over holiday times. Families including siblings may benefit from support from services and their extended family to help them meet these challenges. The home environment however can be designed to allow families to get the best out of their time together.

### **The following are practical, environmental supports might be helpful:**

- Keeping a diary of any challenging incidents can help identify trigger times or situations directing alternative ways of doing something.
- Co-ordinating activities where possible so that the choice is not either/or but both e.g. respite and play schemes. Planning in advance with school dates and service providers to give the most family friendly package.
- Help to co-ordinate and plan schedules in the most appropriate visual format can be provided. These are often used in school but are seldom available for families to use at home. If this support works well in one environment, it can be used to support the young person in all environments.
- Planning family routines to include time with activities for each person, different combinations of family members and as a family may help bring predictability for the young person.
- Planning in advance special events, either social or of more practical or care needs e.g. shopping, hairdresser etc.
- When planning play experiences either with parents, siblings, extended family or carers play boxes with individual, liked toys may be helpful.



- Using choice in small things may be helpful in preventing difficulties in daily life tasks e.g. a choice of blue or red face cloth, the green or blue toothbrush today. This may also help build in flexibility.
- Using emotion cards to display how someone is feeling may help families not only express how they feel but get the message across.
- Planning “free” or “down” time for a young person. Young people with Autistic Spectrum Disorder often do not cope well with unplanned time. To afford the family the opportunity to have this “down” time it can help to make a selection of choices available for the young person to self-select.
- Family life is not normally as structured as school. Many families feel that they would like this time to relax and not rely on fixed routines which resemble work. Children with Autistic Spectrum Disorder however, thrive on routine and it should be seen as a challenge to get the balance right. Achieving this for individual families means that everyone feels supported. Often professional support is helpful here to suggest a diversity of ideas.
- Returning home after a period of intense social concentration e.g. from school, is often a critically difficult time. Planning and thought to using this time is particularly important. It may be that carer support will be the most helpful at this time, or that the young person needs directed to an activity they particularly enjoy, or to use a quiet area.
- Transitions between activities often does not seem relevant to the home environment. However, if transition or story cards, objects or

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counters are used elsewhere, this may be helpful also to reduce stress moving on to different times of the day within the home.

Creating a visual timetable to support transitions may be helpful.

- The young person's bedroom is often a source of stress or a place of relaxation. Use of the bedroom during the day for activity can be planned and activities, toys and layout considered. Routines or changes in layout (e.g. tidying up in boxes at night) may help night to be different.
- Often more unusual routines begin due to children growing up and developing unique ways of managing their world. All these unique features need to be considered in the light of their developmental stage. The family may need support to help the child manage their world, to prevent unhelpful routines being established.
- Each family member needs time to relax. Parents often feel guilty taking time to care for themselves. It is essential that this time is taken to build a strength and inner support to be enabled to meet the care challenges. Often families need help realising and accepting this.

Response to physical touch can also affect emotional attachments in a family. Sometimes this is affected by the young person's ability to tolerate touch or need for touch. This can have great impact on the social and emotional wellbeing of the relationships with family and friends. The following may be helpful to consider to help improve physical tolerance:



Touch Challenges	Suggested Strategies
<p>Child withdraws or punches others who touch him lightly. Child reacts negatively and emotionally when touched lightly (exhibits anxiety, hostility or aggression).</p>	<ul style="list-style-type: none"> <li>• Teach others to touch the child securely. Explain that the child feels light touch more strongly and as if he/she were being hit.</li> <li>• Approach the child from within his/her visual field.</li> <li>• Teach friends and relatives to show affection securely and directly.</li> </ul>
<p>Child reacts negatively when touched from behind or when touched by others.</p>	<ul style="list-style-type: none"> <li>• Tell the child when you are going to touch him/her. Always touch securely. Assure the child that you will touch gently but securely and that you will not move your hands unpredictably</li> </ul>
<p>Infant may prefer the father's firm touch over the mother's firm touch.</p>	<ul style="list-style-type: none"> <li>• Tell the child what you will do and how you will do it. ("I'm going to hug you really securely."). Respect the child's need for control.</li> </ul>
<p>Child may pull away when approached for a friendly pat or caress from a relative or friend.</p>	<ul style="list-style-type: none"> <li>• Make kisses on the cheek a form of secure-touch input. Hold the child firmly and give a firm kiss.</li> </ul>
<p>Child may reject touch altogether from anyone but his mother or primary caregiver.</p>	<ul style="list-style-type: none"> <li>• Teach people always to approach the child from the front and always make sure the child is able to anticipate the hug or expression of affection.</li> </ul>
<p>Self-stimulatory behaviours are often oral e.g. hand biting, spitting and prompted by anxiety. This can deter other people from building relationships.</p>	<ul style="list-style-type: none"> <li>• Provide as much explanation of the situation as possible.</li> <li>• Use of alternative oral stimulus e.g. chewing gum, crunchy foodstuffs.</li> </ul>



## Challenging Behaviour and Environment

Often families are aware that many difficult times with their young child can be as a result of frustration, confusion, altered routine and poor communication. Supporting families to give a full home environmental assessment and alterations to day or building can still leave families with times when incidents of challenging behaviour can be displayed. Close liaison between all agencies is vital to support behaviour. However, the routine, environment or communication challenges can also be a vital part. In the home with each family's unique needs, likes, enjoyments and challenges the support should be ongoing and altered to suit these needs.

All the environments the young person is in, should share experiences which might reduce the behaviour challenge in one or other environment.

Individuals with autistic spectrum disorder may experience an innate weakness in empathising with others' feelings, understanding their motivation and predicting others' behaviour. Specific features which help make life calmer like routines, time alone or rituals when anxious often clash with what is happening in family environments. Understanding that their behaviour is often communicating stress or anxiety or, perhaps, bewilderment at others' behaviour is difficult for a busy family to bear in mind.

Crisis situations when a child displays severely challenging behaviour or distress at home can affect the whole family.



## **Challenges may be supported in the home environment by looking at the behaviour at its different stages**

- Triggers - The cause of the situation. For young people with Autistic Spectrum Disorder it may involve their routine being interrupted, a sensory overload of sound or light etc., relating to too many people at once or a demanding situation which is difficult for the young person and where they cannot ask for help. Times of the day - like the return home from school.
- Escalation time - Sometimes the stress of socially interacting e.g. school, may mean that suddenly when a child returns home they lose control for a time. Other times a longer period of building up anxiety is a pattern and reading the signs at an early stage could prevent escalation.
- Crisis - A clear plan of how families are going to handle the problem may need to be developed. Calm and consistent responses by families are hard but essential. They may need to focus on how they are going to keep people safe.
- Recovery - Time it takes and best method of achieving this needs to be clearly stated. It may be time alone or doing enjoyable activities needs to be in place.
- Discussion & Planning - Talking about the incident with the young person later may be best supported visually. Showing pictures of feelings displayed and looking at how things can be done differently may help the young person understand.

Exploring issues may trigger a new incident, so it should be carried out when all can manage this, when anxiety levels are low. Use visual clues, social stories of what happened and replace them with a social story of how it could be better with a different approach.



## Home Safety – Family Responsibility

Safe home environments are a priority for all parents. Families with young people with Autistic Spectrum Disorder often recognise the need to be even more vigilant about maintaining a safe home environment.

### **House**

There are pieces of equipment families may feel are essential for general safety. Many high street stores have leaflets of their own that can provide a range of suggestions and ideas including safety catches for cupboards, washing machines, fridges, safety gates for stairs, plug safety caps, seat belt safety covers etc. Safety glass in furniture is also essential and families may wish to check this in their home environment. Promoting an appropriate calming and safe environment is essential. Bearing in mind young people with Autistic Spectrum Disorder are easily distracted by detail many families try to keep this detail to a minimum e.g. keeping to a plain rather than a patterned colour scheme. Often creativity is needed to make a home environment a clutter free environment e.g. using a toy box to signify end of play sessions. These examples can reduce anxiety and the potential for the young person to become highly aroused and stressed.

### **Garden**

As a safe play area is essential to all young people, this area requires good visual supervision to promote both the safety and developmental needs of young people. Blind spots to supervision, dangerous objects in the garden, greenhouse glass and areas which can be climbed are all dangerous areas for families with young people with Autistic Spectrum Disorder to address. Many young people feel insecure with a lot of detail in the garden or with inappropriate toys.

Positive experience of a safe play area as a place to calm them or to let off energy may not be achieved for the young person if these issues are not addressed..



## **Safety from Access to Rooms and Cupboards**

Care needs to be taken when considering fire and safety. Appropriate locks to rooms and cupboards should be used (not bedrooms), as young people are unaware of the danger of items inside and so there must be a constant awareness that when distressed a child/ young person may exhibit challenging behaviour, which can result in damage to property and so themselves and others. Consider where young people are unaware that rooms are out of bounds e.g. belong to a sibling. These locks require advice and support from the Fire Brigade to minimise risk of fire and safety.

## **Safety from Water**

Various devices can be used, for young people with water obsessions, to prevent flooding when running sinks or baths. Thermostats can be used to control water temperatures for baths, showers, sinks etc.

## **Safety from Gas Cookers**

Isolation switches for gas cookers may be appropriate.

AUTISM





## Notes

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## Notes

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This booklet has been produced  
to support Nottinghamshire County's  
Multi-Agency Concerning Behaviours Pathway.  
For more information and pdf copies please visit:

**[www.nottinghamshire.gov.uk/concerningbehaviourspathway](http://www.nottinghamshire.gov.uk/concerningbehaviourspathway)**

Acknowledgements and thanks are made to Lesley Beath and Falkirk Council who produced a similar publication.

Also to Nottinghamshire County Council's graphics and print team for designing and printing this publication.



# A HANDBOOK FOR FAMILIES

**Information on autism and ADHD  
in children**

This handbook is for Kent families who would like to know more about autism and Attention Deficit Hyperactivity Disorder (ADHD) in children.

It was developed with help from parents and carers of children waiting for an assessment for autism and/or ADHD in the Canterbury area. We wanted to make sure it has information that you would find useful.

Sections include where to go for help with health, education, rights and benefits, and a listing of local and national organisations. We've also included tips that may help manage your child's behaviour and pages for you to make notes.

It is important to know that an assessment and diagnosis of autism or ADHD is not needed to access the majority of the support listed in this handbook. The only specific help that is dependent on a diagnosis is a place at a grant-maintained specialist school or an independent specialist school.

We checked all the details of organisations early in 2020 but as information in printed handbooks goes out of date we cannot guarantee it is accurate. If you find anything that needs updating, please email [handbookforfamilies@nhs.net](mailto:handbookforfamilies@nhs.net) to let us know.

Please visit [www.kent.gov.uk/localoffer](http://www.kent.gov.uk/localoffer) This website is kept up to date and explains what the Local Offer is for families with children with special educational needs in Kent.

*Families and Partners from the Canterbury Pilot*

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We would like to acknowledge and thank SNAAP who originally developed this handbook and have supported us in updating it. This would not have been possible without their dedication in working with parents from the Canterbury District to provide an extensive range of services to children with every kind of disability.

# THE LOCAL OFFER

Kent County Council provides information on their website about local support for children and young people with special educational needs and disabilities (SEND), their families and professionals.

This information is known as the Local Offer and can be found here: [www.kent.gov.uk/localoffer](http://www.kent.gov.uk/localoffer)

The Local Offer provides information about education, health and social care services available to children and young people up to the age of 25, and their families.

Knowing what is out there and having the right information in one place gives you more choice and more control over the services you use.

The Local Offer has been developed in partnership with parents, carers, young people and professionals and new information is added regularly.

The Local Offer will:

- give you information about education, health and care services, leisure activities and support groups
- hold all the information in one place
- be clear, detailed, accurate and accessible
- make it easier to find out what you need to know
- help you to find the nearest and most suitable services.

The council continually develops the Local Offer using feedback from people who use it so it will be more up to date than this printed handbook.

Go to: [www.kent.gov.uk/localoffer](http://www.kent.gov.uk/localoffer)





## SOME DEFINITIONS

### **Special educational needs**

A child or young person has special educational needs (SEN) if they have a learning difficulty or disability which calls for special educational provision to be made for him or her.


A child or a young person of compulsory school age has a learning difficulty or disability if he or she:

1. has a significantly greater difficulty in learning than the majority of others of the same age, or
2. has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions.

# EDUCATION

All schools are expected to meet the needs of children with special educational needs or disability (SEND). Children with SEN/SEND are entitled to attend a mainstream school if they and their parents/carers want them to, and it will not be detrimental to their education to do so. Some children and young people need more specialist provision in a special school.

All schools must publish their SEN Policy on their website. This policy sets how the school supports children and young people with SEND.



## MYTHS & TRUTHS

**Myth:** *To get help with my child's behaviour I need a diagnosis of a special educational need like autism, Asperger's or ADHD.*

**Truth:** A diagnosis is not required to access support from schools, social care or other organisations. A diagnosis may help provide additional information that informs the support offered but it is important that parents/carers do not wait for a diagnosis to seek help for their child.

Special educational needs and disabilities (SEND) can affect a child or young person's ability to learn. They can affect their:

- behaviour or ability to socialise, for example they struggle to make friends
- reading and writing, for example because they have dyslexia
- ability to understand things
- concentration levels, for example because they have attention deficit hyperactivity disorder (ADHD)
- physical ability.

## **Here are some explanations about terms used about education:**

- Code of practice

A statutory guide for parents, schools and local authorities about the help children with SEN/SEND should receive.

- Statutory needs assessment

A statutory needs assessment is a very detailed assessment of your child's needs. It involves information being gathered by Kent County Council from a range of services including education, health, an educational psychologist and medical, and social services plus any other agencies that you, the parents, wish to consult. Kent County Council will also want to know your views and concerns. Its findings will form the basis of a draft education, health and care plan (EHCP) if Kent County Council decides that one is necessary.

- Educational psychologists

Educational psychologists use a range of psychological techniques to carry out assessments of children who have learning, emotional or behavioural difficulties.

Their work includes planning intervention programmes and monitoring children's educational progress. Each school has access to the education psychology service.

- Learning support assistant

A learning support assistant (LSA) is a person, in addition to the teacher, working with a child with SEND in a school class.

- Draft education, health and care plan

A draft of the education, health and care plan (EHCP) is sent to parents for their comments, before the final EHCP is issued. Parents may request to meet or discuss the draft with an officer from Kent County Council before the draft EHCP is made final.

- Education, health and care plan

The EHCP is a legal document, issued by Kent County Council, that sets out a child's special educational needs, the outcomes the child or young person is expected to achieve, provision to meet those needs and outcomes, and the school that the child will attend.

- Special Educational Needs and Disability Tribunal

Special Educational Needs and Disability Tribunal (SENDIST) is the court which decides appeals made against decisions made by local authorities about children or young people with special educational needs. Tribunal decisions for education are legally binding on parties involved in the appeal. The tribunal can also make non-binding recommendations for issues relating to health and social care. The tribunal also hears cases of disability discrimination.

## PRE-SCHOOL

If you have any concerns about your child's development before they start school you should talk to your GP, health visitor or pre-school/playgroup leader.

### **Getting help before starting school**

Children can be referred for assessment and help by a paediatrician, health visitor, pre-school/playgroup leader or GP to a pre-school adviser. The pre-school adviser can set up further meetings with other professionals.

Some pre-school children have education, health and care plans. Help may be in the form of Portage, advice to mainstream pre-school/playgroup staff, or a place in a group meeting.

### **Portage**

Portage is a service for children from birth to five with learning difficulties or developmental delay. Children may be referred by a GP, health visitor, speech therapist, or by their parents. Portage is delivered to parents and children in their homes by the pre-school additional educational needs (AEN) service. It is intended to help parents work with their children to manage their difficulties.

For more information about Portage, visit the National Portage Association:

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

To find out more about Portage in Kent, visit:

[www.kelsi.org.uk/special-education-needs/special-educational-needs/kent-portage](http://www.kelsi.org.uk/special-education-needs/special-educational-needs/kent-portage)

If your child is attending a pre-school/playgroup they should conduct a review of your child's progress. This Early Years Foundation Stage (EYFS) progress check is carried out when your child is aged between two and three years old.

### **Aims of the EYFS progress check:**

- review a child's development progress
- ensure that parents have a clear picture of their child's development
- enable professionals and parents to understand the child's needs and plan activities to meet them
- note areas where a child is progressing well and identify any areas where progress is less than expected
- describe actions the setting intends to take to address any

developmental concerns (including working with other professionals where appropriate).

The check should be completed by the place where the child spends the most time in. It is a statutory requirement for the provider to share the progress check with the parents. There is an expectation that the parents will share it with their health visitor.

Ambitious about Autism has a practical toolkit to guide parents and carers through their child's journey in the early years: [www.ambitiousaboutautism.org.uk/right-from-the-start](http://www.ambitiousaboutautism.org.uk/right-from-the-start)

### **Special Educational Needs Inclusion Fund**

The SEN Inclusion Fund (SENIF) is a statutory requirement made available by Kent County Council to provide

funding to support pre-school children with SEN to secure better outcomes. It can provide funding when children are attending:

- pre-schooling in Kent registered to take two, three and four year old children, a registered Kent childminder, or registered Kent out of hours provider and SENIF criteria is met
- for a maximum of 30 hours per week pro rata on attendance and eligibility for the Free Early Education Entitlement (FEEE).

It is non-statutory to provide this funding for eligible two-year olds in receipt of FEEE, but Kent will continue to fund support for these children up to a maximum of 15 hours attendance.

## SCHOOLS

Most children with special educational needs can be taught in mainstream schools. If your child has more severe or complex needs they may need to go to a special school or school with a special unit. Our special schools and specialist units in mainstream schools only admit children with education, health and care plans whose needs are very severe and complex.

More information  
is available online here:  
[www.kent.gov.uk/  
localoffer](http://www.kent.gov.uk/localoffer)

## SCHOOL SUPPORT FOR 5-19 YEAR OLDS

All schools will support children with SEN/SEND. Children whose needs cannot

be met in a mainstream school may attend a special school. Children attending special schools all have education, health and care plans.

If you have any concerns about your child's education the first thing to do is to talk to your child's class teacher. If you need more information, find out who is the school's special educational needs coordinator (SENCO) and discuss your worries with them. You may also wish to talk to the head of year, headteacher, governor with

responsibility for SEN or the chair of the governing body.

### **SEND Support**

To meet your child's identified special educational needs and disabilities in school, the SENCO and class teacher will put together a plan and targets for your child called a provision plan.

The provision plan will identify all the support your child is being given in the school and any interventions that are needed. This will include support from agencies that



**Myth:** *We need a diagnosis of autism or ADHD to access support from the school.*

**Truth:** Every school has a duty to meet the needs of all children. Support for children is not dependent on a diagnosis for any condition. An EHCP can be offered to any child who has special educational needs whether they have a diagnosis or not.

are outside of school e.g. speech therapy should this be needed. You (and your child if appropriate) should be shown this provision plan and meet with the SENCO and class teacher to review your child's progress.

### **Funding for schools for pupils with SEND**

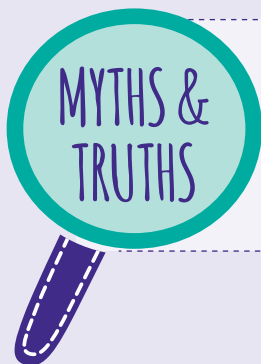
All schools are provided with money to meet the needs of pupils with SEND – you may hear this referred to as the "SEND notional budget".

When a child needs a lot of personalised provision to be able to make progress

and be included in school life, and if the cost of this provision is greater than £6,000, schools can apply to Kent County Council for high needs funding (HNF). HNF is a contribution towards the cost of this provision. This is not dependent on a diagnosis of autism.

### **Statutory Needs Assessment – does my child need an EHCP?**

If, despite the provision in place for your child being reviewed and adapted at least three times, your child is not making progress or things are getting worse, you can discuss



**Myth:** *My child's school has to apply for an EHCP.*

**Truth:** Parents/carers can make an EHCP application, not just school.



## MYTHS & TRUTHS

**Myth:** *My child won't be given an EHCP if they're achieving academically.*

**Truth:** An EHCP is not based on academic performance but on meeting the needs of a child.

with the school's SENCO whether to ask Kent County Council to consider carrying out an education, health and care needs assessment.

Either you or the school can make this request by contacting the Kent SEN Assessment and Placement team. The SEN Assessment and Placement Service fulfils Kent County Council's statutory duties in relation to special educational needs and disabilities (SEND), particularly in relation to SEN assessments. The SEN Assessment and Placement Service monitors your child's

progress via annual review specialist placements. The service will:

- make decisions about whether to conduct a statutory assessment and ensure annual reviews take place
- where a statutory assessment is conducted, make a decision as to whether an EHCP is issued
- make statements of SEN and Education, Health and Care Plans (EHCPs)
- where an EHCP is issued, monitor the progress of the child or young person via annual review

## **Kent County Council SEN Assessment and Placement Service**

These teams makes decisions about whether or not to conduct a statutory assessment, or whether an EHCP is needed.

If an EHCP is issued, they make sure that the progress of the child or young person is regularly monitored and formally reviewed annually.

Information about the statutory assessment process including timescales can be found here: [www.kent.gov.uk/localoffer](http://www.kent.gov.uk/localoffer)

## **NORTH KENT**

**Joynes House, New Road,  
Gravesend, Kent, DA11 0AT**

- 03000 41 93 45 or
- SENNorth@kent.gov.uk

## **SOUTH KENT**

**Kroner House, Eurogate  
Business Park, Ashford,  
Kent, TN24 8XU**

- 03000 42 08 89 or
- SENSouth@kent.gov.uk

## **EAST KENT**

**Brook House, Reeves Way,  
Whitstable, Kent, CT5 3SS**

- 03000 42 11 60 or
- SENEast@kent.gov.uk

## **WEST KENT**

**Worrall House, 30 Kings  
Hill Avenue, West Malling,  
Kent, ME19 4AE**

- 03000 42 09 97 or
- SENWest@kent.gov.uk

## STAGE: POST-16 PROVISION

Post-16 educational establishments have the same duties in identifying and meeting the needs of young people with SEN as schools. Young people may

be identified as requiring SEN Support, may have an EHCP, or a request for a statutory assessment can be made at this stage of their education.



## CHILDREN NOT AT SCHOOL

A child may not be in school for a number of reasons. You may choose to educate your child at home, or the school may have excluded them. Except for disciplinary reasons this is very rare, but the school may feel that inclusion is impossible without adversely affecting the education of other children. Kent County Council still has a duty to provide education unless you have elected to educate your child at home.

## FINANCIAL ASSISTANCE

### Transport

Kent County Council must provide free transport if it is necessary to enable the child to get to the nearest suitable school. Transport may be needed because of your child's medical condition or because you live further than walking

distance from the school. Walking distance is up to 2 miles for pupils under 8 years, and up to 3 miles for pupils from 8 to 16 years. Kent County Council may provide a free bus pass or a taxi, or if the parent provides the transport Kent County Council may give a car allowance.

### Free school meals:

If your child is in Year 2 or below, they can receive free school meals.

**Year 3 or above:** If your child is under 19 and in full-time education, they may be eligible to receive free school meals if you receive any of the following:

- Universal Credit – if you apply on or after 1 April 2018 your household income must be less than £7,400 a year (after tax and not including any benefits you get)

- Income Support
- income-based Jobseeker's Allowance
- income-related Employment and Support Allowance
- support under Part VI of the Immigration and Asylum Act 1999
- the guaranteed element of Pension Credit
- Child Tax Credit (provided you're not also entitled to Working Tax Credit and have an annual gross income of no more than £16,190)
- Working Tax Credit run-on – paid for 4 weeks after you stop qualifying for Working Tax Credit.

The quickest and easiest way to apply for free school meals is to apply online [www.gov.uk/apply-free-school-meals](http://www.gov.uk/apply-free-school-meals)

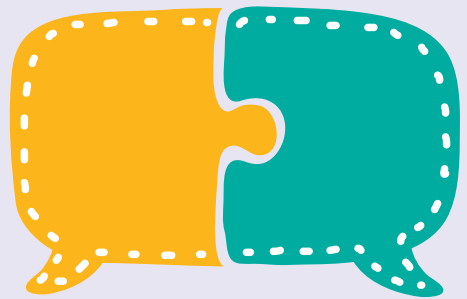
## SUPPORT

### Social Care Support

- 03000 411111

An autism or ADHD diagnosis is not required for social care support. Social care will undertake their own assessment to determine the level of support a child/family require following a referral.

An autism or ADHD diagnosis would be additional information that would contribute to the assessment process.



## Information, Advice and Support Kent (IASK)

A helpline is open Monday to Friday, 9am – 5pm.

- 03000 41 3000
- [iask@kent.gov.uk](mailto:iask@kent.gov.uk)
- [www.iask.org.uk](http://www.iask.org.uk)

You should receive a response within two days.

IASK offers impartial support for families of children and young people (0 – 25 years) with special educational needs or disabilities. They help support children/young people and their parents to make informed choices about their children's education, other

outcomes and communicate confidently. Their advice and support is confidential and impartial. They are not on anybody's side and can:

- help you make informed decisions
- help you plan how to communicate your views or concerns in meetings or on paper
- come with you to meetings as a neutral person
- provide face to face support
- provide information about other agencies and processes
- help you prepare paperwork

- provide independent support for the statutory assessment process and at annual reviews
- offer you training and workshops.

### **Independent Provider of Special Education Advice (IPSEA)**

IPSEA is a registered charity. It offers free and independent legally based information, advice and support to help get the right education for children and young people with all kinds of special educational needs and disabilities (SEND) in England including:

- the legal duties that nurseries, schools and colleges have to support children and young people with special educational needs (including a Frequently Asked Questions section)
- school refusals (including anxiety) and exclusion
- letter templates.

You can book a helpline appointment via their website where downloadable resources are also available.

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

### **SOS!SEN**

Offer a free, friendly, independent and confidential telephone helpline for parents and others looking for information and advice on Special Educational Needs and Disability (SEND) in England. They also have Walk-in Advice Clinics in north Kent.

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

■ 0300 302 3731



# HEALTH

There are many health services which you and your child may need. In this section we describe the various professionals who can help, depending on the age of your child, and the way in which you can access their services.

If you have any concerns about your child's health or development, you can either contact your own GP, your health visitor (if your child is under 5), or your school nurse.

## WHO CAN HELP:

### **General Practitioners (GPs)**

Your family GP practice is staffed by qualified doctors and other health professionals. You can ask that your child sees a doctor who has had paediatric training to specialise in helping children.

### **Health visitors**

The health visiting service is a workforce of specialist community public health nurses who provide expert advice, support and interventions for families expecting a new baby or those with children under 5 years old.

The health visiting service provides advice and support on a range of topics such as those listed below:

- growth, physical and emotional development and learning through play
- breastfeeding, introducing solid foods and healthy eating
- immunisations
- common infections, skin problems and minor illnesses in children
- challenges such as teething, temper tantrums, sleeping, eating and toilet training
- post-natal depression, bereavement and violence in the family
- reducing accidents in the home.

The health visiting service provide support in a number of places including in the home, in health visiting clinics, via programmes run

from children centres and through local phone lines.

The service is responsible for making sure that all children under 5 are offered a health review at specific times. The service has qualified staff who have skills in detecting those children who will require extra help from health services and other agencies.

In families where there is a child with special educational needs and disabilities, the health visitor will provide support in partnership with parents/ carers and in conjunction with other agencies.

You can contact the service direct or you can be referred by a GP or healthcare professional. Contact details of your local health visiting team are provided in your red book and are available at [www.kentcht.nhs.uk/service/kent-baby/health-visiting-service/](http://www.kentcht.nhs.uk/service/kent-baby/health-visiting-service/)

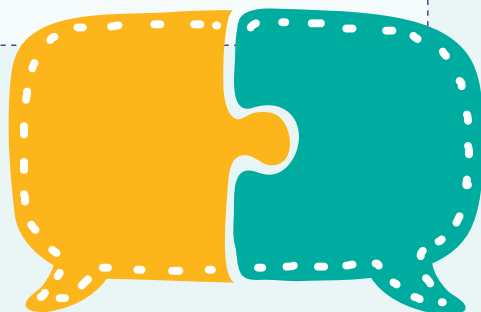
## GETTING HELP WITH YOUR PRE-SCHOOL CHILD

Often, developmental issues only become apparent once a child is in a more social setting, such as a playgroup, pre-school or nursery, at which point the leader may raise concerns with you.

You can discuss your concerns with your own GP, health visitor or pre-school/playgroup workers.

The NHS Health Visiting Service will have offered you regular health and development reviews from birth. They will contact you to arrange a final check of your baby's development when they are between 24 and 30 months old. This review will cover general development, including movement, speech, social skills and behaviour, and hearing and vision.

Your health visitor will discuss any concerns you may have and suggest any actions you can take or further help you can get. You can share any concerns raised by your health visitor at this health review with your child's lead at their pre-school/playgroup, to help inform their progress review of your child.



## School Nurse

The school public health service is a workforce of specialist community public health nurses who provide expert advice, support and interventions for families with a child of school age (5-19). You do not have to be in school to use this service if, for instance, your child is home schooled.

School nurses offer support for schools to develop a whole-school approach to improve the health of all children at school.

School nurses are available for individual health advice and support on a wide range of health needs including: daytime and night wetting and soiling, behaviour management, healthy eating and lifestyle, emotional health and wellbeing, puberty and growing up, stopping smoking, drug and alcohol misuse, sleep and complex health needs.

School nurses support parents and children to complete an online health assessment at key transition points. This makes sure that children receive any support they need as soon as possible.

At primary school, school nurses weigh and measure children in the Reception Year and Year 6 and undertake hearing and vision screening in Reception Year.

If you have any concerns about your child's health, development or well-being you should discuss these with your school nurse.

At secondary school the adolescent health and emotional wellbeing school health service offers health assessments, as well as a range of support for both physical and mental health, plus referral to specialist services when needed.

Each school has a named school nurse who can be contacted through the school.

More information can be found from visiting: [www.kentcht.nhs.uk/service/school-health/](http://www.kentcht.nhs.uk/service/school-health/)

## ACCESSING HEALTH SERVICES AND INFORMATION

Information about local services available including occupational therapy, speech and language therapy, physiotherapy and specialist nursing care can be found on the Local Offer [www.kent.gov.uk/localoffer](http://www.kent.gov.uk/localoffer)

More information about the diagnosis of ADHD can be found here: [www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/diagnosis/](http://www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/diagnosis/)

### The Pod:

- [www.kentcht.nhs.uk/childrens-therapies-the-pod/](http://www.kentcht.nhs.uk/childrens-therapies-the-pod/)

An online resource for children's therapies (physiotherapy, occupational therapy, speech and language therapy and care coordination).

Find out more about how you can support your child's learning and development, watch online films and resources to show you how to help your child to grow and learn. You can also make a referral to children's therapy services on the pod.

### Moodspark

- [www.moodspark.org.uk/](http://www.moodspark.org.uk/)

A place where young people aged 10-16 can learn how to look after their emotional and mental health and find ways to help them bounce back when life gets tough. Provided by HeadStart Kent.

## The Kent Resilience Hub

- [www.kentresiliencehub.org.uk](http://www.kentresiliencehub.org.uk)

A resource that helps young people, parents and carers and professionals to understand emotional growth and resilience. Sometimes it can be hard to know how best to support a child or young person in difficult times. HeadStart Kent have made this one place to go to increase your understanding and awareness, find approaches and tools or navigate your way to appropriate support and services. They have tried to find the best and most reliable information, articles, tools and resources relating to resilience and emotional wellbeing but would welcome suggestions and comments for other things that have helped you.

## Children and Young People's Mental Health Service

- [www.nelft.nhs.uk/services-kent-children-young-peoples-mental-health/](http://www.nelft.nhs.uk/services-kent-children-young-peoples-mental-health/)

For a consultation or to make a referral call the single point of access on: **0300 123 4496**.

