TRAUMA AND AUTISM SPECTRUM DISORDER

A Reference Guide

Rachel K. Earl, Jessica L. Peterson, Arianne S. Wallace, Emily Fox, Ruqian Ma, Micah Pepper, Ghina Haidar

Bernier Lab
University of Washington
Center for Human Development and Disability
Bernierlab.uw.edu

June 2017
Addressing Trauma in Therapy with Individuals with Autism Spectrum Disorder

Individuals with Autism Spectrum Disorder (ASD) may be at increased risk of experiencing victimization or significant stressors and may have limited coping skills to respond to these experiences. We do not fully understand how traumatic stress impacts individuals with ASD, and there is limited research on treatment of trauma symptoms in this population. Trauma Focused- Cognitive Behavioral Therapy (TF-CBT) is the most supported treatment for the impact of trauma in children and treatment applications have been developed for various populations. ASD-sensitive applications of TF-CBT could be an effective treatment for individuals with ASD who have experienced trauma and have clinically significant, trauma-specific impact.

It is important to stay flexible when working with a client with ASD. While using the framework of TF-CBT and its constituent components, be mindful that, as with any therapy, you will need to adapt to your client’s individual needs and learning styles. Also, many clients with ASD may present with a combination of adverse life events and psychiatric comorbidities. For some clients, ASD behaviors may be the primary concern, whereas for others, their most pressing concern for treatment is a comorbid condition or symptoms, such as anxiety, PTSD, ADHD, or depression. Identifying the client’s most pressing need will be important to inform treatment planning.

The strategies presented in this handout are informed by previous adaptations of evidence-based CBT treatments for individuals with ASD and younger typically developing children.

**Trauma exposure screening**
- When assessing exposure to various traumatic events, reliance on the report of an individual with ASD may be difficult. Individuals with ASD may think more concretely about the examples you give, and may fail to generalize your questions to the various scenarios and contexts they experience. Differences in social awareness and perception that characterize ASD may impact the way events and experiences are interpreted. Something caregivers or other adults might perceive as traumatic may not impact a client with ASD as negatively. Conversely,
events that might be perceived as minor to others may be experienced as traumatic to a client with ASD (e.g., an adolescent with ASD experiencing significant distress over a single instance of spanking when they were a toddler). It is important to identify the source of the trauma with the use of multiple reporters (e.g., other caregivers, siblings, teachers) to make sure an accurate picture of an adverse event is being provided.

- If decisions need to be made regarding supervision, child protection, or legal response (i.e., objective support of the client), it may be difficult to gather necessary information directly from the client. Rather, the client’s caregiver may need to be your primary source of information. If the caregiver is the perpetrator, determine other caregivers, teachers, or providers that may help in understanding the client’s support needs.

- When presenting a list of traumatic events to your client with ASD, such as the Child and Adolescent Trauma Screen (CATS)\(^\text{17}\), it may be helpful to modify your presentation of the list to accommodate the client’s developmental level (e.g., provide the list both orally and in writing, complete the screener together with the client, include caregivers in the screening process, simplify language used).

- Individuals with ASD demonstrate a wide array of communication abilities and difficulties and may require extensive supports with pragmatic and syntactic aspects of language when reporting traumatic events and when developing the trauma narrative (e.g. providing concrete descriptions of events, simplifying language used, avoiding use of metaphorical speech, combining oral speech with visual representations and/or written language).

- Explore alternate means for your client to share their experiences, such as visuals, puppets, drawing, play with their own toys from home, and sensory activities (e.g., play-doh, sand).

**Psychoeducation about trauma**

- Visual Activity Schedules (VAS)\(^\text{18}\) are visual representations of an individual’s schedule which provide that individual with concrete understanding of what to anticipate for a given period of time. VAS are flexible and can be adapted for different contexts. A VAS could be created during the psychoeducation component of treatment to describe the course of treatment and to help create structure, which can then be used throughout treatment.

- Use of visual aids when discussing trauma symptoms can be helpful (e.g., use of cartoons and formation of a story surrounding symptoms).

- Involvement of the caregiver may be especially important to determine the optimal ways to teach concepts to your client.
• When making sure basic needs are being met for the client, such as regular sleep, diet, and hygiene, it is important to note these behaviors can be uniquely disrupted in individuals with ASD. Explicit teaching and contingency plans may be needed to help caregivers establish healthy daily-living routines for individuals with ASD.

