Autism, Emotions, and Mindfulness



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On his way home from school, 12-year-old Liam tells his mom about his day at school. "Life is like a game of dodgeball," he says, "and people are like heat-seeking dodgeballs." For his age, Liam is a skilled computer programmer and an insightful writer, although he usually forgets to turn in his homework. Like many autistic¹ children, Liam feels overwhelmed by loud sounds, bright lights, or being in a crowd. He can be sensitive to the feelings of others, but his understanding of emotions is often different than most of those around him, which can leave him feeling left out. Liam is so worried about making the wrong decision that sometimes he cannot make any decision at all. Liam especially dislikes any degree of ambiguity about schedules or expectations and incessantly asks his exasperated mom what's coming next. The most unpredictable aspect of Liam's environment is how other people will react—the heat-seeking dodgeballs that leave Liam feeling always on edge.

¹Conventions about what to call a child or adult who has been diagnosed with autism are controversial. The "person-centered" viewpoint argues that one aspect of a person (e.g., autism) should not define that person. On the other hand, many autistic people such as blogger Lydia Brown counter that "autism is an inherent part of an individual's identity" and should be acknowledged as such, just as we may appropriately refer to people as "American" or "gifted." Of course, in most instances, it is best just to refer to a person by their name, not any one characteristic, but this is harder to do for a group. In this chapter, I will adopt the wishes of many autistic self-advocates and use identity-first language.

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Anxiety in Autism

Better understanding of the causes of mental health difficulties can inform more specific and effective treatments. My work with Dr. Jacqui Rodgers at Newcastle University in England has focused on three important factors that contribute to anxiety in autism. The first factor is unusual sensory processing that is common in autism. The second is difficulty identifying or labeling emotions. Difficulty in these two areas may lead to increased difficulty with ambiguity or uncertainty about the world that psychologists refer to as "intolerance of uncertainty." Figure 1 shows a diagram of how these factors might interact. The following sections provide an overview of how each may contribute to anxiety and how mindfulness-based interventions could be targeted to each of these in turn.

Sensory Processing and Anxiety Our five senses take in a lot of information all at once, and it takes a lot of effort and energy for the brain to sort out what everything means. Up to 80% of autistic children exhibit some atypical sensory-processing behavior, and sensory-processing concerns also persist for many autistic adults. Many autistic people have strong sensitivity to sensory stimuli: they may put their hands over their ears in response to loud or unexpected noises, prefer to wear only soft clothing such as jogging pants, or avoid foods with particular textures or smells. Some autistic people seek out intense sensory stimulation at unusually high levels: they may spend their time feeling the texture of toys rather than playing with them, staring at spinning objects, or being very particular about the way a room is arranged. Many autistic people have both oversensitivity and sensory-seeking behaviors.

There is growing evidence that autistic people have more difficulty sorting out different sensory stimuli, even at a subconscious level in the brain. This would mean that the environment is in a constant state of uncertainty: as one young adult man described his sensory experience: "I feel like I'm at war with the world." In such a world, a person with autism would feel more comfortable doing predictable activities in predictable places. This may be one factor leading to restricted or repetitive behaviors (i.e., a tendency to do the same things and/or talk about the same things more often than usual) which are one of the core features of autism. While these behaviors can be both interesting and useful (e.g., using a specialty in maps to guide city planning), these can also make it difficult to focus on other important things, like completing homework or paying attention in a meaningful conversation.

Fig. 1 Some proposed contributions to anxiety in autism, highlighting the role of intolerance of uncertainty (IoU). Adapted from South and Rodgers (2017)



Mindfulness Approaches for Sensory Processing in Autism This section covers two approaches. The first considers what can be done to make the environment a more sensory-friendly place for people where possible. The second considers how autistic people can use mindfulness skills to tolerate sensory distractions a little better.

