

Kent Academic Repository

Full text document (pdf)

Citation for published version

McCreadie, Michael and Milton, Damian (2020) Autism: Understanding Behaviour. In: The Neurodiversity Reader. Pavilion, Hove, UK, pp. 159-176. ISBN 978-1-912755-39-4.

DOI

Link to record in KAR

<https://kar.kent.ac.uk/83334/>

Document Version

Pre-print

Copyright & reuse

Content in the Kent Academic Repository is made available for research purposes. Unless otherwise stated all content is protected by copyright and in the absence of an open licence (eg Creative Commons), permissions for further reuse of content should be sought from the publisher, author or other copyright holder.

Versions of research

The version in the Kent Academic Repository may differ from the final published version.

Users are advised to check <http://kar.kent.ac.uk> for the status of the paper. **Users should always cite the published version of record.**

Enquiries

For any further enquiries regarding the licence status of this document, please contact:

researchsupport@kent.ac.uk

If you believe this document infringes copyright then please contact the KAR admin team with the take-down information provided at <http://kar.kent.ac.uk/contact.html>

Chapter 17: Autism: understanding behaviour [Chapter head]

Dr Michael McCreadie

Dr Damian Milton

Introduction [A-head]

Being a parent is a demanding role. It places demands on our tolerance, our time, our energy levels, our coping skills and our physical stamina. But in the end the large majority of us consider that the attachments we form with our children, the pleasure they give us, the opportunities to contribute to their lives and the affection we receive back is all worth it. From the moment of our child's birth we attune to their movement and vocalisation, and in the dance of interaction we hope they attune to us.

As our daughters and sons develop, we observe changes in the nature of our interactions. Development necessitates changes in bodies and minds, and so we adapt our own expectations and anticipation of our child's behaviour to retain synchronicity and share common experience. The changes in our engagements reflect the development in reaching common milestones in the nature of parent-child interaction, primarily initiated by the anticipated development of the child.

Ultimately, we expect that our children will become adults and each family may have a set of expectations that may or may not be reached. For a range of cultural, ethical and legal reasons, our children generally become adults in their own right at the age of 16, but it should be remembered that they never stop being our sons and daughters, and the bonds developed in childhood are equally as strong when our children become adults.

Most of us cope well with the demands our children make of us, although we can feel an overwhelming sensation of frustration from time to time. However, some of us find it difficult to cope at times. Irrespective of disability, some parents are just more able to cope than others, and from time to time all of us need help, whether it be from family members, friends or outside agencies.

Parents of autistic children are no different in their coping resources than any other parent, but they can be faced by a range of what they may see as confusing behaviour from their child that can alter how they engage. For some families this can place unanticipated demands, create challenging situations and stress within parent-child interactions, particularly when in public settings where the stakes are high and social cost significant.

This chapter discusses the demands placed on parent-child interactions. It aims to provide some guidance as to how to derive meaning through interaction and offer some tips and strategies that will facilitate engagement.

While this chapter is primarily aimed at parents and carers of autistic children as well as practitioners working with autistic children, not all of the information or strategies will be

relevant or appropriate for a particular child. Each person and situation is unique, so it's important to think about how the issues discussed here relate to your own context.

Finding meaning in behaviour [A-head]

Human behaviour is complex, can serve many purposes and often has multiple causes. Fundamentally, it is an expression of our own experience of our internal world. Historically, some have described behaviour as a means by which we communicate. But this is not the full picture and does not explain behaviour related to illness such as seizures which may be beyond our conscious control. Rather, behaviour is an outward expression of what we experience. However there remains a problem: while we express our own experience, it is others that are required to interpret that experience and to derive meaning from it in order to respond in the most efficient and appropriate way. It can be like breaking a code so that your child and you can share experiences.

For human beings to engage with one another we must move in synchrony, pausing at appropriate times, observing, listening, not judging or jumping to conclusions, but paying close attention to the other's expression. All of this allows us to respond appropriately and share meaning.

Let us for a moment consider how we may care for an elderly relative that we know is unwell. We adjust our verbal communication, demanding little of them but listening intently. Perhaps we may even pay close attention to how they are breathing looking out for any changes showing them compassion.