The Children and Young People's Mental Health Service (CYPMHS) provides emotional wellbeing and mental health advice and support for young people and their families across Kent.

This service is available to children and young people up to the age of 18 and up until the age of 25 for young people with special educational needs or as part of a wider network of support for children and young people in the care of the local authority.

CYPMHS offers advice and support for stress, low mood and depression, anxiety, self-harm or difficult to manage behaviours and assessment for neurodevelopmental difficulties such as Attention Deficit Hyperactivity Disorder (ADHD) or Autism Spectrum Disorder (ASD).

## OTHER SPECIALISTS AND SERVICES THAT YOUR CHILD MAY NEED

### **Children's continence products service**

This is a team of nurses and support workers who support children and young people assessed as needing support with continence products to help with bed and day wetting or soiling.

■ 01227 594633

### **Dental care clinics**

Dental care can be provided for children with special needs at clinics. If you have a dentist who cannot treat your child, the dentist can refer you to the Community Dental Service. If you do not have a dentist, your GP, the school nurse or other healthcare worker can refer.

■ 0330 123 9438

### **Dietitian**

Advice and support on food and nutritional issues may be obtained from a dietitian. When working with children with complex eating and nutritional problems, a paediatric community dietitian may work with a team of people such as doctors, psychiatrists, speech and language therapists and occupational therapists.

Anyone involved in the case of your child can refer you to the dietitian, like your GP, health visitor, specialist nurse adviser or paediatrician.

## Audiology and Vision

If you have any concerns about your child's hearing or sight contact your GP or the paediatrician involved in their care. They may refer your child for further hearing and vision testing.

## INFORMATION

### Life Saver Pods

■ [www.lifesaverpod.com](http://www.lifesaverpod.com)

A tough, waterproof yet small enough to fit on a key

ring pod which contains 10 emergency contact numbers, all your allergy alerts and illnesses and any other emergency or health details you want to put on.

### Medicalert

■ [www.medicalert.org.uk](http://www.medicalert.org.uk)

Supports people with medical conditions and allergies, keeping them safe in emergency situations, by providing the full medical ID service and custom-made medical ID jewellery.

## QUERIES, CONCERNS AND COMPLAINTS

Everyone who provides an NHS service in England must have their own complaints procedure. You can often find information in waiting rooms, at reception, on the

service provider's website, or by asking a member of staff. For more information visit: [www.nhs.uk/using-the-nhs/about-the-nhs/how-to-complain-to-the-nhs/](http://www.nhs.uk/using-the-nhs/about-the-nhs/how-to-complain-to-the-nhs/)



# ACCESSING SUPPORT

## EARLY HELP (SUPPORT FOR FAMILIES)

Kent County Council provide services that can be accessed locally at a time and place that suits families to help them to do well, stay safe and resolve problems at the earliest possible opportunity, before they become more serious.

Find out more by reading the Early Help leaflet for families: [www.kent.gov.uk/education-and-children/early-help-support-for-families](http://www.kent.gov.uk/education-and-children/early-help-support-for-families)

Depending on the help that you are looking for, there are a number of ways in which you can ask for Early Help support.

### Children's centres

Each centre offers different services, including:

- childcare
- early education
- training or finding a new job
- antenatal classes
- baby clinics
- support with breastfeeding
- support with parenting and speech and language
- drop-in sessions for parents and children
- services for children with special needs and disabilities
- opportunities for families to get involved with volunteering and designing services.

Please check with your local children's centre to find out what they offer. You can find more information here: [www.kent.gov.uk/education-and-children/childcare-and-pre-school/childrens-centres](http://www.kent.gov.uk/education-and-children/childcare-and-pre-school/childrens-centres)

## Youth Hubs

Kent County Council provide services which are aimed at young people and adolescents including:

- supporting the personal development of young people
- helping young people develop stronger relationships
- encouraging young people to respect and value differences
- promoting the voice of young people
- helping to set up, plan and evaluate youth club sessions
- clubs and activities for young people with additional needs.

Please check with your local youth hub to find out what they offer. You can

find more information here:

[www.kent.gov.uk/education-and-children/young-people/youth-hubs](http://www.kent.gov.uk/education-and-children/young-people/youth-hubs)

## Additional Support

If you would benefit from some one-to-one support or low-level family intervention this would be classed as “Additional Support”. This support is expected on average to last 6-8 weeks. Please speak to a team member at your local children’s centre or youth hub for more information.

## Disabled Children and Young People’s Teams

- 03000 41 11 11 (Monday to Friday, 9am – 5pm)
- [social.services@kent.gov.uk](mailto:social.services@kent.gov.uk)

The team offer help to 0-25 year olds with:

- severe and profound learning disabilities

- physical and sensory disabilities
- a combination of disabilities.

A member of the Disabled Children and Young People's Team will assess your child's and family's needs. This means we will talk to you about your situation and find out what you are worried about or what changes you would like to make in your life.

After the assessment, we'll agree what kind of care and support you need. This could include:

- services that can offer you or your child support
- direct payments
- help at home
- local support groups so you have people to talk to
- short breaks, including specialised social activities, play schemes and overnight residential short breaks.

If your assessment shows you're not eligible for our specialist disability services, we will always tell you about other organisations that could help you.

## LOCAL ORGANISATIONS

### **Kent wide:**

#### **Kent Autistic Trust – Children's Support Groups**

- [www.kentautistic.com](http://www.kentautistic.com)

Runs groups for families, parents and carers of children and young people, to develop a community network to help each other.

If you would like more information regarding these groups, please contact: Wendy Boorman, Family Support Officer at the Kent Autistic Trust by calling **01634 405168** or emailing [wendy@kentautistic.com](mailto:wendy@kentautistic.com)

### **The Kent Parents and Children Together (PACT) Service**

- [www.kentpact.org.uk](http://www.kentpact.org.uk)

Support with information and opportunities to meet with other parents/carers of children with SEN.

### **Headstart Kent**

- [www.kentresiliencehub.org.uk](http://www.kentresiliencehub.org.uk)

Supporting 10-16 year olds to cope better with the pressures of everyday life. HeadStart Kent is part of Kent County Council's Integrated Children's Services and aims to help young people cope better when faced with difficult circumstances in their lives, preventing them from experiencing common mental health problems.

### **Advocacy for All**

- [www.advocacyforall.org.uk/self-advocacy-groups/kent-groups/](http://www.advocacyforall.org.uk/self-advocacy-groups/kent-groups/)

They have support groups across many areas of Kent. They help people gain confidence, meet others, join in social events and hold peer support groups. They work with over 18s who live in Kent and have a diagnosis of high functioning autism or Asperger's syndrome.

### **BEMIX**

- [www.bemix.org](http://www.bemix.org)

An organisation of people with and without learning difficulties and/or autism who support people with learning difficulties and/or autism to speak up, make choices and become powerful by working and learning together. Most of their work is in Canterbury, Dover, Thanet, Sittingbourne and Medway but they do offer some support in other areas.

Bemix offers specific support for 16-24 year olds to find work with “Supported Internships” – a work coach helps find work in Swale, Medway, Thanet or Canterbury with support to get a paid job at the end of the placement.

## So You’re Autistic?

- [www.soyoureautistic.com](http://www.soyoureautistic.com)

This site forms part of So, You’re Autistic (SYA)? at the University of Kent, a support programme teaching those with a diagnosis, awaiting a diagnosis, or self-diagnosed HOW to be autistic – to understand what being autistic means for YOU. SYA? are also consultants delivering workshops on autistic experience, neurodiversity, & stigma-reduction.

## LOCAL ORGANISATIONS

In most areas of Kent parents and families have set up

support groups to help other parents. They vary in what they offer and how they operate but most families find their services helpful.

## Ashford

### ASD Ashford

- [www.asdashford.com](http://www.asdashford.com)

A parent-led group which aims to support families in the Ashford area, with children and young adults on the Autistic Spectrum as well as those with ADHD.

## Canterbury, Whitstable and Herne Bay

### SNAAP – Special Needs Advisory & Activities Project

- [www.snaap.org.uk](http://www.snaap.org.uk)
- [info@snaap.org.uk](mailto:info@snaap.org.uk)

Provide an extensive range of services to children with every kind of disability, aged from 0-25 years, in partnership with parents. The focus of the services is upon all of the child’s needs including educational,

social, developmental and emotional. We focus upon the whole family and not just on the child with disabilities.

### **Altogether Extraordinary**

- <https://www.facebook.com/pg/AltogetherExtraordinary/>

Facebook group for parents and carers of children and young people with ADHD, Autism, and/or Additional Educational Needs.

### **Dartford, Gravesham and Swanley**

#### **Beams**

- [www.wearebeams.org.uk](http://www.wearebeams.org.uk)
- [admin@wearebeams.org.uk](mailto:admin@wearebeams.org.uk)

Provide comprehensive support services to families of children and young people with any form of physical, learning or sensory impairment living in Dartford, Gravesham, Sevenoaks and the surrounding areas.

### **Sheppey**

#### **ADHD Sheppey**

- [www.adhdsheppey.com](http://www.adhdsheppey.com)
- [info@adhdsheppey.com](mailto:info@adhdsheppey.com)

Helping to educate, empower and enrich the lives of people affected by ADHD and autism. There is a weekly face to face support group that meets at the Sheppey Healthy Living Centre and a closed Facebook group for parents and children.

### **South Kent**

#### **Includes us 2**

- [www.facebook.com/pg/IncludesUs2/about/](http://www.facebook.com/pg/IncludesUs2/about/)
- [info@includesus2.org.uk](mailto:info@includesus2.org.uk)

A small, parent driven charity that provide support to disabled children, young people and their families. They operate across the districts of Ashford, Folkestone and Hythe, and Dover and support parents/carers of disabled children by providing regular, informal support groups and practical workshops.

## Swale

### For Us Too

- [www.forustoo.org](http://www.forustoo.org)
- [info@4us2.org](mailto:info@4us2.org)

Based at the Orchards centre for disabled children, Sittingbourne. The charity is run by parents and carers of disabled children and young people and aims to empower families across east Kent.

### The Autism Apprentice

- [www.autismapprentice.co.uk](http://www.autismapprentice.co.uk)

Provides information and advice and host regular information days in Sittingbourne, where parents can meet providers of services, listen to talks from experts and meet other parents who are going through similar situations.

## Thanet

### For Us Too

- [www.forustoo.org](http://www.forustoo.org)
- [info@4us2.org](mailto:info@4us2.org)

Based at the Green Banks centre for disabled children, Margate. The charity is run by parents and carers of disabled children and young people and aims to empower families across east Kent.

## West Kent

### Space 2 Be Me

- [www.space2beme.org.uk](http://www.space2beme.org.uk)
- [info@space2beme.org.uk](mailto:info@space2beme.org.uk)

They work across west Kent (mainly Maidstone, Tonbridge & Malling and Tunbridge Wells) with disabled children and young people with additional needs aged from birth to 25 and their families. They work in partnership with our member families to design all our activities and services so that they support disabled children, support parents, and support the whole family.



# HELP FROM NATIONAL AND INTERNATIONAL ORGANISATIONS

## ADHD

The NHS provides information on ADHD here: [www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/](http://www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/)

Information from Great Ormond Street Hospital for Children about ADHD: [www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/attention-deficit-hyperactivity-disorder-adhd](http://www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/attention-deficit-hyperactivity-disorder-adhd)

### **ADDers.org**

■ [www.adders.org](http://www.adders.org)

Set up to promote awareness of ADD (Attention Deficit Disorder) and ADHD, and to provide information and as much free practical help as it

can to those affected by the condition, both adults and children and their families.

### **ADDISS**

■ [www.addiss.co.uk](http://www.addiss.co.uk)

An ADHD information service that provides training and support for parents, sufferers and professionals in the fields of ADHD and related learning and behavioural difficulties.

### **ADDUP**

■ [www.addup.co.uk](http://www.addup.co.uk)

Addup was set up to bring families together, to guide parents in the right direction to find the practical help they need for their children and to promote both public and professional awareness of ADHD.

## **ADHD Foundation**

- [www.adhd.foundation.org.uk](http://www.adhd.foundation.org.uk)

Works in partnership with individuals, families, doctors, teachers and other agencies to improve emotional wellbeing, educational attainment, behaviour and life chances through better understanding and self-management of ADHD, ASD and related learning difficulties such as dyslexia, dyspraxia, Irlen's Syndrome, dyscalculia and Tourette's Syndrome.

## **ADHD Kids**

- [www.adhdkids.org.uk](http://www.adhdkids.org.uk)

A website set up by a parent who shares her experiences of parenting her son, Daniel, who has ADHD and what she has learnt that might help other families.

## **Living with ADHD**

- [www.livingwithadhd.co.uk](http://www.livingwithadhd.co.uk)

Provides advice whether you are a teenager who has been diagnosed with ADHD, or you are the parent/carer or teacher of someone who has the condition.

## **UKAP – the UK ADHD Partnership**

- [www.ukadhd.com/](http://www.ukadhd.com/)

Established by mental health and allied professionals to improve outcomes and secure better futures for children and young people affected by Attention Deficit Hyperactivity Disorder (ADHD), together with their carers and families.

## **Young Minds**

- [www.youngminds.org.uk/find-help/conditions/adhd-and-mental-health](http://www.youngminds.org.uk/find-help/conditions/adhd-and-mental-health)
- [www.youngminds.org.uk/find-help/for-parents/parents-guide-to-support-a-z/parents-guide-to-support-adhd/](http://www.youngminds.org.uk/find-help/for-parents/parents-guide-to-support-a-z/parents-guide-to-support-adhd/)

An organisation that is there to make sure young minds get the best possible mental health support. They have an explanation of ADHD and some advice for parents on their website.

## **AUTISM**

The NHS provides information on autism here: [www.nhs.uk/conditions/autism/](http://www.nhs.uk/conditions/autism/)

## **Ambitious about Autism**

- [www.ambitiousaboutautism.org.uk](http://www.ambitiousaboutautism.org.uk)

Provide services, raise awareness, offer training, support and advice for children and young people with autism and their families.

## **Autism Awareness Centre Inc.**

- [www.autismawarenesscentre.com](http://www.autismawarenesscentre.com)

The Autism Awareness Centre Inc. believes that education is the key to success in assisting individuals with autism and other conditions. They are committed to ensuring their extensive autism resource selection features the newest titles available in North America.

Their blog post about Sensory Processing Disorder (SPD) contains a link to a set of checklists from infants to adulthood.

## **The Autism Directory Charity**

- [www.autismdirectorycharity.com](http://www.autismdirectorycharity.com)

A directory of autism related services, products and autism friendly business in your local area and beyond. They also run a national helpline on a range of issues such as benefits, diagnosis, employment and education.

## **Autism links**

- [www.autismlinks.co.uk](http://www.autismlinks.co.uk)

Information and vital links to help you find resources, information, support groups and good ideas to support someone living with autism.

## **Child Autism UK**

- [www.childautism.org.uk](http://www.childautism.org.uk)

Provide services to enable children to overcome difficulties with communication, learning and life skills and give families the techniques and strategies to cope with autism through the use of Applied Behaviour Analysis (ABA).

## **The Curly Hair Project**

- [www.thegirlwiththecurlyhair.co.uk/](http://www.thegirlwiththecurlyhair.co.uk/)

The Curly Hair Project is an award-winning social enterprise founded by autistic author and entrepreneur Alis Rowe. The Girl with the Curly Hair is a character created by Alis to communicate the feelings and thoughts of a person who has autism. Curly Hair Project resources are used by individuals, families and professionals worldwide.

## **The National Autistic Society**

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

Offer practical help, information and advice for people with autistic spectrum disorders and their families.

## GENERAL SUPPORT

### **AFASIC**

■ [www.afasic.org.uk](http://www.afasic.org.uk)

Helping families to understand speech, language and communication needs (SLCN) and Development Language Disorder (DLD). Provides support, information and advice.

### **The British Dyslexia Association**

■ [www.bda-dyslexia.org.uk](http://www.bda-dyslexia.org.uk)

Confidential information, advice and signposting

dyslexia-related queries including assessment and specialist teacher-training.

### **Caudwell Children**

■ [www.caudwellchildren.com](http://www.caudwellchildren.com)

Provide family support services, equipment, treatment and therapies for disabled children and their families across the UK.

### **Changing Places toilets**

■ [www.changingplaces.uktoiletmap.org/](http://www.changingplaces.uktoiletmap.org/)

Changing Places toilets have extra features to meet the needs of people with a range of disabilities. The toilets provide enough space and the right equipment, including a hoist and height adjustable changing bench. To see where the Changing Places toilets are in Kent search by postcode on the Changing Places website.

## Contact

- [www.contact.org.uk](http://www.contact.org.uk)

Provide support, information, fact sheets, workshops and events to families of children with any kind of disability. They can also put families in touch with each other or local groups.

## The Contenance Foundation

- [www.contenance-foundation.org.uk](http://www.contenance-foundation.org.uk)

Provide information, advice and expertise on all bladder and bowel problems.

## The Disability Law Service

- [www.dls.org.uk](http://www.dls.org.uk)

Provide free legal advice to people with disabilities and their carers to ensure that they have access to their rights and justice.

## Epilepsy Action

- [www.epilepsy.org.uk](http://www.epilepsy.org.uk)

Offers advice, information and factsheets.

## ERIC (Enuresis Resource and Information Centre)

- [www.eric.org.uk](http://www.eric.org.uk)

Provides information and advice on the common condition of nocturnal enuresis or bedwetting. Also offer advice on childhood day-time wetting and soiling.

## Hidden Disabilities Sunflower

- [www.hidden-disabilitiesstore.com](http://www.hidden-disabilitiesstore.com)

The Hidden Disabilities Sunflower originated in 2016 when Gatwick Airport asked 'How can we recognise that one of our passengers may have a non-obvious disability?' The answer was to create a lanyard with a simple sunflower design on a green

background as a subtle but visible sign enabling airport staff to recognise that the wearer (or someone with them) may require some extra help, time or assistance. It's starting to be recognised globally and has been adopted in the UK by all major airports, many supermarkets, railway stations, leisure facilities, in the NHS and an increasing number of small and large businesses and organisations.

## Listening Books

- [www.listening-books.org.uk](http://www.listening-books.org.uk)

Provides an audio book library for anyone who has difficulty reading the usual way. Can be downloaded to a portable player.

## Mencap

- [www.mencap.org.uk](http://www.mencap.org.uk)

Provide information, advice and support for people with learning disabilities.

## National Center for Child Anxiety Resilience Education and Support

- [www.carescenter.ucla.edu/](http://www.carescenter.ucla.edu/)

The UCLA Child Anxiety Resilience Education and Support (CARES) Center is an innovative American centre dedicated to supporting the development of resilient, emotionally healthy children. The centre is also focused on training, research, and community outreach to help clinicians, researchers, school staff, and parents recognize the early signs of childhood anxiety and support families in accessing resources to build family strengths and resilience.

## Selective Mutism Information & Research Association (SMiRA)

- [www.selectivemutism.org.uk/](http://www.selectivemutism.org.uk/)

SMiRA's team consists mainly of volunteers who all have knowledge of selective mutism, whether as parents, professionals or from their own personal experience. SMiRA operates a very active Facebook page, and has links to other groups and professionals throughout the world.

## Sibs

- [www.sibs.org.uk](http://www.sibs.org.uk)

Provide support and information for people who grow up with a brother or sister with a disability.

## Winston's Wish

- [www.winstonswish.org](http://www.winstonswish.org)

Winston's Wish provides bereavement support for children after the death of a parent or sibling. Autistic people can sometimes understand death in a very concrete way and so may benefit from the resources used for younger children.

Check this information is up to date by visiting [www.kent.gov.uk/localoffer](http://www.kent.gov.uk/localoffer) – this website explains what the Local Offer is for families with children with special educational needs. As a printed document this handbook can go out of date so it is always best to check online.



# RIGHTS AND BENEFITS

## HELPLINES

### Benefit Enquiry Line

■ 0800 1690310

A free helpline for people with disabilities that provides information, advice and help with form filling.

### Carers Support East Kent

■ 01304 364637

Information on benefit rates and help with form-filling.

### Contact

■ 0808 808 3555

A charity for families with disabled children – provide factsheets, information and advice on benefits.

## WEBSITES

### Benefits and Work

■ [www.benefitsandwork.co.uk](http://www.benefitsandwork.co.uk)

Downloadable step-by-step guide that can help with completing DLA forms.

### Carers UK

■ [carersuk.org/DLA](http://carersuk.org/DLA)

Find out more about the UK Disability benefits, how to claim, factsheets and online forum.

### Department for Work and Pensions

■ [www.dwp.gov.uk](http://www.dwp.gov.uk)

Government information on all benefits.

## Contact

- [www.contact.org.uk](http://www.contact.org.uk)

A charity for families with disabled children – provide factsheets, information and advice on benefits.

## BENEFITS

### Carer's Allowance

- 0800 7510297
- [www.direct.gov.uk/carers](http://www.direct.gov.uk/carers)

An allowance for the carer of a disabled person. To qualify the carer must be aged over 16 and spend at least 35 hours per week caring for the disabled person who is getting Disability Living Allowance (DLA). It is not available to people who are full-time students (studying 21 hours or more per week) or who earn over £123 per week (current rates, net, after costs such as childcare). Carer's Allowance is

not means-tested, it is taxable and counts as income for Tax Credits and Universal Credit.

If you are paid Carer's Allowance the person you care for cannot get the Severe Disability Premium included in the award of any pre Universal Credit means-tested benefit they receive.

### Disability Living Allowance (DLA)

- 08457 123 456
- [www.dwp.gov.uk](http://www.dwp.gov.uk)

This is a non-means tested benefit for children under the age of 16 years with disabilities, to help with the extra costs of bringing up a disabled child. To claim for a child, they should be one or more of the following:

- aged 3 months or over and generally needs extra help or looking after
- aged 3 or over and has severe difficulty walking

- aged 5 years or over and needs extra help getting around out of doors

Just before your child reaches their 16th birthday you will be sent an application form to fill out to claim Personal Independent Payment (PIP).

There are two components to this allowance:

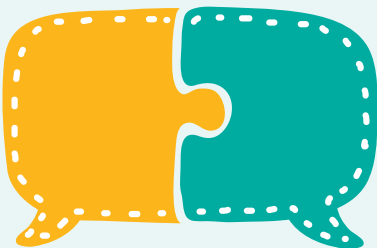
1. **Care component** which is payable at three rates depending on how much care is needed:

- **High rate** – For extra help during the day and night.
- **Middle rate** – For extra help during the day or night.
- **Low rate** – For extra help during part of the day or part of the night.

2. **Mobility component**

which is payable at two rates depending on how much help is needed.

- **High rate** – for a child who is unable to walk or has severe difficulty in walking; children who are deaf and blind; those whose health might suffer from the exertion of walking; those claiming the highest rate care component who have severe mental impairment or severe behaviour problems. This rate is payable for children 3 years and over.
- **Low rate** – for a child who can walk but may need someone to supervise or guide them. Rate payable for children 5 years and over.



You can also receive the following additional elements depending on which rate you receive.

## Care component:

### Low rate

- Child amount and disabled child addition (at the lower rate) on Universal Credit.
- Benefit cap exemption in Housing Benefit and Universal Credit
- Disabled child element/ disabled child rate on Child Tax Credit
- Disabled child premium on Housing Benefit

### Middle or high rate:

- Carer's Allowance and Carer's Test on Universal Credit
- National Insurance Carer's Credit
- Carer's eligibility on Income Support

### High rate:

In addition to the above section you can also claim:

- Enhanced Disability Premium child on Housing Benefit

## Mobility component

### Low rate:

- Same as low rate care component

### High rate:

- Exemption from Vehicle Tax
- Eligibility for a Blue Badge
- Eligibility for the Mobility Car Scheme

## Premiums for people on Income Support

If you are still receiving Income Support, you can apply for the Severe Disability Premium. Income Support is transferring to Universal Credit.

## Universal Credit

Universal Credit is a means-tested benefit paid to people of working age who are on a low income. You can claim it if you're looking for work, if you are unable to work through sickness or disability, if you are a lone parent, if you are caring for someone or if you are working and your wages are low.

Universal Credit is being introduced over several years and replaces the following benefits;

- Child Tax Credit
- Housing Benefit
- income related employment and support allowances

- income based Job Seeker's Allowance
- Working Tax Credit

There is a carer amount included in your award if you have regular and substantial caring responsibilities for a severely disabled person. You do not need to have made a claim for Carer's Allowance to have the amount included in your award.

The benefit cap does not apply if you are receiving DLA or PIP for a child or young person you are responsible for.

## Council Tax Reductions

Contact the council you pay your council tax to, to find out if you are entitled to a reduction.

There are 2 types of reductions you may be entitled to:

**25% reduction** – If you care for at least 35 hours per week for someone receiving the highest rate of the care

component of DLA, you may be classed as a 'disregarded person' and be entitled to a 25% reduction in council tax.

**Reduction in band** – If your home has been specifically adapted to meet the needs of a disabled resident who is substantially and permanently disabled, you may be entitled to a reduction in your council tax band. Adaptations that qualify are:

- a room (not kitchen or bathroom) mainly used by the disabled person or
- an extra kitchen or bathroom to meet their needs or
- enough floor space for a wheelchair used indoors.

### **NHS Low Income Scheme**

- 0300 1230849
- [www.nhs.uk/using-the-nhs/help-with-health-costs/nhs-low-income-scheme-lis/](http://www.nhs.uk/using-the-nhs/help-with-health-costs/nhs-low-income-scheme-lis/)

If you receive benefits on low income grounds you can fill out an HC1 form to see if you are eligible for free travel to hospital, free prescriptions, free dental care and free eye tests. There are 2 certificates available, HC2 (full entitlement) HC3 (partial entitlement).

### **National Key Scheme (Public Toilets)**

- [www.radarkey.org](http://www.radarkey.org)

National Scheme run by RADAR which gives access to specially adapted public toilets in most towns and cities. Keys are available from your local council offices, and are also available to buy online.

### **Relief from VAT**

- 0845 010 9000

Some gadgets and equipment designed solely for people with disabilities are zero rated for VAT. These include

medical and surgical appliances, specialised articles such as special beds, lifts and hoists and installation costs of special equipment. Certain building work such as improving access to a building, adaptations to a bathroom and the installation of a lift are also exempt from VAT.

### **Water Meter Charges**

If you have metered water, are on income related benefits (such as Income Support, Housing or Council Tax benefit or Tax Credits) and use more than average, you may be able to get your bill capped. You must also have either 3 or more children under 16, or you or your child has a flaky or weeping skin disease, incontinence, Crohn's or Ulcerative Colitis abdominal stoma or renal failure requiring dialysis at home. Contact the organisation who you pay your water bill to.

## HELP WITH FUNDING

There are some organisations that provide financial support and grants for children with disabilities. Each organisation will have different criteria for funding. Have a look on their websites to see if you may qualify.

### **Always Look on the Bright Side of Life**

- [www.thebrightsideoflife.org.uk](http://www.thebrightsideoflife.org.uk)

To relieve the needs of children (under 18 year olds) by reason of finance, illness, or other disadvantage, by the provision of grants to improve their conditions of life.

### **Cauldwell Children**

- [www.cauldwellchildren.com](http://www.cauldwellchildren.com)

Provides grants for special buggies and car seats, therapy trikes and multi-sensory equipment.

## Family Fund

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

Provides grants to families who have a disabled or seriously ill child. Criteria applies, for more information visit their website.

## My AFK

- [www.my-afk.org](http://www.my-afk.org)

Provides grants for equipment and mobility aids for children and young people with physical and mental disabilities.

## Tree of Hope

- [www.treeofhope.org.uk](http://www.treeofhope.org.uk)
- 01892 535525

Crowdfunding charity that helps children and young people with a disability or illness by supporting their families to raise the money they need to pay for specialist care that is not freely available through the UK healthcare system.



Check this information is up to date by visiting [www.kent.gov.uk/localoffer](http://www.kent.gov.uk/localoffer) – this website explains what the Local Offer is for families with children with special educational needs. As a printed document this handbook can go out of date so it is always best to check online.



# TRANSPORT

## Help with hospital fares

If you receive Income Support, income-based Job Seeker's Allowance, Universal Credit or Pension Credit, you can claim help with travel costs to and from hospital for NHS treatment when escorting your child. You can obtain a refund of your fares directly from the hospital if you produce proof that you are in receipt of benefits. Ask at the hospital for form HC1.

If you are not receiving these benefits but are on a low income (if your child is 16 years or over it is their income that counts, not yours) you may still be able to get help. Ring the hospital and ask who you need to speak to, to find out what help is available.

## Blue Badge scheme

- [www.kent.gov.uk/social-care-and-health/care-and-support/disability/apply-for-a-blue-badge](http://www.kent.gov.uk/social-care-and-health/care-and-support/disability/apply-for-a-blue-badge)

If you're disabled or have a health condition that affects your mobility, you can apply for a Blue Badge. You can also apply for a badge if you care for a child with a health condition that affects their mobility. Apply online through Kent County Council.

## Bus pass

- [www.kent.gov.uk/roads-and-travel/travelling-around-kent/bus-travel/bus-passes/bus-passes-for-older-or-disabled-people](http://www.kent.gov.uk/roads-and-travel/travelling-around-kent/bus-travel/bus-passes/bus-passes-for-older-or-disabled-people)
- 03000 418383

Free off-peak travel on local bus services for a disabled person and a companion, between

9.30am and 11.00pm, Monday to Friday and all day at weekends and public holidays. An application form can be downloaded from the Kent County Council website.

### **Disabled Persons Railcard**

- [www.disabledpersons-railcard.co.uk](http://www.disabledpersons-railcard.co.uk)
- 0345 605 0525

For people with a disability that makes travelling by train difficult. Get 1/3 off adult rail fares and, if you're travelling with another adult, they will also get 1/3 off their rail fare. There are no time restrictions on the Disabled Persons Railcard, so you can use it to get a discount on tickets at any time of the day and each railcard costs £20 a year.

### **Exemption from vehicle tax**

If your child gets the higher rate DLA or PIP mobility component, you should automatically be sent a

vehicle tax exemption form (DLA 403) from the DLA unit. It is important that you complete and return the exemption form to the address stated on the letter enclosed with the form.

### **London congestion charges**

- [www.cclondon.com](http://www.cclondon.com)

Blue Badge holders are exempt from the congestion charge in central London. You need to register with Transport of London and make a one-off payment of £10.

### **Motability scheme**

- [www.motability.co.uk](http://www.motability.co.uk)

The motability scheme enables disabled people to get mobile by exchanging their mobility component of their DLA or PIP to lease a new car, scooter, powered wheelchair or wheelchair accessible vehicle (WAV). You can apply after your child is three. You may have to make an advance payment.



# AIDS AND EQUIPMENT

## TRANSPORT

### Crelling Harnesses

- [www.crelling.com](http://www.crelling.com)

Supply a large range from simple belts and adult walking reins to full harnesses including the 'Houdini Stop' strap and rear fastening harness.

### McClaren Major Buggy

- [www.maclarenmajor.com](http://www.maclarenmajor.com)

Lightweight special needs buggy suitable for children up to 50kgs.

### Mission Cycles

- [www.missioncycles.co.uk](http://www.missioncycles.co.uk)

Range of tricycles for children and teenagers with various balance problems and disabilities.

### Strider

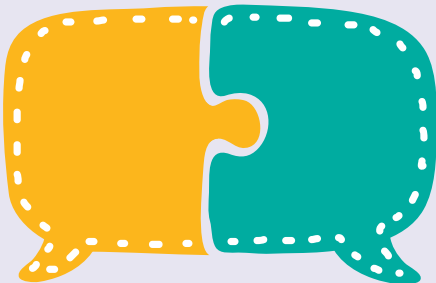
- [www.striderbike.co.uk](http://www.striderbike.co.uk)

Provide Balance Bikes to help children learn how to build their coordination and balance before moving onto a pedal bike.