Creating Safe Places Most people benefit from quiet time and spaces to help calm down and manage emotions, especially in times of stress. Because sensory processing in autism can be so intense, this need for space and quiet can be even more essential. A number of organizations are finding ways to create autism-friendly environments without much additional cost. For example, in 2016, the Melisa Nellesen Center for Autism at Utah Valley University—in collaboration with the Utah Autism Academy and the Woodbury Art Museum—held an art exhibition by autistic artists. The designers built a "relaxed gallery" in one corner of the large hall, a small separate room with reduced lighting, earphones, a soft chair, and a voga mat where anyone feeling overwhelmed by the sensory or social experience could take a break. Many J. C. Penney department stores sponsor times before regular shopping hours when their store lights are dimmed and the overhead music is muted, where families affected by autism can shop in a welcoming place. Quite a few professional sports teams now offer autism-friendly experiences: for example, the Atlanta Braves baseball team has an "Exceptional Fan" program that includes quiet spaces in the stadium, maps of the ballpark that show where loud sounds such as fireworks or a big drum may happen, noise-cancelling headphones, lanyards with contact and safety information attached, and a "social story" to prepare them for the stadium experience. Autism-friendly meetings now ask the audience to wave or wiggle their hands to show appreciation for a speaker, rather than applause, in order to reduce the noise level.

Similar principles can be adopted at schools, workplaces, and homes. One school accommodation that we frequently recommend is the availability of a quieter place—perhaps in the lunchroom at some times of day, a counselor's office, or even a quieter corner of the classroom, where an overwhelmed child can go to relax. Of course, whatever assignments are due must still be completed when the child returns, but hopefully, the time away will help the child be more successful. I remember a family I worked with while I was in graduate school, a single mother and her 14-year-old autistic boy who came home each day from school and needed 30–40 min to pace while talking to himself. He usually did this pacing in a large rectangle around the borders of the lawn in his backyard, and at first, his mom was very frustrated that her son was damaging the lawn and sometimes yelled at him to quit pacing. After a short time, however, she had the idea to pave an asphalt path for him to walk on: this recognized and accepted his need for quiet time while also allowing her to mow, water, and otherwise take care of the yard without further trouble.

Expanding and Encouraging Sensory Success. Not all environments can be easily adapted, and finding ways for autistics to manage within the world is also

important. One common treatment is occupational therapy, which uses swings, balls, trampolines, and other equipment to engage a child's motor and tactile systems. The therapist challenges the children's sensory boundaries to gradually improve their comfort and to help them learn to organize their sensory world. Sensory-based therapies include activities and devices intended to help reduce arousal, such as weighted blankets or pressure vests, massage, or brushing to reduce sensitivity to touch. Unfortunately, the actual procedures used in treatments for sensory processing have not been well-standardized, and research on the effectiveness of such treatments is quite scattered. Thus, it is not certain what techniques or practices work best in autism, so some trial and error may be needed for each individual.

An intriguing model being developed at Children's Hospital of Philadelphia has the goal to decrease sensory sensitivity to food and to reduce picky eating in autism. The Building Up Food Flexibility and Exposure Treatment (BUFFET) is a 14-week program using cognitive behavioral therapy techniques that build on mindfulness skills such as deep breathing, distraction, and cognitive flexibility. A big focus for BUFFET is on "being in the moment" with one's food. The program includes steps to explicitly but gradually expose children to foods that make them anxious, to teach scripts geared toward flexibility with food, to provide education about sensory aspects of foods, and to train children to identify tastes more effectively. A review article by Emily Kuschner and her colleagues highlights flexibility training using a "Plan A/Plan B" script to prepare for the unexpected, such as not knowing what will be on the menu when visiting a new restaurant: "Plan A will be to order chicken fingers, but if they don't have chicken fingers, my Plan B is to order pasta." Working in groups, children develop a "Food Dictionary" for each snack time food, talking about how each food looks, smells, tastes, and feels; how to eat it; and so forth; they include a "review" of each food culminating in a rating ranging from "one fork" to "five forks." Parents are involved at all aspects of treatment and help to practice at home. A small pilot study has shown that children, parents, and clinicians tolerate the treatment well and believe it to be effective. This type of treatment may be effective for sensory-processing difficulties beyond just food sensitivity (Fig. 2).