In this way we approach the child, pausing, observing, listening and responding to them when they are able to listen rather than interjecting, giving direction or instructing, which can be difficult for a child to process, particularly when they are in a high state of distress.

Challenged by behaviour? [A-head]

We often hear the term 'challenging behaviour' applied to a whole range of behaviours that are described in terms of how the behaviour makes us feel or its impact upon our health and well-being. Moreover, many parents of children with autism report that they are continually exposed to stressful events involving their child that have elements of both low and high perceived controllability.

What does this mean?

Perceived controllability means how much control we **feel** we have over a situation. It does not necessarily mean that we are correct in our estimation. This is important, as the strategies we use will be influenced by how much we perceive we have control over the situation.

Let us for a minute consider the following scenario involving Child A who self-injures:

We know that her self-injury (which involves slapping her face) is more likely in the presence of unfamiliar people. As such we take steps to avoid areas where there are unfamiliar people. This is called *problem-focused* coping. Here we perceive that in preventing self-

injury we have a high degree of control and use coping strategies in which we try to control exposure to certain environments where unfamiliar people may be present. We are viewing the situation as a problem that we can influence. This seems a fairly reasonable strategy and we observe that, in general, it seems to work.

However, there are times when things may happen that we have no control over. On one occasion the doorbell rings and we open it to find that someone campaigning on behalf of a political party is standing there and they launch into a speech regarding a current local issue. By coincidence, Child A is standing in the hallway and observes this. In response she lets out a scream and runs through the house shouting 'stranger danger' and slapping herself hard on her left cheek. In this situation we realise there is very little we can do (low control) and so we switch to an *emotion focused coping strategy*. Such a strategy requires us to read the emotional distress of the other and ensure that we remain focused on keeping our own emotions in check. By correctly assessing that there is little control over the situation we keep our voice low, use minimal language, ensure that we provide Child A with space and minimise any feelings they have of being under *threat*. This may be achieved by offering gentle re-assurance until Child A is calm. Here it has been necessary that we keep calm and are aware of how we present in the situation. To do otherwise may have maintained the distress felt by Child A or have made it worse. Knowing when to switch between the two coping styles and being able to do this across situations is called *adaptive coping*.

In considering the situation above, we can see that, had we been unable to identify the change in controllability when Child A became distressed, we would have maintained a *problem-focused* coping style. In so doing we may have attempted to provide instruction to Child A by telling them to calm down or stay calm, have followed them closely through the house and tried to prevent them from hitting themselves, or offered them objects or food as a means of distraction. As we engage in desperately seeking out solutions to fix the problem, we may notice that our own distress increases and that we become more psychologically and physically aroused. This increase in our own arousal can result in us speaking faster, being less clear in our communication and choosing options that are less helpful to the situation. As such we become out of synch with the child.

We have now learned that, perhaps rather than using terms such as 'challenging behaviour', it is really the notion of *threat* that is more important here. In the situation above, Child A feels under threat by the unfamiliar person and we, as the adult, feel under threat by the child's response. The result being that we can both become highly stressed.

We have now learned that in starting to address the issue of behaviour that challenges us we must first examine how we have traditionally responded to those times we have felt stressed by the child's behaviour. It is important then to ask ourselves the following questions:

- How good am I at correctly identifying the amount of control I have in a situation?
- How good am I at switching between problem and emotion focused coping as the situation changes?

- How much time do I spend discussing with my own support network how I respond to stressful encounters?
- How do I bring myself back on-line when I feel under threat?

Are there strategies that work across all situations? [B-head]

The scenario of Child A may be familiar to you, or you may say, 'Well, that's not how my child behaves'. This raises the question, are there any strategies that work with everyone in every situation? The answer is, of course, no. Human behaviour in general is complex and is not the result of any single factor. Our behaviour is caught up in our thinking and emotion and how we feel about ourselves in our own bodies. It is far more productive to learn about our own reactions in situations that threaten us so that we can adapt as situations arise.