### In Car Safety Centre

- [www.incarsafetycentre.co.uk/special-needs](http://www.incarsafetycentre.co.uk/special-needs)

Offers a range of special needs car seats, harnesses and clips and guards to adapt car seat belts.



## CLOTHING

### **Born Anxious**

- [www.bornanxious.co.uk](http://www.bornanxious.co.uk)

Label free clothing range for children and adults can also be personalised with disabilities and information to help you explain your child's needs.

### **M&S Easy Dressing School Uniform**

- [www.marksandspencer.com](http://www.marksandspencer.com)

Uniform designed with sensory needs and fine motor skill difficulties in mind.

### **Rackety's**

- [www.disabled-clothing.co.uk](http://www.disabled-clothing.co.uk)

Specialist disabled clothing available in bigger sizes, washable swim pants and costumes, all in one pyjama, washable continence pads and bibs.

## COMPUTERS AND IT

### **Abilia Ltd**

- [www.abilia.com](http://www.abilia.com)

High quality assistive tools to help people live richer lives using communication aids. Also have a handy calendar app to help organise your day and clearly see what needs to be done when with simple pictures, symbols and checklists.

### **Inclusive Technology**

- [www.inclusive.co.uk](http://www.inclusive.co.uk)

Leading supplier of software, hardware and apps for people with special needs.



# SOME ADVICE ABOUT BEHAVIOUR

Some children have behaviours that parents find difficult to manage and that cause considerable stress to the whole family.

It is always useful to start by trying to identify the reason for behaviour from the child's perspective and considering what the child is trying to communicate through their behaviour.

Some behaviours are directly linked to difficulties trying to

communicate. Other triggers might be social situations which they find stressful, unstructured time, sensory difficulties or change.

Understanding your child's difficulties can help you develop strategies to help behaviour problems.

You may find it helpful to track your child's behaviour in a diary, so you can begin to see patterns in behaviour and notice small, positive changes as you develop strategies.



Some possible underlying reasons for behaviour

- **frustration:** they can't do something or can't tell you what they want
- **fear:** they are frightened of something
- **strong feelings:** they are unhappy or angry about something
- **hyperactivity:** they have excess energy and cannot seem to burn it off
- **discomfort:** they are in pain
- **attention:** they have learnt they get your attention by behaving a certain way
- **lack of understanding:** they may need time to work out what you mean and so don't respond to an instruction when you expect them to
- **difficulty processing:** or making sense of sensory experiences in the environment.



**Myth:** *Children are just naughty, and if parents knew how to bring up their children they would behave like other children.*

**Truth:** This is probably the most hurtful myth as it shows a complete misunderstanding of what a child is feeling.

Autistic children and children with ADHD may behave in a way that is perceived by some as just naughty but no amount of good parenting can alter the fact that a child has a special educational need or disability.

## SETTING THE SCENE FOR POSITIVE BEHAVIOUR

All children will communicate their needs and respond to situations differently. But there are some general rules that will help you manage your child's day to day behaviour.

### ■ Establish daily routines

- Most children will cope more easily if they know in advance what is going to happen. Visual timetables can help with this
- Routines can also be used to set up clear boundaries and acceptable behaviour, which can be reinforced with rewards.

### ■ Build communication

- It is vital to have two-way communication with your child
- If your child has limited understanding, or little or no speech, there are ways of communicating you can try. This may be using simple language (one step instructions or key words), giving children time to understand what you've said or signed and repeating key instructions
- If you're asking your child to do something, give brief instructions and be specific. Instead of asking: "Can you tidy your bedroom?" say: "Please put your toys into the box and put the books back onto the shelf." This makes it clearer what your child needs to do and creates opportunities for praise when they get it right

- Don't forget your own non-verbal language/behaviour. Your tone, warmth, posture, eye contact and facial expression will all affect how your child responds to you
- You can also communicate by using visual supports – some people will understand things better if they see it rather than hear it. Seeing it, rather than saying it, helps the person retain and process information. You can use symbols, photographs or pictures familiar to the child.

The National Autistic Society has a section on their website about behaviour [www.autism.org.uk/about/behaviour.aspx](http://www.autism.org.uk/about/behaviour.aspx)

### Visual Timetables

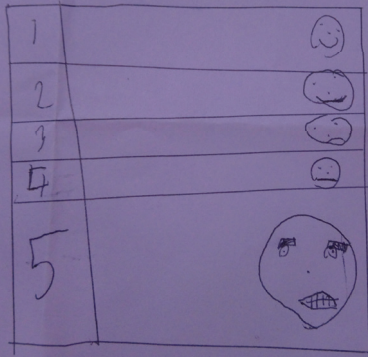
Often used with children who are on the autism spectrum and might be helpful to children with ADHD as can help them make sense of everyday life. Often used as a daily timetable, they enable children to understand what they are doing and when, give structure to the day and can reduce anxiety levels. Symbols are used to represent the tasks, activities or lessons.

### Visual supports

These are usually a single symbol, picture or message used to provide structure and routine, encourage independence, build confidence, improve understanding, avoid frustration and anxiety, and provide opportunities to interact with others.

Visual supports can be used in a range of ways:

- as a single message, the child takes a yellow card



from their pocket when they need to go to the toilet, or puts purple card on the board when they're feeling stressed

- different coloured tablecloths, e.g. white for dinner time, blue for colouring time
- basic symbol to allow a person to express an opinion, e.g. by putting a thumbs down symbol next to one of today's activities, to show they didn't enjoy it
- emotion thermometer so an individual can place a marker to explain how they are feeling and learn how to recognise emotions
- time trackers to help with starting and finishing activities, and transition between activities.

More information here:

[www.autism.org.uk/about/strategies/visual-supports.aspx](http://www.autism.org.uk/about/strategies/visual-supports.aspx) and here: <https://autismawarenesscentre.com/5-point-scale-emotional-regulation/>

## Praise and rewards

Be positive when your child behaves as you'd like. Give specific and evidence-based praise, instead of saying a general: "Thanks for doing that," you could say: "You washed the dishes really well. Thank you."

Give praise immediately and make it clear to your child that you're pleased and why.

Giving praise has so many benefits:

- helps a child's self-esteem
- shows them the difference between good and bad behaviour
- helps to set boundaries and rules, and

- reinforces the behaviours that you do want to see.

You can use a reward chart when your child needs to work on changing their behaviour. Your child collects stickers or tokens for the chart each time they behave the way you want. They then get a reward based on the number of stickers they have gathered. The stickers and the reward reinforce the praise that you give.

Alternatively, you can fill a jar with objects – glass beads, stones, and marbles. At the end of the day or week convert any objects into pocket money or small treats.

### **Social stories**

Social stories™ were created by Carol Gray in 1991. They are short descriptions of a particular situation, event or activity, which include specific information about what to expect in that situation

and why. The terms ‘social story’ and ‘social stories’ are trademarks originated and owned by Carol Gray.

A social story is a present tense story written about a situation which the child finds difficult to cope with. The aim is to increase their understanding and help them be more comfortable in situations.

Social stories may:

- describe a situation in terms of the relevant social clues and/or correct responses in a non-threatening format
- translate goals set into smaller understandable steps
- teach routines as well as helping to accommodate changes to routine
- address a wide variety of behaviours, including aggression, fear, obsessions and compulsions.

Social stories work especially well for autistic children because often they lack the ability to see situations from the perspective of others.

More information here:  
[www.autism.org.uk/about/strategies/social-stories-comic-strips.aspx](http://www.autism.org.uk/about/strategies/social-stories-comic-strips.aspx)

### Exercise

Make sure your child gets lots of physical activity during the day. Walking, skipping and playing sport can help your child wear themselves out and improve their quality of sleep.

Living with ADHD's compact guide for parents includes 15 tips for parents: [www.livingwithadhd.co.uk/files/adhd-a-compact-guide-for-parents-livingwithadhd.co.uk.pdf](http://www.livingwithadhd.co.uk/files/adhd-a-compact-guide-for-parents-livingwithadhd.co.uk.pdf)

NHS advice about ADHD can be found here: [www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/living-with/](http://www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/living-with/)

NHS advice about autism can be found here: <https://www.nhs.uk/conditions/autism/autism-and-everyday-life/>

"Separate the child from the behaviour"  
(K, aged 13)

## MANAGING DIFFICULT BEHAVIOUR

In some situations, children become anxious or distressed, which can trigger behaviour that challenges. It can take time to work out some triggers but it's important you do, so you can find ways to deal with the behaviour.

Keep social situations short and sweet. Invite friends to play, but keep playtimes short so your child doesn't lose self-control. Don't aim to do this when your child is feeling tired or hungry, such as after a day at school.

### **Devise strategies that remove or reduce the effect of triggers**

If difficult behaviour keeps happening and you are unsure about the triggers, it can be helpful to keep a diary, or a behaviour chart, to try to learn more about it. A good example is an ABC chart:

- **A – antecedents** – the things that lead up to the behaviour
- **B – behaviour** – what the child is actually doing
- **C – consequences** – what happens in response to the child's behaviour

There is a similar model that some teachers and other professionals use called STAR – Settings, Triggers, Action, and Result. They may discuss this system with you.

## Worry/Anxieties

The world can be an extremely challenging environment for an autistic child and many experience anxiety difficulties. If they do not have the tools to calm down when anxious, they may have a meltdown so developing strategies to manage anxiety and teach your child how to regulate their emotions will help.

Pick your battles carefully – when your child is autistic or has ADHD, it can seem that your entire day is spent reprimanding them. Focus on the behaviours that are the most worrying and work on those first.

## Emotional recognition

Autistic people often struggle to recognise their emotional states. They can struggle to give them a label (e.g. angry, sad) and to recognise how they feel within their body and how this might make them behave.

Parents can support emotional recognition by:

- Modelling their own experience of emotions by labelling the emotion they are experiencing and talking about how it feels and how it makes them behave (e.g. “I have burnt the toast. I’m feeling angry now, it feels all hot inside.”)
- Using emotion cards and talking about how different emotions feel
- Drawing pictures of the body and talking about how different emotions affect your body (e.g. worry can make your heart go faster). There are lots of online resources to support this such as Blissful Kids’ website [www.blissfulkids.com](http://www.blissfulkids.com)
- Accepting the emotions their child is feeling. All emotions are ok; it is the behaviour that can be difficult

- Labelling the child's emotions when you know they are experiencing them (e.g. "You seem angry now, that's ok.")
- Modelling coping strategies e.g. "When I'm angry I sometimes put on loud music."

Try to understand that there is always a reason for your child's behaviour; you may not be able to see the trigger or understand how important it is to them but just knowing there is one helps.

Here are some ways you can help your child manage anxieties and emotions:

- share different emotions together and talk about it being OK to feel worried, anxious, sad etc.
- talk about worries you have and encourage your child to tell you about the feelings they have like butterflies in their tummy
- praise your child when they tell you about worries and anxieties or use techniques they have been given
- use visual resources to teach the different feelings and emotions and talk about how to regulate emotions
- use worry monsters, worry beads, worry books, worry stones and other resources to help you child identify and manage to control their worries. Explain that once they pass the worry on it is someone else's worry to deal with and not theirs
- teach breathing techniques and introduce calm music or apps they can listen to when anxious to help them regulate themselves
- limit a child's exposure to violent, scary books, videos games and if they see anything like this that worries them talk about it and explain

- offer distractions when you see your child is becoming anxious, move their focus onto something else around them, give them a comforter, encourage them to run or jump
- make sure your child has downtime in their day to regulate themselves and manage stimulation
- introduce a calming box, punch bag or dark den which your child can use in the recovery phase.

I love chewing things.

I don't like loud noises like  
are school fire alarm.

I don't like eating.

I find it hard to go to sleep.

I do not like waking up at  
01:00 to 04:00 in the morning. I wake  
up because I have got myself used  
to it.

Please may you help me get  
to sleep.



**Myth:** “Stimming” is strange behaviour.

**Truth:** The word “stimming” refers to self-stimulating behaviours, usually involving repetitive movements or sounds. Almost everybody stims in some way such as tapping feet or chewing gum. There are various forms of behaviour that are characterised as stimming; it’s not just rocking, chewing, waving arms, or repetitive playing. It could be whistling or doing anything repetitively. The point is that a child who stims is behaving in that way as they find it comforting. It is part of a diagnosis tool for autism.

## Stimming

The word ‘stimming’ refers to self-stimulating behaviours, usually involving repetitive movements or sounds. There are several reasons for stimming which include:

**1. Over-stimulation:**

Stimming can help block out sensory overload.

**2. Under-stimulation:**

Stimming helps provide extra sensory input when needed.

**3. Management of emotions:**

Both positive and negative emotions can

trigger stimming. We’ve all seen physical reactions to joy or excitement, such as jumping or waving of hands. Frustration or anger may intensify a stim to the point of it becoming destructive.

**4.**

**Self-regulation:** Some stims serve the purpose of soothing or comforting.

## Meltdowns

A meltdown is an intense response to overwhelming situations. It is not a temper tantrum; it is not bad behaviour and it is not a child being naughty.

A meltdown happens when someone becomes completely overwhelmed by their current situation and temporarily loses control. This can be expressed verbally (shouting, screaming, crying), physically (kicking, lashing out, biting) or both.

Many will show signs of distress before having a meltdown, which is sometimes referred to as the “trigger” or “rumble”.

They may start to exhibit signs of anxiety such as pacing, seeking reassurance through repetitive questioning or physical signs such as rocking or becoming very still. At this stage, there may still be a chance to prevent a meltdown.

Strategies to consider include distraction, diversion, helping the person use calming strategies such as fiddle toys or listening to music, removing any potential triggers, and staying calm yourself.

Tips to help you and your child through them:

- keep calm, limit communication and stay positive
- talk to your child in a slow, calm, controlled voice
- empathise with them, reassure them you love them and are there to help them when they are ready
- if you can, safely get down to the child's level to talk to them but give them space. If they are hitting out or shouting to be left alone give them space
- offer a hug, hold of their hands, massage their feet, rub their back etc. when they have calmed down

- create a safe place for them to feel secure and away from others, provide items they can stretch, pull, pinch, punch, squeeze and express any feelings they have bottled
- stay close but give them space to stretch out and roll if needed.

Once calm try to teach deep breathing exercises, clenching and unclenching fists, play relaxing music and reassure them again they are loved no matter what.

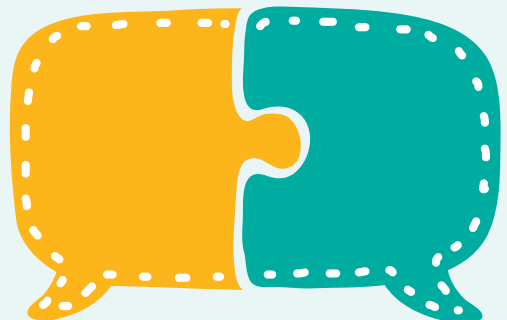
Shutdown is being frozen following a very stressful event. Some autistic people can become very quiet and self-contained or “freeze” in response to stress rather than experiencing a “meltdown”.

The Challenging Behaviour Foundation’s website has a lot of helpful information about behaviour support [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

### **Self-injuring behaviours**

There might be a number of factors causing a young person to self-injure which include:

- They feel they are not being listened to
- They have been told off
- They feel they have little or no choice about things
- They have been bullied
- They are feeling unwell.



The Royal College of Psychiatrists have information on their website for parents and carers: <https://www.rcpsych.ac.uk/mental-health/parents-and-young-people/information-for-parents-and-carers/self-harm-in-young-people-for-parents-and-carers>

**Helpful tip:** The National Autistic Society's website has a section around 'self-injury': [www.autism.org.uk/about/behaviour/challenging-behaviour/self-injury.aspx](http://www.autism.org.uk/about/behaviour/challenging-behaviour/self-injury.aspx).

## Sleep Advice

Many people with autism or ADHD are likely to suffer from disturbed sleep patterns at some point in their lives.

Reasons for this could include:

- waking repeatedly during the night, or having difficulty getting back to sleep after waking up to go to the toilet
- increased anxiety or an inability to relax causing insomnia
- social cueing problems, where an autistic person doesn't make the connection between others in the house going to bed and their own need to sleep
- irregular secretion of the sleep hormone melatonin, which regulates sleep patterns, or having atypical circadian rhythms (body clock)
- neurological conditions such as epilepsy
- sensory differences, such as increased sensitivity to blue light from smart phones, laptops and other screens, or sensitivity to certain sounds or white noise,
- having difficulty settling, winding down and going to sleep

which may be upsetting or distracting and keep them awake

- problems caused by food allergies, which could cause gastrointestinal issues and discomfort, or increased sensitivity to caffeine or other stimulants, which can disturb sleep
- hypersomnia – sleeping too much. Increased exhaustion could be caused by the additional stress autistic people experience in social situations.

### **Strategies for dealing with sleep disorders**

- Keep a sleep diary. This can help establish any unusual patterns of sleep and identifying factors but also be shown to professionals such as teachers, GPs etc.
- Establish a reassuring routine. Use visual timetables to make it easier to follow, limit screen time (TV, computer, tablet,



smart phone) or exposure to bright lights an hour or two before bedtime, as these can inhibit the production of the sleep hormone Melatonin

- Make the bedroom more comfortable. Some children have sensory difficulties which makes it harder for them to relax, as well as stay asleep
- Block out light using dark curtains or black-out blinds
- Help reduce noise by using thick carpets, shutting doors, turning off appliances and moving your child's bed away from a wall with activity going on the other side

- Block out noises by letting the person use ear plugs or listen to music through headphones
- Remove labels from bedding and night clothes, or try bedding and nightclothes made from other materials
- Reduce smells coming into the room by closing the door fully, or by using scented oils that the person finds relaxing
- Remove distractions, such as toys on the bed and pictures on the wall (unless the person finds these relaxing), and consider a different colour on the walls
- Use relaxation techniques such as having a bath, massage, quiet time or gentle exercise such as yoga, to help the person wind down before bedtime.

## TOYS AND BEHAVIOURAL AIDS

### Do2Learn

- [www.do2learn.com](http://www.do2learn.com)

Free printable activities and picture cards plus forms to assess behaviour and implement strategies to manage it.

### Orkid Ideas

- [www.orkidideas.com](http://www.orkidideas.com)

Provide tools to help children develop coping strategies to manage their day.

Downloadable resources for anxiety, behaviour and emotions, communication and social skills, timetable, schedule and routine.

### The Play Doctors

- [www.theplaydoctors.co.uk](http://www.theplaydoctors.co.uk)

Provide resources and visual aids to support

communication, behaviour, anxiety (worry books and toolkits), social skills including social stories and emotions.

## **Twinkl**

■ [www.twinkl.co.uk](http://www.twinkl.co.uk)

Large range of free downloadable behaviour and reward charts.

## **Widgit**

■ [www.widgit.com](http://www.widgit.com)

Printable symbols for use with visual timetables and visual aids/supports.

## **Chewigem**

■ [www.chewigem.co.uk](http://www.chewigem.co.uk)

Offer a range of chewing, fidget and sensory aids.

## **Fledglings**

■ [www.fledglings.org.uk](http://www.fledglings.org.uk)

Toys, clothes and sensory products for disabled children.

## **ROMPA**

■ [www.rompa.com](http://www.rompa.com)

Provide specialist play, leisure, therapy and sport equipment including sensory toys and equipment.

## **Sense Toys**

■ [www.sensetoys.com](http://www.sensetoys.com)

Sensory toys and educational resources for children with special needs, including autism and ADHD.

## **Spacekraft**

■ [www.spacekraft.co.uk](http://www.spacekraft.co.uk)

Supply an extensive range of multi-sensory toys and equipment.

## **TFH Special Needs Toys**

■ [www.specialneeds-toys.com](http://www.specialneeds-toys.com)

Wide range of robust toys and equipment including multi-sensory, soft environment equipment, toys, switches and music.



# HOW AUTISM AND ADHD CAN AFFECT YOU AND YOUR FAMILY

Having an autistic child or one with ADHD can put a lot of strain on you and your family. You might need to spend a lot of time helping your child get the support they need. This can be very stressful and exhausting.

It may be hard to make time for the rest of your family and can affect your relationships with each other. If you feel you need help, you can get support from lots of places.



## THINGS THAT CAN HELP YOU AND YOUR FAMILY

### DO

- ask friends and family if they can help with day-to-day things or just be there to talk to
- get advice from other parents of autistic children or autistic adults
- look at websites listed elsewhere in this handbook – like [www.kent.gov.uk/localoffer](http://www.kent.gov.uk/localoffer)
- listen to other parents' stories – the charity [www.healthtalk.org](http://www.healthtalk.org) has stories about living with autism and ADHD or you can search online for blogs, videos and books
- ask your local council for a Carer's Assessment – you might be able to get extra support and financial benefits **(see Rights and Benefits section of this handbook, pages 49-57).**

### DON'T

- feel guilty for taking time for yourself when you can – even just going for a walk on your own can help give you a break.

## TALKING TO YOUR CHILD ABOUT AUTISM OR ADHD

It's your choice when you want to tell your child about their autism or ADHD but you should seek advice about it from health professionals. Some parents do it straight away, while others wait until their child's a bit older.

### **When you tell your child, it may help to:**

- do it when they're feeling calm or relaxed
- talk to them in a place where they feel comfortable, with no distractions
- explain they do not have an illness, but they might need extra support to help them with some things

- explain they might find some things harder than other people, and some things easier
- bring them to a support group to meet other children.

The Autism Easy Read Guide from the National Autistic Society website might help you explain autism in a way your child will understand:

[www.autism.org.uk/about/what-is/asd/intro-easyread](http://www.autism.org.uk/about/what-is/asd/intro-easyread)

Some guidance from a parent about explaining ADHD to children can be found here:

[www.adhdkids.org.uk/explain-adhd-child](http://www.adhdkids.org.uk/explain-adhd-child)

**"So, You're Autistic?"** has a website containing resources and signposting for autistic young people.

[www.SoYoureAutistic.com/young-people-portal](http://www.SoYoureAutistic.com/young-people-portal)

## SUPPORTING YOUR OTHER CHILDREN

Some children can find it hard if their brother or sister is autistic or has ADHD. If you have other children, there are things you can do to help them.

### DO

- make time for them whenever you can – try to do some activities with just them
- talk to them about what's going on and ask if they have any questions or worries
- let them have time on their own or with their friends – for example, sleepovers at friends' houses
- check the advice from Sibs, a charity for siblings of disabled children [www.sibs.org.uk](http://www.sibs.org.uk) or the Kent young carers website [www.imago.community/Children-and-young-people/kent-young-carers](http://www.imago.community/Children-and-young-people/kent-young-carers)

### DON'T

- exclude them in things like meetings with health professionals – it can help them understand what's going on.

## AFTER YOUR CHILD'S DIAGNOSIS

An autism or ADHD diagnosis can be difficult to come to terms with at first. You might know very little about it while at the same time be trying to find new ways for everyone to live together and feel supported.

The National Autistic Society's website [www.autism.org.uk](http://www.autism.org.uk) has a wealth of information you may find useful, including for parents, partners and siblings, and includes real-life stories. It also provides information for grandparents, and for the children of autistic parents.

Here are some key areas of the website to look at:

- [www.autism.org.uk/about/family-life](http://www.autism.org.uk/about/family-life)
- [www.autism.org.uk/about/family-life/siblings](http://www.autism.org.uk/about/family-life/siblings)
- [www.autism.org.uk/about/diagnosis/children/recently-diagnosed](http://www.autism.org.uk/about/diagnosis/children/recently-diagnosed)
- [www.autism.org.uk/about/benefits-care](http://www.autism.org.uk/about/benefits-care)

Living with ADHD have resources for parents and teenagers that can all be accessed here: [www.livingwithadhd.co.uk/parents/resources.html](http://www.livingwithadhd.co.uk/parents/resources.html)

## LOCAL HELP FOR CARERS

### **Kent: Crossroads Care Kent**

- [www.crossroadskent.org](http://www.crossroadskent.org)
- 03450 956701

### **East Kent – Carers Support East Kent**

- [www.carersek.org.uk](http://www.carersek.org.uk)
- 01304 364637

### **North Kent – Imago Community**

- [www.imago.community](http://www.imago.community)
- 01992 530330

## **West Kent – Involve**

- [www.involvekent.org.uk/carers](http://www.involvekent.org.uk/carers)
- 0300 0810005

## **West Kent ASD Carer's Support Group**

- [www.westkentmind.org.uk/what-we-offer/asd-carers-support-group](http://www.westkentmind.org.uk/what-we-offer/asd-carers-support-group)
- 01732 744950

A support group for parents and carers of autistic children – there is a referral procedure to join this group.

## **SELF-CARE**

Self-care describes an activity that we do to take care of ourselves mentally, emotionally and physically. Looking after ourselves is key to improving our mental health, increasing our ability

to cope as well as maintaining positive relationships. It could be as simple as having a nice bath or going for a walk, to keeping a mood diary or finding some “me-time”.

If you don't look after yourself you will probably find it more and more difficult to look after your child.

## **Talking Therapies Providers**

Sometimes you may feel the need to speak to someone (who is not a member of your family or a friend) about how you are feeling. The Improving Access to Psychological Therapies (IAPT) programme is a range of NHS evidence-based interventions and treatments, such as counselling, cognitive behavioural therapy (CBT), stress management, Eye Movement Desensitisation and Reprocessing (EMDR), and sometimes group work.

Services are available for people aged 17 and upwards through your GP. You can self-refer if you want – type in IAPT and where you live into a search engine like google.

**If you are worried about yourself, or finding it hard to cope, please contact your GP or, if it is an emergency and out of normal working hours, Release the Pressure.**


## **Release the Pressure**

Release the Pressure has a highly trained and experienced team available 24/7 to provide expert advice no matter what you are going through. Phone **0800 107 0160** for free confidential support at any time, or visit the website for more details. [www.kent.gov.uk/social-care-and-health/health/release-the-pressure](http://www.kent.gov.uk/social-care-and-health/health/release-the-pressure)

Check this information is up to date by visiting [www.kent.gov.uk/localoffer](http://www.kent.gov.uk/localoffer) – this website explains what the Local Offer is for families with children with special educational needs. As a printed document this handbook can go out of date so it is always best to check online.



# COMMON MYTHS ABOUT AUTISM AND ADHD



## MYTHS & TRUTHS

Here are some of the common myths we hear about autism and ADHD.

**Myth:** *Autistic people and people with ADHD are stupid.*

**Truth:** Autism and ADHD bring with them just as many exceptional abilities as challenges. Many people with autism and ADHD have normal to high IQs and some may excel at maths, music or another pursuit. Autism is a developmental disability, not an intellectual one. It affects somebody's ability to communicate and interact with people, it can make a person rather fixed in their habits, and it can give them some sensory issues – but none of these affect intelligence. It can be hard to concentrate and pay attention with ADHD which can lower academic achievement but this is not about intelligence and can change with support and treatment.

**Myth:** *Autism and ADHD only affects children.*

**Truth:** Autistic children grow up to become adults with autism. ADHD used to be thought of as something that happened just in childhood. However, it is now recognised that ADHD can persist to adulthood for many people and can cause adults significant difficulties if not treated.

**Myth:** *Autism means people can't understand the emotions of others.*

**Truth:** Autism often affects an individual's ability to understand unspoken interpersonal communication, so somebody with autism might not detect sadness based solely on one's body language or sarcasm in one's tone of voice. But, when emotions are communicated more directly, people with autism are much more likely to feel empathy and compassion for others.

**Myth:** *Autism is caused by the Measles, Mumps and Rubella (MMR) vaccine.*

**Truth:** This idea is based on a research study published in 1998 by Dr Andrew Wakefield which has since been discredited. His study only involved 12 children, and those children weren't randomly selected – which means, in terms of method, it cannot be relied on. Two major properly run studies since have found no link.

**Myth:** *ADHD can be cured.*

**Truth:** ADHD is a behavioural disorder rather than an illness so there is no medical "cure" although it can be treated. ADHD can be treated using medication or therapy, but a combination of both is often best. No medication can be a permanent cure for ADHD but may help someone with the condition concentrate better, be less impulsive, feel calmer, and learn and practise new skills.

**Myth: *Autism is a mental illness.***

**Truth:** No, it is a neurological condition that means the brain processes information differently. A mental illness is a condition that a person can experience at any time and sometimes recover from. A developmental disorder like autism, on the other hand, is something you're born with and which will be part of you for the whole of your life. Autistic people can have good mental health, or experience mental health problems, just like anyone else.

**Myth: *Girls don't have autism or ADHD.***

**Truth:** Presently, more boys than girls are diagnosed with autism and ADHD. However, there's some debate as to whether this is a completely accurate reflection of the real statistics, as girls often 'present' their autism or ADHD somewhat differently from boys and may be under-diagnosed as a result.

**Myth: *Autistic people have mental superpowers.***

**Truth:** This is what families often call the 'Rain Man' myth: that all children with autism have some kind of 'special ability' like brilliant mathematics or musicianship.

What this idea refers to is the phenomenon of the savant (someone with a skill that's exceptional by the standards of the general population) but the fact is that most people with autism aren't savants, and not all savants have autism.

# SOME FREQUENTLY USED INITIALS

**ADHD:** Attention Deficit Hyperactivity Disorder

**AEN:** Additional Educational Needs

**ASC:** Autism Spectrum Condition

**ASD:** Autism Spectrum Disorder

**CBT:** Cognitive Behavioural Therapy

**CYPMHS:** Children and Young People's Mental Health Service

**DAMP:** Deficits in Attention, Motor Control and Perception

**DfE:** Department for Education

**DLA:** Disability Living Allowance

**EHCP:** Education, Health and Care Plan

**EMDR:** Eye Movement Desensitisation and Reprocessing

**FE:** Further Education (at a college)

**FEEE:** Free Early Education Entitlement

**FLO:** Family Liaison Officer

**HE:** Higher Education (at a university)

**HLT:** High Level Teaching Assistant

**HNF:** High needs funding

**IAPT:** Improving Access to Psychological Therapies

**IEP:** Individual Education Plan

**KCC:** Kent County Council

**KEPS:** Kent Educational Psychology Services

**LA:** Local Authority

**LIFT:** Local Inclusion Forum Team

**LSA:** Learning Support Assistant

**MLD:** Moderate Learning Difficulties

**OFSTED:** Office for Standards in Education

**PDA:** Pathological Demand Avoidance

**PIP:** Personal Independent Payment

**PLP:** Personal Learning Plan

**PTSD:** Post-Traumatic Stress Disorder

**SEMH:** Social, Emotional and Mental Health

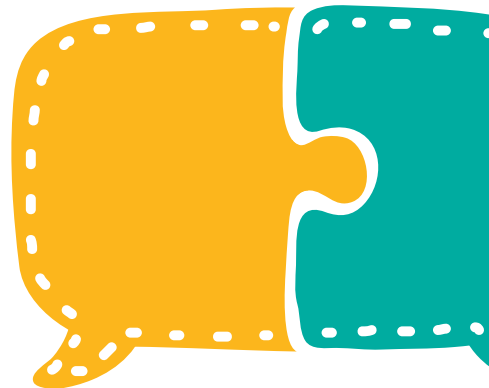
**SEN:** Special Educational Needs

**SENCO:** SEN Coordinator (school)

**SENDIST:** SEN and Disability Tribunal

**SLD:** Severe Learning Difficulties

**SpLD:** Specific Learning Difficulties





# Autism Spectrum Conditions (ASC)



Surrey Autism  
Partnership Board

## Introduction

This factsheet aims to give you a basic understanding about people with autism.

People think, process information and experience the world differently. This can lead to difficulties with communication, relationships and thinking & behaving flexibly.