Emotion Recognition and Anxiety It is a myth that autistic people do not feel emotion—in fact, many autistic people feel emotion very keenly. But knowing what those emotions mean, and what to do in response, can be difficult. The ability to identify and describe one's feelings is very important for emotion regulation. Difficulties labeling emotions—which scientists refer to using the Greek term "alexithymia" (meaning: "can't read emotions")—can lead to feeling overwhelmed by emotions. One example is seen in the popular Snickers© candy bar advertisements which depict "hangry" people who mix up feeling hungry with feeling angry and therefore act grouchy.

Alexithymia is common in many mental health conditions including depression and anxiety. But it seems especially prevalent in autism. This may include difficulties describing one's own emotions, which we see frequently in our interviews with autistic children, teens, and adults. Our standard interview questions ask people to describe situations when they feel happy, sad, angry, and worried and to describe

Food Dictionary Carrots									
Look?	Straight and orange	2							
Smell?	Garden-like								
Flavor?	X Sweet	Salty	Spicy						
	Sour	Bitter	X Bland						
Texture?	Crunchy/Crispy	Gummy/Chewy	☐Thick-Smooth						
	Liquid	Gooey/Sticky	☐Thick-Textured						
	Fizzy								
Food Category?	Fruit	X ∨egetable	Protein						
	Dairy	Grain							
	Sweet Snacks	Salty Snacks							
How to eat?	Use your hands, cook them or dip them, make them into a smoothie or juice, put them in a salad								
Thoughts?	Food Foe Thought: are vegetables and like vegetables.	I don't I can tak	Food Friend Thought: Maybe I can take a bite. Not all vegetables are the same.						
FOOD REVIEW	Okay. Better dipped	l in something							

Fig. 2 Sample Food Dictionary entry from the BUFFET program (Kuschner et al., 2017)

their body reactions in such situations. These turn out to be some of the hardest questions, and many autistic teens and adults tell us that they don't really know the difference between the negative emotions; they also have a hard time making a facial expression to match each emotion. Alexithymia can also make it difficult to understand emotions in others, and research studies in autism have suggested a link between alexithymia and measures of empathy, which require labeling how others are feeling. Other research studies have now shown strong links between alexithymia and anxiety in autism.

One possible explanation for high levels of alexithymia in autism comes from brain imaging studies that show atypical organization for autism groups in the insula 58 M. South

region of the brain. The insula is a critical area for linking sensory and emotional experience. It is likewise important for integrating social and emotional cues from internal (within the person) and external (with relation to others) states. The neuroscientist Antonio Damasio has argued that "feelings are mental experiences of body states," meaning that if we are being attacked by a bear, our heart will automatically beat faster and we'll start to sweat and then we will experience the feeling of fear or horror. It makes sense that atypical connections in the insula could lead to difficulty in sensory processing and in emotion awareness for both self and others.

Mindfulness Approaches for Emotion Awareness in Autism When we first started doing group therapy for social skills in children with autism, we worked a lot on building conversational skills, asking for help, and other important social behaviors. However, we soon realized that paying attention to social skills was going to be difficult until the children in our groups could learn to manage their anxiety, anger, and other emotions a lot more effectively. So, we started an emotion skills group as a precursor to social skills training. In line with theories that link body states and emotion states, our first group focused on body awareness: what do your breathing, muscles, heart, and skin tell you about how you are feeling? Figure 3 shows a shortened "Body Detective" chart that we assigned for homework.