That is not to say that we cannot have some general sense of how our reactions also depend on how we are feeling at the time: if we are under a lot of pressure we are likely to become annoyed more quickly than we would if we were relaxed.

Common assumptions [A-head]

Culture plays a significant role in our interpretation of others' behaviour, the intentions we ascribe to their behaviour and, ultimately, our responses. In UK culture we observe a number of common beliefs surrounding behaviour, which often places the problem within the child rather than seeing behaviour as a result of the interaction between the child and their environment. These include:

- 'He's just doing it to get attention.'
- 'She should have known better.'
- 'He knows exactly what he's doing.'
- 'If I let him get away with it this time he'll think it's OK to behave like that all the time.'
- 'I shouldn't let him win.'
- 'If I give her what she wants then that just rewards the behaviour.'

It can be easy to find yourself locked into a battle of wills, to think that someone is behaving that way deliberately, or that you must 'win'. This is especially true if you are feeling anxious, tired, scared or frustrated.

It is important that we question our beliefs, especially in a challenging situation when our emotions are running high. If you can, it is more helpful to focus on helping a child to cope with a situation or to regain control. It is also helpful to remember that autism is a different pattern of development, no worse or better than typical development, but this may mean that your child has problems understanding the consequences of their own or others' actions. Equally, a parent may have difficulties understanding the consequences of their own actions on their autistic child.

Common underlying causes of distress [A-head]

For some autistic people, distress is often brought on by stress, anxiety, sensory differences, or difficulties with communication, all of which can create difficulties in interaction and mutual understanding.

Stress and anxiety [B-head]

'I get anxious and I'll stop eating and I'll be sick every day. Anxiety attacks, they're called. So I make myself not worry about anything.' (Ian)

Earlier we discussed the concept of threat and how this can result in a stress response that affects the quality of interactions. The behavioural scenario of Child A illustrates that the stress experienced by Child A in response to a perceived threat has an impact on the stress experienced by her parents.

Stress occurs when we feel under threat and while stress and anxiety are not characteristic of autism itself, many autistic people experience unprecedented levels of stress as a response to a situation they find threatening. While there may be some common threats for autistic people, the important thing is to identify situations where the child in your care feels under threat.

In contrast to stress which occurs as a response to threat, anxiety is more closely aligned with worry. When an individual is worried, they tend to spend a lot of time thinking about a potential threatening situation. Here, it is the act of engaging with thoughts of threat and the experience of them going around in our mind (rumination) that causes distress. This can be more harmful to our physical and psychological well-being as we cannot run away from our thoughts. As such we experience more distress over time and this can lead to mental and physical illness.

By viewing a child's behaviour as a means of coping with threat. It becomes more obvious to us that their behaviour that we find challenging is generally a means of coping with that threat. For example, let us consider ritualistic behaviours. This may involve repetitive movements such as rocking, flapping or spinning. We may have a desire to prevent our child from engaging in this as we perceive it to be socially undesirable, but in fact this may be a coping mechanism to manage stress (McDonnell & Milton, in Jones & Hurley, 2014). In fact, there is a growing body of evidence that suggests preventing a child from engaging in these behaviours increases the release of damaging stress hormones (Hirstein *et al*, 2001).

Change [B-head]

Many autistic children find change difficult. Sometimes changes that seem apparently small and insignificant, such as changing clothes for a PE lesson at school, may cause more difficulties than a significant change, such as moving house.

Change can lead to an increase in stress and this can quickly become overwhelming for a child.

Escape or avoidance [B-head]

A child's behaviour may be an indication that they want to escape or avoid a situation. This may be due to being overwhelmed by sensory information, which can be threatening and can prevent them forming a coherent picture of the world. In some children this can trigger a dramatic stress response, and so running away from or avoiding the situation may be the only means the child has of coping with it.

Transition [B-head]

People in general can find unstructured time particularly stressful. For autistic people, who may have difficulty predicting activities, transition times, where they are moving between activities and places, perhaps seeing different people, can be especially stressful. Some examples of transition times include break times or moving between lessons at school, waiting for an activity to start, leaving work or school and going home. There is an element of uncertainty at these times and a child may not be sure what they should do; this is likely to cause anxiety. Sometimes the anxiety can become so overwhelming that it results in distressed behaviour.