## Each person is different

However, there are common experiences many people with autism share.

People may have a small range of interests that they are very passionate about.

People may have routines they rely on.

People often find it hard to work out what others are thinking and feeling.

People often find the way other people talk and behave confusing.

The world can seem like a mass of people, places and events which are hard to make sense of.

People may get anxious quite often.

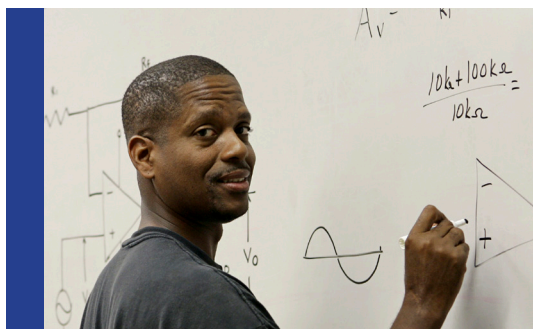


# The autism spectrum

In 2013 the term Autism Spectrum Condition (ASC) was introduced to cover and replace the different conditions previously diagnosed such as Autism and Asperger's Syndrome.

*People can be so different from each other that we think about ASC as a spectrum, like a rainbow.*

Although people's needs may be very different, everyone with an ASC shares a difficulty in making sense of the world.



## Brian has an ASC

- He is very knowledgeable and is doing a physics degree.
- He gets anxious in social situations.
- He has a small group of friends who share his interests.
- He finds it hard to understand other people's feelings.



## Tony has an ASC and a mild learning disability

- He takes words literally and makes mistakes socially such as being over friendly.
- He can sometimes get taken advantage of.
- He likes structure, routine and predictability and gets anxious if things change.



## Sue has an ASC and a profound learning disability

- She doesn't use speech, but signs a little.
- She joins in activities with support, but is often happy on her own.
- She loves going out in the car and walking on a windy day. She finds busy places frightening.

*People may have 'uneven abilities'*

A person may have GCSEs and even be able to drive a car but may still need a lot of support in other areas of life to be independent, such as shopping and cooking. People may have difficulties organising themselves and need support with this.

# There are over 500,000 people with an ASC in the UK

*There is strong evidence to suggest that there are more men than women with an ASC*

- The causes of ASC are still being researched. Many experts believe the pattern of behaviour from which autism is diagnosed may not result from a single cause.
- A lot of people say getting a diagnosis of autism has helped them understand why they have difficulties with some things and are especially good at other things.

## Strengths

People with an ASC have many strengths.



*Many people become experts in their areas of interest*

People with an ASC are often more passionate about their interests than other people.

# Difficulties people may have

## Social interaction and communication



John can seem unfriendly

### People may:

- have difficulty making and keeping friends.
- not value socialising as much as other people and struggle to understand social rules such as turn taking in conversations.
- find it hard to understand other people's thoughts, point of view and judge how they are feeling.



Tim sometimes gets confused

### People may:

- take the meaning of words literally and have difficulty understanding keeping up with group conversations which can be overwhelming.
- have difficulties understanding and using non verbal communication such as eye contact, tone of voice, gesture and facial expression.

## Social interaction can be exhausting for people.



Carl finds social events tiring

### People may:

- find the social side of work difficult. Things like lunch breaks and training courses have social rules which people can find hard to intuitively understand.
- be 'on alert' during social events, trying to work out the right way to interact and avoid social mistakes. Being alert the whole time can be very mentally tiring.

See our factsheet on *Communication and social interaction*

The issues explained on this page are explored in more detail in this factsheet.



# Difficulties people may have

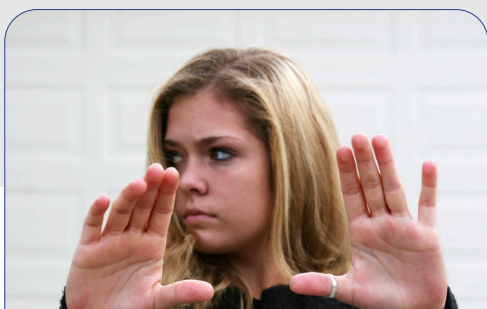
## Interests and routines



Greg spends all day on his hobby

### People may:

- find choice difficult and have a small range of, often solitary, activities which they become absorbed by.
- become very fixated on the activity for hours at a time, ignoring other things they may need to do.
- struggle to imagine something they haven't done before. They can be anxious about doing new things.



Sue doesn't like plans changing

### People may:

- want to have set routines they follow and find unexpected or sudden changes difficult to cope with and get very anxious.
- find unstructured time stressful and find it hard to think of things to do to occupy themselves. People may rely on their routines and interests more than most people.

*People's interests can be a strength as well as a difficulty.*

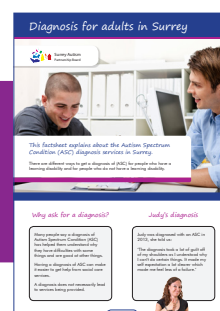
People can become very skilled and knowledgeable about their interests. Being absorbed in their interest can be a person's most effective way of relaxing. Describing a person's interest as an 'obsession' can be unhelpful.

## Diagnosis of Autism Spectrum Condition (ASC)

A combination of the difficulties a person may have with communication, social interaction, interests and routines are used to diagnose whether people have an ASC.

*See our factsheet on Diagnosis for adults in Surrey*

The diagnostic service in Surrey is explained in detail in this factsheet.



# Difficulties people may have

## Sensory issues

People with an ASC may also perceive noise, light, smells, touch and tastes differently from other people. A person may be over or under sensitive in one or more of their senses.

Tim finds busy places overwhelming.

He doesn't like fluorescent lighting because it seems to flicker.



He doesn't like it when people stand too close to him.

He cuts the labels out of his clothes as they irritate him.

Some of Tim's senses are very sensitive

Aran loves music to be played loudly.

He doesn't notice strong smells and often doesn't realise food has gone off.



He's not aware of personal space and often stands too close to other people.

He likes movement and flaps his hands a lot.

Some of Aran's senses are under sensitive

Some people may need time to familiarise themselves with the sensory feel of a new environment.

## Filtering out the sensory world.

People with an ASC often find it more difficult to filter out background visual stimuli, noises, and even the smells that the world throws at us on daily basis.

A busy environment can feel like it's assaulting a person's senses. For example someone may struggle to focus on a timetable in a busy train station or pick out words in a conversation in a busy bar.

# Difficulties people may have

## Anxiety

*Anxiety is a common issue for people with an ASC.*

People often find the world a confusing place where the rules, and especially people are not consistent. This can lead to high levels of anxiety.



For many people with an ASC an important goal is to reduce the anxiety they feel in a world they often find intense and confusing.

People may need support to develop a range of strategies to help them to manage their anxiety.

### *Some things people may find difficult*

Many people with ASC find it hard to relax. They are constantly on alert trying to make sense of the world around them and its social rules – it can be exhausting.

People may panic and struggle to think of a way out of situations they are finding difficult.

People may have difficulty understanding their own emotions so at times do not realise they are feeling worried until it becomes overwhelming.

People may find it hard to switch off their mind and try to relax. Their mind can just keep going over the same thing again and again.

People may find it difficult to organise themselves and struggle to meet deadlines at work or college which causes stress.

People often like things to be correct and certain. They may worry a lot about minor details that others don't see as important.

People may worry about making social mistakes, or how they will manage a social event.



*See our factsheet on Useful Strategies For Life*  
Strategies for managing anxiety are explored in this factsheet.

# Useful websites

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

- The website of the National Autistic Society.

[www.nassurreybranch.org](http://www.nassurreybranch.org)

- The website of the National Autistic Society Surrey branch.



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

- The website of the Surrey Autism Partnership Board. Click the Surrey Autism Partnership Board logo on the home page of the learning disability partnership board site to go to our pages.

*There are seven factsheets in our series about Autism Spectrum Conditions.*

You can download our factsheets from [www.surreypb.org.uk](http://www.surreypb.org.uk)

This is the website of the Learning Disability and Surrey Autism Partnership Board



1. Autism Spectrum Conditions (ASC) - An Introduction
2. Diagnosis
3. Communication
4. Useful strategies for life
5. Social care and community life
6. Health services and support
7. Our stories - three stories from people with ASC

## Credits

This factsheet was developed by Howard Childs, Tom Moore and Mike Leat.

The developers would like to thank The Surrey Autism Partnership Board, Surrey County Council, Surrey & Borders Partnership NHS Foundation Trust, Assist through the National Autistic Society and The Smart Enterprise.

Design by Mike Leat of The Clear Communication People Ltd

Version 2 - July 2015 (reviewed April 2021)

# Useful Strategies For Life



Surrey Autism  
Partnership Board



## Introduction

This factsheet is about strategies and tips that can help people with an Autistic Spectrum Condition (ASC) manage their day to day lives.

Use your strengths

Managing anxiety

Sensory issues

Support groups

Visual supports

Diagnosis

Be yourself



# A diagnosis of Autism Spectrum Condition (ASC)

*A diagnosis can give a person insight into themselves and their needs*

Having a diagnosis of ASC can help people to begin to understand why the world can often seem a confusing, chaotic and stressful place.

It can also help others who are close to the person to better understand them.



Judy was diagnosed with an ASC in 2013.

'The diagnosis took a lot of guilt off of my shoulders as I understood why I can't do certain things.

It made my self expectation a lot clearer, which made me feel less of a failure.'

## How to ask for a diagnosis if you are an adult in Surrey.

### Diagnosis for people who do not have a learning disability.

The Surrey Neurodevelopmental Service offers a diagnosis service for people in Surrey who do not have a learning disability. It is a free service your GP can refer you to.

### Diagnosis for people who do have a learning disability.

A diagnostic assessment can be carried out by the Surrey and Borders Partnership NHS Foundation Trust's Community Learning Disability Teams.



See our factsheet called 'Diagnosis for adults in Surrey'.

The factsheet explains in detail about how to get a diagnosis in Surrey and what is involved.

# Using your strengths

People with ASD often have strengths in certain areas of life and can use these strengths to their advantage.

Peoples' strengths can be a benefit in both a work environment and in leisure activities.

## Tony's strengths



Tony is a van courier and has a strong ability to focus on a task and memorise routes.

He keeps an accurate spreadsheet record of each journey he makes.

His records are better than his colleagues, who often ask him for advice about a route.

## Juliette's strengths



Juliette plays guitar professionally.

She can learn a new piece of music more quickly than most other musicians.

She has a fine ear for pitch and can detect an off-key straight away.

## Edward's strengths



Edward has a strong interest in vintage buses and goes to rallies with his support workers.

People at the events are impressed that Edward can name the model and manufacturing year of every bus there.

# Being yourself

*It's important that people are encouraged to 'be themselves'*

It's ok not to value the things most other people do. People need support to feel good about who they are.

Nathan is not keen on social gatherings.



Nathan's family go for Sunday lunch at the pub every week.

It's a family social gathering and Nathan prefers not to go, but does sometimes.

He would rather have dinner at home on his own because it's cheaper and quieter.

Alicia likes her home to look bare.



Alicia finds clutter makes her feels anxious.

She has decorated the walls of her flat white and doesn't have any pictures or ornaments.

People sometimes comment that it looks a bit institutional, but this is how she wants it to look – she calls it minimalist.

Adam is happy to be 'different'.



Adam describes other members of his family as having 'Neurotypical Syndrome'.

He says their desire to hug each other, make small talk and worry about what other people think helped him make the diagnosis!

# Coping with the sensory world

*Some people can find the world a confusing mixture of sights, sounds, noises and smell.*

Some people often feel over stimulated and need periods of peace and quiet.

Alison needs to escape sometimes.



Alison has a safe place she goes to when she's feeling overstimulated.

She has a small box room upstairs at home that has a blind on the window and a comfortable chair.

She has a 'do not disturb' sign for the door. She relaxes in the chair in the dark, sometimes for an hour or two until she starts to feel less stimulated and calmer.

Andy gets easily distracted on the golf course.



When he's taking his shot he's acutely aware of any movement his playing partners make.

He can even get distracted by people talking on the other fairway even though they are quite far away.

He finds it uncomfortable if people are stood too near him, even if they are behind him and keeping still.

He tends to only play on his own, or with his brother who understands him. He ends up getting irritable and playing badly if he plays with other people.

He describes himself as hyper-vigilant.

## Some people find they want or need extra stimulation

Movement and stimulation can be relaxing for some people.

Zara likes to be very active.



Zara needs a lot of movement to help her stay calm.

She does well at college, but finds the lessons very intense and struggles to sit in a classroom for more than an hour.

Before each lesson her tutors encourage her to have a run around the grounds for 5 minutes, as this helps her to start the lesson in a relaxed frame of mind.

Pete craves very spicy flavours.



Pete likes his food to have a strong smell and likes plenty of garlic and spices.

When he was younger he liked to have marmite on everything and would sometimes be found eating it straight out of the jar with a spoon.

He will generally only eat meals if there is a spicy sauce to go with it. He tends to put chilli sauce on his chips, and peri peri chicken is his favourite meal.

He also likes strong smells and has many different aftershaves in his bedroom that he enjoys smelling.

# Anxiety

*For many people with ASC an important goal is to reduce the anxiety they feel in a world they often find intense and confusing.*

For many people with ASC 'thinking, thinking, thinking' is their default position.

Jane describes her brain as like a fruit machine, where the reels are whirring round and round, and sometimes it just doesn't stop.

Mike explains that his thinking is sometimes like water trying to flow through too small a gap. The pressure is enormous.



John needs plenty of rest.

Many people with ASC find it hard to relax. They are constantly on alert trying to make sense of the world around them and its social rules – it can be exhausting.



John has learnt that he needs to go to bed early after a day where he's had a busy social event, such as a family gathering.

John finds social situations like these confusing, hard work and quite stressful at times.

He can manage these social situations, but finds them very tiring, as he's always on alert trying his best to 'fit in' with everyone else.

John now understands that because of his ASC he will find social situations more tiring than other people, because he has to work so much harder at them.

Andrew has been getting more anxious lately.

Andrew's parents were worried that, in their words 'his autism was getting worse'.  
What was really happening was that the more anxious Andrew became, the more he would rely on his routines and behaviours, like rocking, that help him cope with the stress he was feeling.



*Many people with an ASC can find it difficult to understand emotions.*



Learning about emotions can help people identify their feelings and what makes them anxious.  
For example understanding that you feel frightened and vulnerable going into a new situation helps to explain what causes your anxiety.  
You can then use that knowledge to plan strategies to enable you to better cope with these situations.

Lydia keeps a diary of how she feels.



Lydia's diary helps her to identify how she feels before, during and after different situations.  
Her diary has helped her to understand that she was scared about getting lost when travelling on a new bus route and would start worrying about it days before she had to make the journey.

# Supporting people to manage anxiety

## *People may need support to switch off their mind and try to relax*

People may need support to develop their own range of calming activities and prompts to remember to use them.

Keeping occupied is often an effective way to keep your mind off your worries. It gives your mind some breathing space and stops your brain whirring around, and around the same concerns.

Vicky keeps a list of calming activities in her handbag.



Sometimes when she's feeling anxious she can't focus her thoughts and think of what to do to help her feel better.

Her list includes: play minecraft on my iPad, have a bath and go for a run.

Serena often takes her rainstick out with her.



When Serena gets anxious she talks very loudly and sometimes starts to shout.

When they go out, her supporters take Serena's rainstick with them. This calms her down as she focuses on the noise and vibration that the stick makes as she moves it.

*For many people with ASC, common strategies people use for anxiety, like talking to friends and family, are not so effective.*

Some people with an ASC would find the question 'How do you feel about that?' perplexing as they may struggle to understand and interpret their emotions in real time. A more practical, 'problem solving' approach can be more effective.

# Predictability and routine

*Most people, whether they have an ASC or not, rely on routines to give them the security to predict what will happen in life.*

If you are feeling unsettled inside, having things organised and clear around you can feel comforting. Routine and organisation can give you a sense of control. People with an ASC often rely on routine and predictability more than other people.

Frank works in his local council office three afternoons a week.



Frank's job is to do the filing. He's very accurate and never makes mistakes.

The staff in the office make sure that Frank always has the same desk and that his work is laid out exactly the same each week.

Frank gets on with his work and is faster and gets less distracted than other employees. His workplace is a safe, predictable environment that causes little anxiety.

People with an ASC can become quite rigid about their routines and struggle to be flexible if something happens that creates a change in the routine.

After leaving school Graham found it hard to find a job.



He developed a routine of listening to a particular radio show at home every afternoon.

He wouldn't answer the door or the phone when the show was on and became very stuck in this routine. Missing the structure that school gave him, Graham developed his own structure that became rigid and he found it hard to explore other options for using his time.

Graham managed to introduce some flexibility into his routine by accepting that if he missed the show at 1pm he could listen to it on BBC iplayer later.

# Structured activities

*Many people with an ASC find structured activities easier to manage than social activities that have no distinct beginning or end.*

A party invite that says 'come when you're ready and stay til late' is not usually very helpful!

People may feel they can't 'escape' from activities that are unstructured.

Susan finds it stressful when someone wants to visit her at home.



She worries about seeming unfriendly and people staying longer than she can manage.

She enjoys company for short periods of time – up to 45 minutes.

These days she usually suggests that they meet at the other person's house, or in a local café so she can leave when she needs to.

Gareth sometimes meets his friends to watch a football match.



The match gives him a structure. He arrives just before kick off and leaves 10 minutes after the final whistle.

He copes with this better than a situation that has no clear beginning or end.

He finds unstructured social situations make him anxious, because he struggles to work out the right time to leave.

Many social activities, like clubs and societies, have clear structures and routines that some people with an ASC find helpful, as they are able to predict what will happen.

# A set of rules

Some people with ASC find that having a set of rules they follow helps them to manage in situations that make them feel anxious.

The rules can be useful to 'fall back on' when they feel trapped and unsure what to do. People may need support to develop rules and strategies to manage when unexpected situations occur.

Amanda travels by bus to and from work.



Amanda finds it uncomfortable if someone she doesn't know talks to her at the bus stop.

She has a rule that she will comment on the weather and if the person keeps talking she will say "Oh dear I've forgotten something I needed to buy" and walk around the block and come back for the next bus.'

Having a 'crisis plan' can be useful for those times where a person becomes so stressed they can no longer think straight and need help.

Sanjay has a crisis plan which is written down.



He keeps it in his wallet, along with his autism alert card.

He explains how he uses it:

'If I am out and about and have a panic attack I read my crisis plan. I have four people I can phone and there is always someone who will answer.

I read out the words that say "Hello it's Sanjay and I'm having a panic" – they know what to do to help me and I do what they say.'

# Planning in advance for situations

This can reduce anxiety and help the person to plan for what is likely to happen.

*David used to struggle at job interviews as he didn't think to tell employers about the things he had achieved.*

David went to several interviews without getting a job.

He didn't know how to 'sell himself'. If the interviewers didn't ask him about specific things, he wouldn't think to mention them.



His supporters helped him write a list of things to remember to say at interviews and did some practice.

He now takes his list to interviews.

He won an 'apprentice of the year' award one year, which he never used to think to mention at interviews.

*Darren enjoys walking in open spaces, but gets very scared if he sees a dog that's not on a lead.*

There is a local park where people have to keep dogs on leads.



Darren's supporters often take him there.

They always show him the sign as they enter the park.

# Explaining social situations in writing

*Written stories can be used to explain the social rules of a social situation or event.*

The story says what will happen in the situation to help people to predict events, learn about other people's point of view and understand what they can do if things don't go to plan.

Stories are sometimes illustrated to make them easier to follow.

Craig has a story written about his journey to work.



Below is part of Craig's written story.

Sometimes my train will arrive later than 8.40am.

There could be many reasons for this, including leaves on the line or a signal failure.

It is not the driver's fault if his train is late.

I can look at the boards to see if there is a message saying what time they think my train will arrive.

If there is no message, I can ask a member of staff who is wearing a railway uniform if they know what time the 8.40am train from Caterham is due to arrive.

If I am worried about being late for work, I can use my mobile to phone my boss John and tell him my train is late.

John knows that trains are sometimes late and will not be angry.

*This idea has been developed by Carol Gray into a technique called 'Social Stories'*

Visit her website for more information: [www.carolgraysocialstories.com](http://www.carolgraysocialstories.com)



# Visual supports

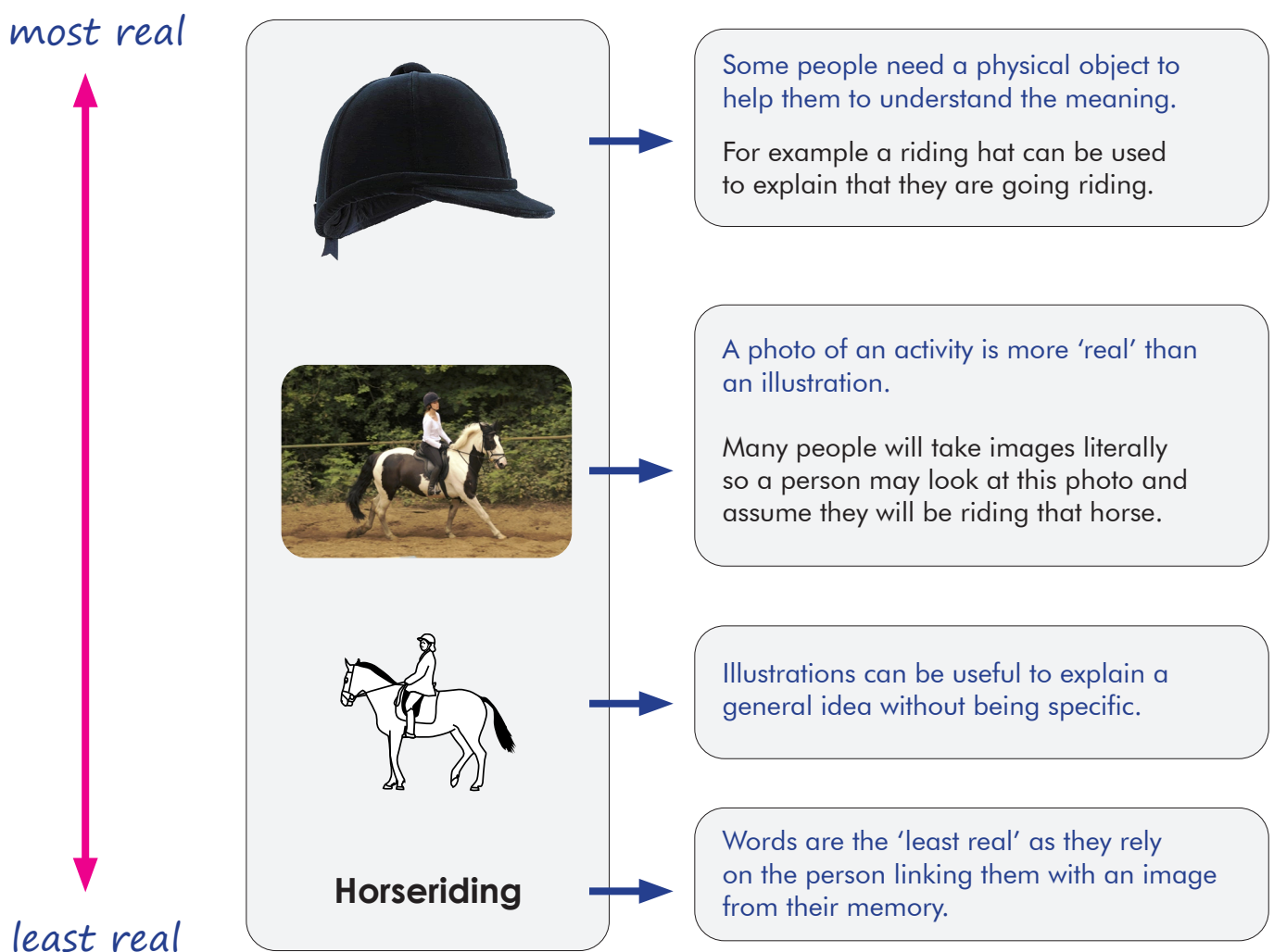
We all use visual prompts in our lives such as road signs, calendars and shopping lists.

Things that are visual are more permanent than things that are spoken. Many people with an ASC find that 'learning through seeing' is a good way to learn.

Visual supports can be simply written words, physical objects or words illustrated with pictures.

It is important that visual supports are designed for an individual.

Some people will find the use of pictures patronising. Other people struggle to take meaning from written words and need pictures or objects for meanings to be real for them.



*Ella has an objects timetable at the dayservice she attends.*



**Her timetable enables her to predict activities.**

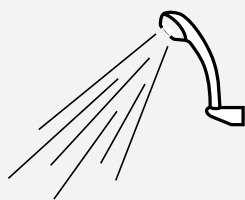
Staff use physical objects to help Ella to understand what activity is happening next. A wooden spoon is used for cookery, a paintbrush for art and a trowel for gardening.

Ella is given the object to hold for a few minutes before the activity is due to start. This helps her to predict what will happen next. In time the physical object will be replaced by a photo of the object.

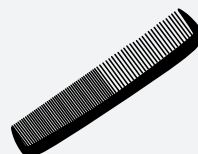
*Josh uses a visual support to help him to get ready in the right order in the morning after he's had breakfast.*



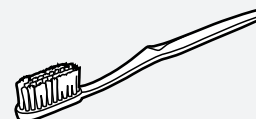
Toilet



Shower



Comb hair



Brush teeth

His visual support is laminated and stuck to the wall in the bathroom.


He used to take 30 minutes to get ready, but can now get ready in half that time.



Jayden found it difficult to understand when it was her turn to choose the CD to play and when it was other people's turn.

This chart, with a removable CD image, enabled her to see whose turn it was at a glance.

She could also predict when her turn was coming, which reduced her anxiety.

WHOSE TURN IS IT TO CHOOSE THE CD ?	
ADRIAN	
ELAINE	
JAYDEN	
THOMAS	



Sam found it difficult to move from one activity to another.



His tutors at college use a 'countdown clock' that clearly shows in red how long there is left for an activity.

Sam now finds it easier to predict when activities will end and to prepare himself to move on.

Scott has a detailed weekly timetable on his bedroom wall that lists activities and main meals.

Mon Monday	Tue Tuesday	Wed Wednesday	Thu Thursday	Fri Friday	Sat Saturday	Sun Sunday
College	College	Opticians for eye test	College	Swimming	Trip to Brighton	Church
		DVD afternoon		Gardening		DVD afternoon
Meatballs and spaghetti	Fishfingers and chips	Tuna and cheese wraps	Pasta bake with cheese	Sausages and mash	Takeaway	Roast dinner



Scott likes to be able to predict everything that will happen and gets anxious if he's not sure what meals he will be eating.

He designs the timetable himself and the layout helps him to discuss options and make choices. If a change happens, Scott edits the timetable himself and prints a new copy.

Barry uses the notes app on his phone to list the order in which he will do things that day.

He used to find it difficult to organise himself and often missed deadlines for college work.



He splits the day into morning, afternoon and evening.

He starts a new page for each section of the day and deletes tasks as he does them. He feels this gives him a sense of order and control.

# Support groups

*People can learn from each other and from autism specialists who help to run support groups.*

For many people the social contact in a safe environment where people will understand your needs is very helpful.

Rebecca goes to her local Aspergers Group.



'I attend an Aspergers group once or twice a month where I can meet and talk to other people who have Aspergers.'

The good thing about this is that we can share stories, ideas and helpful information about living with Aspergers.'

Support groups are often supported by autism specialists, who can offer support and advice.

## Adjustments services make to be 'autism friendly'

*Services can make 'reasonable adjustments' so that they are accessible for people with an ASC.*



Alex enjoys films, but finds cinemas too noisy and busy.

He goes to 'autism friendly' screenings where the volume is set lower. He also takes headphones with him to cover his ears if the film is too loud in places.

Many local cinemas have 'autism friendly' screenings.

# Useful websites

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

- The website of the National Autistic Society.

[www.nassurreybranch.org](http://www.nassurreybranch.org)

- The website of the National Autistic Society Surrey branch.

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

- The website of the Surrey Autism Partnership Board.



There are seven factsheets in our series about Autism Spectrum Conditions.

You can download our factsheets from [www.surreypb.org.uk](http://www.surreypb.org.uk)

This is the website of the Surrey Autism Partnership Board



1. Autism Spectrum Conditions (ASC) - An Introduction
2. Diagnosis
3. Communication
4. Useful strategies for life
5. Social care and community life
6. Health services and support
7. Our stories - three stories from people with ASC

## Credits

This factsheet was developed by Howard Childs, Tom Moore and Mike Leat.

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Design by Mike Leat of The Clear Communication People Ltd

Version 1 - July 2015 (reviewed April 2021)

## *Planning for Successful Transitions* ACROSS GRADE LEVELS

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TRANSITION IS A NATURAL PART OF ALL EDUCATIONAL PROGRAMS.

*Students with and without disabilities must adjust to changes in teachers, classmates, schedules, buildings and routines. The transition from one grade to the next can be especially challenging for a student on the autism spectrum (ASD). However, these students can make this shift more easily with careful planning and preparation.*

 **AUTISM SOCIETY**



Images used for illustration purposes only. Models may not have autism.





MANY TEACHERS MAY NOT HAVE PREVIOUS EXPERIENCE WITH STUDENTS ON THE AUTISM SPECTRUM. THEREFORE, THEY WILL NEED BASIC INFORMATION ABOUT ASD AND HOW IT IMPACTS THE STUDENT.



## THINKING ABOUT TRANSITION

When thinking about transition, sometimes it is helpful to start the process with a list of questions to act as a springboard for discussion. Some parents use similar questions when preparing for an IEP meeting. Other families like to hold family meetings with siblings and the individual with autism so that they can all share in the planning. Below is an example of such a list:

- What does your child like to do?
- What can your child do?
- What does your child need to explore?
- What does your child need to learn to reach his or her goals?
- What transportation will your child use to get to school and for extracurricular activities?

Many people think of school in terms of curriculum, but having friends and a sense of belonging in a community also is important. To address these areas, following are a few additional questions to consider:

- Are supports needed to encourage friendship?
- Do people in the school community know your son or daughter?
- Are supports needed to structure time for recreation? Exercise?
- Does your child have any special interests that others might share, which could lead to participating in extracurricular activities?
- Can you explore avenues for socializing with peers, such as religious affiliation or volunteer work?

Part of transition planning should be preparing the student to play an active role in all decisions that impact their life. The best place to begin this preparation is to have the student with ASD involved all aspects of educational planning, including the transition process from the very beginning. As mentioned in Student-Led IEPs (McGahee, Mason, Wallace, & Jones, 2001), given the great variance of student ability, there is a wide range of options. Some students

may just be able to state or read part of their plan for the future to the IEP team, others may go on to explain their disability, describe the need for accommodations, share their strengths and challenges (present levels of performance), and talk about plans for the future. The eventual goal is a student-led IEP meeting (under the watchful eyes of the IEP team). Dealing with the paradigm shift from being advocated for through the IEP to having to advocate for oneself after high school requires much long-term work. Starting the process of teaching self-advocacy ideally could begin before transition planning for school is mandated into the Individual Education Plan (IEP). Providing students with a well-developed sense of self-advocacy through the process should be an integral part of education. Doing so is vital for gaining a greater understanding of how to obtain the required accommodations upon entering the community, in higher education, employment, and relationships during adolescence and adulthood years.

The transition process also should involve taking action. After identifying areas of interest and setting goals, steps should be taken to meet those goals. For example, an older student with ASD who has particularly sharp computer skills is dismissed from school early a few days a week to work with an aide at a data processing office. This position was acquired through the vocation rehabilitation office, which continues to provide support. Before beginning this job, the student was taught appropriate office social skills (including unwritten rules) and important office procedures, such as using a time clock. Another student, who prefers to be outdoors, received school credits for joining peers to work on a community clean-up project.