We then practiced body awareness every week during our sessions. A favorite activity evolved from a classic child anxiety treatment called "robot to ragdoll," but we found that many children were having a hard time connecting with "robot" and nobody knew what a "ragdoll" was. So, one of our therapists modified the terminology on the spot to "Hulk to jellyfish": children get their bodies super tense all over, like the Incredible Hulk when he's angry; they then totally relax like a jellyfish and fall over the floor. This turns out to be very relaxing and really increases awareness of how our bodies and feelings are linked. We also worked on cognitive awareness with practice identifying "red light" thoughts that make us feel worried, scared, afraid, or angry versus "green light" thoughts that make us feel calm, relaxed, and happy. Children practiced with each other in pairs and in groups and had other fun

TOP SECRET

Write down 3 events that made you feel worried or upset this week. Then write down what body clues helped you know you were upset. Ask your parents for help if you need it, they're great assistant detectives!

As a reminder, here are some of the body clues we talked about in group: body shaking, heart pounding, red face, sweaty hands, empty stomach/butterflies in stomach, tense muscles.

1. Event:

Body clues:

Fig. 3 Sample body awareness chart

activities such as watching brief movie clips where they had to identify the characters' emotions and describe how they could tell.

Since we started these groups, a number of other great resources have been published to teach body and emotion awareness and coping skills. Although there are many books, workbooks, and websites that cover similar principles, we especially like the book *Sitting Still Like a Frog: Mindfulness Exercises for Kids (and their Parents)* by the Dutch therapist Eline Snel. The book includes many concrete exercises to help children improve awareness, beginning with breathing exercises to learn to attend to the body in the moment and then moving to fun ideas such as a "spaghetti test" to see whether our body is feeling anxious and stiff (like uncooked spaghetti) or relaxed and soft (like cooked spaghetti). The program then moves into practicing emotion identification, including a feeling thermometer to rate physical and emotional well-being, and a "personal weather report" about feelings that can be tracked over time: am I feeling the same way now as I was earlier in the day? Finally, the book covers strategies for reducing emotional upset, with a variety of activities such as "First Aid for Worries." The author now has a sequel for teens and parents called *Breathe Through This*.

Body and Mind: Principles for Older Teens and Adults Explicit instructions about body cues and emotions, with lots of practice, are also good principles for teens and adults. This is depicted in my favorite scene from the movie Adam, which tells the story of a young adult man diagnosed with an autism spectrum disorder who has a special interest in space exploration and who becomes friends with a woman named Beth from the upstairs apartment. One day, Beth comes home from work to find Adam hanging upside down from the balcony above, dressed in a NASA spacesuit, cleaning her windows so that she can better see the stars. She is obviously taken aback and after she lets Adam into her apartment stands looking at him from a distance with her arms folded. Adam says, "I can see that you're upset, but I don't know what to do." Beth then gives a somewhat ambiguous instruction, "can you give me a hug" (to which he replies "yes"), before giving a very clear instruction: "Adam, I'd like you to give me a hug" (which he does). Autistic adults report being frustrated by psychological counseling approaches that expect them to make leaps of emotional insight on their own. Much better practice is to practice clearly defined steps to label emotions and to practice how to react in beneficial ways.

One particular focus of many mindfulness interventions is on increasing flexibility in thinking, especially in thinking about emotions. Because flexibility is often difficult for autistic people, this focus offers both a challenge and a unique window for successful treatment. For example, the concept of "cognitive fusion" refers to being "fused" to one's thoughts too closely. Perhaps I drop a drinking glass while loading the dishwasher, the glass breaks, I exclaim "I'm stupid," and then I generalize that thought to believe I am stupid about everything. Mindfulness treatments encourage one to be less attached to such thoughts. For instance, in a therapy session, the counselor may have a person say a silly word, such as "milk," over and over again for 30 s and pay attention to how silly that sounds. Then the person may take a summary of the negative thought, such as "stupid," and repeat that over and

over for 30 s while paying attention to how silly it sounds. Alternatively, the person could tell the story of the dropped glass using a cartoon voice such as Donald Duck, noticing that it really doesn't sound so bad as it did in the moment.