Mood or physical state [B-head]

Our mood affects our level of tolerance for others and our ability to relate to ordinary day-to-day situations. If a child is tired, hungry, stressed or ill, they may become more agitated or frustrated than usual, or more sensitive to sensory stimuli. Just like you, their tolerance may be less at such times and we should consider how we relate to them, perhaps placing less demand at that time, or providing them with more space and time to engage in preferred activity.

Sensory differences [B-head]

Many autistic people experience sensory processing difficulties. In some environments, certain sensory stimuli such as noise, smells, tastes and colours can be overwhelming.

If a child is sensitive to noise in some environments, they may cover their ears to block it out or become very distressed. They may even experience physical pain. On the other hand, if a child does not receive enough auditory sensory feedback in certain environments, they might seek out loud noises, or make a lot of noise in order to reach some kind of sensory equilibrium.

As autistic children can have a different pattern of development, it may be that their perception of sensory experience is organised and perceived in different ways. This means that the way that a child responds (their behaviour) may not always be the same across each situation and so it is worth observing your child's response to sensory stimuli across many environments.

Communication difficulties [B-head]

Some autistic people have a degree of difficulty with communication. Some people are non-verbal or have limited expressive vocabulary; others are highly articulate but may still have difficulty understanding what other people mean at times, as well as understanding the common etiquette associated with social situations.

Your child may be unable to communicate their feelings and needs effectively through conventional means for their age, and may lack speech and gesture. For example, they may lead someone to a door to indicate that they want to go out of the door and across the hall to use the toilet, a means of communicating common in very young children. Here it can be beneficial to create a rich communicative environment where speech, gesture and visual supports are all available to the child to help them express their needs. We must be patient with the child as they may be frustrated by their difficulties in expression that may cause an increase in feeling stressed.

Losing control [B-head]

Losing control is scary, challenging and upsetting for anyone. In situations where raw emotion takes over and we are unable to express how we feel, all that can be done is to allow the person to calm in their own time and keep them safe. After such an event, a child may feel distressed or regretful about what has happened and perhaps seek comfort and reassurance. In such situations, it can be difficult for us to offer comfort, particularly if we have just been through the experience with them and have been injured or have pent-up feelings of our own. Nonetheless, do try to offer support and reassurance.

Try also to take a bit of time to deal with any residual feelings you have, and if possible talk to someone else and 'debrief'. This will help everyone involved to continue supporting your child in a consistent, constructive way. You may find that there are useful services, such as family support services, parent groups or counselling centres in your area.

Thinking about behaviour [A-head]

Here are some questions that may help you to think about a particular behaviour:

- Is the child experiencing any pain, illness or physical discomfort (such as toothache, earache, digestion problems, allergies, seizures)?
- How does the child communicate their needs, wants and feelings? Could the behaviour be a way of compensating for communication difficulties?
- Have there been any recent changes in a child's life (e.g. a new teacher, moving house, disruption to routine)?
- Is the child experiencing any sensory differences which may be affecting them? This may be very subtle: a change in the washing powder you use, for example.

Remember, more overt behaviour can also be a coping strategy. For example, a repetitive movement such as rocking or hand-flapping could help your child to cope with a stressful situation, to relax, or to deal with sensory over- or under-stimulation. It should also be noted that responses to stress can be varied. At times, people may withdraw or lose communicative abilities that they would otherwise be able to draw upon.

Lets look at an example:

An autistic young man is taken to the supermarket but finds the environment very distressing because of the sensory stimuli present (harsh lighting, background music, the number of people) and his own worries about what is expected of him.

As a result, the young man becomes highly stressed and begins biting his hand and hitting himself. This behaviour could serve several purposes: a coping strategy, a way of blocking out other stimuli, or a way of avoiding or escaping from the situation altogether. The young man has learnt that this behaviour is likely to result in him being taken away from the supermarket to a quieter place to calm down.

