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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.

Contents

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?

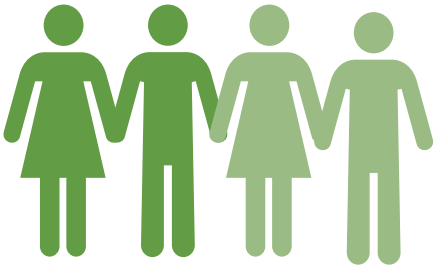
Anxiety is a feeling of worry or fear that we experience when we expect that a situation might have adverse consequences for our psychological or physical well-being. This may include situations such as preparing for an exam or test (for fear of failure), travelling during rush hour (for fear of being 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.

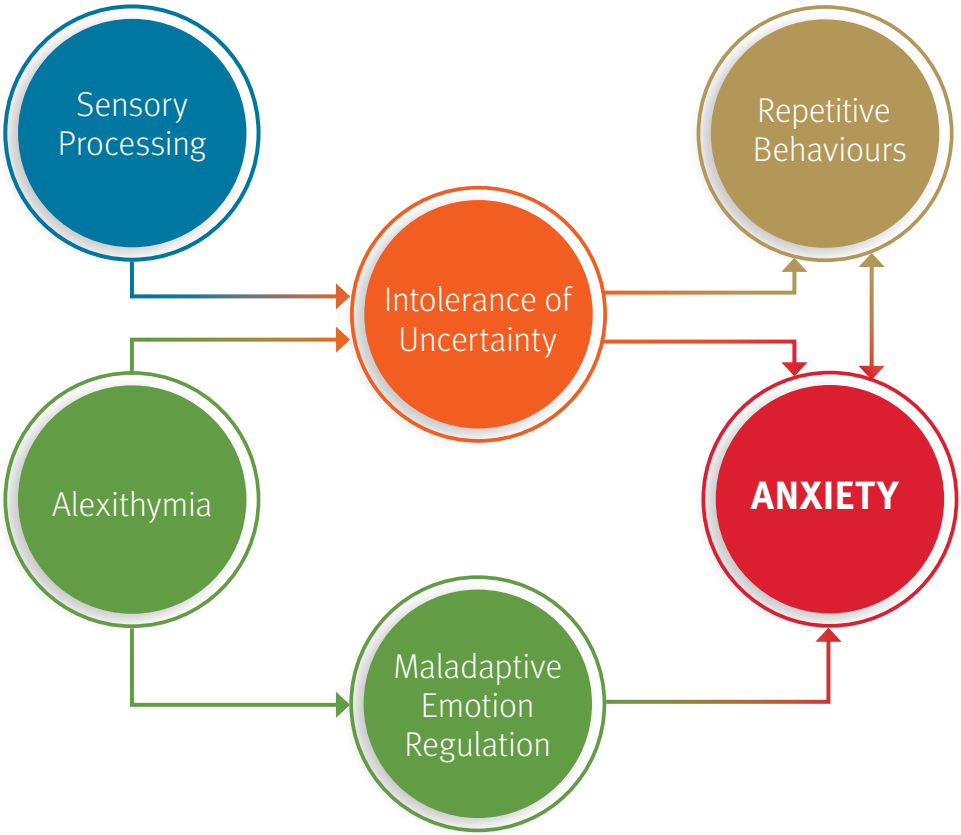
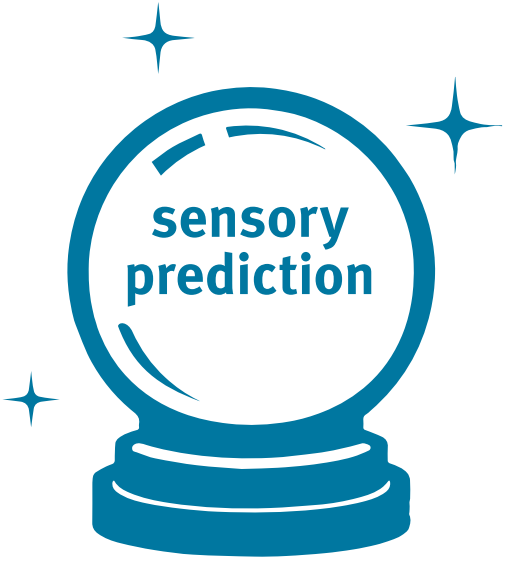


Figure 1: A model of anxiety in Autism (adapted from South & Rodgers 2017 and Maisel et al., 2016)

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).

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.