Researchers in the Netherlands have adapted standard mindfulness-based protocols to better address the unique styles in autism. This includes such modifications as making activities more concrete, less reliance on examination of thoughts (with more focus on sensory and other cues), and longer activities and duration of treatment. These and other studies of mindfulness—and acceptance-based interventions (MABIs) have shown real promise for reducing anxiety and depression in children, adolescents, and adults with autism. Studies of parent-involved treatments have also shown similar benefits for the parents, as well as improved social communication skills in the children with autism. Table 1 is a summary of the mindfulness intervention used by the Dutch therapist Dr. Annelies Spek and her collaborators. They ran a 9-week treatment with 20 adults diagnosed with autism, while a comparison group of 21 autistic adults did not receive treatment until after the study ended. Every session lasted about 2½ h, which included review of previous work and instructions on homework exercises, as well as time to discuss difficulties with the previous week's homework. Compared to the no-treatment group, the mindfulness treatment group showed reduced depression and anxiety as well as increased positive feelings. These benefits seemed to last for at least 2 months following treatment. As can be seen in Table 1, there is a big emphasis on awareness of body, breathing, and eating and on the negative content of thoughts. There is then an emphasis on managing reactions to such sensations through practice such as breathing, meditation, yoga, and cognitive defusion.

Intolerance of Uncertainty Underlies Anxiety in Autism A common theme in the previous sections is that of uncertainty: uncertainty about the sensory environment and uncertainty about the meaning of strong emotions. Like most species,

Table 1 Summary of mindfulness treatment for adults, reported by Spek, van Ham, and Nyklíček (2013)

Week 1. Mindful eating exercise and body scan (pay attention to various sensations in the body in an accepting way)

Week 2. Practice body scan, attention to situations of biggest stress, and several mindful breathing meditations

Week 3. Information on physical reactions to stress. Mindful walking exercise, movement exercise (yoga), and more breathing meditations

Week 4. Sitting meditation, focused on breathing and bodily sensations. A listening meditation "in which attention was paid to sounds as they naturally occurred"

Week 5. More sitting and breathing exercises and talk about how to use mindfulness techniques in stressful situations

Week 6. More sitting and breathing exercises and information about ruminative thoughts (e.g., rehearsing negative thoughts repeatedly). Meditation focused on observing thoughts "from a detached perspective"

Weeks 6–9. More practice of above exercises and discussion of how well things are going and possible solutions for overcoming obstacles

humans dislike uncertainty and will go to great lengths to find or create a more predictable situation—even at risk of losing money or other resources. But some people have an especially strong aversion to unpredictability, referred to by psychologists as an "intolerance of uncertainty." It's already known that intolerance of uncertainty is a strong driving force for many people with anxiety disorders and depression. Real-life experience suggests that intolerance of uncertainty is nearly constant for many autistic people and can be paralyzing. For example, a recent television advertisement created in England (view it at www.autism.org.uk/toomuchinformation) depicts a woman who is trying to leave home for an appointment, but she stands at the mirror by her front door imagining all the things that *might* happen should she go out. She is feeling completely overwhelmed. In the end, she stands frozen, crying, and unable to leave. Another example comes from a 10-year-old boy whose parents were phoned by the school to tell them he would be receiving an award the next day. He had a miserable night because, even though he knew that it would be a good thing, he didn't know exactly what the award was going to be. We are just now creating ways to study autism and intolerance of uncertainty in the lab, but several studies using questionnaires, given to parents of autistic children as well as to autistic adults, show strong evidence for our intolerance of uncertainty model.

Researchers at Johns Hopkins University conducted a study with children diagnosed with autism, ages 8–14, using cognitive behavioral treatment (CBT) for anxiety using the *Facing Your Fears* treatment which has been modified specifically for autism. The researchers measured levels of general anxiety as well as levels of intolerance of uncertainty both before and after the treatment. Overall, while the treatment was somewhat effective at reducing anxiety, it did not reduce intolerance of uncertainty. Importantly, levels of intolerance of uncertainty predicted how well the treatment worked for reducing anxiety, such that those who had high intolerance of uncertainty before treatment did not show much improvement in their anxiety after treatment.