It may be tempting to interpret this as manipulative or that he is trying to control the situation. However, if we again consider that this environment is threatening to him, we can consider his response within a coping framework. By doing this we can also re-consider what we are trying to achieve here.

What is the purpose of going to the supermarket? If it is to obtain shopping, then can this be done in an alternative shop where there are less sensory stimuli?

How have we prepared this young man? If it appears that he gets anxious and we feel it is due to anticipation, we should examine how we prepare him for the environment. We may wish to audit what we have done so far: do we offer pictures of what the shop will look like? Do we tell him what to expect? Do we provide him with enough information?

Monitoring behaviour [A-head]

Autistic people can't always express their feelings through facial expressions, body language or speech. Instead, these feelings may be expressed through other means.

Your child might be trying to tell you that they are tired, stressed, annoyed by something that happened earlier, or in need of some time alone – but if this isn't always immediately obvious, how do you find out what they want?

It can be helpful to use a behaviour diary to try and determine the reason for a particular behaviour, however a word of caution here. Without being able to ask the person directly as to why they present the way they do, interpretation of the diary is always purely subjective and so you should rely more on your relationship with your child and being attuned to them. A behaviour diary allows you to monitor a child's behaviour over time, simply to notice patterns that you can then cross reference with your own feelings of a child's needs as you relate to them.

The author Philip Whitaker (2001) suggests thinking of behaviour as an iceberg: the behaviour you are actually seeing is the tip of the iceberg but there's a lot more going on under the surface. Here are some questions you can ask yourself to determine the underlying causes of behaviour:

- What behaviour is occurring?
- How often does it occur?
- What happens before and after?

- Are other environmental variables affecting behaviour?

Other things that you can consider include:

- The time of day.
- The temperature.
- The sound level.
- The people around you.
- Your location.

When you are completing a behaviour diary, or monitoring a child's behaviour in some other way, try to focus on *the actual behaviour that is occurring*. Therefore, rather than describing a child as 'getting angry while watching TV', think about:

- exactly which point did your child started to get angry?
- where you were?
- what you were doing immediately beforehand?
- how exactly your child behaved, i.e. did they hit out at a particular person? In what way?

At this point it is also useful to look at how factors in the environment may have affected a child's behaviour. Was the television on really loud when the behaviour occurred? Were other people in the room at the time? What were they doing? Does the child engage in other behaviour that perhaps serves a similar purpose, for example does a similar thing happen whenever they want to avoid a particular task or gain access to a desired item or activity?

However, all of this comes with a huge health warning for parents: don't over burden yourself! If you feel that you do not have the energy, time or are just too exhausted and this is another thing for you to do, then just being available to your child is enough. The reality is that we can place a lot of pressure on ourselves by feeling we need to do more. You may find that some of these suggestions are helpful, but you do not have the internal resources to create diaries. That is ok, just being available to interact with your child is enough. If you feel that you can adopt some monitoring strategies, then perhaps you can create some type of diary that gives some information but does not go into great detail. Remember, you are the expert when it comes to your child.

In this chapter we try to offer a balanced view, and look at the relative merits of different approaches. This is to enable you as a parent or practitioner to choose approaches that work for you in your situation. As such, an alternative to a diary that focuses on situations where a child was in distress, is a diary that records when they are engaged, happy, content and able to self soothe. This can often be more helpful as it can provide information that helps the child regulate their emotions.

Helpful strategies [A-head]

Proactive strategies (that is, strategies that are planned and developed in advance) are a very important part of supporting your child to regulate their levels of arousal. They are more effective in the long-term than reactive strategies (reacting to a situation that is already happening), as they aim to prevent distress rather than responding once it arises. Proactive strategies can be time consuming to put in place and often require a lot of work.

If a particular behaviour represents a threat to safety, then sometimes a quick decision has to be made. However, if the behaviour is something that is undesired but not immediately threatening (e.g. spitting), then it may be better to gradually suggest alternatives.

Remember, a behaviour that we find challenges us possibly helps your child to cope – so taking it away could make them more stressed and anxious. Also, a person will not replace one behaviour with another if it doesn't actually meet the same purpose for them.

With self-injurious behaviour it is important to intervene, but you may find that a child needs to finish the behaviour before being able to move on: it may serve a meaningful purpose for them. If there is a threat to your child's health or safety, or that of those around them, measures may need to be taken immediately to reduce risk. This responsibility should not fall solely on you. Emergency interventions can be planned for as well and so you should seek professional advice to help you draw up a plan to manage these situations. There should also be an onus here on social services providing families with adequate support.

Adapting the environment [B-head]

We have already looked at how autistic people can experience sensory processing difficulties, and how stimuli in the environment (such as certain noises or colours) may cause stress and anxiety and result in distress. Often, fairly simple adaptations can help to make the environment much more manageable. For example, if the sound of a lawnmower makes your child distressed, could the lawn be mowed while they are out at school or college? Or could your child wear ear-defenders? Alternatively, you might also use music that is gradually increased in volume until it matches that of the lawn mower.

Where children are faddy eaters, new foods can be introduced through fun touch and taste sessions in the kitchen. Here children learn to explore food through texture and smell as well as taste, in a non-threatening manner where getting messy (if the child enjoys it) is a new way of relating to food. Some aversions to smell and taste once entrenched can become lifelong stressors, and so caution is also advised. Again, if a child's diet becomes unhealthily restricted, then you should seek professional advice.

Another way to help reduce stress and anxiety is by creating a low arousal environment. This might mean having clear, uncluttered rooms (not too many pictures or ornaments on display), low levels of light, calming music, or a quiet area or chillout room so that your child has a place to go to relax. The low arousal approach extends to thinking about our own behaviour, too, and the way we interact with children. We can promote a low arousal environment by being calm and consistent.

You may also be able to identify things in the environment that repeatedly trigger a particular behaviour. It may be best to remove the trigger if possible to prevent the behaviour, then to consider a planned, step-by-step process to reintroduce it if necessary.

For example, if a child pours pepper all over their dinner because the pepper pot is on the table throughout the meal, try offering pepper at the beginning of the meal then putting it away. This may mean that you don't have to remind the child not to use too much pepper, thereby saving them from becoming agitated or stressed.

Introducing structure [B-head]

As we have already said, many autistic people become stressed or anxious if they cannot predict what will happen next, or if they are unsure how to behave in a particular situation. For this reason, your child may prefer a structured, predictable environment. It is possible to introduce structure at home using some simple strategies. It should also be remembered that structures need to be put in place that help understanding and reduce stress. Imposed structures and routines that do not make sense to an autistic person can increase stress and resultant anxiety.

Visual supports can help to address behavioural difficulties by reducing some of the anxiety that people on the autism spectrum experience when they are not sure what to expect.

Daily or weekly **visual timetables** can show clearly what a child will be doing in the day or week ahead. Timetables can be adapted to suit a child's level of understanding. You could use picture symbols or words, and different media – a diary, a wall planner or the calendar function on a smart phone may all be suitable. It depends what works for that particular child.

Other forms of visual supports include **now and next cards**. Again, these could contain words or pictures.

Here is an example of how Ali's parents used visual supports:

Ali loved his swimming lessons, which were held every Tuesday afternoon. However, his parents were finding it increasingly difficult to cope with the constant questioning by Ali about his next lesson. Each day, Ali would insist it was swimming day and get his swimming costume and towel ready. Sometimes Ali would get very distressed when told that he wasn't going swimming that day.

His parents decided to try a strategy that Ali's teacher was using successfully at school: a weekly timetable with picture symbols showing different activities that took place throughout the week. The swimming symbol was placed under Tuesday.

Ali's parents stuck the visual timetable on a wall in the kitchen and, each time Ali asked to go swimming, his parents would refer him to the timetable which reminded him of the day's activities and showed him how many days remained until his next swimming class.

After a week of redirecting Ali to the timetable, the constant questioning gradually reduced and Ali started referring to the timetable independently. The distress also decreased as Ali

could clearly see when he would be able to go swimming again and what activities he would be doing on the days before that.