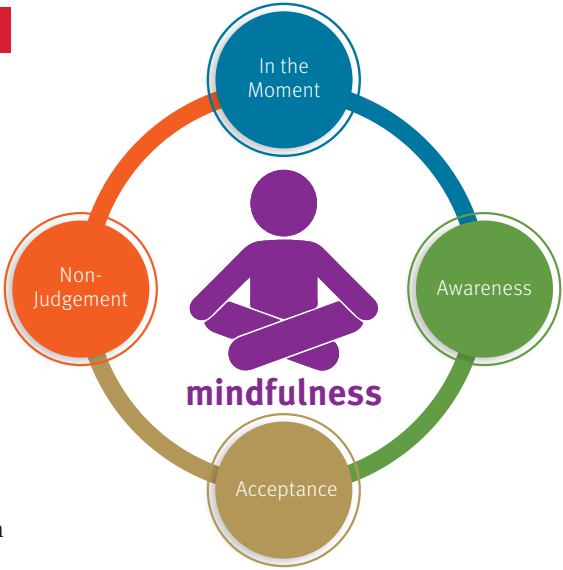
Coping with Uncertainty

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/ transparent 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.

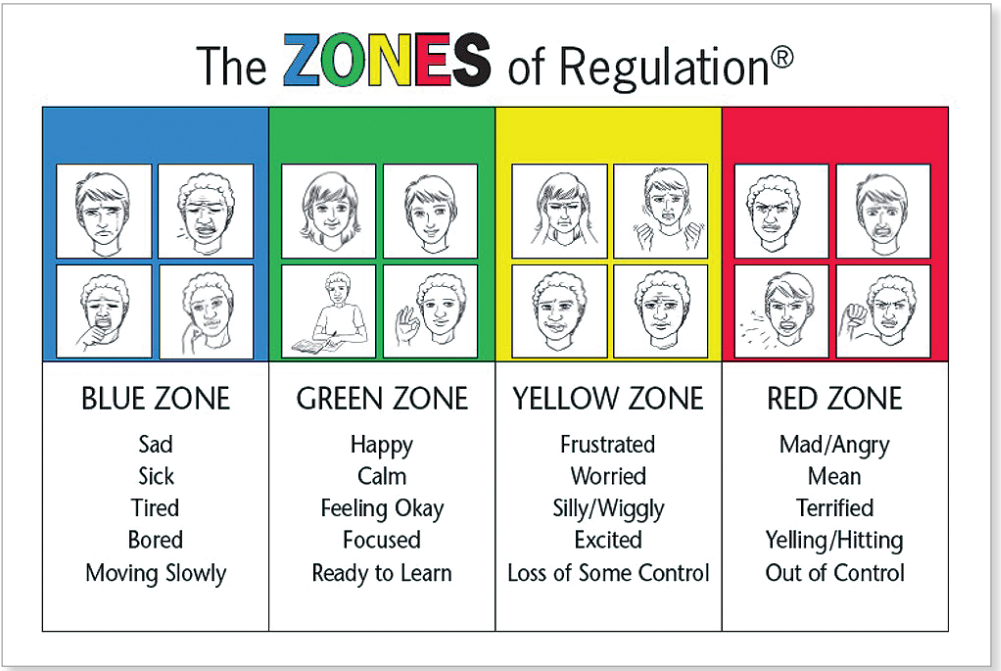
This book provides practical and user-friendly introductions to tried-and-tested mindfulness-based strategies for promoting emotional and mental well-being in young people. The tools will help to prevent the escalation of difficulties and will provide anyone wishing to develop a programme of support 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.



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.

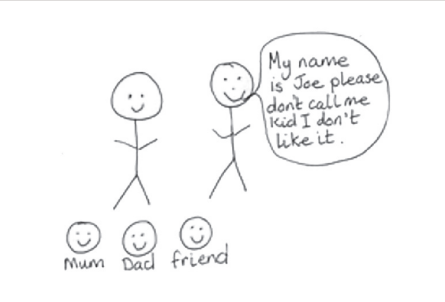
This book combines stick-figures with 'conversation symbols' to illustrate what people say and think during conversations. Showing what people are thinking reinforces that others have independent thoughts, which autistic children often find difficult to understand intuitively. It also helps children 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/anxietyscaleforchildren-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.aettraininghubs.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

Emotional Literacy Resources
www.elsa-support.co.uk

General Educational Resources (Social Skills; Emotion Regulation; etc.)
www.do2learn.com

Visual aids for learning
www.visualaidsforlearning.com

Useful Apps

National Autistic Society's Brain in Hand App
www.autism.org.uk/services/education/brain-in-hand.aspx

Autistica's Molehill Mountain app
www.autistica.org.uk/get-involved/molehill-mountain-app

The Smiling Mind App
www.smilingmind.com.au

Positive Penguins
positivepenguins.com

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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. We would greatly value feedback on the current version through a short survey that you can access via the QR link on the right, which also provides a link to an electronic copy of this guide. Alternatively, please send any comments directly to Dr Sebastian Gaigg (s.b.gaigg@city.ac.uk).

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

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