One possible consequence of this incessant uncertainty could arise for learning when it's okay to feel safe. As with many species, the human brain responds quickly to any perceived threat, including a powerful fight/flight/freeze response when danger arises. Within the brain, the region called the amygdala is a small, almondshaped group of nuclei that recognizes danger and initiates the body's defense response. In a brain imaging study using functional magnetic resonance imaging (fMRI), we explored differences in amygdala activity between adults with autism and neurotypical, non-autistic adults. During their brain scan, research participants watched a monitor that could show two colors of square in the middle of the screen. One color—the threat cue—was sometimes followed by a very surprising burst of air onto the lower part of the neck. The other color—the safe cue—was never followed by the burst of air. For the neurotypical adults, the amygdala was significantly more active during the threat cue than during the safe cue (see Fig. 4). We did not see this same difference between threat and safe cues for the autistic adults, however. We are still investigating why this might be, but we suggest that difficulties of knowing when to feel safe could contribute to the default response of feeling

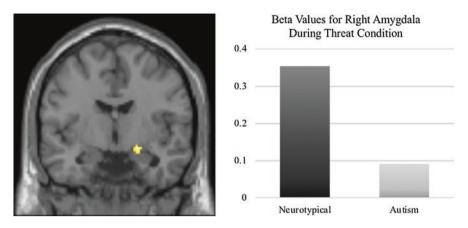


Fig. 4 During fMRI scanning, a sample of neurotypical adults shows greater activation of the amygdala for threat cues than safety cues, while a sample of autistic adults does not show the same differences

threatened, which may in turn contribute to frequent feelings of anxiety. We are collecting other evidence that adults with autism show elevated levels of threat reaction—for example, increased pupil size—even during nonthreatening activities.

Mindfulness Approaches for Managing Uncertainty in Autism I was speaking recently with an autistic adult about how I was writing this chapter about anxiety in autism. I told him that I was going to highlight the contributions of sensory processing, emotion awareness, and uncertainty. He replied that those are all important to talk about, but in his mind, "it all comes down to uncertainty." This reminds me of another story about Liam, the young boy whose metaphor about human dodgeballs began this chapter. His mom reported that during a family party, most people were watching a movie in the living room when someone said that Liam had made a mess in the bathroom. First his mom and then his stepdad became increasingly agitated while telling Liam to clean up his mess; he sat on the floor in the next room crying but not moving. Finally, Liam's grandmother went to him and asked, "What's wrong, Liam?" To which he replied: "I don't know what to do!" His grandmother took him to the bathroom, reviewed the situation with him, and gave him specific suggestions on what to do about it. Liam then cheerfully cleaned up the mess. This brings up the question of "will versus skill"; e.g., when struggling to do something they are asked to do (at home, at school, at work), is it because the autistic person is intentionally refusing to do it or because they don't know how? While it's often easy to assume the former, the latter is often truer.

Knowing this provides an opportunity for others to provide assistance, both by increasing the level of instruction or support that is needed to complete a project and also by helping those affected by intolerance of uncertainty to manage it better. At home and school, adults can provide more certainty in the autistic child's world wherever possible. We recommend using lists, schedules, or charts to organize

Erik's Homework Chart								
What To Do	Minutes I Can Earn MINECRIFY	Did I Earn Points?						
		Mon	Tue	Wed	Thur	Fri		
Show signed homework card	10	~	~		~			
Put homework on table when I get home	5	~	~	~	~			
Do homework by myself	10	~	~	~	~			
Show mom or dad my homework all done	10	~	~	~	~			
Put homework in backpack	5		~	~				

- · If needed, I can take a 5 minute break between assignments
- Mom or dad can give me two reminders before I lose my screen time for that assignment
- · If I don't finish my earned time on time then I lose 10 minutes from the next day