• With some clients with ASD, more time may be needed to teach emotional states and physiological cues for different emotions. However, recognition of affective states may be a consistent challenge for clients with ASD. It is okay to move on if you feel that you have reached the limit of your client’s understanding of emotions. This is true of other stages of treatment as well.

• Utilize a caregiver to help reinforce information and skills learned in session through review and homework.

Referencing trauma reminders during coping skills training

• Individuals with ASD often struggle with verbal and abstract reasoning, and they may not be able to identify, analyze, or modify cognitive schema during the cognitive coping stage of treatment.

• Extensive use of visual stimuli (e.g., visual schedules, pictures, timers) will likely be helpful.

• Creating a structured way of organizing trauma cues or triggers may be beneficial for the client. For example, create a list of possible triggers and support the client in choosing which ones apply to them.

• Increasing structure and repetition for specific coping strategies will be important for individuals with ASD.

• Incorporating motivating metaphors (e.g., related to circumscribed interests) can help increase client engagement and buy-in. For example, if an individual was particularly interested in Batman comics, the therapist might create a Batman-themed visual schedule and generate behavioral expectations that incorporate Batman (e.g. “When Batman gets frustrated, he takes a deep breath to help him cool down”).

• Social stories are a widely-used strategy for preparing individuals with ASD for challenging situations, and may be particularly helpful when teaching safety skills and socially appropriate behavior. The topic of the story is flexible to individual needs, but generally includes concrete contextual details (“After lunch we go to recess”), a social expectation (“When the whistle blows that means it is time to line up and go inside”), and individual instructions and consequences (“I will try and line up as soon as the whistle blows. This will make my teachers happy”). The story can be created by the therapist and read to the client in session. It may be
helpful to incorporate a client’s specific interest in the story (e.g. “Batman goes to recess”).

- Role-playing can be helpful for individuals with ASD, but concrete guidelines may also be needed to increase participation and learning. For example, create a “stage” for role-play (e.g., a paper with shoe-prints on it) and draft specific rules and/or steps for participating in each role-play.
- Sensory needs should also be taken into account when introducing stress-management strategies. Activities such as movement games, sensory tables with water or sand, blowing bubbles, and listening to calming music can be used to help with relaxation and coping with distress.

**Trauma narrative (imaginal exposure and cognitive processing)**

- Use of a trauma narrative during therapy may require a range of adaptations when working with an individual with ASD.
- For some clients with ASD, the trauma narrative may not be conducive to their developmental level and communication abilities. If you find that your client is struggling significantly with the development of a trauma narrative, despite adaptations, it may be appropriate to focus on other elements of treatment (e.g., coping skills training, in vivo exposures) rather than getting stuck in this phase of intervention. Alternatively, when the trauma narrative component seems appropriate and clients with ASD are struggling to generate material, therapists may provide a simple and concrete narrative for clients (e.g., “The boy did a bad thing to you when he hit you with the stick. It is not your fault. It is his fault. You are strong and can handle it”). However, therapists should utilize caution in these instances and avoid including unnecessary details or interpretations of the event or experience.
- Some individuals with ASD may have trouble conducting imaginal exposures from the first person, as well as difficulties with self-reflection and communication of past experiences. Some individuals may refer to themselves in the third person or may confuse the pronouns “you” and “I.” If this arises while the client and therapist are developing the trauma narrative, it is important to identify and accommodate the client’s unique use of language to communicate their experiences (e.g., referring to self as character related to preferred interest (e.g., batman), using “you” pronoun to mean “I”).
- It may be useful to construct a trauma narrative with the client and caregiver through visual aids, the creation of a story, or (familiar, concrete) play. Since play skills are often underdeveloped in individuals with ASD, there may be a limit to the use of play to incite processing of a traumatic event.
Utilizing technologies to create a story (e.g., iPad, video clips) may be particularly useful for this population.

Explicit teaching of self-regulation strategies will be particularly helpful to curb more disruptive behaviors in response to the distress of the narrative process.

**In-vivo exposure to trauma reminders**

- Many individuals with ASD respond well to exposure when it is presented in a concrete and scaffolded manner. This may be an area of strength when conducting treatment with this population.
- Create a step-by-step plan for exposure and introduce the activity in a structured way.
- Develop clear contingency plans to incentivize exposure practice. External rewards are essential when conducting in-vivo exposure with individuals with ASD.
- It may be necessary to modify the rating system (e.g., SUDS) used to measure distress during exposure (e.g., reduced scale, individualized visual representation).
- Provide clear examples of different ratings, along with personalized physiological cues. More time may be needed to teach your client to accurately rate their distress.