These examples emphasize the need to develop a plan tailored to each student's skills and preferences. Many professionals and families believe that three or four different vocational experiences can be helpful in assessing a student's desires and capabilities while he or she is still in school. The bottom line for all students is to ultimately prepare them to make good choices leading to the greatest degree of independence possible and the kind of life they want after high school. Keep in mind the greater goal of experience and knowledge gained through appropriate transition planning across grade levels.

## FACILITATING A SMOOTH TRANSITION

Following are some suggestions that can help ease the impact of the transition process for a student on the autism spectrum:

- Preparation for transition should begin early in the spring. Whether a student is moving to a new classroom or to a new building, it is helpful to identify the homeroom teacher, or general or special educator who will have primary responsibility for the student.
- Once the receiving teacher is identified, this person should be involved in the annual education plan process so that he or she can learn about the student's level of functioning, strengths and weaknesses, likes and dislikes, and can be actively involved and provide input into projected goals.
- Written transition plans may facilitate the student's successful movement. A meeting should be conducted to allow key participants to exchange relevant information. Responsibilities and timelines for those involved should be clearly stated.
- Either during the annual education plan conference or at the transition planning meeting, information should be exchanged about effective instructional strategies, needed modifications and adaptations, positive behavior support strategies and methods of communication. The receiving teacher should learn about the strategies that have worked in the past, so that precious time is not lost at the beginning of the new school year.
- The receiving teacher may find it helpful to observe the student in his or her current classroom or school setting. This will provide important insight into the student's learning style and needed supports.
- Instructional assistants who will be involved in the student's daily education should be identified, educated and informed about their role in the student's education.
- Many teachers may not have previous experience with students on the autism spectrum. Therefore, they will need basic information about ASD and how it impacts the student. Student-specific information about learning styles, communication systems, medical issues and behavior supports is also critical. Cafeteria workers, custodians, bus drivers, the school secretary and the school nurse should also be included in the training. Classmates of the new student also may need information. This should be

provided in a respectful manner and without stigmatizing the student.

- Before entering a new school, any anxieties the student may have about the new setting should be alleviated. Preparation for this move can be facilitated by providing the student with a map of the school, a copy of his or her fall schedule, a copy of the student handbook and rules, and a list of clubs and extracurricular activities.
- A videotape can be developed about the new school, providing written information about specific situations so that the student can learn and rehearse for the change at his or her own pace.
- Visitations should be conducted to allow the student and his or her family to meet relevant school staff, locate the student's locker and become familiar with the school culture.
- Key people or a mentor should be identified that the student can contact if he or she is having a difficult time adjusting to or understanding a certain situation. Finding a location where the student can go to relax and regroup also is helpful, as is providing the student with a visual menu of coping strategies.
- Parents should receive information about bus schedules, parent-teacher organizations and available resources (e.g., counselors, social workers, nurses).
- Prior to the new school year, methods and a schedule should be established for communicating between home and school. Suggestions for maintaining ongoing communication include journals, daily progress notes, mid-term grades, scheduled appointments or phone calls, informal meetings, report cards and parent-teacher conferences.
- Once in the new school, peers should be identified who are willing to help the student with the transition and acclimation to the new school. By gaining the support of a friend without a disability, the student with autism may have greater access to social opportunities during and after school.

The ultimate goal is to promote a successful experience for both the student and the rest of the school community. By systematically addressing the transition process, students with ASD can be prepared to participate in their new school or grade.

# Autism source™

#1 in Autism Information

LOOKING FOR AUTISM RESOURCES? VISIT [WWW.AUTISMSOURCE.ORG](http://WWW.AUTISMSOURCE.ORG)

## AUTISM SOCIETY

4340 East-West Highway, Suite 350  
Bethesda, Maryland 20814  
Phone: 301.657.0881 or  
1.800.3AUTISM  
Fax: 301.657.0869  
Web: [www.autism-society.org](http://www.autism-society.org)

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The National Information Center for Children and Youth with Disabilities has a transition summary series that helps families and students with disabilities focus on taking definite steps toward a successful transition. To read the entire article, go to the NICHCY Web site at [www.nichcy.org/](http://www.nichcy.org/).



If you appreciated the information contained in this publication, please consider offering support through a donation that will continue the availability of this information to others in need. Help us continue the work so vital to the autism community by making a tax-deductible donation at [www.autism-society.org/donate\\_home](http://www.autism-society.org/donate_home).



Academic excellence for  
business and the professions

# The **Autism** Research Group

## An Evidence Based Guide to **Anxiety in Autism**

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# Foreword

Over the past 10-15 years, research has confirmed what many parents and teachers have long suspected – that many autistic children often experience very significant levels of anxiety. This guide provides an overview of what is currently known about anxiety in autism; how common it is, what causes it, and what strategies might help to manage and reduce it. By combining the latest research evidence with experience based recommendations for best practice, the aim of this guide is to help educators and other professionals make informed decisions about how to promote mental health and well-being in autistic children under their care.



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## A note on language in this guide

There are different preferences among members of the autism community about whether identity-first ('autistic person') or person-first ('person with autism') language should be used to describe individuals who have received an autism spectrum diagnosis. A survey by Kenny et al., (2016) suggests that many autistic individuals prefer the use of identity-first language, which will therefore be the language adopted in this guide.

# What do we know about anxiety in autism?

## What is anxiety?

**Anxiety is a feeling of worry or fear that we experience when we expect that a situation might have adverse consequences for our psychological or physical well-being.** This may include situations such as preparing for an exam or test (for fear of failure), travelling during rush hour (for fear of being late or having an accident), preparing for a public speech (for fear of being judged negatively), or travelling to new places and meeting new people (for fear of the unknown). In many such situations, feelings of anxiety are completely normal and even important because the associated increase in our levels of arousal (e.g. increased heart rate) and general vigilance prepares us for dealing with whatever a situation might throw at us.

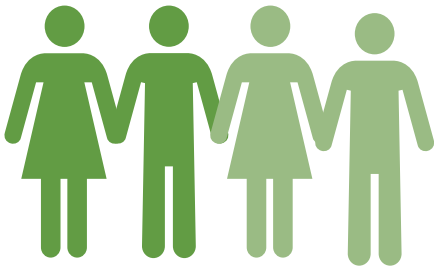
Unfortunately, for some people, feelings of anxiety can arise so frequently, persistently and with such unusual intensity, that they interfere with a person's day-to-day functioning and general quality of life. For instance, children may be so worried about failing a test or being teased that they resist going to school or any social events. Others may have such persistent fears of dogs that they refuse to go to parks or visit friends who own a dog. And others still may generally worry so much about something bad happening that they are constantly in a state of heightened arousal and vigilance. When anxiety interferes with life in such ways for prolonged periods, we recognise it as an anxiety disorder and depending on the specific nature of the anxiety, different forms can be distinguished including *Generalised Anxiety Disorder*, *Social Anxiety Disorder*, *Specific Phobias* (e.g. heights or spiders), *Panic Disorders* and *Separation Anxiety Disorder*.



## How common is anxiety and what does it look like in autism?

A considerable body of evidence now shows that anxiety disorders are substantially more common in autism than in the general population. Whilst around 10-15% of the general population have an anxiety disorder at some point in their life (most commonly a specific phobia; Kessler et al., 2012), around **40% of autistic children, adolescents and adults are thought to have at least one and often more anxiety disorders** (van Steensel et al., 2011), with specific phobias and social anxiety among the most common forms.

It is important to appreciate that **anxiety disorder is not simply a part of autism but an independently co-occurring disorder that can be addressed and treated in its own right**. This is important because it means that accurately identifying anxiety can provide an opportunity to bring about significant improvements in an individual's quality of life and daily functioning.



**40%** of autistic children, adolescents and adults are thought to have at least one and often more than one anxiety disorder.

Unfortunately, **it can be difficult to identify anxiety disorder in autism because it frequently presents in an unusual way** (Kerns et al., 2014). For example, social anxiety is often associated with a fear of being embarrassed or humiliated in front of others but autistic individuals often experience social anxiety because they find it difficult to navigate social situations, not because they worry about what others might think or say about them. Similarly, many autistic individuals worry excessively that certain routines might be disrupted or that they might be prevented from engaging in certain (potentially repetitive) activities or behaviours. This sounds similar to Obsessive Compulsive Disorder (OCD), but in the case of OCD individuals engage in repetitive behaviours to relieve distress caused by persistent, intrusive and unwanted thoughts, not because of a desire to pursue a routine. Finally, autistic individuals may experience excessive fear of unusual and highly idiosyncratic objects or events (e.g., the happy birthday song, TV sets or walking through doors) that would not commonly be associated with a specific phobia.

Since most clinical assessments and screening tools have been developed on the basis of what anxiety typically looks like, the unusual presentations of anxiety in autism may often be overlooked. **This problem is compounded by something known as diagnostic overshadowing whereby symptoms of anxiety are simply regarded as part of autism rather than signs of a co-occurring anxiety disorder.**

Fortunately, awareness is growing that anxiety is a major mental health concern for many autistic children and adults and therefore diagnostic screening tools are being developed that are specifically designed to identify different forms of anxiety in autism (e.g. Rodgers et al., 2016; see also the online resources section on page 18).

## What causes anxiety in autism?

Over the past decade, research has made substantial progress toward identifying the key mechanisms that seem to be responsible for the high levels of anxiety in autism, and that are now increasingly becoming the focus of interventions and treatment. Figure 1 below, provides an overview of current thinking, which places an 'Intolerance of Uncertainty' at the heart of anxiety disorders in autism.

Briefly, frequent sensory processing differences and difficulties in understanding one's own emotions (which is known as alexithymia) are thought to make the world more uncertain and unpredictable for autistic individuals, which can be difficult to tolerate. The resulting intolerance of uncertainty, therefore, causes high levels of anxiety, which autistic individuals may attempt to manage by engaging in repetitive behaviours (to make the world more predictable). In parallel, alexithymia may also contribute to anxiety by making it difficult for the individual to effectively regulate their emotions.

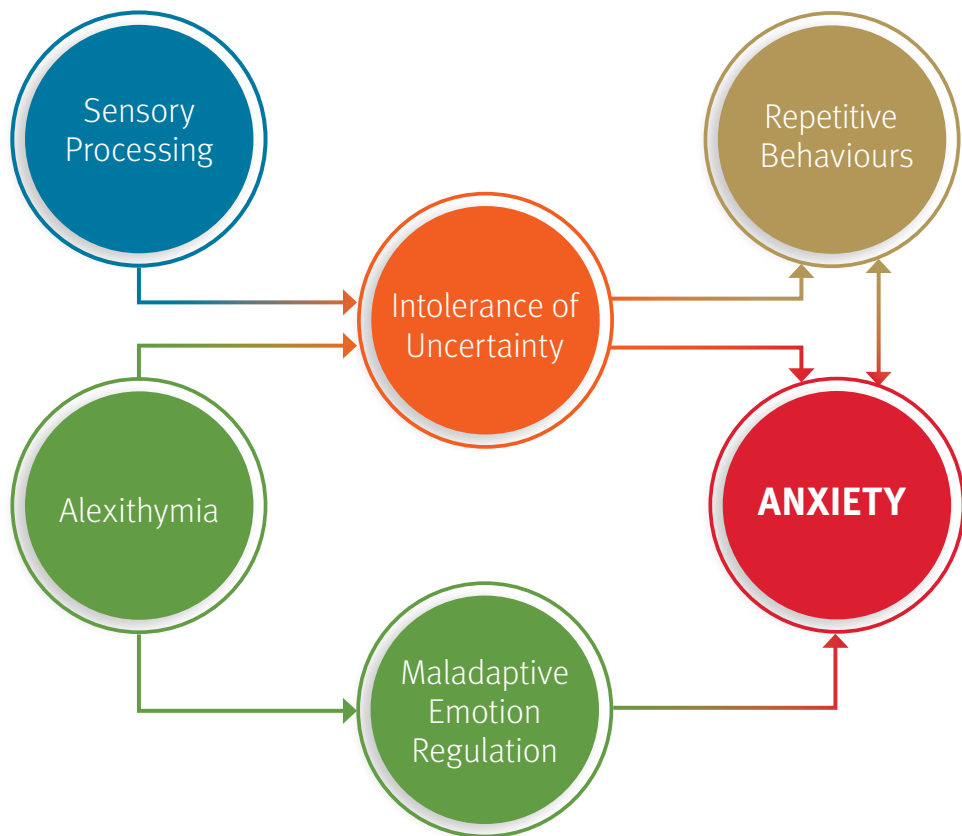


Figure 1: A model of anxiety in Autism (adapted from South & Rodgers 2017 and Maisel et al., 2016)

## A closer look at the role of sensory processing differences

Our brains are continuously exposed to sensory input from our external (e.g., smells, sounds, etc.) and internal (e.g., body temperature, arousal levels) environment. This sensory input is often incomplete or ambiguous and therefore **our brains do not only simply receive information but also try to make predictions about what is most likely going to be experienced next.** This sensory prediction is very important for helping us make sense of the world around us. For instance, when we talk to someone in a noisy environment, we may not hear every single word but the gist of the conversation lets us fill in the gaps unless the conversation takes an unexpected turn. Similarly, when we try to make out objects in a poorly lit room we use our expectations to see what we can't quite see – a round object in a fruit-bowl will look like an orange or apple whereas the same shape next to a tennis racket will look like a tennis ball.



Sensory prediction is very important for helping us make sense of the world around us.

In addition to helping us make sense of the world, sensory prediction processes are also important for filtering incoming information. Specifically our brains tend to suppress expected sensory input whilst amplifying unexpected events so that we can deal effectively with new situations. This is illustrated by the fact we cannot generally tickle ourselves whilst others can. When we try to tickle ourselves, our brains generate very good predictions about what it will feel like and therefore the expected sensation is suppressed. However, when others tickle us, our sensory predictions are less accurate and therefore the tickling feels considerably more intense.

Sensory prediction processes also generally alert us to new and unexpected events so that we can deal with them effectively. As our brains make predictions about our sensory environment, they also continuously compare them to the actual information that our senses receive. **Any mismatch between the predictions and our actual experiences tends to be associated with a mild sense of anxiety that helps us deal with the unexpected event until the uncertainty is resolved.**

It is well known that sensory processing differences constitute part of the clinical characteristics of autism and recent evidence suggests that differences in sensory prediction processes are partly responsible (Sinha et al., 2014; Pellicano & Burr, 2012). As a result, **autistic individuals may always perceive the world as more uncertain and unpredictable, leading to the more persistent states of anxiety that interfere with day-to-day functioning** rather than facilitate adaptation to new situations (Green & Ben-Sasson, 2010; Black et al., 2017).

Many autistic individuals (around 50%) also have difficulties identifying and describing their own emotions.



## A closer look at alexithymia

In addition to the common sensory processing difficulties associated with autism, **many autistic individuals (around 50%) also have difficulties identifying and describing their own emotions.** As illustrated in Figure 1 on page 7, it is thought that this alexithymia contributes to anxiety through two independent routes. On the one hand alexithymia has been linked to difficulties in accurately sensing the internal signals of arousal that often accompany emotional experiences, such as changes in heart rate or a rush of adrenalin (Gaigg et al., 2018; Garfinkel et al., 2015). This can make internal sensations confusing and unpredictable, leading to anxiety in a similar way to how sensory processing difficulties do. In other words, differences in sensory prediction processes may not only render the external sensory environment more uncertain for autistic individuals but also the internal sensory environment.

In addition, alexithymia is thought to contribute to anxiety by making it more difficult for autistic individuals to regulate their emotions, for example, by trying to worry less about a certain situation or by accepting that a certain degree of worrying is okay in a given situation (thus preventing an escalation of anxiety). Such **strategies of reappraisal or emotional acceptance, are usually very effective in managing difficult feelings such as anxiety or stress.** However, for someone who struggles to identify and describe their emotions, it is generally more difficult to use such adaptive emotion regulation strategies effectively. As a result people with alexithymia often engage in maladaptive emotional suppression, which aims to push the confusing feelings away, only to make general feelings of anxiety worse in the long-run.

# Implications for treatment: how to help someone with ASD and anxiety?

## Cognitive Behaviour Therapy

**Cognitive Behaviour Therapy (CBT)** is a form of psychological therapy that is widely used in the general population to treat anxiety by guiding individuals to change their thoughts and beliefs about the objects and situations that elicit excessive anxiety. CBT starts by making a person aware of the thought patterns involved in their anxiety. The person is then exposed to situations that trigger anxiety, whilst giving them tools to manage it, for example through relaxation methods, or by examining the realistic outcomes of a particular situation. Because examining thoughts and understanding emotions are often a source of difficulty for autistic individuals, several adaptations have been recommended for making CBT more accessible and effective for them. These adaptations include the use of visual aids and social stories to explain complex social situations, and to support understanding of

emotions. Other adaptations serve to reduce the demands of interacting with a therapist, such as communicating via an internet chat rather than face-to-face.

**The evidence suggests that CBT generally leads to a moderate decrease in anxiety and an improvement in well-being in autism** (Lang et al., 2010), but the approach can be very resource intense due to the need for a trained therapist. Moreover, traditional CBT primarily targets a person's emotion regulation skills as a way of reducing anxiety, which may be problematic for the large number of autistic individuals who experience alexithymia. Because of these limitations, some researchers have therefore begun to examine whether treatments could also be helpful that target some of the other factors that contribute to anxiety in autism such as the intolerance of uncertainty, alexithymia and sensory processing differences as shown in Figure 1 (page 7).

## CBT

generally leads to a moderate decrease in anxiety and an improvement in well-being in autistic people.



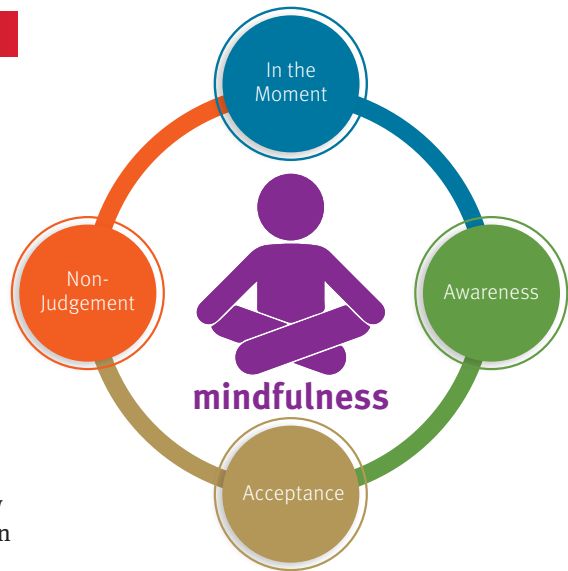
## Coping with Uncertainty

Researchers at Newcastle University are developing a new programme that seeks to teach parents how to help their autistic children to cope better with uncertainties in life (Rodgers et al., 2017). The main aim of the **CUES (Coping with Uncertainty in Everyday Situations)** programme is to gradually introduce children to uncertainty, and help them develop strategies for tolerating it. For instance, a child who might be anxious about possible changes to a routine (e.g. preparing for school every morning), might be encouraged to engage in some role-play to explore what it might feel like to change the routine. Parents learn how to encourage their child to practise relaxation techniques and other CBT based strategies to regulate their feelings during this 'safe' exploration of uncertainties. Gradual exposure to the anxiety-provoking situation is increased until the child can independently tolerate it more readily.

**Evidence from an initial pilot study suggests that this parent-mediated programme can reduce anxiety in both children and parents.** Larger scale trials are now under way to test the efficacy of this new programme more broadly.

## Mindfulness Based Therapy

At City, University of London, researchers are examining whether **Mindfulness Based therapies (MBT)** might offer a fruitful alternative to standard CBT. Mindfulness refers to the ability to focus on present moment experiences, including sensations and feelings, and to accept them without judgement or reaction. Mindfulness can be increased through meditation-like practices such as focusing on the sensations in different parts of the body, carefully exploring textures of objects, or attending to the different thoughts that might come to mind without trying to change them.



In the general population, a considerable amount of evidence shows that MBT is effective in reducing anxiety and stress and improving well-being (Grossman et al., 2004; Strauss et al., 2014) and programmes have been developed that are specifically tailored to young children. MBT might be particularly useful for managing anxiety in autism by targeting the type of sensory processing difficulties and difficulties introspecting on own emotions that play such an important role in this group. **Initial evidence indicates that practising mindfulness does indeed reduce anxiety in autistic adults (Kiep et al., 2015) and parents of autistic children (Cachia et al., 2016).** Moreover, the work by researchers at City, University of London shows that online-based self-help mindfulness tools are effective in reducing anxiety in autistic adults (Gaigg et al., 2017), suggesting that this approach may be scalable and flexibly adapted to different settings. Work is currently underway to establish how MBT strategies can be adapted effectively for autistic children, and how such strategies might be integrated with regular school activities.

# Tools to support the management of anxiety in autism

Considering how important sensory processing difficulties and alexithymia are to anxiety in autism, supporting children with these difficulties will play an important role in looking after their mental health. A number of resources are already available that those caring for autistic children can draw on in this context.

## Sensory processing toolbox

Given how variable sensory processing differences are across autistic children, it is important to identify individual sensory profiles before considering what hyper- or hypo- sensitivities might represent appropriate targets for sensory related work. A useful checklist, in this context, is the West Sussex County Council sensory toolkit (see online resources on page 18).

From this checklist, an individualised programme of sensory activities can be developed, which may include opportunities to satiate hyposensitivities (e.g., to address maladaptive sensory seeking behaviours), or de-sensitise hypersensitivities (e.g., to make unavoidable sensory experiences more tolerable). Objects and activities that could be considered for developing individualised sensory activities are listed in the following box.



### Visual resources

including blowing bubbles, kaleidoscopes, reflective/translucent materials.



### Tactile resources

including PlayDoh, Thera Putty, shaving foam, soft and/or rough fabrics/materials.



### Auditory resources

including access to music or other auditory stimuli through headphones.



### Taste and smell resources

including aromatherapy oils, foods and spices.



### Proprioceptive activities

including rolling over an exercise ball, jumping on a trampette, carrying heavy books, pushing against walls.



### Vestibular resources

including access to climbing equipment that allows hanging upside down or equipment that provide balancing opportunities.

In the context of sensory hypersensitivities, resources such as ear defenders or tinted glasses may also be useful to reduce the impact of the sensory stimulation the individual finds distressing. When facilitating desensitisation, it may be possible to gradually withdraw such resources as the individual builds tolerance to the relevant sensory stimuli. More generally, gradual exposure to sensory stimuli is important when facilitating desensitisation.

In addition to developing individualised sensory programs, consideration should also be given to the environment and whether opportunities exist to make adaptations that would benefit learners with sensory processing differences irrespective of their individual profiles. For instance, a low arousal space with little visual and/or auditory sensory stimuli could be provided to serve as a 'safe space'. Children and staff could also be encouraged to be mindful of sources of sensory stimulation, for example

by writing down 5 smells they noticed during lunch or 5 sensations they had during physical activity. These experiences could then be shared to encourage communication about sensory processing differences. Additional strategies for helping children manage their sensory processing differences can be found in the following book resource.

---

**Sensory Strategies: Practical ways to help children and young people with autism learn and achieve**

Corinna Laurie (2014).

The National Autistic Society, London, UK.

*This book has a lot of practical solutions to help children who have sensory processing difficulties that might result in difficult behaviours. As an Occupational Therapist with expertise in Sensory Processing Disorder, the author helps the reader to identify possible sensory triggers to difficult behaviours and strategies for dealing with them.*

---



## Emotional awareness and alexithymia toolbox

Supporting the development of children's emotional awareness and literacy is important for providing them with the foundations for learning how to manage and regulate their feelings. Both CBT and Mindfulness based strategies for managing anxiety rest on the assumption that an individual can identify and think about their feelings, either to try to regulate them (as in CBT) or simply to accept and observe them (as in MBT). The resources listed in this toolbox section provide a range of strategies that should prove useful for fostering children's emotional awareness and literacy and their ability to develop strategies for managing their emotions.

### The Zones of Regulation

Leah M. Kuyper (2011).

Think Social Publishing Inc, USA.

*The Zones of Regulation uses a cognitive behaviour approach to help children become more aware of, and independent, in controlling their emotions and impulses, managing their sensory needs, and improving their ability to problem solve conflicts.*

### When My Autism Gets Too Big

Kari Dunn Buron (2004).

AAPC Publishing, Kansas, USA.

*This book gives young children an opportunity to explore, with parents or teachers, their own feelings as they react to events, while learning some useful relaxation techniques.*

### When My Worries Get Too Big

Kari Dunn Buron (2013).

AAPC Publishing, Kansas, USA.

*This illustrated children's book is written to help children who are overburdened with worry and anxiety. It provides children opportunities to participate in developing their own self-calming strategies.*

### Dealing with Feeling

Tina Rae (2008).

SAGE Publications Ltd., London, UK.

*This book provides teachers of children aged 7-14 with structured opportunities to develop their emotional literacy and emotional well-being, with a focus on developing an emotional vocabulary, empathy, tolerance, resilience and motivation.*

### The Essential Guide to using Mindfulness with Children & Young People

Tina Rae, Jody Walshe & Jo Wood (2017).

Hinton House Publishers, Banbury, UK.

*This book provides practical and user-friendly introductions to tried-and-tested mindfulness-based strategies for promoting emotional and mental well-being in young people. The tools will help to prevent the escalation of difficulties and will provide anyone wishing to develop a programme of support with a range of problem-solving ideas and techniques.*

**Starving the Anxiety Gremlin:  
A Cognitive Behavioural Therapy Workbook  
on Anxiety Management for Young People**

Kate Collins-Donnelly (2013).  
Jessica Kingsley, London, UK





*Starving the Anxiety Gremlin is a unique resource to help young people understand different types of anxiety and how to manage them. Through cognitive behavioural principles, the techniques described help young people to understand why they get anxious and how they can 'starve' their anxiety gremlin in order to manage their anxiety. This engaging workbook uses fun activities and real life stories, and can be used by young people aged 10+ on their own or with a parent or practitioner.*

**The Homunculi Approach to Social and Emotional Wellbeing. A flexible CBT programme for young people on the autism spectrum or with emotional and behavioural difficulties**

Anne Greig & Tommy Mackay (2013).  
Jessica Kingsley, London UK.

*The Homunculi are miniature agents with problem-solving missions and special gadgets who live inside the brain and help out with distressing thoughts, feelings and behaviours. By inventing their own Homunculi characters and stories, children learn to cope with their real-life problems. The book helps build social and emotional resilience in children and young people, aged 7 upwards and is particularly suited to those with an autism spectrum diagnosis who often have difficulty identifying troubling feelings such as anger, fear and anxiety.*

The **ZONES** of Regulation®

			
<p><b>BLUE ZONE</b></p> <p>Sad Sick Tired Bored Moving Slowly</p>	<p><b>GREEN ZONE</b></p> <p>Happy Calm Feeling Okay Focused Ready to Learn</p>	<p><b>YELLOW ZONE</b></p> <p>Frustrated Worried Silly/Wiggly Excited Loss of Some Control</p>	<p><b>RED ZONE</b></p> <p>Mad/Angry Mean Terrified Yelling/Hitting Out of Control</p>

## Intolerance of uncertainty toolbox

To help children manage their intolerance of uncertainty as a source of anxiety it is useful to make their lives more predictable. However, this can have the undesired consequence of reinforcing maladaptive coping strategies such as insisting on routines that may interfere with day-to-day life or even present health risks. Since uncertainties are impossible to avoid in day-to-day life, it is therefore equally important to help children build greater tolerance of uncertainty. A useful strategy, in this context, is to gradually expose children to uncertainty within an otherwise well structured environment and to encourage them to practice managing their anxiety in these situations. For example, children who tend to become distressed when certain routines are interrupted or prevented might be encouraged to think about how big a deal

it would be for certain aspects of the routine to be disrupted (e.g. is it a bigger deal to sit somewhere else during lunch than to eat with different cutlery?) before exploring how they feel when the disruption actually occurs. Alternatively, staff can expose children to uncertainties in play activities by, for example, asking them to guess what is in a bag based only on exploring the texture of the hidden object.

Tools that can help to make the environment more predictable for children include visuals such as timetables, schedules and event sequences (e.g. for dressing, washing and daily routines) as well as resources that foster greater understanding of what to expect in different social situations (see the resources in this section). Tools that can help children learn ways of managing their anxiety, include those described in the 'Emotional awareness and alexithymia toolbox' in the previous section.



---

## The Incredible 5-point Scale

Kari Dunn Buron & Mitzi Curtis (2012).  
AAPC Publishing, Kansas, USA.

*A primary goal of the scale is to help autistic children notice and functionally respond to their own and others' social behaviour. It provides teachers and parents with a simple way to teach social rules and expectations, problem-solving skills in how to respond to others, a way to troubleshoot past and future social scenarios and support for creating plans for self-management.*

---

## The New Social Story Book

Carol Gray (2015).  
Future Horizons Inc., Texas, USA.

*Social Stories™ provide an effective and meaningful tool to support social understanding. The book offers over 180 ready-to-use stories that parents and educators can use to explain social situations in ways children (and adults) with autism understand, while teaching social skills.*

---

## Comic Strip Conversations

Carol Gray (1994).  
Future Horizons Inc., Texas, USA.

*This book combines stick-figures with 'conversation symbols' to illustrate what people say and think during conversations. Showing what people are thinking reinforces that others have independent thoughts, which autistic children often find difficult to understand intuitively. It also helps children understand that what people say is not always what they mean.*

---

## Comic Strip Conversations Example

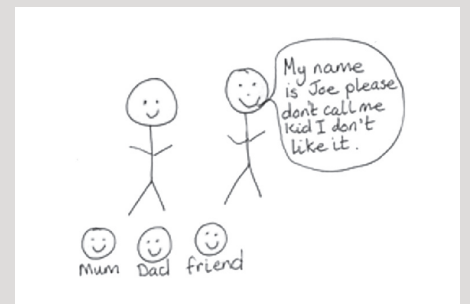
Child draws the incident...



Then adds details about the triggers and thought bubbles to explain perspectives...



Then draws alternative way of responding



# Additional resources and further reading

## Online resources

### **The Anxiety Scale for Children with Autism Spectrum Disorder (ASC-ASD)**

<https://research.ncl.ac.uk/neurodisability/leafletsandmeasures/anxietsyscaleforchildren-asd>

### **Social and Emotional Aspects of Learning**

<http://webarchive.nationalarchives.gov.uk/20110812101121/http://nsonline.org.uk/node/87009>

### **Autism Educational Trust Progression Framework: Assessment tool:**

[www.aetraininghubs.org.uk/schools/pf](http://www.aetraininghubs.org.uk/schools/pf)

### **West Sussex County Council Autism & Social Communication Team Sensory Plan Toolkit:**

[https://westsussex-local-offer.s3.amazonaws.com/public/system/attachments/1116/original/NEW\\_Sensory\\_Toolkit.pdf](https://westsussex-local-offer.s3.amazonaws.com/public/system/attachments/1116/original/NEW_Sensory_Toolkit.pdf)

### **Emotional Literacy Resources**

[www.elsa-support.co.uk](http://www.elsa-support.co.uk)

### **General Educational Resources (Social Skills; Emotion Regulation; etc.)**

[www.do2learn.com](http://www.do2learn.com)

### **Visual aids for learning**

[www.visualaidsforlearning.com](http://www.visualaidsforlearning.com)

## Useful Apps

### **National Autistic Society's Brain in Hand App**

[www.autism.org.uk/services/education/brain-in-hand.aspx](http://www.autism.org.uk/services/education/brain-in-hand.aspx)

### **Autistica's Molehill Mountain app**

[www.autistica.org.uk/get-involved/molehill-mountain-app](http://www.autistica.org.uk/get-involved/molehill-mountain-app)

### **The Smiling Mind App**

[www.smilingmind.com.au](http://www.smilingmind.com.au)

### **Positive Penguins**

[positivepenguins.com](http://positivepenguins.com)

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**For more information about the work of the Autism Research Group, visit:**

[www.city.ac.uk/arts-social-sciences/psychology/research/autism-research-group](http://www.city.ac.uk/arts-social-sciences/psychology/research/autism-research-group)

**For more information about the work of the Autism and Social Communication Team, West Sussex County Council, visit:**

<https://westsussex.local-offer.org/services/114-autism-and-social-communication-team>

**YOUR OPINION MATTERS!**

We are committed to keeping this guide up to date and will aim to revise it as significant new evidence and practice guidance emerges. If you have any feedback or comments regarding the contents of this guide, please do not hesitate to e-mail Dr Sebastian Gaigg ([s.b.gaigg@city.ac.uk](mailto:s.b.gaigg@city.ac.uk)).