Fig. 5 Making tasks simple and easy to know when they are done can be very helpful. Avoid allor-nothing reward systems

activities such as chores, homework, or other areas of conflict. Such lists can rely on pictures and/or words according to the needs of the individual. At home, parents may use a homework chart with simple rewards for concrete tasks, like the one pictured here. This can make power struggles less frequent because the instructions are on the chart, not with the parent. When the person knows what to do, they are much more likely to do it then if they are confused. At school, teachers may write up the order of daily activities on the board, including places the child needs to go during the day. Many teachers do this already, and we think it would help in every classroom but especially classrooms with autistic children. To-do lists are helpful for adults especially if they can be checked off when finished. Keep expectations simple and avoid all-or-nothing scenarios: have a few activities with good instructions that will encourage and reward success, and let the rest go (Fig. 5).

Similar ideas are true for the workplace. An adult with autism that I know was very successful at his internship working in IT, until he got a new supervisor who was loose with expectations and often changed instructions midway through an assignment. The intern began to struggle, and the company threatened to let him go. But his job coach talked to the company's HR department who agrees that their managers were doing a poor job. More training was provided for management especially around keeping expectations predictable and fair, and the intern was able to

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resume work more successfully. I know a therapist who works with many autistic adults and who decorated his office with muted colors, lighting, and sounds. He also has a predictable routine for each session, which his clients really appreciate.

There is also a need to help people most affected by uncertainty to better manage it on their own. Dr. Rodgers and her team in England are now developing the Coping with Uncertainty in Everyday Situations (CUES©) program for children with autism and their parents. Rather than modifying CBT from non-autism programs, CUES has been developed from the ground up based on substantial input from autistic people and their caregivers. The program is aimed at the parents of children with autism who in turn help their children to better manage intolerance of uncertainty (IoU). CUES first aims to raise awareness of IoU and to "enable the child to become more able to tolerate uncertainty, rather than attempting to reduce uncertainty" (Rodgers et al., 2017, p. 3961). Parents work with therapists and with each other during group sessions to identify existing patterns of behavior that maintain IoU and then develop alternative strategies to cope more effectively. Finally, the program aims "to encourage reflection and evaluation" of how the family system manages uncertainty on an ongoing basis. Many families don't realize how much they work around a child's IoU, and we encourage some gentle pushback—become aware of when IoU is a concern and help the child to accept change and uncertainty a little bit at a time. Early results for CUES are promising, and a version meant for adults with autism is now being developed.

Intolerance of uncertainty can be so emotionally crushing that autistic people will not even begin a project unless they know exactly how to do it without making a mistake. While speaking some years ago at a workshop in Utah about anxiety in autism, I mentioned that I didn't have many good ideas about how to help people overcome this intense fear of failure. Fortunately, a woman from South Dakota, who was watching the talk via livestream, texted the conference hotline about her experience with her autistic husband on just this topic. She gave some really good tips which I repeat here:

- (a) Celebrate risk-taking at every opportunity.
- (b) Reinforce attempts more than completion.
- (c) Reframe unsuccessful attempts as practice.
- (d) Give extra support/instruction for learning new skills.
- (e) Normalize failure.
- (f) But acknowledge that failures in some areas may be frequent.



Modifying Treatment for Autism Many autistic teens and adults report being frustrated that their mental health therapists don't understand their point of view and that therapists insist on using standard protocols without any recognition of unique challenges for autism. This section reviews a few ideas for adapting standard treatment approaches to better address autism. Of course, the first rule is always to ask the client how things are going and whether there are specific ideas for improving the treatment approach. An autistic person may be timid about speaking up regarding their needs but likely would respond to specific questions. And if a client does speak up, definitely take their ideas seriously! This may be especially important for suicide prevention: instead of relying on an autistic person that you are concerned about to bring up the topic, direct and specific questions are in order: are you thinking about hurting or killing yourself? Have you made a plan to do it? And provide specific help and assistance, including crisis hotlines such as the National Suicide Prevention Lifeline (800-273-8255), the crisis text line (text "talk" to 741741), or The Trevor Project (866-488-7386).