**Sharing the trauma narrative with a safe caregiver**

- Active involvement of caregivers will be essential throughout treatment. When sharing the trauma narrative, it will be important to determine the optimal way the client can communicate their feelings and experiences, whether that be through verbal or nonverbal communication.
- Family members of individuals with ASD may present with their own social-communication challenges, making it important to spend ample time ensuring their understanding of their child’s symptoms, triggers, and coping skills.

**Safety**

- Individuals with ASD often struggle to distinguish socially appropriate interactions from inappropriate ones. Your client may want to share their trauma narrative with individuals you do not consider safe (e.g., strangers, peers at school). It is important to be explicit about safe people to share their thoughts, feelings, and experiences with.
- For some individuals with ASD, social disinhibition is a presenting challenge (e.g., climbing onto strangers’ laps, hugging, holding hands). This might be hard to tease apart from behaviors associated with an adverse event.
Teaching safe versus unsafe behaviors will be important and may require more time and repetition for clients with ASD.

Commonly Asked Questions from Providers

**Q:** What are some suggestions for individuals with ASD who tend to become aggressive, disruptive (e.g. throw things), or withdraw (e.g., hide, run away) when distressed during therapy?

**A:** Individuals with ASD often have increased difficulties with emotion regulation (ER), as well as with effective understanding and communication of affective states. Several strategies that may be helpful in these situations include:

- Spend additional time building emotion recognition and regulation skills/strategies that the client is able to implement with support before progressing to more distress-evoking aspects of treatment. It will be important to be creative with ER strategies, given that not all typical ER strategies are likely to be effective for individuals with ASD (e.g., deep breathing, progressive muscle relaxation). ER strategies based on sensory needs (e.g., movement breaks, mini-trampoline, handheld massage ball, a favorite song or video, essential oils, weighted blanket, etc.) may be particularly helpful.

- Individuals with ASD are likely to need significant support from caregivers and providers to utilize ER strategies before more independent implementation.

- Set up an individualized system for communicating distress (e.g., visual system or use of a “code word”, personalized “SUDS”) so that providers can help clients communicate distress and use identified strategies.

- Evaluate the function of the behavior, task demands, and whether the client has the skills and tools to meet expectations. A mismatch between demands and skills before sufficient teaching opportunities and supports are in place can lead to significant distress and difficulties with compliance. It will be important to help clients with ASD progress through the necessary treatment (e.g., not avoiding essential components of therapy such as exposure) while keeping this balance in mind.

- To help reduce stress, set up an expected routine and make sure individuals with ASD are aware of expectations.

- Adjust the environment to be more conducive to successful sessions (e.g., reduce items that are distracting or can be used during aggression, providing comforting and regulatory materials).
Q: How can providers distinguish between the negative effects of chronic abuse and neglect and ASD?

A: The effects of chronic abuse and, particularly, neglect (e.g., environmental deprivation) during early development may be associated with symptoms and patterns of development that are consistent with an ASD diagnosis, such as language and other developmental delays, intellectual disability, pervasive impairments in social communication and emotional reciprocity, and even restricted and repetitive behaviors (e.g., repetitive play and motor movements, sensory differences). ASD is a behavioral disorder that is not bound by etiology of impairments for the diagnosis to be made. Therefore, an ASD diagnosis may be appropriate, given the client meets all necessary diagnostic criteria, even when providers suspect the impact of abuse and neglect contributed to longstanding developmental and social-communication challenges. When possible, it is important to assess for changes in behavior and symptoms for individuals exposed to abuse or neglect later in development. This will help determine whether the presentation is more consistent with an acute response to stress and adverse experiences versus neurodevelopmental differences that are present early in development and longstanding.

Q: How do providers differentiate between ASD and PTSD?