Comic strip conversations [B-head]

Comic strip conversations are another way of visually representing the different levels of communication that occur during a conversation. They might include stick characters with thought bubbles and speech bubbles to show the different elements of a conversation, for example the difference between the words we say and our inner thoughts and feelings. Comic strip conversations can also be a useful way to explore differing perceptions of a situation (where possible), if they are mutually created. Such activities can therefore also help build understanding and rapport.

Intensive Interaction [B-head]

Intensive Interaction is a technique that was originally developed for use for people with learning disabilities, but has been adapted by practitioners such as Phoebe Caldwell for those who are also autistic. These techniques involve building a dialogue with an autistic person in their own 'language' (or way of communicating and relating). Such methods can be useful in building rapport and relating better to how a child may be experiencing the world around them.

Technology [B-head]

Technology has now quickly become part of our lives and there are a range of technologies, from apps to digital cameras, that can be helpful. You can take photos and videos to use as visual supports and colour-coded diaries can be helpful to many people, either on phones or tablets.

One particular approach, Video Interactive Guidance (VIG), helps parents examine interactions with their children. Parents benefit by receiving constructive feedback where opportunities for interaction may have been missed. By using this technology and approach, parents are able to adapt their behaviour to assist and support their child's development and engagement, as well as understand how their child communicates.

Visual supports [B-head]

Visual supports may really help a child to communicate. A number of systems, such as Widgit, Boardmaker or the Picture Exchange Communication System (PECS), allow a child to communicate a short sentence, for example 'I want a drink'. They can gradually build up a library of symbols to communicate more and more complex sentences.

If a child is becoming stressed or anxious, they can use PECS or another form of visual communication to tell others that they are feeling and if they would like to go to a quiet area to calm. Some people may find electronic communication aids helpful and there are now a range of portable electronic devices that can produce either synthetic or digital speech for the user.

The incredible five-point scale is a simple idea that is popular with children and young autistic people, as many find it quite hard to talk about feelings, but easier to relate to a numerical scale. Making feelings and emotions – both rather abstract concepts – more ‘concrete’ can be helpful. For example, if your child is a 1 it means they are feeling relaxed and happy. If they are at a 5 it means they’re extremely anxious. You can then link the numbers back to physiological changes in the body, for example ‘When I’m at a 5 I’m clenching my teeth and my fist’.

Once your child recognises where they are on this numbered scale, you can develop strategies for them to use in each situation. Here is an example.

	What I do	How it feels	What I can do
5	Swearing Breaking stuff Clenched teeth	I have to break something I need to leave	Get someone to help me leave or take a walk with me
4	Swearing	Cross	Leave the room, with permission, to go to a safe place
3	Not talking Pacing A little swearing	Upset	Go to bedroom
2	Keeping to myself Still talking with others	Not happy	Talk to a safe person Get a drink Go for a walk
1	OK	OK	No action needed

You may also be able to use numbers to help manage a situation, even if you do not have the numbered chart to hand.

A young autistic girl was in a restaurant with her mother. She began to get anxious and her mother, noticing this, put three fingers on the table. This helped her daughter to understand that she was getting anxious and was ‘at a 3’, without the need for anybody to say anything. Their strategy, which they’d previously worked out, was to go back to the car for five minutes to calm down.

This kind of strategy can take time to put together and won’t produce results overnight but, in time, the focus is on supporting your child to recognise when they are in a heightened emotional state and what they can do to manage it. How you use it will depend on the level of understanding a child has.

Some autistic people may prefer to use pictures rather than numbers. One child used a picture of a house to explain and communicate his feelings: the ground floor represented feeling uncomfortable, the first floor was ‘warning time’, and smoke coming out of the chimney meant he felt he had lost control and was very scared.

Relaxation techniques [B-head]

Relaxation techniques may help your child to manage their anxiety levels and stress.

Techniques include:

- breathing exercises
- progressive muscular relaxation
- mindfulness
- redirection to pleasant, calming activities such as taking a bath, listening to relaxing music, aromatherapy, rocking and twiddling with objects, swinging or jumping on a trampoline.

Jennifer always seemed to be extremely agitated when she got home from school in the afternoon. She would often shove furniture around, yell at family members and physically lash out if anyone got too close to her.