There are some principles that may be useful for modifying traditional mental health treatments to make them more autism-friendly. Table 2 summarizes formal recommendations established by the United Kingdom's National Institute for Health and Care Excellence (NICE guidelines) regarding modification of cognitive behavioral treatment of anxiety in autism. The same principles are entirely applicable to mindfulness-based treatments.

One example of such modification is the *Facing Your Fears* treatment for anxiety, which adapted a standard cognitive behavioral treatment for children to be more autism-friendly. *Facing Your Fears* uses "visual schedules," a predictable flow for each session, gradual introduction of exposure to anxious situations, and substantial parent involvement in treatment. But treatment can and should be individualized as needed for each person. One challenge for mindfulness-based treatments is their frequent reliance on metaphors, such as "imagine your thoughts floating away on a leaf in a stream," which can be difficult for autistic people to follow. One of my doctoral students introduced a metaphor about how crowded our thoughts can become to a young adult woman with autism who told him that "I don't get it." So, he asked her if she could think of something that made sense, and she created her

Table 2 United Kingdom's National Institute for Health and Care Excellence (NICE) guidelines for cognitive behavioral therapy for anxiety in autism

- 1. Emotion recognition training
- 2. Greater use of written and visual information and structured worksheets
- 3. A more cognitively concrete and structured approach
- 4. Simplified cognitive activities, for example, multiple-choice worksheets
- 5. Involving a parent or caregiver to support the implementation of the intervention, for example, involving them in therapy sessions
- 6. Maintaining attention by offering regular breaks
- 7. Incorporating the child or young person's special interests into therapy if possible

Adapted from Walters et al. (2016)

own metaphor: a whiteboard completely full of text, where she could then imagine herself erasing it a little at a time, which helped her feel less overwhelmed.

Final Thoughts: Letting Go of Expectations

However, it's important to remember that there are many thoughts and behaviors that autistic people don't need to change at all, and just because a behavior is "quirky" doesn't mean it ought to be "fixed." Variety is an essential element of any healthy system, and I often tell parents that as long as your child's behavior isn't hurting someone or otherwise interfering with necessary activities, there is no need to try altering the child personality or sense of self. Let it go!

This hands-off approach can be hard for non-autistic, neurotypical people to follow. I sometimes hear about one parent who can't stand hearing about their autistic child's topic of conversation or a teacher who is insistent that a child with both autism and atypical motor skills has to learn cursive handwriting, to which I respond: who is the one being rigid? I recently met with the mother of a 10-year-old boy who will only eat about eight foods but is growing well enough. She'd just come from a lecture from her pediatrician about making sure her children get enough fruits and vegetables. What I thought was, "I'd like to see that doctor take that kid for a week and try to feed him!" What I said was, "if your son is healthy and growing, don't worry too much right now about forcing the food issue," at which point the mother burst into tears, because she's been feeling so much pressure to do everything just right even though her son's sensory concerns and anxiety make things so difficult. She was very interested in the ideas from the BUFFET program reviewed above and now will be able to work on eating in a way that makes sense for autism and at a speed that makes sense for her child. This will reduce stress for everybody.

Summary

This chapter has highlighted how frequent anxiety and depression and other mental health struggles can occur in autism. I have reviewed mindfulness-based ideas which may be useful for helping to reduce the impact of these challenges. Because of the frequency of anxiety in autism, I have focused most of the examples there. But they are equally applicable for depression as well as for other mental health concerns. Some of the ideas are particularly applicable for mental health professionals, but many of the principles apply to home, school, and workplaces. As research into mindfulness-based treatment for autism grows, more specific information on what works well and what might not work so well will increase the effectiveness of treatment and help autistic children, teens, and adults to feel less distressed and more successful.

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