Or, if you have any questions for the Autism and Social Communication Team of West Sussex County Council, please send your query to [schoolsABC@westsussex.gov.uk](mailto:schoolsABC@westsussex.gov.uk)

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# Bullying and autism spectrum disorders

a guide for school staff

If you work in a mainstream or special needs school, you will inevitably come across instances of bullying from time to time. Pupils with an autism spectrum disorder (ASD) are at particular risk of being bullied.

This booklet helps you to understand why this is the case and provides strategies and ideas for promoting understanding of ASDs among staff and pupils, tackling and reducing bullying incidents and supporting pupils with an ASD who have been bullied.

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

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

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

***Together, we are going to change this.***

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

Autism Helpline: 0845 070 4004  
(Mon-Fri 10am-4pm)  
Minicom: 0845 070 4003  
[autismhelpline@nas.org.uk](mailto:autismhelpline@nas.org.uk)  
[www.autism.org.uk/a-z](http://www.autism.org.uk/a-z)

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# Bullying and autism spectrum disorders

a guide for school staff



# Bullying and autism spectrum disorders

a guide for school staff

**By Alice Stobart**

## Acknowledgements

I am grateful to the authors of the many great resources available in print and on the web, which have informed the writing of this guide. Key web resources are listed on page 28.

## About the author

Alice Stobart coordinates The National Autistic Society's (NAS) Education Support Service in the South East of England. Before this, she taught children with autism in an NAS school and supported children with a range of learning disabilities in South Africa.

Alice's current role involves working directly with both mainstream and special educational needs (SEN) schools to develop practical ways to improve their provision for children with autism. She delivers training for groups involved with education, and is a member of the Autism Accreditation team, a body established by the NAS to provide an autism-specific quality assurance programme for services across the UK.

*Cover artwork by Jeanette Byrne, aged 13, who entered our make school make sense art competition*

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### A note on terminology

We use the term autism spectrum disorder (ASD) throughout this booklet to refer to the full range of diagnoses on the autism spectrum, including Asperger syndrome.

Although in real-life contexts children should not be labeled as 'bullies', for ease of communication we have used the terms 'bully' and 'bullies' to refer to children who display bullying behaviours. For the same reason, we refer to the child on the receiving end of the bullying behaviour as the 'target'.

### A note on case studies

All the case studies described in this booklet are based on real incidents, but with names and some details changed.

## 1 Introduction

If you work in a mainstream or special needs school, you will inevitably come across instances of bullying from time to time. While most schools have a clear policy for dealing with bullying, it may not always take account of the needs of pupils with autism spectrum disorders (ASDs), who are among the pupils at greatest risk of being bullied.

This booklet will help senior management, class and subject teachers and school support staff to:

- > understand why pupils with ASDs are at risk of being bullied
- > promote understanding of ASDs among school staff and pupils
- > implement strategies to tackle and reduce bullying
- > support pupils with ASDs who have been bullied
- > manage perceived bullying behaviour in pupils with an ASD.

Most of the guidance in this booklet applies to both primary and secondary schools, but where approaches and strategies are more appropriate for one setting or the other, this is made clear.

Although this booklet focuses on pupils who have an ASD, many of the strategies for understanding, preventing and dealing with bullying will be of practical use when you are supporting other children too.

You may also find it useful to read *Autism spectrum disorders: a resource pack for school staff*, available from the NAS Autism Helpline on **0845 070 4004**. See *Useful resources*, starting on page 25, for more details.

### What is an ASD?

An ASD is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. 'Spectrum' means that, while all people with an ASD share three main areas of difficulty, their condition will affect them in different ways. With support, some young people with an ASD are able to live relatively typical childhoods but others may have an accompanying learning disability and need continuous specialist support at school, and for the rest of their lives.

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

#### > social interaction

Children with an ASD often have difficulty recognising or understanding other people's emotions and feelings, and expressing their own. They may not

understand the unwritten social rules which most children pick up without thinking. They may appear insensitive, prefer to spend time alone and behave in ways that seem 'strange' or inappropriate. Not understanding how to interact with their peers can make it hard to form friendships.

#### > social communication

Children with an ASD have difficulties with both verbal and non-verbal language. Many have a very literal understanding of language and may find it difficult to use or understand facial expressions, tone of voice, jokes, sarcasm and common idioms. Some children with an ASD may not speak, or have very limited speech, while others may have good language skills but still find it hard to understand the give-and-take nature of conversation.

#### > social imagination

Many children with an ASD find it difficult to understand and predict other people's intentions,

Artwork by Jack Field, aged 10, who entered our make school make sense art competition



# Bullying and autism spectrum disorders

thoughts, feelings and behaviour and to imagine situations outside of their own routine. They may find it impossible to predict what will or could happen next, may not understand the concept of danger and may have difficulty with imaginative play. This can be accompanied by a narrow, repetitive range of activities and an inability to cope with new and unfamiliar situations.

Children with an ASD may also experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours. This can make the hustle and bustle of the school environment frightening and even painful.

Asperger syndrome is a form of ASD. Children with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language. They do not usually have learning disabilities but may have specific learning difficulties, including dyslexia.

## What do we mean by bullying?

There are five main categories of bullying:

- > physical (causing physical pain or taking belongings)
- > verbal (name-calling, insults, taunting)
- > non-verbal (eye-rolling, gesturing, ignoring)
- > indirect (spreading rumours, excluding from social groups)
- > cyberbullying (sending malicious emails, texts or social network messages).

Bullying is usually distinguishable from friendly teasing or conflict situations. If a pupil is being bullied, they will often:

- > be targeted with repeated, negative actions with harmful intent

- > experience an imbalance of power in their interactions with the bully (for example, psychological, verbal, social or physical)
- > be affected by these interactions in a contrasting way to the bully (the target is usually distressed).

As well as the five main categories of bullying, some pupils experience 'backhanded bullying'. This involves the bully misleading the target or persuading him or her to carry out inappropriate activities, such as stealing from another pupil's bag or locker, which draws negative attention or gets the target into trouble.

## 2 Why pupils with an ASD are at risk of being bullied

Forty per cent of parents who have a child with autism say that their child has been bullied. This figure is even higher for children with Asperger syndrome<sup>1</sup>.

Children with an ASD have difficulty 'reading' social situations and knowing how to engage in ever-changing social contexts. They find it hard to predict other people's behaviour and to interpret their body language and expressions to guess what they are thinking or feeling. This makes it difficult for children with an ASD to understand other people's intentions, and makes them an easy target for bullies.

At school, children with an ASD often become targets of backhanded bullying, where they are offered 'friendship' by someone who intends to mislead them or they are directed by their 'friend' to engage in absurd and inappropriate activities. Their social naivety means that pupils with an ASD may be unsure whether someone is being genuinely friendly or whether they are 'winding them up'. Some will do things that their peers suggest in order to be accepted into a group, but be unable to predict that their actions may be harmful, or get them into trouble.

Pupils with an ASD may prefer to play alone and this isolation from their peers, without any support structure from other pupils, will increase their vulnerability to bullying. Pupils with an ASD may also speak in an unusually formal manner, behave in an eccentric way or make inappropriate comments. They will often not understand sarcasm or punchlines, and they may have an 'obsessive' interest in a particular item or topic that their peers will use as an excuse to taunt or upset them.

Their difficulties with communication mean that pupils with an ASD may not be able to report an incident of bullying to school staff or their parents.

"In many respects, children with Asperger's make perfect 'victims'; a fact that most bullies are quick to discover: we have no tactics for verbal or physical self-defence, we are extraordinarily naive... We can be reduced to tears of frustration and rage with delicious ease by simple plays like making fun of our obsessions."

Clare Sainsbury, *Martian in the playground*<sup>2</sup>

### Dominic

Dominic is in Year 7 and has a special interest in trains. He knows all the local destinations and connections. Dominic reads books about trains and collects pictures of them. He often tries to engage his peers in discussions about trains. When he becomes anxious, Dominic calms himself down by talking about trains and looking at the scrapbook he has compiled.

Some of the boys in Dominic's class make fun of him by getting him to repeat information, confuse him by talking about non-existent destinations, or try to upset him by reporting fake incidents involving trains. He finds it difficult to discern when people genuinely share his interest and when they are using it to tease him. On one occasion, the boys took his scrapbook out of his bag and laughed while he chased after them, becoming increasingly upset. He eventually caught up with them and was seen hitting one of the group by a member of staff. Because the staff member had not witnessed the lead up to this incident, and because Dominic was unable to clearly explain what had happened, Dominic was given detention for being physically aggressive.

<sup>1</sup> The National Autistic Society. (2006). *B is for bullied*. London: NAS

<sup>2</sup> Sainsbury, C. (2000). *Martian in the playground*. Bristol: Lucky Duck Publishing

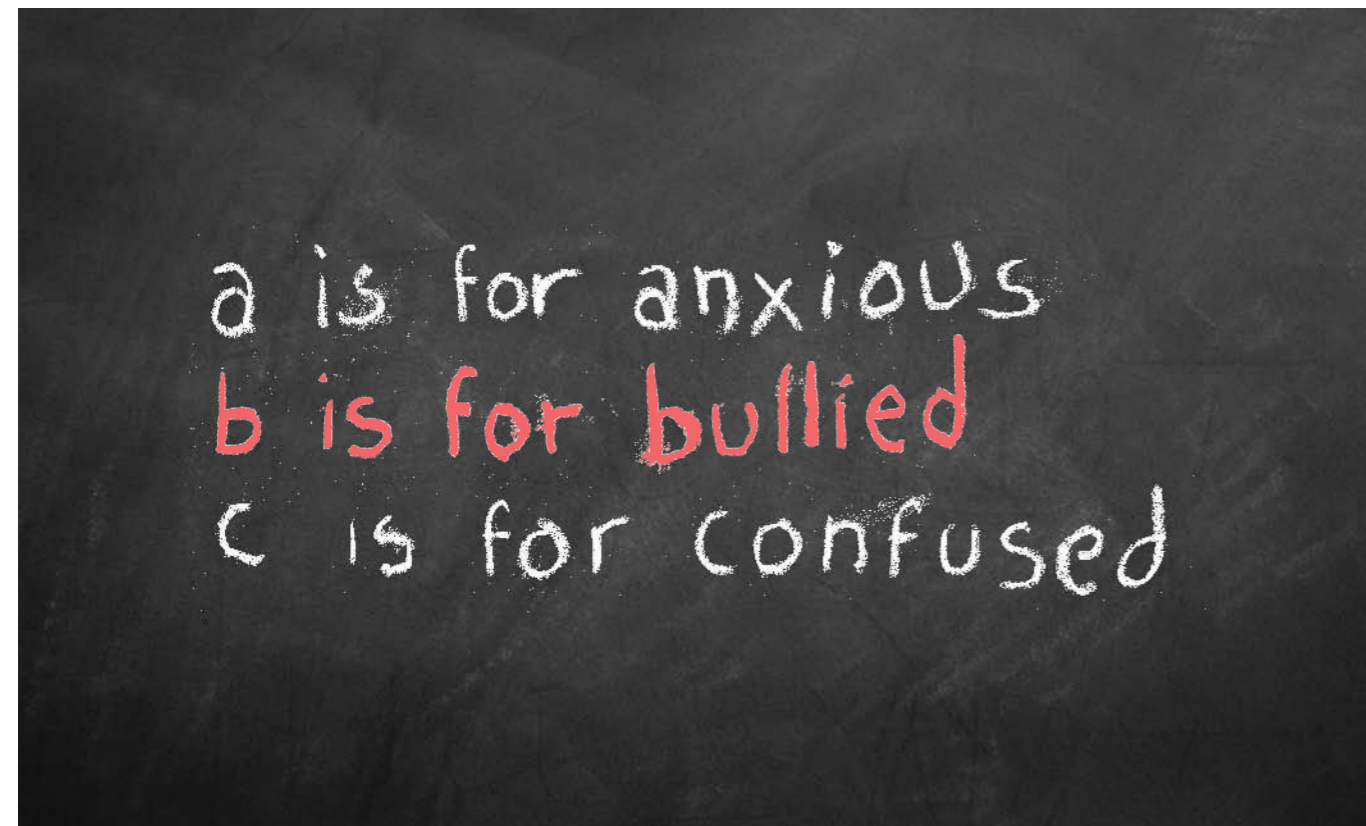
# Bullying and autism spectrum disorders

Many of the characteristics we find in pupils who are the target of bullies are also common traits in people with an ASD. These include:

- > anxiety
- > passivity
- > low self-esteem (as a result of their difficulties in social contexts)
- > a seeming lack of humour
- > lack of friends (they may easily frustrate other children and therefore be rejected by them)
- > submissiveness to suggestions and instructions from peers
- > inflexibility
- > emotional vulnerability
- > clumsiness.

## Key points

- > The behavioural characteristics and social naivety that accompany ASDs (for example, overly formal speech, unusual behaviour and obsessive interests) can make pupils with an ASD very vulnerable to bullying.
- > Pupils with an ASD are particularly vulnerable to 'backhanded bullying' because they take friendship at face value and find it difficult to discern ulterior motives.



## 3 Taking bullying seriously

Schools must meet a number of legal duties when it comes to bullying. These are set out in Government guidance (see *Useful resources* starting on page 25). Schools are expected to have anti-bullying policies<sup>3</sup> which include a definition of bullying agreed by the whole school, and follow the principles of the Government's Anti-Bullying Charter<sup>4</sup>.

### Principles of the Anti-Bullying Charter

- > Discuss, monitor and review the school's anti-bullying policy.
- > Support everyone in the school community to identify and respond appropriately to bullying.
- > Ensure that parents/carers expressing bullying concerns have them taken seriously.

- > Ensure that children and young people are aware that all bullying concerns will be dealt with sensitively and effectively.
- > Learn from effective anti-bullying work elsewhere.

The law also requires schools to make sure that people with disabilities are not discriminated against or substantially disadvantaged, and to eliminate harassment of disabled people, including bullying of children with autism<sup>5</sup>. Schools are required to develop a Disability Equality Scheme which describes how they intend to do this.

The Government is clear that it expects schools to create an ethos in which bullying is not tolerated. It is important not to view bullying as an unavoidable part of growing up or an inevitable part of school life, or to confuse it with typical peer conflict.

Figure 1 (below) may be useful in helping you to determine whether an incident is 'typical peer conflict' or bullying.

Figure 1

Typical peer conflict	Bullying
Equal power between pupils	Imbalance of power between pupils
Pupils involved may be friends	No real friendship between pupils
Negative actions don't follow a pattern	Negative actions are repeated
Conflict not premeditated and no real intention to cause harm	Actions are purposeful and possibly premeditated
Followed by sincere remorse	Bully shifts blame, no sincere remorse
Interest in repairing relationship	No interest in repairing relationship
Both pupils play active role	Incident is one-sided
Pupils may be supported by other peers	Target is alone without peer support
There is an intention to resolve a situation	Intention is to gain power, control, or items

<sup>3</sup> Department for children, schools and families. (2007). *Safe to learn: embedding anti-bullying work in schools*. London: DCSF

<sup>4</sup> Department for children, schools and families. (2007). *Bullying – a charter for action*. London: DCSF

<sup>5</sup> Department for children, schools and families. (2008). *Bullying involving children with special educational needs and disabilities*. London: DCSF

## Signs that a child is being bullied

A pupil who is being bullied may display some of the following common responses:

- > increased anxiety (displayed through increasingly obsessive behaviours, hand movements, repetitive questioning and statements, or short temper)
- > withdrawal
- > aggression
- > seeming over-sensitive or over-reacting to minor occurrences (being 'on edge')
- > seeking revenge
- > repeatedly exposing him- or herself to the same kind of bullying situation. Although the pupil may know it is a negative interaction, they may still consider this better than no interaction at all. It becomes a scenario they are familiar with and which follows a predictable sequence.

### Adam

Adam is a pupil with an ASD at a small independent school. The other children have learned that he has a short temper and finds it difficult to control his anger when he becomes upset. At break time the children like to play tag in the wooded playground. They are supervised by three members of staff but the trees make it difficult for the staff to see clearly what the children are up to.

Adam desperately wants to be included in the game but the other children will only let him do so if he's 'it'. So he always agrees and spends his playtime chasing other children as they run away from him. To make the game more exciting, the children have devised ways of provoking Adam so that when he chases them he is really cross, giving the game a 'dangerous' element. The children call out 'Adam Poopy Pants' and block their noses as if he has soiled himself. Adam becomes furious and chases

after them. On occasions where he has caught up with them he has been removed from the playground for thumping them.

The pattern repeats itself day after day because Adam wants to be included and this is the only way he knows how.

*(How can this problem be addressed? See page 12).*

## Promoting understanding among school staff

No one deserves to be humiliated or teased, regardless of their idiosyncrasies, and school staff play an important role in communicating this to pupils and in promoting respect for others. An environment where intolerance and discrimination are accepted or ignored could be a contributing factor in children willingly humiliating others.

School staff can sometimes think that pupils attract or provoke a bullying response from other pupils because of their eccentricities, and that the bullying would stop if they modified their behaviour. A teacher might, for example, try to stop a pupil with an ASD flapping his or her hands when he or she is anxious in order to prevent teasing or mocking. Although this action is well-intentioned, it can serve to highlight difference rather than promote tolerance. Instead, the teacher should try to explain to the pupil's peers why it is unacceptable to imitate someone who behaves differently when anxious.

Regardless of their behaviour, manner or appearance, children can never be held responsible for provoking a bullying response from their peers. Schools should consider training for all staff, including supervisory staff, to develop their understanding of pupils with an ASD. This will help to prevent staff from unwittingly contributing to a pupil's mistreatment by being punitive or critical of idiosyncrasies that are beyond the child's control.

*"A good teacher would be helpful, not impatient. They'd understand me and always get the full picture of what's going on. Not that long ago my teacher just didn't get the full picture of what was going on, so someone knocked my pencil case in class and I went to get it off them and then he shouted at me, who had just got up to get it back."*

Pupil with an ASD

But while it is wrong to lay the blame for bullying on the eccentricities of the target, it is also unrealistic to allow the sometimes challenging behaviour of a pupil with an ASD to go unchecked in the classroom. Your actions to promote understanding of ASDs among the pupil's peers will be more effective if accompanied by a pro-active Behaviour Support Plan (BSP) for the pupil in question (see **Appendix 1**). This plan should recognise and tolerate the pupil's likes, dislikes and needs, but identify the things that trigger his or her anxiety and develop strategies to help him or her cope when things are difficult or stressful. Through long-term careful planning, as opposed to reactive behaviour control, the situations that lead to bullying can be kept to a minimum.

## Key points

- > Schools are required by law to take measures to prevent and act on bullying and to make sure that people with a disability are not discriminated against.
- > School staff play a vital role in promoting understanding and tolerance of difference.
- > Training in ASDs can help staff to recognise why pupils with an ASD behave in certain ways, detect when they've been bullied, and help to prevent bullying situations from occurring in the first place.

As part of this support structure, it may be useful to assign one member of staff to mentor pupils with an ASD. This staff member would need to know how to support each pupil when they are feeling anxious or upset, and be able to offer guidance to other staff on dealing with situations that arise. Because children with an ASD often struggle to communicate what is happening to them, all staff - and especially the mentor - need to be alert to signs of distress.

It is also helpful for school staff to have regular opportunities to discuss issues that arise from having pupils with an ASD in their school. By understanding how the condition affects each pupil, what support is needed and what strategies work well - and by sharing this information with other colleagues - the school can establish a consistent supportive approach from all staff. This will be particularly helpful in secondary schools where pupils are taught by many different teachers. All this information should also be added to the pupil's profile.

See *Useful resources*, starting on page 25, for more general information about supporting pupils with an ASD in school.

## 4 Strategies for reducing bullying

Bullying is more likely to take place at unstructured times, such as lunchtime, break times, transition times between lessons and in the periods before and after school. Bullying is also more common in under-supervised areas, such as the playground, corridors, the lunchroom, school toilets and on the bus travelling to and from school.

Many of the strategies suggested in this section – some of which may already be familiar – will be helpful in preventing bullying across the school, not just the bullying of children with an ASD.

### Strategies for all schools

- › **Make sure the school rules about bullying are very specific** so that there can be no misunderstanding about what constitutes bullying. Pupils should be encouraged to contribute to the list and should be aware of the consequences of bullying.
- › **Identify risk times and places** and, if possible, increase the level of informed staff supervision for these periods and areas.
- › **Choose groups and teams yourself** in lessons where pupils need to work in this way, and where bullying is more likely (for example, less structured lessons such as PE and games). This will prevent certain pupils from always being picked last for teams and prevent known bullies from targeting vulnerable individuals.
- › **Introduce a 'bullying box'** to the school. Many children who are bullied, or who witness someone else being bullied, are likely to be afraid of reporting the incident for fear of retaliation. Also, due to their communication difficulties, pupils with an ASD may struggle to communicate an incident effectively to a member of staff. A

'bullying box' allows pupils to write an account of a bullying incident and post it anonymously. An assigned member of staff reads the reports daily and deals with incidents as necessary.

- › **Examine group dynamics** in cases of persistent bullying. During risk times, groups of children may need to be split up to prevent intimidation or group pressure to gang up on individuals. If practical, this could mean designating different play areas, staggering play times to reduce the number of children in the playground at any one time, or designating specific tables in the lunch room. You could also consider changing class groupings in schools where there is more than one class per year group.
- › **Provide positive role models and celebrate positive behaviour.** Assemblies and classroom sessions that focus on and celebrate friendship, kindness and supportive peer relations, as well as academic achievement, can be a valuable part of your overall anti-bullying strategy. You could also consider rewarding pupils for their social achievements, perhaps through the school's existing credit or reward system.
- › **Tackle cyberbullying.** Ensure that your school has an agreed definition of what constitutes cyberbullying and that this is incorporated into the school's overall anti-bullying policy. Children and parents should be made aware of pupils' responsibilities when using ICT (Information and Communication Technology) and what the consequences are for their misuse. Positive use of technology can be promoted through sessions on 'netiquette', e-safety and digital literacy. The Department for Children, Schools and Families has produced guidelines for tackling cyberbullying, which are available from [www.teachernet.gov.uk](http://www.teachernet.gov.uk)

### The specific role of support staff

Teaching assistants and other support/supervisory staff can play an important role in the detection

and prevention of bullying, as they often see things that a teacher who is delivering a lesson may miss. It can be tricky for support staff to support a pupil with an ASD without getting in the way of them interacting with their peers. As children grow older, staff who supervise them too closely can become a barrier to them developing friendships because children are reluctant to include someone who has an adult tagging along. But if staff don't supervise closely enough, they may not notice or be around to help if the pupil becomes a victim of bullying. Each individual situation needs to be carefully considered according to need, and support staff need to have a clearly-defined strategy for supervision in each case.

### Strategies for primary schools

- › **Develop a 'circle of friends'** - a group of six to eight children who volunteer to support and include the pupil with an ASD. This can be a positive experience for both the pupil in question and the circle, who will learn to understand, support and appreciate someone with a disability. The circle could take part in social skills sessions with the pupil with an ASD or work with them in group tasks. They could sit with them at lunchtime and include them in games in the playground. As there are six to eight children in the group it shouldn't become a burden for the individual group members, and it may be that the class decides to rotate members of the group on, say, a fortnightly basis.
- › **Introduce a 'friendship bench'** in the playground. This is a designated bench where anyone who wants to be invited to join a game can sit. Members of the 'circle of friends' or an identified 'playground friend/monitor' are then responsible for including those sitting on the bench in a group game.
- › **Designate an area of the playground for 'quiet play'** or allow break-time access to specific rooms in the school building. As most children with an ASD have sensory sensitivities, a noisy, chaotic playground can feel overwhelming. They may

prefer to retreat to a quiet space by themselves to unwind from the pressures of their day. Because such physically isolated spaces can be a target for bullies, staff supervision would be needed to make sure that these spaces are safe.

- › **Create structure at break times.** Children with an ASD respond best to structure, so they can find the unstructured nature of break times very challenging. If certain areas of the playground are designated for specific activities (for example, ball play, skipping, hopscotch), pupils with an ASD might find it easier to take part in one of these, or to avoid areas they find overwhelming. Also, other children will be less likely to bully if they are not bored in the playground.
- › **If possible, increase the level of supervision at break times.** This may mean staff staggering their break times so that more staff are available at these risk times.
- › **Assign specific seating positions to some children.** During classes and at lunchtime, the pupil with an ASD could be seated near to children who are more likely to include them. Any children who are likely to bully in pairs could also be separated from each other and from the target.

### Strategies for secondary schools

- › **Introduce mentors or mentor groups** for pupils with an ASD. This is a more age-appropriate strategy than the 'circle of friends' suggested for primary-school settings. The mentor or mentor group wouldn't need to be with the focus pupil all the time; they would look out for them or support them during identified risk times. Bullying is less likely to occur if the target is in the company of a supportive group. It will be important to ensure that the mentors have a clear understanding of their responsibilities and of the difficulties the focus pupil faces, and are themselves supported by all staff.

# Bullying and autism spectrum disorders

- > **Introduce 'buddies' for travelling to and from school.** Pupils who use public transport to and from school may be vulnerable to bullying at these times. If possible, they could be 'buddied' with other pupils who they can travel with. As with mentors, these 'buddies' should be fully supported by school staff. It may be necessary to carefully plan the focus pupil's route and to assign a member of staff to bus stops around the school in the mornings and afternoons.
- > **Some schools have found it helpful to stagger break times** to avoid the whole school eating lunch or using outdoor space at the same time. This can prevent older pupils from picking on younger, more vulnerable pupils. Staff supervision must be carefully planned to avoid supervisors becoming another factor that provokes a bully to pick on a pupil with an ASD. During these times, the supervisory staff member should be situated close enough to have a clear view of vulnerable pupils but far enough away to avoid drawing attention to them.
- > **Allow pupils with an ASD to use a dedicated quiet area, perhaps a learning resource centre, during break times.** Many teenagers with an ASD say that they find the small talk of other teenagers tedious and alien, and they don't find the social interaction at such times a relaxing activity. Of course, social skills development should be an important part of their curriculum but this needs to be carefully planned and structured, and it won't necessarily be achieved by forcing these pupils to spend their 'down time' in noisy, overwhelming environments.
- > **Introduce lunch clubs.** Some schools have had great success with lunch clubs. These are supervised by staff and provide structured activities during longer break times. Any pupil can join a club, and activities are chosen by the pupils according to their interests. Examples include drama, dance, music, art and crafts, football, and one day a week for homework

support. Clubs can be rotated on a daily basis or run at the same time in different classrooms, depending on how many members of staff are available to run them.

## Jessica

Jessica was a pupil in a secondary mainstream school. Carrying her backpack at all times helped to reduce her anxiety. She liked it to be tightly zipped and when she needed to open it to take out her belongings or put them away, she carried out a ritual of zipping and unzipping the bag three times.

Some of her peers found it amusing to see Jessica do this, and began to tell her that her bag wasn't properly zipped shut so that she would immediately stop what she was doing and carry out the ritual of zipping and unzipping the bag. Sometimes her peers would do this repeatedly so that Jessica became increasingly upset. She was unable to break the cycle of her ritual and became more frantic as they teased her. Sometimes, when she was moving from class to class, peers would follow her in the corridor and unzip her bag slightly. Again Jessica became highly anxious and upset. The other pupils were careful not to tease her when staff members were present.

One day Jessica had reached her limit and in her heightened state of anxiety scratched the face of one of the bullies. She was called to speak to the head of year after a teacher reported the scratches, and was unable to explain her side of the story. Fortunately, another classmate who had witnessed the incident gave a full account of what had happened. Jessica was assigned a 'mentor' - another pupil who volunteered to walk to lessons with her. Jessica was advised to join a lunch club so that she was not isolated during the long lunch break. After these measures were put in place, the bullying stopped.

"Normally, if I'm only feeling a little bit distressed, I try to cope with it. If it becomes uncontrollable the teacher asks me to leave the class and I go to a calm area, like the library or the entrance hall. The teaching assistant goes with me if they're there."

Pupil with an ASD

## Key points

- > Bullying is most likely to take place at unstructured times and in under-supervised areas.
- > Support staff need to tread a difficult line between supporting a pupil with an ASD and allowing them to interact with – and be accepted by – their peers.
- > The school can adopt a number of strategies to help prevent bullying. These include: having clear rules about bullying and its consequences for the bully and making these known to all pupils; identifying areas and times when bullying is more likely to take place and increasing supervision at these times; celebrating 'positive behaviour'; providing quiet and safe places for pupils with an ASD; encouraging other pupils to look out for pupils with an ASD; being aware of group dynamics and separating 'trouble-makers'.



Artwork by Taylor Robertson, aged 7, who entered our make school make sense art competition

## 5 Promoting understanding of ASDs within the peer group

Understanding promotes tolerance. Inclusion is not about pretending that everyone is the same; it's about understanding, respecting and accommodating people's differences. A school with a culture that celebrates difference will be more successfully inclusive.

While it is up to the pupil with an ASD and his or her family to decide whether to disclose his or her diagnosis to the peer group, such a disclosure often vastly improves the way the peer group relates to and supports this pupil. It is also likely that other pupils will have already noticed that there are differences in the way the pupil with an ASD communicates, behaves, interacts and relates to the world, and knowing about the diagnosis will help them to make more sense of these differences.

When young people understand these differences and the difficulties associated with ASDs, they are less likely to target the pupil for being different, and are more likely to tolerate his or her idiosyncrasies. Talking to the peer group about ASDs in general will allow them to make links to the pupil they know without unnecessarily drawing attention to that pupil. Some pupils with an ASD may want to develop and deliver a presentation on ASDs themselves; others may choose not to attend the session where ASDs are discussed.

There are a number of books, DVDs and other materials available for teaching pupils of different ages about ASDs (see *Useful resources*, starting on page 25). By relating the information or characters in a book to a peer with an ASD, pupils develop understanding and tolerance, and learn practical ways to support their peer.

### Adam

When Adam's teacher showed a short DVD and presentation about ASD to her Year 4 class she didn't mention any reference to Adam (in fact, he chose not to be in class that morning). The presentation included information about the social and communication difficulties experienced by children with an ASD, including sensory sensitivity.

The class played a game to feel what it might be like to try to concentrate on a task while noises were louder, or there were constant interruptions. The presentation also covered differences in behaviour and how children with an ASD find it hard to control their behaviour when they get very frustrated or angry. It explained special interests and the fact that many people with an ASD know a lot about some subjects and are really good with particular skills, like computers or Maths.

Before long, one of the children asked if this was what Adam had. They began to give examples of how Adam related to the information. The teacher then asked if they could think of any ways to show Adam real friendship and support him with the things he finds difficult. The class decided to form a 'circle of friends' and to take turns to include Adam in their games. They agreed to stop trying to 'wind him up' and instead stay out of his way if he needed space to calm down.

In the weeks that followed, the difference in Adam's interactions with his class was remarkable. The class group were much more tolerant of Adam's idiosyncrasies, much more willing to include him, and instead of laughing when he struggled to control his temper they reminded him of his appropriate calming strategies.

(See page 6 for the first part of this case study)

Here are some suggestions for promoting understanding and tolerance of ASDs among pupils. Some of these will be more appropriate for primary schools, while others will work better in a secondary school.

- > **Develop workbooks** where pupils learn to understand their own strengths and the areas where they need support. This will help them to understand that everyone is different. Pupils can find out information about their peers by sharing their strengths, interests, likes and dislikes, and the workbooks could use age-appropriate language to explain the common difficulties experienced by people with disabilities, including ASDs. Related activities might include: learning to sign their name in Makaton or BSL (British Sign Language); guessing objects by feeling them while blindfolded; having a 'silent' snack time where all requests are made using PECS (Picture Exchange Communication System) symbols instead of talking. Useful activities and worksheets can be found in *Autism spectrum disorders: a resource pack for school staff*, available from the NAS website ([www.autism.org.uk](http://www.autism.org.uk)).
- > **Hold whole-school assemblies** on a range of disabilities, including ASDs, teaching pupils practical ways of being tolerant and supportive of each other.

### Key points

- > Understanding, respecting and accommodating people's differences is the key to successful inclusion.
- > By learning about ASDs, pupils are more likely to be tolerant and supportive of the pupil with an ASD in their peer group.
- > Permission to disclose a pupil's diagnosis must always be gained from parents/carers and the pupil, where appropriate.
- > Books, DVDs, suggestions for activities, worksheets and lesson plans are available to help explain ASDs to different age groups. (See *Useful resources*, starting on page 25).

## 6 Addressing the topic of bullying

### In primary schools

Role-play can be an effective tool in addressing bullying, particularly with smaller groups (perhaps a class or year group). Pupils take turns to play the 'target', the 'bully', the bully's 'followers' and 'witnesses', and together work out the best outcome in different scenarios. Role-play allows 'targets' to practise responses to being bullied and allows 'witnesses' to practise helping a 'target' or reporting the incident to a member of staff. Pupils can end by holding a 'pupils' court' where a suitable consequence for the 'bully' is decided.

There are a number of worksheet ideas that could also help your pupils address the topic of bullying. For example, you could ask pupils to rewrite a more appropriate ending to a bullying incident, in which the target develops new ways to avoid or respond appropriately to bullying and the bully finds a better way of entertaining him- or herself in the playground. Your worksheets could also include "what if..?" scenarios that develop problem-solving skills and empathy. These will give your pupils the chance to think about how they might respond to being bullied, being pressured into joining in with bullying, or witnessing a bullying incident.

Pupils need to be reassured that, if they report a bullying incident, staff will take steps to prevent retaliation on the part of the bully, and that they can report incidents anonymously using the 'bullying box' (see page 8). When you talk to pupils about reporting bullying incidents they've either witnessed or been involved in, it's important to explain that only by doing this can something be done to help someone or change a bad situation. It's also important to remind them of the difference between genuine reporting and 'telling tales', and to point out that by not reporting incidents, they might be

contributing to the target's distress. All pupils should understand that they have a responsibility to help stamp out bullying in their school.

**Please note** that while pupils with an ASD may be able to participate in role-play and "what if..?" scenarios, they might also find it difficult to imagine themselves in situations beyond their own immediate experience.

### In secondary schools

Bullying can be addressed in depth during PSHE lessons by encouraging pupils to talk about scenarios or actual past incidents of bullying they have experienced. It is important that they are able to recognise different forms of bullying, not just physical bullying, and understand that intention, premeditation and 'balance of power' determine whether an incident is bullying, friendly teasing or straightforward conflict. You can use role-play to help pupils determine where the boundaries between these are, and to illustrate how 'winding someone up' can be interpreted differently according to the response of the person on the receiving end, the intention behind the incident and the relationship between the people involved.

You should also discuss more subtle kinds of bullying, especially 'backhanded', indirect and non-verbal bullying, which pupils with an ASD are particularly vulnerable to, so that pupils will recognise them as such. It would also be valuable to tackle issues like peer pressure and, by discussing the impact of different types of bullying, using role-play and acting out 'pupil courts' as described above, equip pupils with the strategies to resist the pressure to join in with bullying.

Talk about practical ways in which pupils can support a peer who is the target of bullying. These may include asking the target to join them at lunch time, waiting for the school bus with them, and being willing to report incidents they witness, either

in person to a member of staff or by using the 'bullying box'.

For more information on addressing the topic of bullying, see the DCSF's *SEAL (Social and Emotional Aspects of Learning)* guidance at <http://nationalstrategies.standards.dcsf.gov.uk>

SEAL encourages pupils to develop empathy, build positive relationships and establish a learning community where they feel responsible for including their peers. The guidance also outlines activities that explore and develop social and emotional skills within the context of bullying incidents.

### Key points

- > PSHE lessons can be used to explore bullying in depth.
- > Role-play and "what if..?" scenarios are effective tools in helping pupils develop and try out new responses to bullying.
- > Discuss the difference between reporting bullying incidents and 'telling tales' and reassure pupils that measures are in place to prevent retaliation.
- > Involve pupils in developing strategies for eradicating bullying.



Artwork by Craig Docherty, age 9, who entered our make school make sense art competition

## 7 Dealing with bullying

If a pupil or group of pupils are known to have bullied a child with an ASD, the following approach may help in tackling and changing their behaviour.

- > If the peer group knows about the target's diagnosis, talk to the bully or bullies about disability in general and about ASDs more specifically. Firstly, remind them that deliberately mocking someone else is wrong, and that they wouldn't like it if someone made fun of the things they themselves find difficult. If the bully responds with the familiar excuse, "I was only joking", remind them of the difference between joking and mocking. Move on to explain how an ASD affects a person's communication, social interaction, ability to process information, and their senses. Make particular reference to the characteristic that was the focal point of the bullying. For example, if a pupil was bullied for wearing ear defenders during noisy activities, emphasise the sensory difficulties faced by people with an ASD; if a pupil was bullied for getting upset about an unexpectedly absent class teacher, discuss how people with an ASD find it difficult to cope with unpredictability and unexpected change. It's important to explain the impact of the bully's behaviour on the pupil with an ASD, including the seriousness of increased anxiety, and the effect it may have on the pupil's self-esteem.
- > If the peer group doesn't know the target has an ASD, a more general one-to-one discussion with the bully about aspects of the target's behaviour could still take place, but without mentioning autism or the fact that the pupil has a disability. For example, you could say something like: "Ahmed finds it difficult to cope with changes to his routine. He's working on it, but it's unfair for you to make fun of him just because of his differences. It's a form of bullying and it makes

school life horrible for him. If you can't be supportive when he's upset, then it's better to leave him and go and find someone else who can help him. We don't allow bullying in this school and if you bully Ahmed again you'll face sanctions." Make sure you explain clearly to the bully what the consequences of bullying will be, according to the school rules.

- > Allow the bully to make amends for his or her behaviour through an apology and state that, now the bully is better informed, you expect him or her not to repeat the bullying behaviour, and to show more empathy when interacting with the pupil with an ASD.
- > Clearly state the consequences for any further incidents of bullying (or retaliation for having been 'grassed') and carry these through if any more incidents occur.
- > In cases of cyberbullying, all of the above actions still apply, but it will be important to establish the bully's motivations and control over the incident. In some cases, the 'bully' may have quickly lost control of the circulation of offensive material, and the full extent of the incident may have been unintended. If the cyberbullying is shown to be deliberate, there should be specific consequences in place. You should also talk to the bully about using technology responsibly.
- > Record incidents of bullying in a detailed way that allows for risk situations and patterns of behaviour to be identified. The STAR recording system (see **Appendix 2**) allows you to do this in a quick and simple way:

**S**etting: where did it happen and who was involved?

**T**rigger: what happened just before the incident?

**A**ction: what were the exact actions of the bully?

**R**esult: how did the incident end and how did the target/witnesses respond?

### Key points

- > Explain to the bully how his or her behaviour has affected the pupil with an ASD, referring to specific areas of difficulty that affect that pupil.
- > Make sure that the bully knows the consequences of his or her behaviour and that the appropriate sanctions are consistently carried through.
- > Record incidents in a format that provides enough detail to identify patterns and helps to develop future preventative measures.



Artwork by Charles Hall, aged 9, who entered our make school make sense art competition

## 8 Helping pupils with an ASD develop an awareness of bullying

Children with an ASD find it hard to 'read' social situations and understand other people's thoughts and intentions. This means that they may not always be able to correctly identify when they are being bullied. They will often think they're being targeted when a bump or push is accidental; or they may think repeated targeting is accidental or another person's way of interacting, without recognising it as bullying.

The naïve, and very literal, understanding of a child with an ASD means that he or she may accept an offer of friendship from a peer even if the peer's actual behaviour suggests they are anything but their friend. If someone tells a child with an ASD to do something potentially harmful or humiliating in exchange for friendship, the child may well do it out of a desperate desire to be included.

People with an ASD commonly find it hard to generalise across incidents and situations, and they may not be able to link current and previous experiences, making them vulnerable to repeated episodes of bullying.

You can help a pupil with an ASD to distinguish between bullying and one-off accidents or misunderstandings by teaching him or her social skills through role-play, or through problem-solving social scenarios using cartoon strips that illustrate situations. A well-established method of explaining social situations to children with an ASD is to use Social Stories™, which provide step-by-step visual depictions of particular situations (for books about Social Stories™ see page 26). Older children may benefit from multiple-choice quizzes, in which they are taught to pick appropriate responses to hypothetical situations (see also *Promoting positive interactions for pupils with an ASD* opposite).

Some pupils with an ASD may need very explicit explanations of bullying, and perhaps a visual reference (for example, a list or set of photos or pictures) that illustrates the difference between scenarios that constitute bullying and those which are less serious peer conflicts or misunderstandings. Other pupils may prefer written or spoken explanations – it depends on the method of communication that they respond best to.

Figure 2 provides some examples of the level of explanation that may be required.

### Promoting positive social interactions for children with an ASD

Schools can adopt a proactive approach to developing social skills in pupils with an ASD through structured training sessions, preferably in small groups. These groups should address a range of skills at an age-appropriate level; for example, how to join in a game, ask others to play or initiate a game or interaction. These sessions could also cover notions such as winning and losing, asserting yourself politely, engaging in 'small talk' and initiating conversation about shared interests. Pupils with an ASD may well enjoy the structure of belonging to a club, where they are able to share common interests with other members.

Pupils with an ASD need to be taught that they're not expected to be friends with everyone, but that they need to behave in a friendly manner (giving specific examples) and display mutual respect to all other pupils. Social Stories™ (See page 26) can provide cues for different social situations and help children with an ASD to respond appropriately. They can be used to explain what is expected of them, giving practical suggestions of how to behave in different settings or circumstances.

Figure 2

 Bullying	 Accidents or misunderstandings
Someone thinks it's fun to upset you. They say things again and again and laugh when you get cross or sad.	Someone says something that they didn't know would upset you and they say sorry. They are sad you are upset.
They carry on when you ask them to stop.	They stop if you ask them to.
They take your things in order to see you get upset.	They borrow something without asking but give it back when you ask.
They kick, push, punch, or hurt you on purpose.	They accidentally bump into you or push past and then say sorry.
They mock things you say or call you names if you make a mistake.	They don't agree with everything you say but respect your opinion.
They send nasty messages to your phone or email.	
They ask you to do something that makes you look silly or might get you into trouble.	

### Key points

- > Because of their difficulties with 'reading' social situations, pupils with an ASD need to be taught how to distinguish between bullying and accidents or misunderstandings.
- > Pupils with an ASD would benefit from structured social skills training to improve their social understanding and to help them learn how to respond in different social contexts.
- > Social Stories™ are an excellent tool for teaching pupils with an ASD how to do this.

## 9 Supporting the bullied pupil

If bullying has taken place, you should allow enough time for the target to disengage him- or herself from the negative experience and then speak to the target privately to avoid him or her feeling intimidated.

Anxiety decreases a person's ability to communicate effectively, so the bullied pupil with an ASD may relay his or her perception of the incident more effectively through drawing, writing or creating cartoons. It will also help if you tell the pupil what measures are in place to prevent any retaliation by the bully.

Bullied pupils may need to be taught and practise set strategies, so that they know what to do if they recognise that they are being bullied. These strategies may include using standard phrases and following a prepared plan of action. For example, bullied pupils could:

- › use a standard statement, such as "I don't like that, please stop". A pupil with an ASD will need to give an honest response as he or she is likely to have difficulty pretending that the bully is having no effect.
- › walk to a safe place and report the incident to a safe person (for example, an allocated teacher, teaching assistant or mentor).

### Key points

- › Pupils with an ASD may need to communicate incidents in other ways than talking; for example, through drawing, writing and creating cartoon strips.
- › Pupils with an ASD may need to practise set strategies in the event of being bullied, such as using standard phrases and following a prepared plan of action.
- › The school should maintain close links with the parents/carers of vulnerable pupils, and bullies where appropriate, and share strategies to reduce the risk of bullying.

- › focus on the facts of the incident (rather than feelings) in order to report it effectively.

"If I get anxious I get in a fizz. If I need help I ask my teachers and they tell me not to worry. If I feel upset I can go to another room."

Pupil with an ASD

Pupils with an ASD may also need a format for reporting incidents, and extra support to distinguish between fact and opinion. It is important not to imply to the target that his or her reaction to a situation may be a cause of the bullying or that a different reaction would be a solution (for example, "If you didn't cry then they would stop copying you"). This puts too much pressure on the pupil, who may have reduced control over his or her responses when upset.

Maintaining links with the parents/carers of the vulnerable child will often help both the school and the pupil to deal with bullying. These links may include periods where a daily diary is sent home so parents/carers can be kept informed of the day's events (something a child with an ASD may struggle to do). Parents/carers should be encouraged to reinforce strategies implemented by the school in order to reduce the risk of bullying. They should also be given a contact at the school who they can approach with any concerns. It will usually be appropriate to inform the bully's parents of any incidents, action taken, and why.

## 10 Perceived bullying behaviour in pupils with an ASD

It is unlikely that a child with an ASD would actually bully another child according to the typical definition of bullying. This is because people with an ASD have difficulty understanding other people's feelings and the affect of their behaviour on other people. They may learn these concepts cognitively, but still have difficulty internalising them. If a pupil with an ASD is seen to 'wind up' or target another pupil, their intention may be to get a particular response in a 'cause-and-effect' way, rather than to humiliate or gain power over them.

Pupils with an ASD may present with bullying behaviour for the following reasons.

- › It may be a learned behaviour that they have witnessed or used previously to gain a desired response.
- › 'Cause and effect' may be the only kind of interaction they know how to initiate - the motivation behind the behaviour is unlikely to be to cause intentional harm.
- › They may lack the skills to maintain an interaction appropriately, and have difficulty 'reading' another person's responses, so they don't realise when the other pupil is no longer enjoying the interaction.
- › They may seek out interactions in an 'in your face' way, lacking boundaries.
- › They may be following a 'leader's' instructions or be seeking approval or acceptance into a gang by joining in with someone else's bullying.
- › They may be mimicking incidents or behaviour that they have witnessed or been a part of.

- › Their behaviour may be an attempt to retaliate, without any understanding of the consequences of their own behaviour.
- › Displaying aggressive behaviour may be a strategy to avoid being bullied themselves.
- › They may be feeling frustrated at being left out and want to force other pupils to be their friend.
- › Many children with an ASD experience difficulties with winning and losing, and if they have lost a game, they may be aggressive towards the winner.

### David

David is in Year 1. His teachers were concerned that he was displaying aggressive behaviour in the playground. He would run up to other pupils and jump on them from behind. They would often turn around frightened and push or hit out at David to get him to move away, but David would just laugh and try to jump on them again.

After speaking to his parents, school staff established that David liked to watch wrestling on TV and was trying to re-enact scenes with his peers. They developed a Social Story™ to help David understand that rough and tumble games were only for playing with Dad at home. He was also given a pack of cards with different, more appropriate, playground games and activities on each. At playtime, staff encouraged David to hand a card to a peer as a way of initiating an appropriate game with them.

The teachers also explained to the other pupils that they could help David learn to play better by following what the card said whenever they were handed one. Friendship qualities were reinforced in other pupils by giving them stars for helping David and responding to his cards.

## Strategies for managing perceived bullying behaviour in pupils with an ASD

If a pupil with an ASD appears to display bullying behaviour, the school needs to decide what action to take. While it is important to apply behaviour and anti-bullying policies consistently, schools also have legal duties to make sure that pupils with a disability are not discriminated against or put at a substantial disadvantage because of their disability. Schools should consider what has led to the behaviour and make sure that these underlying causes are addressed.

Social skills training sessions (as described in section 8) can be used to help the pupil develop appropriate ways to engage with others, initiate interaction and gain attention.

Although children with an ASD have difficulty empathising with others, they can be taught about the effect their behaviour has on others. They may need clear guidelines for what constitutes acceptable and unacceptable ways of expressing their feelings. These should be specific, so that the child knows exactly what behaviours you are referring to. For example, you should say “Hitting, kicking and pushing are unacceptable” rather than “No

hurting others”. In this way, you can ensure that the pupil with an ASD understands what you mean by unacceptable and bullying behaviours.

Don't assume that pupils with an ASD know what you mean when you say “be kind”. You may have to list behaviours or actions that constitute being a good friend or which are expected in any given interaction. Pupils with an ASD need positive direction; for example, it is better to say “Now think of your own clever things to say” rather than “Stop copying Mark”. It will be beneficial to practise the positive, constructive actions involved in friendship through role-play, and through support during real-life situations.

To make sure the pupil with an ASD understands the potential consequences of their ‘bullying’ or aggressive behaviour, you could produce a written or pictorial list of these consequences. This list should be specific and relate to behaviours that the child has been known to display. For example, pushing at playtime might result in five minutes on the time-out bench. Consequences should always be fair, consistent, immediate and appropriate to the pupil's understanding. It may be helpful to point out to the pupil that people are only nice to bullies because they are scared of them.

You could reinforce specific acts of appropriate interaction through praise, a reward system or an explicit, positive consequence; for example, if the pupil shares his or her time on the computer particularly well, he or she could be rewarded with an extra five minutes on the computer. This kind of positive reinforcement is vital for children with an ASD if they are to understand what behaviour is required of them.

Pupils with an ASD also need to be taught strategies for calming down when they are upset, as an alternative to expressing their anger or frustration inappropriately. Many children on the autism spectrum experience high levels of anxiety and frustration, and this needs to be considered and catered for if they are to learn to manage their emotions. Some will need a designated area they can go to in order to remove themselves from a situation they can't cope with.

Behaviour issues can be addressed by setting pupils clear targets through their IEPs (Individual Education Plans) and equipping them with strategies to meet them. The following examples show the kind of targets that might be appropriate, depending on the pupil's specific difficulties.

- › David to hand a game card to a peer at playtime and engage in the game for at least five minutes.
- › Sam to take turns playing ‘Pop-up Pirate’ with a classmate. On the occasions when the other child wins, Sam to say “well done” and remain calm.
- › Nisha to hand the teacher a ‘five-minute chill-out’ card when she is frustrated during group work. Nisha to leave the room and sit on a bench in the corridor reading a magazine, then return to the group task after five minutes.

## Key points

- › Due to their social and communication difficulties, it is unlikely that a child with an ASD would actually ‘bully’ another child in the typical definition of the word. But there are many reasons why pupils with an ASD may display behaviour that appears similar to bullying, such as poor understanding of interactions and a reaction to previous social experiences.
- › Pupils with an ASD should practise appropriate ways of engaging with others, initiating interaction and gaining attention, through social skills training sessions.
- › Pupils with an ASD need clear, specific guidelines on what are acceptable and unacceptable ways of expressing their feelings.
- › Pupils with an ASD will need to be taught cognitively how their behaviour can affect others.
- › Consequences should always be pre-determined and explained clearly to the pupil with an ASD in advance. They should be fair, consistent, immediate and appropriate to the pupil's understanding.
- › Specific acts of appropriate interaction should be reinforced through praise, a reward system or a specific positive consequence.
- › Pupils with an ASD will need to be taught strategies for calming down when they are upset, as an alternative to expressing their anger or frustration inappropriately.
- › Behaviour issues can be addressed by setting targets in IEPs.



## 11 Conclusion

Autism affects every person differently, so your response to cases of bullying involving pupils with an ASD will vary according to the pupil's individual needs. The strategies outlined in this booklet have been tried successfully in many settings and will provide an invaluable starting point for tackling bullying in your school.

Dealing with bullying involving pupils with an ASD should never be a case of simply reacting to incidents as they arise. By giving the pupil with an ASD a clear behaviour support plan, and supporting them to develop coping strategies, he or she can be helped to avoid the circumstances that lead to bullying. Likewise, by encouraging all pupils to address the topic of bullying and feel involved in developing the school's strategies to overcome it, you can create an environment where peer pressure works against bullies, rather than the other way around.

Pupils with an ASD can and do flourish in mainstream education settings, and their presence in the classroom can be a positive experience both for them and their peers, encouraging tolerance and understanding of difference. By using the right strategies and support, you can turn the difficulties faced by pupils with an ASD into opportunities that enrich the education of all pupils.

"I feel like I'm finally getting to the end of the tunnel. In the primary maths challenge, I got through to the final. They were a bit shocked because everyone thinks I'm dumb. Some of them thought I'd cheated, but most of them changed their opinion. It made me very proud."

Pupil with an ASD

## 12 Useful resources

Publications marked '\*\*' are available through The National Autistic Society. Please order through our distributor, Central Books, on 0845 458 9911 or order online at [www.autism.org.uk/pubs](http://www.autism.org.uk/pubs)

### Anti-bullying strategies and guidance

Cohen-Posey, K. (1995). *How to handle bullies, teasers and other meanies: a book that takes the nuisance out of name calling and other nonsense*. Highland City, FL: Rainbow Books Inc.

A resource for teaching children assertiveness skills. Suitable for key stages 1 and 2.

\*Csoti, M. (2008). *How to stop bullying: positive steps to protect your child in your care*. London: Rightway

Dubin, N. (2007). *Asperger syndrome and bullying: strategies and solutions*. London: Jessica Kingsley Publishers  
Describes the bullying behaviour that is often targeted at people with Asperger syndrome and offers effective strategies for addressing bullying.

Field, E. (2007). *Bully blocking: six secrets to help children deal with teasing and bullying*. London: Jessica Kingsley Publishers

\*Thorpe, P. (2005). *Bullying and how to deal with it: a guide for pupils with autistic spectrum disorders*. London: The National Autistic Society

**(DVD)**. *Being bullied: strategies and solutions for people with Asperger syndrome*. (2006). London: Jessica Kingsley Publishers

Outlines practical strategies for parents, schools and individuals on how to prevent bullying.

### General support for pupils with an ASD

\*Beaney, J. and Kershaw, P. (2003). *Inclusion in the primary classroom: support materials for children with autistic spectrum disorders*. London: The National Autistic Society

\*Beaney, J. and Kershaw, P. (2006). *Inclusion in the secondary school: support materials for children with autistic spectrum disorders*. London: The National Autistic Society

\*Colley, J. (2005). *Working with an Asperger pupil in secondary schools*. London: The National Autistic Society

\*Hannah, L. (2001). *Teaching young children with autistic spectrum disorders to learn: a practical guide for parents and staff in mainstream schools and nurseries*. London: The National Autistic Society

\*Leicester City Council and Leicestershire County Council. (1998). *Asperger syndrome - practical strategies for the classroom: a teacher's guide*. London: The National Autistic Society

The National Autistic Society. (2009). *Autism spectrum disorders: a resource pack for school staff*. London: The National Autistic Society

This resource pack includes lesson plans for explaining ASDs to primary and secondary school pupils and is available through the NAS Autism Helpline on 0845 070 4004 or to download free from [www.autism.org.uk](http://www.autism.org.uk)

\*Nguyen, A. (2009). *Environment and surroundings: how to make them autism-friendly*. London: The National Autistic Society

\*Perepa, P. (2005). *Classroom and playground: support for children with autistic spectrum disorders*. London: The National Autistic Society

# Bullying and autism spectrum disorders

\*Sainsbury, C. (2000). *Martian in the playground*. Bristol: Lucky Duck Publishing

A beginners' guide to Asperger syndrome. Includes thought-provoking chapters on inclusion, labelling, normalisation and life after school.

\*South Gloucestershire Council. (2005). *Guidelines for working with children with autism spectrum disorders at Foundation Stage and Key Stage 1*. London: The National Autistic Society

\*South Gloucestershire Council. (2005). *Guidelines for working with children with autism spectrum disorders in Key Stages 3 and 4*. London: The National Autistic Society

\*Thorpe, P. (2009). *Moving from primary to secondary school: how to support pupils with autism spectrum disorders*. London: The National Autistic Society

\*Thorpe, P. (2009). *Understanding difficulties at break time and lunchtime for pupils with an autism spectrum disorder: a guide for school staff*. London: The National Autistic Society

## Social skills and behaviour

\*Baker, J. (2003). *Social skills training for children and adolescents with Asperger syndrome and social communication problems*. KS: Autism Asperger Publishing Company  
A useful guide for social skills training groups. Includes session plans appropriate for key stages 2 and 3.

\*Dunn Buron, K. (2003). *When my worries get too big: a relaxation book for children with autism spectrum disorders*. KS: Autism Asperger Publishing Company

\*Dunn Buron, K. and Curtis, M. (2003). *The incredible 5-point scale*. KS: Autism Asperger Publishing Company

\*Gammeltoft, L. and Nordenhof, M. (2007). *Autism, play and social interaction*. London: Jessica Kingsley Publishers  
A guide to helping children build their communication and social skills through play.

\*Gray, C. (2002). *My Social Stories book*. London: Jessica Kingsley Publishers  
A resource containing 150 Social Stories for common social situations and guidelines for producing individualised Social Stories.

\*Howley, M. and Arnold, E. (2005). *Revealing the hidden social code: Social Stories™ for people with ASD*. London: Jessica Kingsley Publishers  
Useful examples and advice on producing tailor-made Social Stories for older children and adolescents.

\*Knott, F. and Dunlop A.-W. (2007). *Developing social interaction and understanding: a resource for working with children and young people with autistic spectrum disorders*. London: The National Autistic Society

Painter, K. (2006). *Social skills groups for children and adolescents with Asperger's Syndrome: a step-by-step programme*. London: Jessica Kingsley Publishers

Patrick, N. (2008). *Social skills for teenagers and adults with Asperger syndrome*. London: Jessica Kingsley Publishers  
A resource aimed to increase understanding of common social scenarios, and strategies for appropriate responses. Suitable for key stages 3 and 4.

Simmonds, J. (2003). *Seeing red*. MN: New Society Publishers  
Improving anger management for children on the autism spectrum. Suitable for key stages 1 and 2.

\*Whitaker, P. (2001). *Challenging behaviour and autism: making sense – making progress*. London: The National Autistic Society

## Explaining ASDs to other pupils

\*Hannah, L. (2007). *My friend Sam: introducing a child with autism to a nursery school*. London: The National Autistic Society

Explains autism in terms that very young children will understand. Suitable for nursery and reception.

Lears, L. (1998). *Ian's walk*. IL: Albert Whitman

A story book that helps children gain an insight into ASD. Suitable for key stages 1 and 2.

The National Autistic Society. (2009). *Autism spectrum disorders: a resource pack for school staff*. London: The National Autistic Society

This resource pack includes lesson plans for explaining ASDs to primary and secondary school pupils and is available through the NAS Autism Helpline on 0845 070 4004 or to download for free from [www.autism.org.uk](http://www.autism.org.uk)

Peters, C. (2007). *That's not fair! Explaining autism to very young children*. Leicester: Leicester City Council  
Explains autism in terms that very young children will understand. Suitable for nursery and reception.

\*Pike, R. (2008). *Talking together about an autism diagnosis*. London: The National Autistic Society  
A guide for parents and carers who want to discuss diagnosis with their children.

\*Telmo, I. (2004). *Play with me: including children with autism in mainstream primary schools*. London: The National Autistic Society

A story book about understanding differences and playing with children who have social difficulties. Suitable for reception and key stage 1.

Veenendall, J. (2008). *Arnie and his school tools: simple sensory solutions that build success*. KS: Autism Asperger Publishing Company.

Covers appropriate tools and strategies to help classroom peers understand and address sensory processing difficulties. Suitable for key stages 1 and 2.

\*(DVD). *A different life: Rosie's story*. London: Eye Television  
The story of a girl with classic autism as described by her brother. Suitable for key stages 1 and 2.

\*(DVD). *A is for autism*. (1992). London: Channel 4 Television  
An insight into the world of autism through the narration of individuals on the spectrum. Suitable for key stages 3 and 4.

\*(DVD). *Autism and me*. (2007). London: Jessica Kingsley Publishers  
Teenager Rory Hoy gives first-hand insight into the world of autism and what it is like to take things literally and rely on routines. Suitable for key stages 3 and 4.

## Government guidance

Department for children, schools and families. (2009). *Safe from Bullying: guidance for local authorities and other strategic leaders on reducing bullying in the community*. London: DCSF

A suite of resources to help children's services tackle bullying, covering play and leisure, youth activities, children's homes, extended services, further education colleges, cyberbullying and bullying on journeys. It includes guidance for local authorities and training resources.

Download from: [www.dcsf.gov.uk/behaviour](http://www.dcsf.gov.uk/behaviour)

**All Government documents below can be downloaded for free from [www.teachernet.gov.uk](http://www.teachernet.gov.uk)**

Department for children, schools and families. (2007). *Bullying: a charter for action*. London: DCSF  
The government's Anti-Bullying Charter for schools, endorsed by the Anti-Bullying Alliance and teaching unions.

# Bullying and autism spectrum disorders

Department for children, schools and families. (2008). *Bullying involving children with special educational needs and disabilities*. London: DCSF

Government guidance for schools on bullying of children with SEN and disabilities.

Department for children, schools and families. (2007). *Safe To Learn: embedding anti-bullying work in schools*. London: DCSF

Government guidance for schools on what the law says about bullying and how to deal with it.

## Useful websites

### **About.com: Autism (<http://autism.about.com>)**

The autism section on About.com contains a large number of articles about diagnosing, treating and living with autism, including features on education and school life.

### **Beat Bullying ([www.beatbullying.org](http://www.beatbullying.org))**

A UK-wide charity that aims to support young people who are being bullied, re-educate and change the behaviour of young people that bully and prevent bullying in schools and communities.

### **Bullying UK ([www.bullying.co.uk](http://www.bullying.co.uk))**

Bullying UK is one of the country's leading anti-bullying charities. It works with young people, parents, schools and adults to tackle bullying, and the website provides information and resources for schools.

### **Department for children, schools and families (<http://nationalstrategies.standards.dcsf.gov.uk>)**

The DCSF website contains guidance on a wide range of national teaching strategies, including guidance on behaviour and SEAL (Social and Emotional Aspects of Learning).

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

A charity established to prevent child bullying and sexual abuse. It provides information and advice on bullying and offers training programmes and workshops for professionals.

### **The National Autistic Society (NAS) ([www.autism.org.uk](http://www.autism.org.uk))**

The NAS is the UK's leading charity for people affected by autism. This website is probably the most comprehensive online autism resource in the world, containing wide-ranging information about autism and Asperger syndrome.

### **Research Autism ([www.researchautism.net](http://www.researchautism.net))**

Research Autism is a charity dedicated to researching interventions into autism. The website contains information about a wide range of support strategies and treatments, and gives advice about their effectiveness and scientific validity.

### **Scottish Autism Service Network ([www.scottishautismnetwork.org.uk](http://www.scottishautismnetwork.org.uk))**

A support network for professionals working with people with autism in Scotland, providing information, advice and training.

### **Teachernet ([www.teachernet.gov.uk](http://www.teachernet.gov.uk))**

Government website which provides resources for teachers and other professionals in education, including downloads of official bullying guidelines and strategies.

## 13 Contact The National Autistic Society

### **NAS Head office**

393 City Road  
London EC1V 1NG

**Tel:** 020 7833 2299

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

### **Autism Helpline**

(Mon-Fri, 10am-4pm)

**Tel:** 0845 070 4004

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

### **Information centre**

(Advice and resources for professionals, researchers and students)

**Tel:** 0845 070 4004

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

### **Conferences**

**Tel:** 0115 911 3367

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

### **Training and consultancy**

**Tel:** 0115 911 3363

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

### **Publications**

**Tel:** 020 7903 3595

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

### **NAS Scotland**

Central Chambers  
1st Floor  
109 Hope Street  
Glasgow G2 6LL

**Tel:** 0141 221 8090

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

### **NAS Cymru**

6/7 Village Way  
Greenmeadow Springs Business Park  
Tongwynlais  
Cardiff CF15 7NE

**Tel:** 029 2062 9312

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

### **NAS Northern Ireland**

57A Botanic Avenue  
Belfast BT7 1JL

**Tel:** 028 9023 6235

**Email:** [northern.ireland@nas.org.uk](mailto:northern.ireland@nas.org.uk)



## 14 Appendix one: Behaviour Support Plan

### Likes and Dislikes

- > Likes Factual information, Solar system, Spongebob squarepants, Maths, Science, Geography, teachers using humour
- > Dislikes Writing, Games (PE), wearing a coat

### Sensory Issues

- > Hypersensitive hearing: wears ear-defenders when concentrating on written tasks
- > Hypo-proprioception: poor body awareness; difficulty organising movements (ie catching a ball); if unfocused/stressed may forget to go to the toilet; rocks on chair during lesson; bumps into people/objects; difficulties with dressing
- > Tactile defensive: dislikes certain clothing, especially coats; often takes clothes off when arriving home from school
- > Poor eater: possibly due to taste/tactile defensiveness or not noticing own hunger.

### Triggers/Cues to Behaviour

- > Unfairness/perceived injustice
- > Making mistakes on work
- > Noise
- > Laborious writing tasks
- > Peers taunting him
- > Insufficient time given for Ben to express his thoughts

### Rewards/Motivators

- > Refer to reward chart: collects stickers towards reward, is able to 'bank' stickers to achieve bigger reward
- > See rewards on chart
- > Helping/participating in class

### General Strategies

- > Allow him to wear ear-defenders
- > Write short instructions in filofax for each lesson
- > Use short comments on post-it notes to redirect/refocus attention on work tasks
- > Allow time for Ben to respond to instructions as his processing of verbal language can be delayed, especially if anxious or stressed.
- > Allow plenty of time for Ben to express himself clearly as his word retrieval is slow
- > Ben to request time out to calm down and sit on landing with a book. Teachers to use code word in order to suggest he has some time out.
- > All staff to follow reward and card charts
- > Staff to refer Ben to Mr Smith to issue cards according to list.
- > Staff to give warning and time to process instruction before referring Ben to Mr Smith.
- > When dealing with an incident, wait until Ben is calm and tell him to see Mr Smith at next break time.
- > All staff to use STAR approach sheets to record incidents.

### Specific Behaviours and Strategies

#### 1 See White list on card chart (Making a noise in class or assembly; Refusing to work; Not doing homework)

- > Give verbal warning
- > Send to Mr Smith at next break time
- > Mr Smith to issue white card
- > Complete work with Mr Smith
- > Mr Smith to discuss reasons for expected behaviour

#### 2 See Yellow list on card chart (Running in corridors; Swinging pencil case/knocking people with it; shouting/screaming in class or dining room; crawling under tables/on floor; Throwing things; Jumping on people; Pushing people)

- > Give verbal warning
- > Send to Mr Smith at next break time
- > Mr Smith to issue yellow card
- > Mr Smith to carry out cartoon conversations to debrief incident and find a better solution for next time.
- > Or complete worksheets related to behaviour with Mr Smith.

#### 3 See Red list on card (Hitting; Kicking; Hurting people in any way)

- > Remove Ben from situation
- > Send to Mr Smith at next break time
- > Mr Smith to issue red card
- > Mr Smith to carry out cartoon conversations to debrief incident and find a better solution for next time.
- > Or complete worksheets related to behaviour with Mr Smith
- > Card to be sent home to be signed by parents

### Medication/Diet

Teacher: ..... Parent: .....

Headteacher: ..... Senior Master: .....

## 14 Appendix two: STAR recording system

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### STAR Approach

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Name:		Date:	Time:
<b>Settings:</b> Where? Lesson? People?	<b>Triggers:</b> What happened just before incident? What seemed to start it?	<b>Actions:</b> What did the child do? Behaviour?	<b>Result:</b> What happened next? Staff action? How did incident end? Consequence?

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# FACT SHEET: Keeping Autism in Mind

With a clear understanding of the nature of Autism there is much that can be done to help people with Autism through their everyday life. In highlighting some of the features of Autism this article aims to show that with a range of practical support strategies we can help ease many difficulties. Our aims will always include:

## 1. Relieving the frustration of communication:

Any person with communication difficulties, without appropriate support, is likely to express him or herself in ways that others might find “difficult”. A person with Autism might have little ability to influence or negotiate the demands of the social environment i.e. to communicate basic needs, to articulate distress, or to ask for help. In addition, they will invariably have difficulty with receptive language (i.e. being able to fully understand what is being said). This aspect of language ability with Autism is often not recognized by people who are not familiar with the Autism Spectrum.

### “Do you understand?”

The person with Autism might have a seemingly impressive vocabulary (usually around their own special interests). However, people very close to them will be aware of the limits of that language ability. When asked “do you understand?” the child or adult with Autism might reply “yes”, having in mind that’s what they are expected to say. In fact, they might not fully understand the situation. Their ability to deal with the spoken word will also be greatly reduced once stress levels rise. Instances are known where individuals with Autism who generally have good comprehension and verbal skills lose those skills when they become stressed. They have simply been unable to process language which they could deal with quite easily when they are calm. Another factor to keep in mind is the longer processing time that is often required for the person to deal with other people’s spoken words (see “Strategies”).

### Strategies:

- ❖ Allow extended time for the person to process the meaning of what has been said. Ten, twenty seconds or sometimes even a little longer might be required for a person with Autism to be able to process our language and respond. This might seem unduly lengthy. But, people are often surprised when they realize how well the person with Autism can understand our language when we are more patient, and simply wait for a response.



# FACT SHEET: Keeping Autism in Mind

- ❖ Provide visual supports according to the person's skills with representation. Visual supports can include: objects, photographs, computer generated supports e.g. Boardmaker, line drawings, pictures from magazines etc. The written word is, of course, for those more able. These visual supports can be incorporated into a timetable to show the sequence of everyday activities. Similar supports can also be extremely helpful for the person to express his or her needs and wishes (including making choices).



## 2. Providing structure to the environment:

Although large, open-plan classrooms are not ideal for children with Autism, much is now being done by teachers in many schools to provide structure within the open-plan environment.

***N.B: a more structured environment does not imply a more restrictive one. The structure enables people to understand the environment. They can SEE what is expected.***

### Strategies:

- ❖ Define space e.g. provide boundary markers where children are expected to be seated during periods such as mat time. Similarly, in work areas, place tape markers on table tops to show limits of work space.
- ❖ Label shelves and drawers to identify contents. In order to meet the needs of everyone within the environment it might be necessary to label with words and with pictorial representation (visual supports, as above).
- ❖ Colour code books and folders e.g. use coloured stickers to identify all materials that relate to specific subjects.
- ❖ Provide an independent work station within the classroom where the student can work without disturbance at tasks with which he or she is familiar.



## FACT SHEET: Keeping Autism in Mind

- ❖ Provide a structured approach with work systems enabling the person to work independently. Clearly identify how much work is to be completed, where to place completed work, and what they will do when the work is completed. Ensure that what comes next is something the person favours.

For other ideas and resources available on providing structure within educational approaches, especially for preschool and primary see: <http://www.teacch.com/>

### 3. Ensuring that the demands of a task are not too high:

People with Autism are likely to display a very uneven developmental profile. That is, they can be highly skilled in certain areas and extremely poorly skilled in other ways. Consequently, problems sometimes occur due to the assumption that because they are so skilled in one area, they will have a similar level of skill in other seemingly comparable ways. We should therefore keep in mind that if a person resists a specific task, or displays stress with the work in hand, we need to consider whether the demands of the task are too high. People with Autism can be very distressed by a sense of failure, and become upset if presented with tasks they do not understand.

#### Strategies:

If the person shows anxiety when presented with a task (and it's not known whether they have ever undertaken the task) do not press the issue. Allow a cooling off period by providing a task that you are sure they can undertake with ease (and preferably one that they will enjoy). Later, the more complex task could be taught, broken down into discrete parts, teaching one part at a time. Whether we are teaching a child in primary school or an adult in the employment sector, 'backward chaining' is often a useful teaching method.

#### Backward chaining:

- ❖ Demonstrate task (once or twice as necessary)
- ❖ Next time, the teacher *almost* completes the task
- ❖ Student completes the very last part of the task

## FACT SHEET: Keeping Autism in Mind

If necessary, provide a prompt to ensure praise can be given for completion of the task. On subsequent occasions the teacher again demonstrates the beginning of the task then hands it over to the student to complete. The aim is for the student to complete a little more of the task each time. Ultimately, they complete the entire task. Teaching in this way can be very effective for children and adults with Autism as it calls for their visual skills (usually far superior to their ability with language). Few words are generally needed. The person simply observes then follows with each step of the task.

#### **4. Accommodating routines and need for sameness:**

People with Autism can be extremely attached to routines. These routines may involve doing things in a certain way, or in a specific order. For example, for one child, it could mean taking a particular route to school; while for another person it might entail performing a particular task in a never-changing way (e.g. from undressing, taking a shower and dressing for bed).

It is often considered that this insistence on routines is a strategy the person employs to cope with a social world that they find overwhelming. It is as if the person makes the world manageable by reducing it, and imposing an order which makes the environment predictable and less confusing.

#### **Strategies:**

Always prepare the person with Autism for change. Use visual supports according to their level of skill— pictures, photographs, Boardmaker etc or the written word. A visual timetable can be helpful to *show* the student (i.e make readily apparent) which activities will occur and the sequence of the activities. The timetable could also include a picture of the teacher/support person to show impending staff changes.

***The person needs to be trained to use the timetable; thus, referring to the timetable becomes the primary routine.***

When reference to the timetable has become routine, the person is likely to be more accepting of the information that it provides. Timetables are known to be great tools of authority! While it is important to encourage toleration of change, it is important also to understand the way in which routines help the person to cope with an environment they sometimes find overwhelming.

## FACT SHEET: Keeping Autism in Mind

### Why disrupt a routine?

Often, there is no good reason to disrupt a routine. If a routine is not preventing learning or other meaningful activity, is not harming self or others and is not socially unacceptable there seems to be no reason to actively focus on disrupting the routine. If the routine helps the person to remain calm this is obviously good for their well-being. The calm person is more likely to be open to learning and generally enjoying activity.

### Changes to some routines

Incremental change can be made to routines that are stigmatizing for the person e.g. carrying large, inappropriate objects. In such cases changes could be made by a program which gradually replaces the object with a more appropriate or less obvious one. For example, provide a similar but slightly smaller object for a while; then smaller again. Over a period of time the person is likely to become more accepting of the smaller replacement. If the 'special object' can be attached to a key ring it can be kept close to hand most of the time.

Alternatively, an agreement could be reached whereby there are set times and places where they can carry their special object. Sometimes, detective work might be required in order to determine the appeal of a particular object. Is it the colour, shape or texture? Is it simply what it represents?

***Routines might change over time, but people with Autism will probably always adhere to a routine or two. They are often a source of great comfort in what is a complex environment for the person with Autism.***

## FACT SHEET: Keeping Autism in Mind

### 5. Respecting personal space:

A person with Autism might find the close proximity of others disturbing for a number of reasons. Apart from sensory issues (see below) the person might be confused by the intrusion of others. With language and social difficulty, sometimes they might be bewildered when another person moves into their personal space. They might feel anxious as to what they are expected to do with this other person so close.

#### Strategy:

Always consider whether a teaching /training style might be overly intrusive; or if the requirement for social proximity with others is too great. For example, a person who is expected to engage in a physical contact activity might cope for a short period of time and then, for no apparent reason, become distressed. In such instances, enable the person to have access to personal space, with reduced periods of close contact with others.

Consider lessening expectations for social participation: work gently and gradually to build the person's tolerance of social proximity and social demands. It is worthwhile noting that many children and older people with Autism will, in time, develop a tolerance and come to enjoy the closeness of familiar people with whom they feel secure.

### 6. Assisting with the Sensory:

Sensory differences associated with Autism have been well documented. Not all, but many people with Autism will experience sensory difficulties including: auditory (distress with sudden or certain sounds); tactile (dislike to being touched, aversion to touching certain substances); visual (might become fixated on flickering light or other repetitive movement); taste and smell (might react negatively to certain foods and smells). For some people with Autism sensory experiences can be overwhelming.

Adult individuals, able to articulate their experiences, have spoken in terms of physical pain especially with tactile sensation (when they are touched by others; or the feel of certain clothing). Discomfort in coping with sound is often recognized: the person covers his or her ears and their facial expression clearly shows discomfort or distress.

# FACT SHEET: Keeping Autism in Mind

## Strategies:

Remain alert to potential for sensory discomfort and alleviate the situation where possible. In certain situations we can:

- ❖ Provide ear muffs or other sound protection
- ❖ Enable the person to be warned of imminent sounds
- ❖ Consider suitability of the environment for the person e.g. shopping centre during peak shopping hours might induce sensory overload
- ❖ Be aware of person's response to touch
- ❖ Develop programs to help expand tactile tolerance i.e. introduce substances (e.g. play dough) in tiny amounts and expect brief contact; gradually increase amount and contact
- ❖ Provide personal space according to person's needs
- ❖ Expand upon the person's choice of foods cautiously

An Occupational Therapist could be helpful in dealing with sensory difficulties, especially if it becomes apparent the person's diet is inadequate due to food rejection.

## Summary:

With an understanding of the key characteristics of Autism and awareness of the person's preferences, we can often prevent difficulties arising for the individual. Our teaching and caring efforts meet greatest success when we can guide the children and adults with Autism along a smoother path throughout the day. Importantly, their days are made happier.

**AUTISM SPECTRUM CONDITION (ASC):  
AN INTRODUCTION**



INFORMATION SHEET

For your autistic employees to feel supported, you will need a neuro-inclusive work environment. When you prioritise neuro-inclusion, **your entire workforce will feel supported**, and you will experience enhanced employee retention, productivity, and well-being.

While there are many coping strategies that neurodivergent adults can put into place, neuro-inclusion is intended to be **a collective**, not a solo **effort**.

## What is ASC?

Autism Spectrum Condition (ASC) is a neurodifference **present from birth**. Although it can be diagnosed in childhood, **many** autistic individuals **reach adulthood before being diagnosed**. Every autistic individual is unique, but some common traits include:

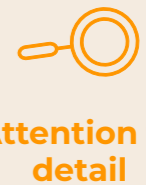
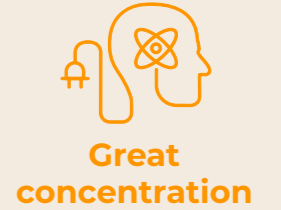
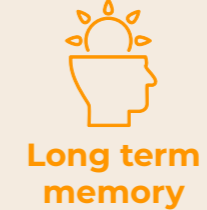
- Misunderstandings and differences when communicating with peers (verbally and non-verbally). Many within the #actuallyautistic community have expressed a desire for others to learn how they communicate and double-check what's being said rather than make assumptions
- Over or under-sensitivity to sound, light, taste and smell; everything from the buzzing of fluorescent lights to other open office environment noises may interfere with productivity if not appropriately accommodated; certain stimuli can be a source of distraction, anxiety, and difficulties processing, communicating and reacting to a specific environment
- Understanding social cues and a tendency to interpret things literally

If someone in your organisation has informed you that they are autistic or their diagnosis is suspected, they must not be met with stigma or discrimination. Being aware of the support an autistic individual may require will empower them in the workplace, but you don't have to be an ASC expert.

This information sheet will help you understand how Lexxic can help autistic employees thrive in the workplace.



## What talents do autistic individuals bring?



- Logical and detailed ideas as well as independent learning and thinking
- Highly visual thinking and great long-term memory
- Honest and direct feedback and non-judgemental listening skills
- Persistence, accuracy, attention to detail and technical ability
- Can spend time concentrating for extended periods of time on tasks that appeal to them





## Supporting the individual How can you help?

### 1. Screening or a diagnostic assessment

If someone you work with suspects that they have ASC **but have not been formally diagnosed**: a screening or a diagnostic assessment is suitable.

**1a. Purpose of the screening assessment** - indicates whether the individual is demonstrating tendencies of ASC, but it does not provide a complete diagnosis.

The standard assessment process includes the following:

- **A pre-assessment questionnaire** - to gain a detailed understanding of an individual's strengths, early development, and educational history. In this part of the process, you'll explore social communication and interaction differences, sensory sensitivities, and managing change
- **A 1.5-hour assessment using an ASC screening tool** - to gather information on developmental history and challenges in several life and work areas
- **The creation of a report** - outlining strengths, challenges, and concludes whether the individual demonstrates tendencies of ASC. It does not provide a complete diagnosis
- This can help to inform the next suggested stage, the workplace needs assessment

**1b. A diagnostic assessment** - confirms whether an individual is autistic.

**This 2-hour diagnostic can also be helpful** if the individual requires adjustments for formal examinations (e.g., extra time).

The standard diagnostic assessment typically involves the following:

- The gathering of information **about the individual's background, childhood, and experiences**
- Several questionnaires - ideally completed **by a parent or close family member and a partner or friend** to obtain objective evidence for the assessment
- This assessment includes a clinical interview and questionnaire discussion with a practitioner. Practitioners vary but commonly include clinical psychologists, psychiatrists, and other mental health professionals.
- **The creation of a report** - that concludes whether the individual does or does not have ASC

### 2. A workplace needs assessment

**A workplace needs assessment** - builds upon the assessment process and provides bespoke advice of adjustments.

The standard assessment process includes the following:

- **A discussion with the individual** - to explore their work environment, daily tasks, strengths, challenges, and current adjustments
- **A discussion with a line manager or HR representative** - to understand the individual's job role, strengths, challenges, and current adjustments
- **The creation of a report** - that outlines the assessment's conclusions and supports the individual and employer in **implementing the recommendations**

**Adjustment recommendations can be implemented at little or no cost.**

Here are a few of the most standard adjustments for autistic employees:

- Specialist equipment e.g., noise cancelling headphones
- E-learning
- Line manager awareness training
- Assistive technology
- One-to-one coaching

### 3. One-to-one coaching

A coach will help individuals develop strategies that work for them. One-to-one coaching sessions **teach soft skills that could be applied to the workplace** and environment.

Individuals can **embed the skills learned in the session** into their work, which can help increase the following:

- Productivity
- Confidence at work
- Retention

Coaching topics that may be helpful for an autistic individual include:

- Communication – verbal and non-verbal
- Managing change
- Organising, planning, and prioritising
- Confidence at work

## 4. Co-coaching

Co-coaching **builds healthy working relationships**. It also brings together Autistic employees and their line manager in a joint coaching session with a psychologist.

Co-coaching is a helpful tool for developing the following:

- Mutual understanding
- Good communication
- Clear goals
- **A safe space** for honest conversations

Building healthy relationships increases collaboration and productivity while fostering a comfortable environment.



**As a team  
How can you help?**

## 5. ASC awareness training

ASC awareness training: **educates line managers and colleagues** working with autistic individuals. It also builds healthy working relationships, which will help individuals flourish.

Through this training, your staff will:

- Gain a **greater appreciation for autistic co-workers**
- **Increase their level of understanding** of ASC in the workplace

The aim of the training is the following:

- Learn to **challenge stereotypes** and misconceptions
- To learn about **the unique talents that autistic individuals bring** to the team
- To provide **advice about adjustments** that can be implemented to support colleagues

## 6. Implement practical solutions at work

Practical solutions that your team can put in place to support an autistic individual include:

- Ensuring one-to-one meetings and routines are **on the same day and at the same time** each week
- **Promoting structured, clear training or mentoring** to help the individual understand the expectations of the job and its unwritten rules
- Ensuring any **instructions are clear, concise, and avoid ambiguity**. For example, suppose the instructions are “send this version of the document to everyone”. In that case, the individual may take this literally and send it to the whole company at a date later than intended. Instead, the instruction should be specific, “send version 3 of this document to Kevin and Bryony by email before 5 pm today.”
- **Providing sensitive but direct feedback** when something goes wrong. Instead of implying that there may be a problem, provide honest and constructive feedback that explains what to do next time



### Why Lexxic?


We are proud leaders in empowering neurodiversity in the workplace. With over 15 years of experience, our in-house psychology team has **extensive expertise** across a wide range of professions.

We pride ourselves on working in partnership with employers. At Lexxic, we bring together business and employee needs so that **everyone**, regardless of job title or neurotype, **can thrive**.

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## Employer Guide to Supervising Individuals with Autism Spectrum Disorders (ASD)

Communication | Understanding | Accommodation

Many employers are interested in hiring a group of capable yet under-utilized individuals: those with Autism Spectrum Disorders (ASD). With prevalence rates of about 1 out of 250 people in the United States, it is likely that you already know someone with ASD. You may also already be working with someone on the Autism Spectrum.

At Rochester Institute of Technology, we enjoy a diverse student population including many students with disabilities and a percentage of students who identify as being on the Autism Spectrum. The [Disability Services Office](#), [Office of Career Services and Cooperative Education](#), and the [Spectrum Support Program](#) at RIT work together to support these students in attaining their career goals.

You may encounter students on the Spectrum when recruiting and hiring RIT students for your organization. This guide will help you work effectively with these students as candidates and employees.

Objectives include:

- 1) Understanding the characteristics of ASD
- 2) Understanding the benefits of hiring individuals with ASD
- 3) What can you do as a manager, interviewer, co-worker, or recruiter
- 4) Resources for further reading

### *Characteristics of Autism Spectrum Disorders*

ASD is a “**spectrum**” disorder, which means that it affects each individual differently. No one descriptor is accurate for all people with ASD. Similarly, effective strategies for working with individuals with ASD can vary greatly. If you are working with (or think you are working with) someone on the autism spectrum, you may notice the following:

- Awkward eye contact, postures, or gestures
- Delayed verbal responses
- Difficulty understanding tone, facial expressions, or other subtle messages
- Strange vocal pitch, intonation, or volume
- Highly developed areas of interest
- Difficulty initiating conversation
- Blunt, pointed remarks (“brutal honesty”)
- Use of calming strategies such as pacing or tapping

*How do I know if someone is on the Spectrum?*

They may tell you. We encourage our students to be open with their employers about any accommodations they might need and share any information that would be helpful for their manager to know. The information that they do or do not share is up to them. Any and all of the strategies included in this guide may be equally helpful whether or not the student has disclosed.

### ***Benefits of employing individuals with AS***

Many managers are seeking individuals on the Autism Spectrum as job candidates. In addition to strong academic performance, individuals on the spectrum often exhibit the following desirable traits:

#### **Characteristics**

- Focus, reliability, honesty, and a preference for work over office politics
- Tolerance of repetition and routine which is valuable many types of jobs

#### **Growing and varied population**

- ASD prevalence in the United States continues to grow. Advances in understanding and supporting individuals with ASD mean that more are completing college than ever before
- Individuals with ASD work successfully in many fields, and are often drawn to computing, scientific research, software testing, and media design and development

#### **Efficiency**

- Supports that help individuals with ASD in their adjustment to the workplace often provide clarity to all employees (such as establishing long-term and short-term goals for employees)

#### **Enhanced supervisory and co-working skills**

- Coworkers and supervisors can learn to communicate more effectively and better understand social dynamics

#### **Skills**

- Attention to detail, accuracy, and a memory for details which can be astounding
- Strong logic and analytic skills

#### **Problem-solving**

- Ability to think outside of the box and discover original solutions

***Common areas of challenge for individuals on the Autism Spectrum*** are organization, reading social cues and understanding someone else's point of view, and sensory and motor integration.

<p>Difficulty with organization means that a person with ASD may...</p>	<ul style="list-style-type: none"> <li>• Have trouble getting started with projects and appear not to take initiative</li> <li>• Not know how long an assignment should take</li> <li>• Focus too much on details</li> <li>• Become locked in black and white thinking</li> <li>• Have trouble with short-term memory</li> <li>• Take longer to complete a task</li> <li>• Need direction about what the finished product should look like</li> <li>• Require written instructions and notes</li> <li>• Need help prioritizing tasks and organizing information</li> <li>• Get overwhelmed with too many interruptions or requirements to multi-task</li> <li>• Ask too many questions in an attempt to clarify assignment</li> <li>• Act impulsively, based on too little information</li> <li>• Resist change</li> </ul>
<p>Difficulty reading social cues and understanding someone else's point of view mean that a person with ASD may...</p>	<ul style="list-style-type: none"> <li>• Take language literally and miss nuances like implied meanings or sarcasm</li> <li>• Speak to a supervisor in the same way that they would talk to a peer</li> <li>• Talk at length about areas of interest and not notice that others are bored</li> <li>• Not know how to make "small talk" and appear friendly and interested</li> <li>• Make statements that are too honest, unintentionally offending others</li> <li>• Neglect to make eye contact or to smile</li> <li>• Have difficulty controlling anger or frustration</li> <li>• Interrupt; talk too slowly/quickly; too loudly/softly</li> <li>• End a conversation simply by walking away</li> </ul>
<p>Difficulties with sensory and motor abilities means that a person with ASD may...</p>	<ul style="list-style-type: none"> <li>• Have sensitivity to lighting, room temperature, noises, smells, or textures</li> <li>• Require written instructions</li> <li>• Take longer to process spoken words and formulate a reply</li> <li>• Need breaks to avoid sensory overload</li> </ul>

***What you can do as a manager, interviewer, co-worker, or recruiter:***

**Communicate effectively**

1. Be direct. Say exactly what you mean and identify exactly what you want. The more detail you can provide, the better your employee will understand.

Implied meaning	Clear, direct statement
"Are you going to work on the database assignment?"	"Please begin your work on the database assignment."
"Let's get lunch later."	"Please meet us in the cafeteria at 12:00pm if you would like to each lunch with us."

2. Put instructions in writing, and then follow up your verbal instructions with an email.
3. Avoid any indirect pattern of speech, including clichés, implied meanings, and idioms.

Statement with idiomatic meaning	Statement with literal meaning
"This assignment is going to give you a run for your money!"	"This assignment is going to present you with a challenge."

- Plan your directions ahead of time. Although re-learning can be a challenge for everyone, it can be particularly painful for someone on the Spectrum because they may rely on routines. Teaching it correctly the first time will save you time and frustration.
- Use primarily your words to communicate. Don't rely on non-verbal communication to get your message across.

Message sent with non-verbal communication	Message sent with clear, verbal directions
Manager notices that a meeting with an employee has gone five minutes beyond scheduled time, and glances at her watch several times.	"Now that our meeting is over, I need you to return to you work station now because we have work to complete."

### Provide clear expectations

Individuals with ASD may not be familiar with abstract concepts like corporate structure, hierarchies of responsibility, reporting requirements, and other structural elements of the workplace. Consider providing the employee with a mentor, who can instruct on the rules and social culture of the workplace. A mentor can also introduce the individual to new people, which someone on the spectrum may not do proactively.

- Provide details such as deadlines (time frames, schedules) and outcomes (what it looks like, formatting)

Unclear expectation	Clear expectation
"Please complete the data-processing project"	"I expect to have the first draft of the data-processing project by completed 1pm tomorrow. It has to be in electronic format so that I can check it and get back to you."

- Don't make assumptions about what your employees does or does not understand. Ensure that directions are understood.

Assumed confirmation	Confirmation
"Do you understand how to accomplish this?"	"Now that I've given you the assignment, what task will you complete first? Second?"

- Given your employee instructions on how you want them to communicate with you (email, face-to-face), and how often. Encourage alternative forms of communication, such as texting.

Supervisory role is unclear	Clear opportunity for supervision
"We can talk about the project later"	"The next time we will talk about the project is during our team meeting, tomorrow at 1:00pm."

- Provide detailed guidance and feedback; focus on behaviors that can be measured.

Undetailed feedback	Detailed feedback
"This report is sloppy."	"The proposal you presented as ready for delivery has numerous spelling and math errors."

5. Establish long-term and short-term goals for employee. Assign projects in a systematic and predictable manner.
6. Assist employees in assigning priority to assignments. For example, divide large assignments into several small tasks, provide a checklist of assignments, or use a wall calendar to emphasize due dates. Consider developing a cheat sheet for high priority activities, people, and projects. You might also try assigning new tasks only after the current tasks have been completed.

### ***Suggested workplace accommodations and self-accommodations for employees on the Autism Spectrum***

Employees often have questions about how to accommodate employees on the Autism Spectrum. There is no pre-established set of accommodations to use; others may only need a few accommodations to complete their jobs and others need none at all. The following is only a sample of the possibilities available. Work directly with your employee to discuss which, if any, accommodations may be helpful.

The following arrangements might be self-accommodations used by the employee, or accommodations that an employer may provide:

**Sensory stimulation:** People on the Spectrum often can exhibit strong focus on one task at a time. They may experience intolerance to distractions such as office traffic, employee chatter, and common office noises such as fax tones and photocopying.

- To reduce auditory distractions:
  - Wear a noise canceling headset
  - Hang sound absorption panels
  - Use a white noise machine
  - Office space that minimizes or eliminates audible distractions
- To reduce visual distractions:
  - Use space enclosures (cubicle walls)
  - Reduce clutter in the employee's work environment
- To reduce tactile distractions
  - Ask co-workers to approach an individual in a way that is not startling, such as approaching from behind or touching the employee

**Atypical Body Movements:** Individuals on the Spectrum may exhibit atypical body movements such as fidgeting. These body movements often help calm the person or assist them in concentrating on tasks, but can also disturb co-workers at times.

- Use hand-held squeeze balls and similar objects to provide sensory input or calming effect
- Work from home if appropriate
- Private workspace allows individual room to move about and also not disturb others by movements such as fidgeting

**Stress Management:** Situations that create stress can vary from person to person, but could likely involve heavy workloads, unrealistic timeframes, shortened deadlines, or conflict among coworkers.

- Provide positive reinforcement
- Modify work schedule
- Provide sensitivity training for workforce

### ***Recommended resources for working with individuals with ASD***

**Hawkins, Gail. How to Find Work that Works for People with Asperger Syndrome. 2004. Jessica Kingsley Publishers: United Kingdom.**

Identified roles and responsibilities for the employer and employee, as well as other stakeholders such as family, job coaches, and other professionals. Also outlines details about how ASD looks and functions in employment settings and tips for effective communication.

**[Job Accommodation Network](#)**

Searchable database of possible accommodations for disabilities including ASD. Offers overview information on accommodation and disability-related topics. Ask a JAN consultant feature offers free, confidential technical assistance about job accommodations and the Americans with Disabilities Act (ADA).

**National Autistic Society of England: “[Employer Factsheet: Managing Someone with an ASD](#)”**

Working with someone with an autism spectrum disorder (ASD), including Asperger syndrome, can be an enriching experience for managers and colleagues alike, but it may also present some challenges. This factsheet explains how to avoid or overcome any difficulties, in order to ensure enjoyable and effective working relationships.

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