Jennifer's mother realised that this was her way of coping with high stress levels caused by a day of concentration and stimulation at school. She decided to structure a period of relaxation time into Jennifer's schedule when she arrived home. In Jennifer's case, this meant spending 45 minutes alone listening to how water from the tap dripped into an old tin cup that Jennifer had found one day on a walk.

Physical exercise [B-head]

There is a wealth of evidence that shows the benefits of exercise in elevating mood and reducing stress and anxiety levels. Going out on strenuous walks, running, cycling or even spending time on a trampoline are not only good for general health but have been found helpful for many autistic people to regulate their arousal.

Responding to crises [A-head]

Sometimes a child's behaviour may escalate to the point where their own safety or the safety of others is at risk. This is particularly the case with aggressive and self-injurious behaviour.

While the best strategy is prevention before the behaviour escalates, this is not always possible and at these times it is important to have a range of strategies that can be used to try to defuse the situation and help a child to calm down.

Being aware of potential factors that increase stress and avoiding these as much as possible, as well as recognising the 'indicators' that a child is becoming increasingly distressed, can help to avoid such situations.

The 'low arousal' response [B-head]

All of the strategies we have mentioned can form part of a **low arousal** approach. Essentially, this means staying calm when faced with behaviour perceived as challenging –

not always easy, but a calm and consistent approach can really help you to manage situations effectively.

The low arousal response is:

- take a break
- reduce verbal and non-verbal communication
- give space
- give a choice
- give warnings.

An important part of the low arousal approach is recognising how our behaviour might increase the likelihood of distress developing and – on the other hand – how we might be able to reduce the chances of a meltdown happening.

For example, when a child is in a heightened state of arousal and feeling extremely anxious, they are likely to be less able than usual to process verbal or non-verbal information. We all know how our ability to process information is reduced when we are angry or stressed. Too much verbal engagement at this stage may only serve to raise anxiety levels further.

In contrast, if you can recognise the signs of increasing anxiety early, this could be a good time to redirect your child to a quiet area or an activity that they find calming. Think about your body language at this time, too. Direct eye contact can appear threatening or confrontational. If a child is already in a state of anxiety this may make them more anxious. Sometimes it can be a good idea to avoid directly confrontational words like 'no' or 'stop'. These words can trigger further arousal, especially if your child associates them with feeling anxious. Find other words to use or try visual symbols instead. You can also think about personal space: try to give a child a bit of space and be aware that they may try to avoid physical contact and interaction with others, possibly because they are very sensitive to touch.

If necessary, think about removing objects or other people so that everyone can remain safe. Removing people from the room also reduces the 'audience effect' which can make a child more anxious.

Remember, people's safety is of paramount importance. Sometimes there is nothing else that can be done except to make sure everyone is safe and okay. Once a child has begun to calm down they will enter a recovery period. During this time their arousal levels drop.

References and recommended further reading [B-head]

Caldwell P (2014). *The Anger Box*. Hove: Pavilion Publishing and Media.

Dunn Buron K and Curtis M (2008). *The Incredible 5-point Scale*. London: The National Autistic Society.

Hirstein W, Iversen P and Ramachandran VS (2001). *Autonomic Responses of Autistic Children to People and Objects*. Royal Society, London.

Jones G and Hurley E (Eds) (2014). *Good Autism Practice: Autism, happiness and wellbeing*. BILD.

Lawson W (2010). *The Passionate Mind: How people with autism learn*. London: Jessica Kingsley.

Milton D (2012). *So What Exactly is Autism?* [resource linked to competency framework]. Autism Education Trust.

Milton D, Mills R and Jones S (2016). *Ten Rules for Ensuring People with Learning Disabilities and Those on the Autism Spectrum Develop 'Challenging Behaviour'... And maybe what to do about it*. Hove: Pavilion Publishing and Media.

Whitaker P (2001). *Challenging Behaviour and Autism: Making sense, making progress*. London: The National Autistic Society.

Woodcock L (2010). *Managing Family Meltdown: the low-arousal approach and autism*. London: Jessica Kingsley.