A: Given the inherent difficulty differentiating between these conditions, as well as the importance of effective treatment planning, it is recommended clients with suspected ASD be seen by a professional with expertise in this area. An important consideration when differentiating between these conditions is that PTSD by definition includes symptoms that are specifically related to the traumatic event or reminders of the event (e.g., memories, active avoidance and specific avoidance, hyperarousal/hypervigilance). Psychiatric comorbidity is common in ASD and requires treatment of these co-occurring symptoms, such as anxiety or depression. It will be important to consult with providers who specialize in ASD, as well as to review suggested adaptations to evidenced-based treatments for this population (see above sections of this handout as well as the Bernier Lab Autism Spectrum Disorder Reference Guide).
Q: What are strategies providers can use for clients with ASD who are lacking internal motivation for change?

A: It is common for individuals with ASD to have difficulties with internal motivation for behavior change. Difficulties with motivation may be related to neurodevelopmental differences, reward processing, or difficulties appreciating and understanding the impact, particularly the social impact, of behaviors and symptoms. Individuals with ASD will likely require extrinsic motivators to be successful (e.g., tangible rewards, time spent in preferred activities).

Q: The provider suspects ASD symptoms but there is no ASD diagnosis. How should providers guide families and when is a referral to an autism specialist indicated?

A: Given the heterogeneity of clinical presentation of ASD, as well as symptom overlap with many other conditions, it will be important for individuals suspected of ASD to be evaluated by a professional with expertise in this area. Concerns regarding social communication and reciprocity, as well as restricted and repetitive behaviors that are long-standing, impairing, and present early in development likely warrant an evaluation to rule out a diagnosis of ASD.

- Common symptoms that may indicate the need for further evaluation include long-standing difficulties making and maintaining friendships/social relationships, communication challenges including ineffective use of nonverbal methods (e.g., eye contact, gestures, facial expressions) to communicate with others, odd or unusual language or behavior, repetitive play or language, sensory differences, unusual interests (e.g., toilet seats, street lights) and/or preoccupations that have persisted across time and are unusual in intensity, and early history of language and motor delays.

Providers should describe red flags or concerns to families, and refer for further evaluation by an autism specialist, such as a psychologist, developmental pediatrician, or neurologist. Waitlists for autism evaluations are often long, and getting an appointment to see a provider may take your client several months. It may be helpful to have the client referred to multiple locations so that they can be placed on several waitlists. After being placed on the waitlist(s), families may want to call sporadically to check their status on the list(s), as there could be appointment cancellations and last-minute openings. If the client’s ASD symptoms appear to be impacting their behavior and school performance, it may be beneficial for caregivers to reach out to school providers about the possibility for accommodations and/or special education services that may support the client’s needs at school. This communication can
happen regardless of where the client’s family is in the diagnostic process. School districts require a separate school-based evaluation be completed to determine educational impact and services. Encouraging communication between the client’s family, teachers, and therapists will help to provide holistic treatment and support.

Q: What should providers do when caregivers have concerns that a child with ASD (or suspected ASD) is experiencing trauma related symptoms but the provider conceptualizes difficulties as related to ASD or a general stress response (versus trauma symptoms)?

Individuals with ASD and other developmental disabilities may be at increased risk of traumatic exposures and more prone to certain stressors (e.g., social confusion, peer rejection or bullying, sensory aversion to daily stimuli) than their typically developing peers.\textsuperscript{2,6,9} Children with ASD also have a higher rate of co-occurring internalizing disorders such as anxiety and depression\textsuperscript{19} than the general population, and often struggle with emotion regulation skills that would facilitate coping with everyday stressors.\textsuperscript{20} Therefore, it may be common for clients with ASD to present with symptoms of general stress, difficulties with adaptive coping, and anxiety or worries. Anxiety and/or mood symptoms may be related to ASD symptoms such as significant stress or anxiety regarding social rigidity, sensory aversions, or mental inflexibility. If the provider has conceptualized the client’s presenting concerns as a general stress response or other co-occurring mental health condition (e.g., anxiety, depression, adjustment disorder) versus a traumatic stress response, it will be important to communicate this understanding of symptoms to caregivers and help them understand the differences between PTSD/trauma symptoms (e.g., disorder of memory including symptoms specifically related to memories of reminders of an adverse event/experience) and general stress responses or other commonly co-occurring conditions. Therapists should discuss the treatment goals and symptoms that will be targeted based on their conceptualization and the methods that will be used (e.g., building adaptive coping skills, using exposures to address worries and reduce avoidant behavior, working with schools to increase supports, etc.) to assure the caregiver that their major concerns and presenting problems will be addressed in therapy regardless of diagnostic label.
References:


