



Communication and Interaction Team

Anxiety and Dysregulation

How these difficulties might present

Children and Young people (CYP) with autism are likely to experience four key areas of difference in terms of:

- Social understanding
- Interests and Information Processing
- Sensory Processing
- Communication

As a result of these differences CYPs are likely to experience heightened anxiety in relation to:

- Unknown situations
- Understanding / responding appropriately to the expectations, demands and social rules of any environment, particularly when new and unfamiliar.
- Understanding how to physically interact within any environment / context, particularly when new and unfamiliar.
- Relating to new or unfamiliar people
- Interpreting and acting on social cues
- Predicting what might happen and coping during times of change
- Regulating arousal levels in terms of sensory stimulus. This is commonly known as 'the coke bottle effect' whereby CYPs anxiety and sensory experiences build up throughout the day. Some CYPs can mask their needs for an extensive amount of time and on the surface appear to be coping. However they cannot sustain or manage this any longer, impacting upon their ability to function (eventually exhibiting in 'meltdowns').

Subsequently CYPs may struggle to modulate their arousal levels and go into a 'fight, flight or freeze' response. This can manifest in the form of what is often referred to as 'challenging behaviour'.

The characteristics of behaviour:

1. Behaviour is not random; behaviour is a form of communication
2. Behaviour is usually about meeting needs, i.e. 'I want that now'; 'I want your attention'; 'Leave me alone'; 'I'm scared.'
3. The same behaviours can have different causes
4. Behaviours are often linked to an individual's level of arousal, i.e. if a CYP is already anxious as a result of an earlier event they may struggle to deal with situations which would not usually pose a difficulty.
5. The 'Iceberg Model': the observed behaviour is the 'tip' of the iceberg; the factors which are causing the manifestation of this behaviour lie beneath the surface and are not always obvious.
6. Behaviour needs to be 'unpicked' in order to analyse in terms of the four areas of difference (see above) and identifying possible 'triggers'. Thinking about what the 'function' of the behaviour is and what purpose it is serving will help to ascertain whether there are particular patterns and the reasons why the behaviour may be being displayed. This process can also be helpful in identifying any subtleties which may be acting as a positive/ negative reinforcer; which in turns creates a pattern of 'undesired' behaviour continuing.
7. Any approach that is utilised should involve 'pulling apart' the incident and adopting a restorative approach that incorporates explicit teaching/support/follow-up intervention to help equip the CYP to handle similar situations differently/in a more appropriate manner in the future. The emphasis is always on what the child 'should do' rather than what they 'should not do.'



Strategies to support

- CYPs with autism may need additional time in order to process verbal information and to respond appropriately. If they are in a state of dysregulation then they may struggle to process language at all. Try to avoid confrontation and keep language to a minimum. The emphasis should always be on defusing / calming; once a child is calm they will be more likely to cope with carefully presented directions and process information more effectively
- The CYP would benefit from a very patient, calm and non-confrontational approach; positive relationships with familiar and trusted adults are also important. Care should be taken to ensure that language is concrete and avoids excessive demands, (minimise the use of questions). particularly at times of stress (see above)
- Visual support will enable the CYP to retain and recall key information and help to reduce anxiety by making the day more predictable; creating a sense of safety and security.
- Where possible CYPs need to know what they are doing, what is expected of them and when things will be finished. The day should have a clear structure and routine, with regular opportunities for the CYP to pre-empt known changes and ways of coping with them.
- A 'first-then' approach both in terms of language and visual prompts can be helpful in explaining key information and in supporting the CYP to understand and anticipate
- The use of social narratives can facilitate CYPs ability to understand specific social contexts and what they can do in such situations. Crucially they are an effective way of providing them with positive reassurance and affirmation. Social stories together with Comic Strip Conversations might be used to assist the CYP to develop greater understanding about specific situations and/or key concepts, whilst reassuring and focusing on aspects they have done well. Comic strips can be particularly useful and help encourage the CYP to 'unpick' situations and recognise what they can try to do to alleviate their stress and manage the situation 'next time'. Concrete visual formats such as these can provide CYPs explicit information about specific contexts, which they may be missing as a result of their autism.
- CYPs are likely to benefit from on-going and direct input to develop their awareness of their emotions, particularly in terms of strategies to help them monitor and control their anxiety. Simple systems such as mood scales / barometers and visual reinforcers can be utilised to help CYPs recognise when they are becoming / what makes them anxious and what they can try to do to cope. The Five Point Scale is an effective tool in this regard; such approaches can support CYPs to develop an awareness of their self-regulatory systems and actively engage and reflect upon what strategies can help them to manage their stress and arousal levels.
- A 'safe / calming' place can be developed where a CYP knows they have the option of accessing if and when they are feeling anxious for any reason. Creating a designated space such as this should be discussed and rehearsed with the CYP when they are in a calm and regulated state, reinforced through simple social narratives so that they understand how and when the area can be accessed, *i.e. through the use of a card cue*, what happens there, what to expect, how long they can spend and what will happen next. This should never be used as a punitive measure and the CYP should be rewarded for using this area appropriately.
- The development of a personalised sensory diet and/or timetabled sensory activities may be important to help a CYP to regulate effectively. Access to a 'toolkit' of calming activities for stressful times can also be beneficial.
- Regular mentoring sessions can provide CYPs the opportunity to plan, reflect and additionally offers them reassurance by:
 - clarifying what is happening, when and with whom.
 - reinforcing strategies for exiting, rules and expectations.
 - providing an opportunity to talk about worries, anxieties and concerns.
 - creating an opportunity to plan for any changes that are happening and the options available instead
 - reviewing, highlighting and celebrating successes.
 - seeking to address problems and provide a visible practical solution.



- giving opportunities to focus on / teach specific social rules/skills with the use of visual supports etc.
- offering a forum to express emotions and explore successful strategies such as 'feelings scale'.
- All strategies should be implemented alongside a continued analysis of triggers / patterns of behaviour, i.e. through the use of ABC (Antecedent, Behaviour and Consequence)
- charts, and the use of social narratives / stories and guidelines to clarify and teach expectations
- It may be helpful to develop a personalized behavior plan / profile which highlights clear strengths and area of needs; identifying key strategies / interventions which have previously enabled positive outcomes for the CYP. This will require regular updating.

Useful resources, links and further reading:

Websites:

A 1 minute guide for parents and carer's of children and young people with Autism -

<https://childrenandfamilyhealthdevon.nhs.uk/wp-content/uploads/2020/04/1-minute-guide-anxiety.pdf>

Guidance on how to write social stories and comic strip conversation -

<https://www.autism.org.uk/about/strategies/social-stories-comic-strips.aspx>

Supporting emotional regulation during times of stress and anxiety -

https://www.youtube.com/watch?v=UUCWWu2F_9E&feature=youtu.be

The zones of regulation - <http://www.zonesofregulation.com/learn-more-about-the-zones.html>

The Iceberg Model (YouTube clip) - <https://www.youtube.com/watch?v=k-LZX3kus98>

The 'coke bottle effect' (analogy for stress) - <https://sarahpfisher.com/2019/09/the-coke-bottle-effect/#:~:text=Think%20of%20your%20child%20as,the%20child's%20stress%20and%20anxiety.>

Preparing CYPs for change - <https://www.autism.org.uk/about/behaviour/preparing-for-change.aspx>

Autism- Coping with Change, Planning etc. - <https://www.asdinfowales.co.uk/asd-videos-for-parents-carers>

Teenager's blog about what change means to them - <https://the-art-of-autism.com/autism-and-the-resistance-to-change/>

Sensory Processing - <https://www.youtube.com/watch?v=D1G5ssZIVUw>

Autism and Girls - <http://www.nasen.org.uk/resources/resources.girls-and-autism-flying-under-the-radar.html>

Reducing Anxiety - https://cdn.shopify.com/s/files/1/0088/6797/1123/files/Reducing_Anxiety.pdf?v=1588090046

Books:

- **The Incredible Five Point Scale - Kari Dunn Buron and Mitzi Curtis**
- **The New Social Story Book – Carol Gray**
- **When My Worries Get Too Big- A Relaxation Book For Children Who live With Anxiety – Kari Dunn Buron**
- **Red Beast (Controlling Anger) – Kay Al-Ghani**
- **My Hidden Chimp – Professor Steve Peters**
- **Panicosaurus (Anxiety) - K I AL-Ghani**
- **The Disappointment Dragon - K I AL-Ghani**
- **Teaching Children with Autism to Mind Read - A practical Guide by Patricia Howlin, Simon Baron-Cohen and Julie Hadwin**