

Tailoring Trauma-Focused Cognitive Behavioral Therapy for Youth with Developmental Disabilities (TF-CBT IDD) and their Caregivers.

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Preface:

This guide is intended for clinicians who have completed basic training in TF-CBT, including the online TFCBTWeb2.0, two-day live training conducted by a certified trainer and follow-up consultation calls.

We have assembled this therapist guide with the hopes of enhancing clinician comfort and flexibility in working with youth with Intellectual and Developmental Disabilities (IDD). It is based on our practice, piloting and supervision of Trauma-Focused CBT (TF-CBT) cases with youth who have IDD and on survey responses of certified TF-CBT therapists about their work with this population. The category of Intellectual and Developmental Disabilities (IDD) is a broad one encompassing many different conditions, often with varied levels and patterns of functioning within each condition. To tailor TF-CBT for such a varying population, we recommend considering the specific pattern of functioning of the individual rather than prescribing distinct approaches for each developmental condition. We provide guidance for considering each client's trauma reaction, their way of communicating, and their functioning in other areas that can impact the therapy, as well as strategies for adjusting the treatment accordingly.

We begin with defining terms, introducing the special population of youth with IDD and offering some understanding of the unique impact of trauma specific to this vulnerable group. We suggest that gaining comfort and confidence working with these youth and their families is akin to developing a cultural competence and we outline the systems issues that are unique to the "IDD culture." To assist with appropriate case evaluation and readiness for trauma work, we offer suggestions for modifications to assessment as well as staging guidelines for when trauma treatment should begin. We then summarize research on successful treatment modifications for youth with IDD and present a therapy accommodations planning tool for applying this information based on the client's individual IDD profile. This planning tool prepares the therapist for navigating a detailed matrix of alternative interventions to consider as TF-CBT proceeds. The matrix assists in tailoring each of the TF-CBT PRACTICE components according to the individual domains of the client's functioning. We then offer some recommendations around case complexity, common comorbidities, adjunctive treatments, etc. Lastly, we discuss treatment maintenance and post trauma recovery.

Chapter 1: Introduction

Definitions: Intellectual and Developmental Disabilities

Intellectual and developmental disabilities (IDDs) encompass chronic mental and/or physical disabilities that begin in the developmental period and have a significant and persistent impact on major areas of functioning. The precise criteria and the specific sub-classifications depend on the context (see <https://www.nichd.nih.gov/health/topics/idds/conditioninfo>). The three major systems used in the United States are:

- a) the federal/state entitlement categories specified by the [Americans with Disability Act of 2000](#);
- b) the school disabilities categories specified by the federal [Individuals with Disabilities Education Act \(IDEA\)](#); and
- c) diagnoses of IDD by medical providers using the American Psychiatric Association's DSM-5 (American Psychiatric Association, 2013) and the ICD-11 (World Health Organization, 2019) terminology.

The reader is referred to Appendix A for more information about these definitions and their implications.

It is important for the therapist to be knowledgeable about these classification systems when serving youth with IDD and their families. In order to communicate with others involved in the child's care or advocate for services on the child's behalf, they will need to understand how the child may be classified by government-sponsored programming (e.g., state agencies), educational programming (i.e., school IEP classification) and medical/ mental health/insurance providers.

We utilize the term IDD throughout this guide to reflect the broad set of disabilities that result from mental and/or physical impairment characterized by early onset, a severe and chronic (generally life-long) course and a range of functional and adaptive skill deficits (Zablotsky et al. 2019). It is estimated that approximately 1 in 6 children in the U.S. is affected by IDD with various causes, features, and courses (see Table 1; U.S. Department of Health and Human Services, 2000; Zablotsky et al. 2019). Youth with IDD are more vulnerable to trauma and to a range of behavioral, social and emotional difficulties throughout life and many have co-occurring disorders. Thus, the IDD designation is heterogeneous, taking into account a broad range of developmental impact and functional presentations.

For example, IDD encompasses children on the autism spectrum with strong cognitive and verbal comprehension skills, children with varying levels of intellectual delay, and multiply and/or physically disabled individuals who require assistance in nearly all activities of life. The scope of this guide is on psychosocial treatment of trauma-related

symptoms in children with IDD. We will focus our attention on conditions that primarily affect cognitive and psychosocial functioning (e.g., ID, ASD, LD).

In the disability field using person-first language, (i.e., “an individual with autism”) often has been recommended as more respectful and some individuals with disabilities prefer this approach. However, identity and empowerment factors lead some individuals to prefer to use identity-first language, such as identifying as an “autistic person.” Autism is part of who they are and not something to be seen as an issue. We recommend asking individuals for their preferences and adhering to preferences in this regard.

Key Points: The Population of Youth with IDD

- **Intellectual and developmental disabilities cover a broad range of conditions that have chronic functional impairment**
- **Therapists need to be familiar with the multiple systems of classification for IDD**
- **IDD affects learning, thinking, language & adaptive functioning**
- **IDD increases vulnerability to behavioral, social, & emotional difficulties including trauma**
- **Individuals and their families vary with respect to how they identify in terms of language usage, diagnostic label and personhood**

Trauma and Maltreatment in Children with IDD

Increasingly, data suggests that potentially traumatic events such as maltreatment and exposure to violence are 2-3 times more prevalent among children with IDD compared with the population of typically developing children (see Brendli et al 2021; Hoover, 2020; Legano et al. 2021 for reviews). Children with IDD are particularly vulnerable to bullying, use of physical restraints and seclusion as well as maltreatment such as physical, sexual, and emotional abuse (Hoover & Kaufman, 2018; Katsyannis et al. 2020; McDonnell et al. 2019).

Bullying is especially common for children with ASD and ADHD. Children with ASD are bullied more often than nondisabled peers, peers with other disabilities, peers with intellectual disabilities alone, and their typically developing siblings (Nowell, Brewton, & Goin-Koche, 2014; Sreckovic, Hume, & Able, 2017; Zeedyk et al. 2014). A recent meta-analysis estimates that children with ASD are bullied at a rate three times that of typically developing children. Bullying of children with ASD has significant negative effects on their social and academic adjustment (Adams et al. 2016), contributing to the increased rate of suicidal ideation and attempts in youth with ASD (Mayes et al. 2016). Bullied children with ASD and their parents also report symptoms consistent with panic disorder, major depression, loneliness, and social anxiety (Storch et al, 2012). Physical restraints and seclusion are applied to individuals with IDD, generally in response to

self-harm and aggressive, destructive challenging behavior in educational or institutional settings. Preliminary evidence suggests that these interventions are more likely to be experienced by individuals with disabilities than by typically developing individuals (Katsyannis et al. 2020). While such methods may be necessary as a last resort to prevent harm to self or others, physical restraint and isolation can be experienced as controlling, harmful, and potentially traumatic (e.g., Embregts et al. 2019).

Adding to the concern about various forms of traumatic exposure, some children with IDD may be unable to disclose abuse in a clear and coherent way due to language or cognitive delays. As a result, while these children are more often the subjects of protective services referrals, substantiation of abuse is reported as being lower at least for some children with autism (Fisher et al. 2018). Among those who have been subject to abuse and trauma, children with IDD have higher risk for placements in out-of-home settings for longer periods than typically developing children. They are often placed in more restrictive settings and in many cases, it is more difficult to find transitional family-based placements (Hall-Lande et al. 2015; Simmel et al., 2016; Slayter, 2016).

Responses to Trauma in Youth with IDD

According to The National Child Traumatic Stress Network (National Child Traumatic Stress Network, 2020) “child traumatic stress occurs when children and adolescents are exposed to traumatic events and these exposures overwhelm their ability to cope with what they have experienced.” Children show a range of responses to potentially traumatic events (Alisic, Conroy, & Thoreson, 2020; Briggs, Nooner, & Amaya-Jackson, 2021; Cohen & Mannarino, 2017) including post-traumatic stress disorder (or partial symptoms of this disorder), anxiety, depression, or other reactions such as increased substance use.

Posttraumatic stress disorder (PTSD) is described in the DSM-5 as a syndrome arising from witnessing, directly experiencing, or being otherwise exposed to serious physical or sexual violence, threats to bodily integrity, or death of family members (American Psychiatric Association, 2013). PTSD symptoms are common in the immediate aftermath of traumatic events for both neurotypical children and those with IDD. While evidence suggests there is a heightened risk of exposure to traumatic events in children with IDD, it is not yet clear whether this heightened risk translates into higher rates of PTSD in this population.

There is evidence to suggest that this adult-based definition of traumatic events is too narrow for youth in general as children may develop PTSD symptoms for a wider range of stressful events (Copeland & McGinnis, 2021), particularly for children with IDD. For example, research is finding that bullying and social ostracism, abandonment by a mother or spouse, and social difficulties are associated with PTSD symptoms in individuals with ASD (Rumball, Happe, & Grey., 2020). It is also possible that difficulties with emotion regulation, deficits in coping abilities and sensitivities to sensory stimuli and ASD-related reactivity may lead to greater risk of trauma-related symptoms in individuals with ASD (Haruvi-Lamdan et al., 2018; Kerns et al., 2015).

It is important to note that several syndromes within the IDD designation have symptoms in common with PTSD such as avoidance, overarousal, and idiosyncratic fearful responses (Haruvi-Lamdan et al., 2018), which can contribute to diagnostic confusion in children with IDD and a trauma history. There are also limited tools for assessing trauma in this population, an area requiring more study (see Byrne, 2020; Rumball, 2019; Stack & Lucyshyn, 2019 for recent reviews of these issues). The problem is further complicated by diagnostic overshadowing, a frequently observed bias in which emotional or other behavioral features in children with IDD are attributed to the developmental disability rather than being seen as separate, treatable symptoms (Kerns et al., 2015; Truesdale et al., 2019). Bearing in mind the increased risk of trauma and the resulting complexity of negative mental health impact on youth with IDD, it is likely that these children would fare no better than has been found for neurotypical peers. They have higher rates of PTSD in cases with prior trauma and low rates of spontaneous recovery 6 months post trauma (Alisic et al, 2021).

Consistent with the discussion above, our experience working with youngsters who have IDD is consistent with findings with neurotypical youth, Trauma exposure increases risk of a range of psychiatric disorders. While trauma is a specific risk factor for PTSD, it is also a non-specific risk for a range of disorders including anxiety, depression, prolonged grief disorder, and externalizing disorders (Alisic et al, 2021; Briggs, Nooner, & Amaya-Jackson 2021). Furthermore, Ford and colleagues (Ford et al, 2018; Spinazzola, Kolk, & Ford, 2021) have proposed an additional diagnosis, developmental trauma disorder (DTD, also called complex trauma), for youth who have experienced both victimization and disruption of attachment relationships. DTD includes but extends beyond PTSD and involves issues with self-regulation and relational insecurity. While DTD is not currently recognized in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013), Complex PTSD (CPTSD) is differentiated from PTSD in ICD-11 (World Health Organization, 2019).

Cohen & Mannarino (2017) report that TF-CBT is an appropriate treatment for children with trauma-related symptoms even if the children do not meet full criteria for PTSD or present with a predominance of other trauma-related symptoms. They note that the course of treatment may need to be longer, and more emphasis placed on the initial stages of treatment when developmental trauma (complex trauma) is involved. They note that when there is high incidence of externalizing symptoms, stabilization may be needed before TF-CBT is appropriate.

Due to the higher likelihood of language and communication challenges in youth with IDD, clinicians need to be keen observers of a child's behavior. New or changed behavior is sometimes a response to a current traumatic experience or a reminder of previous trauma. Providers should be alert to possible behavioral indicators of trauma such as developmental regression, social withdrawal or isolation, reduced self-care, or increase in disorganized and dysregulated behavior, aggression, and self-injury (see Kildahl et al., 2019 for a review in children with ASD and ID).

Trauma Treatment for Children with IDD

The research on trauma treatment with individuals with IDD is only in beginning stages with small sample sizes, an absence of comparison groups, and no published randomized controlled trials at this time (e.g., Byrne, 2020). A systematic review of the research conducted between 2008 and 2018 produced only 12 articles that investigated trauma treatment for individuals with ID (Keesler, 2020). This review identified that four interventions -- Child-Parent Psychotherapy (CPP), exposure therapy, TF-CBT, and eye movement desensitization and reprocessing therapy (EMDR) -- have been studied with this population. Of note, each treatment approach was associated with reduction in trauma symptoms (Grosso, 2012; Harley et al, 2014; Keesler, 2020).

Another systematic review of trauma in individuals with autism identified seven papers on treatment, all of which were case presentations (Rumball, 2019). Treatment approaches included CPP, CBT, systematic desensitization, and EMDR. Of the six cases providing treatment outcome data, all noted reductions in trauma symptoms (Rumball, 2019). There is preliminary evidence that group TF-CBT (a somewhat different European version) can be effective for adults with mild ID and trauma symptoms (Kroese et al., 2016). The few studies that have been carried out have been less than adequate for answering our questions about the impact of TF-CBT on youth with intellectual and developmental disabilities.

There is a lack of current studies supporting TF-CBT effectiveness for youth and children with ID (Byrne, 2020). However, the efficacy and flexibility of TF-CBT in many studies of trauma treatment in children is promising and has been extended by the authors of this treatment manual in developing interventions for traumatized youth with IDD. As discussed further in a later section, there is now a strong evidence base for use of CBT interventions to treat anxiety in youth with ID, and these interventions share many elements with TF-CBT.

Key Points: Trauma in Youth with IDD

Youth with IDD:

- **Are at increased risk for various forms of adverse childhood experiences and traumatic events**
- **Develop PTSD and other traumatic reactions to a broad range of stressful events (e.g., perceiving various forms of bullying as traumatic)**
- **Experience a range of mental health problems including trauma-related symptoms and at a higher rate than neurotypical youth, thus higher comorbidity is to be expected**
- **May have language and cognitive delays that interfere with disclosure and/or communication about trauma**

- **Will more often utilize behavior as communication regarding trauma expression**
- **Cases are often complicated by diagnostic overshadowing**
- **Can benefit from currently established forms of trauma treatment**

Chapter 2: Culture of Disability and Traumatic Stress

Cultural Competency and Clinical Expertise

We assert that there is a significant shift needed in the way we consider professional competency in treating trauma for youth with IDD. We see this as a cultural competency as well as an area of clinical expertise. People with disabilities have unique experiences, language, systems, connections and relationships, and many other commonalities that make up their lifestyle and identities. These youth know very well what it is like to get off the “short bus” at school. They often may know each other through environments or provider relationships directly related to their disability. There are people who do not have disabilities who are not directly a part of this culture but have a familiarity or exposure to the culture of disability. It is our experience that people who have this exposure and experience, whether personal or professional, are more likely to have cultural competency when providing mental health treatment to people with IDD.

The notion of healthy people with disabilities is often an oxymoron in our society. By definition, some may consider people with disabilities to be “lesser-than” or broken, or irreparably damaged. When mental health clinicians experience and become familiar with and ultimately grasp the concept of a “healthy person with a disability,” they are then able to identify the psychopathology when it presents itself in a clinical assessment. The skills described in this section regarding cultural competence may take more work for some clinicians to develop than others, but we believe that most therapists having a reasonable degree of flexibility and openness are able to attain them. Developing cultural competence and increased skills with this population requires basic familiarization with the neurodiversity literature, consultation and supervision, and clinical experience. The latter may be gained by starting with easier or less complicated cases (e.g., higher-functioning individuals or those with less-severe symptoms) and increasing one’s comfort with more demanding clinical needs in a stepwise fashion.

People with IDD are a disempowered minority who experience many stressors that other disempowered minorities experience in our society. One major difference for people with IDD is that they are the only disempowered minority group in our society whose minority status is defined by a medical diagnosis. Collectively these youth are shown to have higher risk and are also underserved, perhaps justifying a broad advocacy approach toward the recognition of trauma and its recovery with this

vulnerable population. This guide offers this general advocacy rationale with the hope of reducing therapist reluctance in accepting cases with IDD, instead considering the gradual inclusion of individuals with IDD into their scope of practice as both a cultural competency and specialized skill set. We believe this competency is basically a form of therapist flexibility which can be learned through deliberate application of the resources shared in this therapist guide with consultation as needed.

We have met many skilled and experienced clinicians who extend their talents to help youth with IDD while continuing to serve typically developing children and adolescents. The majority of these therapists do not identify themselves as IDD specialists but are eager to learn as they already have these patients on their caseload. As therapists become more familiar and informed regarding culturally informed practices generally, they learn to better expand their repertoire of tailoring interventions to the individual when required, thus broadening their comfort zone.

Disability-Related Trauma

Having a disability can in itself be traumatizing. The individual and family are faced with daily reminders of the difference(s), stereotypes, discrimination, ill-designed physical environments, and a host of other “micro-traumas.” These “small-T” traumas are frequent and salient threats to feelings of safety, self-worth, self-efficacy, competency, acceptance and attachment.

The cumulative effects of chronic trauma that come from stigma, social exclusion, isolation, and internalized shame, paired with all kinds of other chronic and persistent learning and social frustrations, may result in long-term physiological stress responses and mental health sequelae such as increased suicidality. This may be compared to racial or sexual discrimination trauma that results in persistent stress responses and depression (see Lund, 2021 for review of this literature).

Working with Families of Youth Who Have IDD

One of the more significant challenges in working with families of youth with IDD is the ongoing struggle of understanding the full scope of a child’s vulnerability and navigating the balance between optimizing their potential and protecting them from harm. Receiving a disability diagnosis for one’s child can be traumatic and a cause for grief and mourning that may be re-opened at each developmental stage transition or setback, though this may be moderated by parents’ acceptance and resolution regarding the diagnosis (Barak-Levy & Atzaba-Poria, 2015). Parents may look toward their child’s future with foreboding, not knowing what to expect. Taking care of a child with physical, behavioral, and cognitive limitations can be a daily drain on energy, requiring sacrifices of money and personal time that go beyond what is required for parents of most typically developing children (Romley et al. 2017).

Another major aspect is the need to advocate for the disabled child's medical, educational, and therapy needs. The fragmented quality of the U.S. health and education systems puts a heavy load on parents. They must learn all they can about services necessary and available, take an active role in IEP meetings, as needed apply for developmental disability benefits and get their child on waitlists for waiver programs, and juggle a variety of treatment appointments, medications, and multiple team members. This extra stress and pressure translate into costs and "spillover" into family relationship distress with a higher divorce rate among parents who have a child with a disability (Factor et al. 2019). Further, some caregivers can expect to take care of their disabled child well into adulthood when most parents have shed child-rearing responsibilities. Parents may worry whether there will be enough money and supportive caregivers for their disabled child after they pass away. Siblings often feel responsible to provide care themselves and may see themselves as the ultimate caregivers after parents are no longer able.

Adding to their burden, children with IDD tend to have a greater likelihood of co-occurring disorders such as physical disabilities and medical conditions, as well as mental health diagnoses (Kok et al. 2016; Siegel et al. 2020).

Key Points: Working with IDD Youth and Their Families as Cultural Competency and Professional Competency

- **People with IDD are a disempowered minority defined by a medical diagnosis.**
- **Competence in disability culture is essential for working with IDD families and can be developed by most clinicians who are open to this.**
- **Disability-based discrimination is a form of chronic trauma with longstanding negative impacts on mental health and well-being.**
- **Clinicians should have basic knowledge about definitions, developmental profiles and characteristics of IDD.**
- **Families with a member who has IDD often carry extra financial, physical, emotional, and relational burden.**

Systems Issues: Silos of care

In addition to disability-based discrimination and increased financial, emotional, physical, and medical burden, families of children with IDD often face significant gaps in mental health services. This occurs secondary to a long-standing siloed approach to IDD-focused services (D'Amico et al., 2021; Henderson-Smith & Jacobstein, 2015) with little communication or interaction between mental health and IDD service systems. In addition, often there is limited communication between IDD care providers. A child with IDD may be receiving formal supports in their schools and communities, including an Individualized Education Plan (IEP), Applied Behavior Analysis (ABA), Occupational Therapy (OT), Speech Therapy (ST), and Physical Therapy (PT), among others. They

may be enrolled in specialized education settings, be involved with assessment providers, followed by developmental pediatricians, and/or be receiving services through Medicaid or other managed care programs.

Children with IDD often also receive supports from informal sources, including extended family, friends, community members, cultural groups, and other families of children with IDD (Ko et al., 2015). These myriad services and supports have historically been siloed, providing services independently, individually, and without collaboration across systems, adversely impacting care, in general. Furthermore, this parallel-systems-of-care approach has contributed to difficulties in obtaining and providing adequate mental health (Cervantes et al., 2022) and trauma informed care for children with IDD (National Center for Child Traumatic Stress [NCTSN], 2020).

This is especially concerning given that cross-system collaboration is a crucial aspect of effective trauma-informed care for children, in general (What is a Trauma-informed Child and Family Service System? NCTSN), and even more so for children with IDD (Charkowski, et al., 2022). In order to successfully work with youth with IDD, therapists will therefore often find an increased need for multi-provider collaboration, more consistent communication with caregivers and providers and case management navigation. Further, therapists will find engagement in adjunctive therapies is common for youth with IDD and their families who often have multiple treatment needs including individual treatment for the caregiver(s), marital therapy, family therapy or collaterals involving siblings, concomitant group therapy, etc.

Cross-system collaboration often involves multiple providers taking on multiple roles (Ko et al., 2015). For example, when preparing to provide trauma-informed care for youth with IDD, a mental health provider may want to collaborate with the child's ABA therapist, their special education teacher, the aunt who watches the child on weekends, and the developmental pediatrician, to name a few. Although this goes beyond the realm of what a mental health provider might typically conceptualize as their scope of practice, when providing trauma-informed care for youth with IDD, this is as relevant to treatment as direct provision of services. Beyond initial communication, regular contact and collaboration will help support the child and their family and generalize skills to different settings.

In the mental health system, there is often reluctance to treat youth with IDD such as those with intellectual disability or autism spectrum disorder for trauma. This likely stems from lack of knowledge that youth with IDD can benefit from trauma treatment and the fact that these youth are sometimes excluded from community mental health programs. In the IDD field, the tendency is to rely on behavior management or functional skills training instead of approaches that help youth process and recover from traumatic experiences (Xu et al. 2019).

Mental health providers may find themselves hesitant to take on these cases, in context of a longstanding history of utilizing a behavior-management approach to trauma care for children with IDD and personal discomfort in working with children with IDD. It has

long been believed that children with IDD are best – and only – treated with behavioral management (National Child Traumatic Stress Network, 2020). This pervasive belief is at least partially a function of the misconception that children with IDD do not experience mental health issues like neurotypical children do (i.e., diagnostic overshadowing; or that children with IDD will not benefit from mental health treatment. Both are untrue, as discussed above. Furthermore, many providers do not feel comfortable working with children with IDD (Ko et al., 2015), often citing lack of experience or knowledge.

One way to reduce service gaps is to assist trauma trained clinicians in becoming more comfortable in expanding their competence working with youth who have IDD and their families. In fact, many providers who have not worked directly with children with IDD, in a trauma-informed capacity or otherwise, already possess the requisite skills. Rather, it is a matter of willingness, exploratory education, and flexibility. Because of the shortage of trauma trained clinicians in the community familiar with the IDD population, we encourage caregivers of youth with IDD to seek a provider who is open to learning how to support their child, take the time to assess their relative strengths and weaknesses and perhaps seek a “cultural broker” or arrange for consultation as needed.

Key Points: Systems Issues Relevant to Youth with IDD

- **Youth with IDD are often involved in multiple systems of care, which operate as independent "silos of care," adversely impacting trauma treatment.**
- **Youth with IDD benefit from collaboration across systems of care, in general, and particularly when treating trauma.**
- **The IDD system is more oriented toward behavior management than mental health.**
- **The children’s mental health system is often trauma informed but lacking in knowledge about IDD and sometimes systematically excludes youth with IDD diagnoses.**

Chapter 3: Assessment Issues and Strategies

Case example: Assessment of trauma in a child with autism.

Maya is an 8-year-old girl of Latino heritage who has been diagnosed with ASD as well as a mild level intellectual disability. She has significant speech articulation impairments making verbal communication almost impossible for most people who try to engage her in conversation. Her mother is able to understand her and often serves

as an “interpreter.” Maya witnessed several instances of violence when the family emigrated to the U.S. from a Central American country. In one episode, she was present when a close family member was robbed and shot. Maya has always displayed considerable anxiety and tended to avoid talking with people outside of her family. Since the shooting, she has become more anxious and hypervigilant. She worries about her mother’s safety when she goes to work. Maya also reports having auditory hallucinations that began after the shooting episode. She does not speak openly about the potentially traumatic event.

In Maya’s case, questions arise about whether and to what degree her symptoms are related to: a) trauma; b) her long-standing developmental delays; c) generalized anxiety; and/or d) changes in her environment. Assessing trauma symptoms in youth with IDD can be a challenge. Differential diagnosis is difficult because of confounding aspects of the developmental disability itself and other comorbid mental health problems. Language impairments, limited emotional expression, and a concrete thinking style may render the usual methods and measures invalid.

It is important to avoid the tendency for diagnostic overshadowing in which her anxiety and hallucinations may be seen as arising from her autism or intellectual differences. Measurement of comorbidity is complicated. Some assessment instruments have been shown to successfully differentiate associated psychological disorders. These generally consist of structured psychiatric interviews administered to caregivers and children and include the K-SADS-E (Kaufman et al. 1997). The Anxiety Disorders Interview Scale, Child and Parent (ADISIV C/P Silverman & Albano, 1996) includes an addendum assessing anxiety in autism spectrum disorders (Kerns et al. 2014). There is also an ADIS adaptation for borderline and mild intellectual disabilities (Mevisen et al. 2016).

Other standardized questionnaire-based measures have proven useful for assessing trauma symptoms in a typically developing population, but these have not been applied particularly to children with IDD. These include but are not limited to the UCLA-PTSD Reaction Index (Steinberg et al. 2013), the Trauma Symptom Checklist (Briere, 1996) which assesses trauma symptoms and other associated problems, the Child and Adolescent Trauma Screen (Sachser et al., 2017), and the Child PTSD Symptom Scale (Foa et al. 2001). As with all measures, it is important to obtain input from a variety of sources.

To address the specific concern about ability to report mental states by children with IDD above age 6 whose cognitive functioning is at a 6-year level or below, some have used versions of instruments that employ DSM-5 PTSD criteria for children ages six and under when diagnosing children with IDD and such delays (Mevisen, Didden, Korzilius, et al., 2016). Using the 6-and-under criteria under such conditions has been recommended by two contributors to the development of the DSM-5 PTSD criteria for young children (J.A. Cohen, personal communication, May 13, 2019; M.S. Scheeringa, personal communication, June 5, 2019).

Using Assessment to Match the Treatment to the Client

Assessment is an ongoing process, not just a tool for initially diagnosing either developmental disability or trauma related symptoms. For each TF-CBT module, the therapist is first asked to assess the degree to which modifications are needed for the child and family. The amount or type of modification will vary across the TF-CBT modules depending on the clients' personal strengths and difficulties. For some higher functioning children and youth, very little modification may be needed to make progress through that stage. For other children and families, significant modification may be needed. As the clinician approaches each TF-CBT module, referencing past intellectual and other testing combined with careful observation, questioning, and accumulating experience with the family will inform a flexible clinical assessment of the client's skills and motivation. The specific accommodation or intervention follows from this assessment and further assessment is informed by the way the client and family responded to previous steps.

For example, in the case of Maya, the 8-year-old with ASD and intellectual delays described above, the therapist's review of her cognitive testing and difficulty discussing and understanding information at the Psychoeducation stage, suggests that she will have trouble identifying thoughts and feelings at the Affect Regulation stage. The therapist should approach Affect Regulation using concrete visual prompts about feelings in specific situations she often encounters (e.g., struggles with homework; going to bed at night) and designing a "toolbox" of affective coping skills tailored to her special interests.

Assessment Considerations

Assessing trauma in children with IDD requires attention to cognitive and functional differences. Trauma measures for children abound but with rare exceptions (Hoover & Romero, 2019; Kerns & Renno, 2016) none have been specifically designed and validated for the IDD population. Assessment tools that are designed for typically developing individuals cannot be relied upon in all cases because of the lack of appropriate norms. There is a particular paucity of trauma measures that elicit self-report in individuals with IDD. Most measures are administered to parents and caregivers, assuming that children with language or intellectual differences are too limited to comment on their own experiences. This approach leaves out a source of information that has been found to diverge from other reports of adults in measurable and important ways (e.g., Adams et al. 2014).

We recommend that trauma assessments include self-report measures whenever possible. These can include developmentally appropriate screeners, structured clinical interviews, and direct questions. As mentioned previously in this guide, there is some

evidence that children with intellectual differences may show regression in previously learned skills as a result of trauma. Use of adaptive skills measures can provide a way of tracking such changes in functioning, especially if a baseline before traumatic events is established.

One self-report instrument currently in development is the Interactive Trauma Scale (ITS). The ITS is a web-based diagnostic tool that is presented in a multi-modal, interactive format, administered by tablet or smartphone. Children of most developmental levels, beginning at approximately age 6 are prompted to select an “avatar” from a graphic display of pictures of characters with varying skin tone, hair styles, and gender presentations. They are then given a series of True-False trauma exposure questions (e.g., “Were you teased or called mean names?” “Did you have someone bigger or older than you touch your private parts?” etc.). The child is then asked which experience troubles them the most. They are then led through a series of symptom-based questions (e.g., “I have bad dreams,” “I feel angry,” “I blame myself for what happened”, etc.) to which they respond in a Likert scale format: “Never,” “A little,” “Sometimes,” “A lot,” “Always” by sliding a thermometer-like scale up and down..

The responses are scored based on DSM-5 criteria, counting symptoms of re-experiencing, arousal, negative emotion, avoidance, dissociation, and overall trauma response. In a pilot study with a small group of children ages 8-14, all with ASD diagnoses and known trauma exposures, children rated the scale highly positively. Their scores on the ITS were moderately correlated with UCLA PTSD-RI child self-report measure and the parent report UCLA. Participants identified more trauma exposures, mainly to bullying or teasing incidents, on the ITS, than on the UCLA self-report form (Hoover & Romero, 2019).

The same adjustments made for therapy and other communication are applicable for assessment. There is usually a need to establish the child’s reading and comprehension level, read items aloud, or provide language supports for the child. These may include the use of assistive communication devices or other ways for the child to answer non-verbally, ASL signing for deaf children or caregivers, or an “interpreter” who understands the child’s communication style. The use of visual items and prompts and simplified scaling can be helpful for youth who may not intuitively or immediately grasp Likert scales. The assessor should use simple language, a slower pace, and provide sequencing from basic to more complex concepts when possible. Stopping and checking for comprehension is always a good idea while proceeding through test items.

While the point has been made about obtaining direct responses from the child, the observations of adult caregivers, teachers, and other supports are invaluable for triangulating information about trauma and symptoms. The assessor is often left to guess at what may have happened. A simple timeline can be valuable for clarifying symptoms, regressions, and behaviors before and after potentially traumatic events.

Importance of Neurodevelopmental Assessment Data. Clinicians who have more extensive training on how to interpret and rely on assessment data in their practice will find they have an advantage in decision-making about the most helpful ways to tailor treatment for youth with IDD. At times, caregivers of these youth will come to therapy with a binder of previous testing reports and evaluations to inform the therapist of the patient's profile of strengths and needs, diagnostic considerations and the family's overall journey in procuring needed supports.

In other cases, clinicians may be waiting for evaluation data that is forthcoming or may want to refer for more in-depth assessment when only limited information exists. In training our therapists to approach working with youth with IDD, we encourage the use of clinical, developmental, and educational data as a formal planning activity to identify specific needs as well as patient strengths and to assist in learning about the patient's idiosyncratic ways of processing information and communicating that warrant special consideration.

We recommend the use of an *Individualized Therapy Accommodations Planning Tool* (see *Appendix B*) for identifying specific needs and strengths in planning for accommodations. The tool specifies seven broad domains that often have impact on therapy: **Language, Cognitive Processing, Visual Spatial, Sensory/Motor, Academic Skills, Willingness and Motivation, and Special Interests.** For each of these, we recommend considering three questions:

- (a) What are the individual's **challenges** in this area that I will to be mindful of when implementing treatment? We provide a checklist of specific issues to consider.
- (b) What **strengths** does the child have that I can build on in treatment?
- (c) What **specific modifications** will I try based on these strengths and weaknesses?

We recommend that this tool be used throughout therapy. Initially a therapist may receive information from formal test data, caregiver input, and other reports. Information should be updated as you get to know the child directly, get additional caregiver or outside information (including new formal assessment reports), and as you work on tailoring treatment to the specific portions of the TF-CBT model (see Chapters 5 and 6). For therapists less familiar with the interpretation and use of formal assessment data or with the specific subdomains of functioning in the planning tool, we recommend an "Assessment Broker," essentially consultation with an assessment expert such as a neuropsychologist. Also in Appendix A is a completed example of the planning tool with recommended therapy accommodations suggested for each domain.

A final consideration regarding assessment relates to attribution of specific symptoms to a diagnostic classification. As discussed in chapter 1, diagnostic overshadowing can lead to the misattribution of observed symptoms to a child's IDD diagnosis rather than trauma response or vice versa. Diagnostic specificity, the ability of an instrument to detect and rule out false positives, should be a consideration in selection assessment

tools to help mitigate this risk. However, where this information is unavailable to the clinician, it may be necessary for the user to rely on their comprehensive interview, history, observation, and clinical judgment to make these distinctions. In some cases, the distinction may not be possible to make, and this should be reflected in the clinician's case conceptualization and any diagnostic report. Additionally, these categories are not mutually exclusive or exhaustive. Some symptoms related to trauma-exposure which may overlap with or look very similar to traits seen in some IDD diagnoses and require care are listed in Table 1.

Table 1. Potential similarities and overlap between trauma-related symptoms and commonly observed characteristics of IDD.

Trauma Related Symptoms	IDD Characteristics
Exaggerated startle response	Sensory hypersensitivity
Social withdrawal	Limited interest in social interaction; preferring to be on one's own
Depressive symptoms	Limited interest in social interaction related to functional support needs, social skills, or personal preference; preferring to be on one's own; preferring to stick to specific interests; bluntness or other differences in social reciprocity
Repetitive play around traumatic themes	Other repetitive behaviors
Intrusive thoughts	Strong or perseverative interests, sometimes related to unusual or highly specific topics

Key Points: Assessment Issues and Strategies

- **Assessment of trauma in youth with IDD is confounded by aspects of the disability itself, diagnostic overshadowing, and high levels of comorbidity**
- **Standardized trauma measures are not typically normed for youth with IDD and specially designed instruments are only now being developed**
- **While most rely on parent or caregiver report, it is recommended that self-report be attempted with accommodations considering the child's reading and comprehension levels**
- **Use of adaptive skills measures can assist in assessing trauma impact**

- **Consider implementation of the *Individualized Therapy Accommodations Planning Tool***
- **Consider the use of an assessment broker to interpret and utilize assessment/evaluation data**

Chapter 4: Readiness and Preparation for Trauma Work

Once the need for a trauma-focused intervention has been established, it is time to determine how to proceed with designing a treatment plan. TF-CBT treatment planning should always include consideration of the child’s broader systems of care and lead to logical “next steps.”

Care Coordination and Collaboration

Many children with IDD are followed by one or more medical specialist (e.g., psychiatrist, developmental pediatrician, neurologist), and receive multiple supportive services such as special education, physical therapy, occupational therapy, and/or speech and language therapy, behavioral support and/or mental health counseling. They are likely to be receiving these services through multiple systems of care. Examples include health, mental health, education, child welfare, and juvenile justice. Given a particular individual’s constellation of needs and supports, it is important to consider how TF-CBT will be integrated into the existing network of care. Information needed and decision-making process are elaborated in Table 2.

Table 2. Assessment of engagement, coordination and collaboration for treatment planning.

Points to assess for parent engagement and accessibility, care coordination and collaboration with other providers:

- *In which system will the child receive TF-CBT? (i.e., school, outpatient mental health, child welfare, juvenile justice, inpatient hospitalization, etc.)*
 - **Considerations:** financing; transportation if needed to service for child and caregiver; overcoming childcare challenges for parents with multiple children or other parent availability issues; availability of private space to meet; telehealth availability; time to service/waitlists; disruptions to service
- *Who is on the child’s care team?*
 - **Considerations:** prioritizing the patient’s voice and choices (e.g., a person-centered approach); establishing ongoing communication

- between members of the care team; leadership and delegation in care activities; “translating” technical language for all members of the team
- *What services is the child already receiving?*
 - **Considerations:** sequence of services; integration of services where appropriate; avoiding redundancy; alignment/fit of services to the child’s current needs, short term goals, and long-term goals
 - *Who coordinates care right now?*
 - *Will some services need to be put on hold while participating in TF-CBT?*

Assessing Readiness and Staging for TF-CBT

TF-CBT is designed to be a discreet and time-limited therapeutic intervention. While there is flexibility built into the model (i.e., extended preparation time for identified caregiver), as described in Chapter 5 of this Guide, it may be necessary to sequence other services with TF-CBT to best support its efficacy. This is particularly the case when the youth with IDD is exhibiting behavior that poses safety risks and there is need for stabilization before trauma recovery can be attempted. Sometimes, TF-CBT may need to be discontinued or paused temporarily to pursue other services. This process of sequencing services to support the efficacy of TF-CBT is called “staging.” Staging is different from coordinating with other services while a child is participating in TF-CBT because staging considers when the process of trauma recovery can begin or resume once discontinued. In addition, it is important to determine whether TF-CBT is the best trauma-focused approach to meet your client’s needs.

Table 3: Essential questions to determine readiness for TF-CBT:

Essential Question	Considerations
<i>To what extent will this child be able to participate in treatment verbally?</i>	Development of alternative communication modalities; availability of caregiver to participate and act as “interpreter” for child in session;
<i>Who are this client’s primary caregivers and are they able to act as active participants in services?</i>	Availability of caregivers to participate; availability of caregivers to listen to and provide support with coaching from therapist
<i>Is this client able to sit in the treatment room and participate in therapy?</i>	Intense aggressive, self-injurious, or dangerous disruptive behaviors such as elopement, especially if exacerbated by discussion of trauma-related details

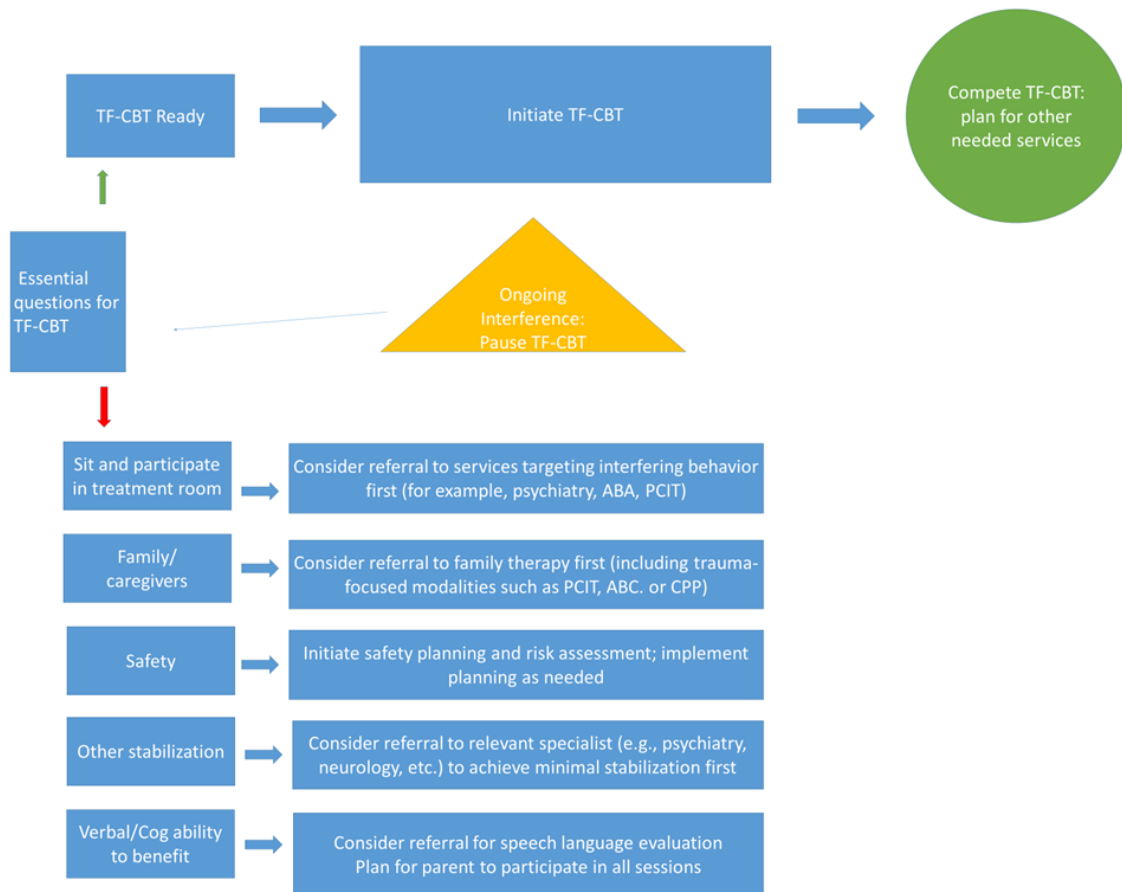
<i>Are there safety or stabilization concerns that must be addressed?</i>	Active substance use; psychosis; suicidality; risk of harm to others; medical conditions requiring intensive care; pharmacological considerations
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Careful evaluation of these considerations may help you to identify that your client is:

1. In need of supportive services prior to initiating TF-CBT
2. In need of services *in addition to* TF-CBT that may be provided concurrently or referred to at any stage in treatment
3. In need of a trauma-focused intervention other than TF-CBT

The logic model below (Figure 1) was developed to aid in evaluating the needs of individual clients and to determine the sequence services with consideration to TF-CBT.

Figure 1: Sequence of services in treatment planning.



One of the primary considerations in preparation for trauma work is to establish whether some level of perceived safety exists or has been restored relative to the experienced trauma. Helping the youth and caregiver recognize or co-construct a relative sense of safety is essential to treatment progression. In our work with IDD youth and their families, significant attention early on with the “Enhancing Safety” component of the TF-CBT model is often needed along with clear acknowledgement of whether some aspect of trauma is - ongoing and preventable, predictable with periods of safety, or persistent and unpredictable (Kagan et al., 2022). Creating and/or articulating a current safety plan already being enacted allows for a paced approach to trauma narration.

In some cases, efforts at “Enhancing Safety” within the TF-CBT model may not be sufficient or advised given the need for stabilization. Some of the more common stabilization domains are listed in the table below. At the patient level, significant behavioral dysregulation in the form of significant oppositionality, conduct problems, or aggression may preclude initial engagement in trauma treatment. An intensive parenting approach like Parent Child Interaction Therapy (PCIT) can help stage for TF-CBT in cases where extended time preparing caregivers within a flexible approach to TF-CBT is not sufficient. Another stabilization domain more often encountered in youth with IDD is psychiatric status and associated pharmacotherapy. Close monitoring of mental status and medication effects in collaboration with the prescribing physician to determine readiness (including transitions to and from higher levels of care) may take a good amount of staging. Given the severity of other comorbid conditions, clinicians may find that associated mental health concerns such as acute OCD or depression require focused attention prior to beginning a course of TF-CBT.

At the family level, baseline functioning may not be sufficient to benefit from only a few extended TF-CBT sessions of parenting and psychoeducation and therefore a more inclusive family intervention like Families Overcoming Under Stress (FOCUS; Saltzman, 2016) can help create the necessary family cohesion and support. In cases where the parent-child attachment may need bolstering, intervention at the dyadic level (such as ARC Grow for TIDD) may serve as a staging intervention for later TF-CBT. Lastly, as mentioned earlier in this guide, cross system collaboration is often poorly coordinated, even prohibitive in its structure of available supports to youth and families with IDD. In these cases, there is likely to be importance of a more systems-oriented approach to develop a more stable foundation for trauma treatment.

Table 4: Domains and Possible Approaches for Staging

As discussed above, the following are examples of unique circumstances that occasionally arise working with youth with IDD (although not exclusive to the population) where staging for trauma recovery may be necessary.

Domains and Possible Approaches for Staging

- Trauma Informed Behavioral Support: Parent-Child Interaction Therapy (PCIT)
- Psychiatric Status, Severity of Comorbid Condition: Pharmacotherapy,
- Family Functioning: Families Overcoming Under Stress (FOCUS)
- Parent-Child Attachment: ARC Grow for Trauma and Intellectual and Developmental Disabilities (ARC Grow for TIDD)
- Level of Care/Service Coordination: Trauma Systems Therapy (when there is systems commitment and availability of this approach)

Case example: Need for Family Stabilization

Manny is a 6-year-old male who was removed from his home in a mid-west state and brought to his maternal aunt's home in the northeast at age 5 to live with his adoptive parents and 2 teenage cousins. Manny experienced severe neglect in his prior (bio parent's) home where there was significant drug abuse, domestic violence and physical abuse and it is reported that Manny spent much time roaming the family farm left for extended periods with only the animals. Upon intake, there were reports of significant elopements and escalations of aggression in both home and the school where Manny was undergoing a special education evaluation for initial impressions of Autism and speech & language delays.

Both his adoptive family and the school were considering the need for residential placement. While his Aunt was committed to working things out with Manny, her husband, 14-year teenage son and 16-year-old daughter expressed much resentment and exasperation with Manny's intensive needs and especially his emotional-behavioral dysregulation with accompanied interpersonal "neediness" and aggression. Significant trauma informed consultation for all family members (and eventually school staff) was accomplished with an adapted version of the FOCUS model (Saltzman, 2016) which facilitated stabilization by fostering family resilience through sharing together each family member's adoption experience in concert with Manny's traumatic history.

Emphasis on interpersonal safety surrounding Manny's trauma reminders of deprivation and personal space/touching were key features that emerged as foundations for approaching and communicating successfully with Manny, reducing his survival reactions of elopement and physically defending himself. Stabilization at home led to a collaborative and trauma informed school plan as well. These efforts which occurred across a period of approximately 3 months helped stage a successful transition for Manny to then engage in a complete trauma recovery through engagement in TF-CBT.

Key Points: Readiness and Staging for Trauma Work with IDD Youth

- **Treatment planning should take into account the child’s system of care and whether necessary support is available**
- **Staging of treatment may be needed**
- **The child’s ability to verbally participate and maintain safety and stability is assessed in terms of readiness to participate in trauma-focused work**
- **Emotional and behavioral regulation need to be sufficient to allow the child to participate in therapy but need not be perfected**
- **Several evidence-based treatments and other interventions are available to promote stabilization and readiness for trauma-focused therapy**

Chapter 5: Trauma Focused Cognitive Behavior Therapy (TF-CBT)

TF-CBT and its Components (overview)

Case Example: Beginning therapy with a boy who has ID and a language disorder

Joseph is a 12-year-old boy who was diagnosed with a mild intellectual disability and mixed expressive-receptive language disorder at age 4. He lives with his mother, stepfather, and two younger half-sisters in a large Midwestern city. Joseph has always been a cheerful boy who has positive relationships with his family members and a lifelong preoccupation with train engines, diesel trucks, and large machinery. Joseph has been known to have occasional tantrums and “meltdowns” when frustrated or surprised by changes to his routine. His usual bright demeanor has changed since the family moved to another city, a major change for him. There he encountered repeated physical and verbal bullying in his new school, and an incident on the school bus, in which he was sexually fondled by an older boy. Since these changes and incidents, Joseph has been increasingly isolated, refuses to leave his home or go to school, has been wetting the bed at night, and his episodes of angry blow-ups have increased on a daily basis. It is only with great difficulty that his parents have been able to get Joseph to an outpatient clinic to receive evaluation and treatment for his trauma.

Treatment strategies are needed to address trauma in the population of children dually diagnosed with IDD and trauma-related disorders. Not only do children with IDD respond differently, perhaps with more sensitivity to trauma than typically developing children, but they also respond differently to treatment as well.

Verbal expression and processing form a key part of most therapies for trauma in children but may be difficult or impossible for some children with IDD. Some children with IDD are entirely non-verbal or lack receptive language comprehension. Those with intellectual or language delays may have limited ability to understand the concepts taught in evidence-based trauma treatments such as TF-CBT.

The core deficits and associated features of various forms of IDD make it important to adapt treatment models to make them effective. While no evidence-based treatment model specifically for IDD has been developed, recommendations for adjusting TF-CBT for children with developmental disabilities have been discussed (e.g., Grosso, 2012). Grosso highlights the need for sensitive assessment procedures using drawings, a “Rain Cloud Likert Scale” and support for completing standard scales such as the UCLA-PTSD Index. The TF-CBT treatment steps are discussed in detail with accompanying suggestions for adapting them for use with children who have a variety of disabilities. Tallant (2010) also makes many excellent recommendations for work with children who have ASD and IDD. This treatment manual incorporates many of these modifications. Hoover, Fleming and Khan (in review) have addressed tailoring specifically for youth with intellectual disabilities. Peterson and colleagues (2019) provide recommendations for treating children with autism by tailoring to key features of TF-CBT for that population.

TF-CBT is a 12-16-session intervention designed for youth ages 3-18 and their non-offending caregivers (Cohen, Mannarino, & Deblinger, 2017). It is the most widely used and best validated treatment model for addressing childhood trauma. During the initial phase of treatment, the therapist provides psychoeducation about trauma exposure and traumatic stress and teaches a variety of stress-reduction skills such as deep breathing, muscle-tension relaxation, emotion identification and regulation, and cognitive coping. Caregivers also receive education and guidance on effective parenting skills and behavior management. A central component of TF-CBT—the trauma narrative—is implemented following the child’s successful incorporation of the stress-reduction skills. Trauma narration functions as a means of therapeutic exposure and facilitates emotional and cognitive processing of the event. The narration involves identifying thoughts and feelings related to the event and correcting distorted beliefs or perceptions. After completion of the trauma narration, the therapist helps prepare the child and caregiver to maintain future safety and healthy coping, and then initiates treatment termination.

Trauma Treatment Tailored for Children with IDD

The purpose of this treatment guide is to suggest ways of tailoring TF-CBT for children with IDD as a basis for high fidelity intervention and clinician training. The modifications are based on a combination of clinical recommendations (e.g., Grosso, 2012) and proven methods for treating anxiety disorders in children with autism. This will allow the model to be tested empirically as a beginning to an evidence base that currently does not exist.

To organize an effort to adapt TF-CBT to work with this population, a matrix table was formed with the steps of TF-CBT on the horizontal axis and core needs and deficits of IDD on the vertical axis (see Table 5). The resulting cells were completed based on clinical experience, literature review, and supporting audiovisual, activity suggestions, educational aids, and other materials obtained from sources designed to help children with IDD. The matrix forms the backbone of this treatment model and is continually being updated as materials are added from the ever-growing literature.

The manual will proceed following the PRACTICE modules of TF-CBT, providing recommended interventions and materials to address commonly encountered challenges unique to IDD. Many of the following points are consistent with TF-CBT provided to typically developing children and families. In order to apply the steps to children with IDD, it needs to be made more explicit and stepwise. During each module, the clinician must assess how the clients' disability impacts the use of the TF-CBT intervention component being considered. Accommodations may be needed to fit each client's unique sensitivities, preferred learning modalities, and conceptual capabilities, throughout the intervention. Further, we cannot assume that the child with IDD will intuitively understand and volunteer to participate in what is being asked of them, and extra motivational aids are often needed to sustain cooperation in a difficult treatment process.

This manual is not meant to replace formal training in TF-CBT. Practitioners should first receive training and achieve some proficiency in the overall model before attempting to apply these modifications for a specialized population. A free online course is available on the National Therapist TF-CBT Certification website (<https://tfcbt.org/training>) that can provide a beginning; further training can be accessed through local and regional training initiatives associated with the National Child Traumatic Stress Network (www.nctsn.org) and the CARES Institute (<https://centers.rowanmedicine.com/cares/>).

General Modifications: Relevant Research on Tailoring of Therapy with IDD Youth

Cognitive-behavioral therapy (CBT) shows promise for treating behavioral and emotional disturbance in children who have IDD. Most of the extant work in this area is the application of CBT to treating anxiety and challenging behaviors in children with autism spectrum disorders. Evidence based packages with documented efficacy for treating anxiety in children with ASD include: Coping Cat (McNally et al. 2013); Cool Kids (Chalfant, Rapee, & Carroll, 2007); Facing Your Fears (Reaven et al. 2011); Behavioral Interventions for Anxiety in Children with Autism (BIACA; Storch et al. 2013; Wood et al. 2009); and Building Confidence (Wood et al. 2009). These interventions are based on a CBT model of change and have many similarities. They all explicitly speak to the adjustments that are necessary to apply established treatment approaches to work with children on the autism spectrum.

CBT-based approaches to anxiety disorder treatment in autistic children have been shown to produce outcomes that are positive in general though not as efficacious as treatment with typically developing children (e.g., van Stensel & Bogels, 2015). Two of these treatment interventions (Reaven et al. 2011; Storch et al. 2013; Wood et al. 2009) have shown reliably measured and replicated efficacy in comparison with other models (Hunsche & Kerns, 2019). In order to apply CBT models to working with children and families with developmental delays and differences, modification is usually required. Modifications noted in the literature consist of tailoring the structure, environment, and intervention strategies and content of CBT treatments to best serve this population. Though empirical support is not yet well-documented for children with ID, it is important to note that the empirically driven modifications detailed below largely overlap with theoretical recommendations for children with ID and the existing empirical studies in this population (e.g., Hronis & Kneebone., 2017; Hronis et al. 2020). Table 5 highlights the central findings and recommendations derived from studies of treating anxiety in children with ASD and ID.

Table 5. General modifications of CBT for children with autism and developmental disorders

- Built-in routine, predictability, visual schedules
- Slowed pace; longer treatment duration; shorter sessions
- Booster and follow-up sessions
- Reinforcement schedules for therapy-related behaviors, e.g., attendance & engagement
- Caregiver involvement and active participation (even in treatment components typically done by the therapist without the caregiver)
- Calm space with sensory supports or “low sensory” environment
- Slowed, simplified language
- Highly structured worksheets
- Using a child’s specific interests for engagement and reinforcement
- Presentation of material using visual aids, concrete aids
- Additional treatment targets which address ASD core deficits, such as social or self-care skill development
- Videos to model skills and for gradual exposure
- Greater focus on in-vivo practice of skills
- Take into consideration the child’s neuropsychological profile, developmental level, and strengths and interests to adapt appropriately

Sources: Danial & Wood, 2013; Dyson, Chlebowski, & Brookman-Frazee, 2019; Grosso, 2012; Hronis, Roberts, & Kneebone, 2017; Moree & Davis, 2009; Moskowitz

et al., 2017; Ollendick et al., 2021; Reaven et al., 2009; Sofronoff, Attwood, & Hinton, 2005; Sung et al., 2011; Tallant, 2010; Ung et al., 2015

Issues in Therapeutic Engagement

Because of some of the unique qualities and circumstances of children with IDD, particular modifications are often necessary for therapy to be successful. Things to consider include: a) the environment of therapy; b) building therapeutic rapport and addressing interpersonal issues with the child; c) building the alliance with the caregiver; and d) management of risk and challenging behaviors in therapy. The following suggestions arise from our extensive review of the literature and our own clinical experience with this population of children and caregivers.

The therapeutic environment should provide comfort, a sense of safety and predictability, with attention to any potentially disruptive sensory stimuli. It helps to meet (in person or by telehealth) in a setting that is calm, quiet, removed from unnecessary distractions, and essentially the same each time the child comes for therapy. Busy families may present the child for telehealth treatment from the back of a parked car outside of school, in various rooms of the house, or in front of a video-game console proximal to the family computer. We have found that the level of distraction and sensory overload in such settings generally overrides the best efforts of the therapist to engage and address therapy goals. This is perhaps more true for children with organizational and intellectual limitations, than for typically developing children, though the case could be made that such settings are not advantageous for most clients.

We recommend bringing up such concerns with caregivers early in the treatment when needed, communicating clearly and directly to convey expectations that will need to be established before therapy can begin in earnest. Moving from a waiting area to the therapy room may be difficult at first. The therapist should be ready to take it slow, meet the client where they are, offer reinforcements of various kinds, and employ strategies of systematic exposure and familiarization to address beginning anxiety and resistance.

Therapeutic rapport can be more difficult for children with IDD. This may arise from the transition itself (e.g., moving from a more-preferred to less-preferred activity; meeting and getting to know a new person). Even more than with their typically developing peers, children with IDD may be anxious, unsettled, or stressed by meeting a new person. This is especially the case when asked to talk about sensitive subjects, such as traumatic memories, in relatively verbal fashion, with a therapist they do not initially know well. It is our experience for example, with children who have autism, that they usually resist starting therapy for multiple sessions until they have gotten more familiar with the routine of seeing the provider. After the routine is established, however, it is our experience that many have just as much trouble ending therapy with us as they did starting it.

It is recommended that therapists enter treatment relationships focusing particular attention on developing comfort and rapport, while recognizing that this process will likely take some time. It is also important to set up a therapy routine from the beginning. This often takes the form of several steps: a) greeting and conveying updates since last session; b) exploring thoughts and feelings of child and family at the time of the session; c) doing therapeutic tasks and skill-building (i.e., PRACTICE skill work); and d) concluding with play or an activity related to the child's particular interest areas. We have found that keeping of a visual schedule (e.g., on a white board or computer monitor) in sight can help regulate attention and participation in therapy throughout these routines.

Caregivers and parents may be equally as difficult to engage, particularly if they have had experiences of providers who did not understand their child or meet their needs. Therapists ask them to be actively involved in the treatment to support learning, generalization, and overcoming any initial avoidance by their child. Caregivers may need some extra attention to address their own anxieties and to make sure that their concerns are being taken seriously by the therapist.

Children with IDD are more likely to present with challenging behavior and co-occurring mental and behavioral symptoms, than typically developing children. They commonly present with comorbid anxiety disorders that amplify trauma reactions. Physical and verbal aggression may be a way of communicating such anxiety or other feelings that are difficult to communicate otherwise. They are more likely to suffer from suicidal ideation, self-harming behavior, feelings of panic, gender identity questions, visual and/or auditory hallucinations, interpersonal alienation and stigmatization. All of these should be addressed directly and in a concurrent manner along with trauma focused therapy. For more serious problems or those impacting safety, the therapist should start with those, obtain consultation or concurrent treatment for problems not in their scope of expertise (e.g., psychiatric consultation for medication; behavioral intervention to reduce self-harm, etc.) and then proceed with trauma therapy when the difficulty is settled enough to proceed safely.

It is important to remember the diversity of youth with IDD and that there will be much variation in the extent to which specific children will need the modifications and aids listed above. To help monitor your need for and use of specific accommodations, we have provided a brief accommodation monitoring checklist, included as Appendix C. More detailed information about tailoring treatment is provided in the next chapter.

Key Points: General Modifications to Consider from Relevant Research

- Recommendations to tailor TF-CBT are based on autism research, IDD interventions, and clinical experience.
- Tailoring interventions are aided by a Matrix of TF-CBT PRACTICE components and key modification needs.
- Special consideration should be given to engagement in treatment, including environment, risk management, rapport with child, and alliance with parents.
- Adapting CBT has been studied by autism and ID researchers with resulting recommendations including having caregivers in session, modifying language and sequencing, adding visual-spatial prompts, and incorporating interests.

Application of TF-CBT for Children with IDD

Review of the literature suggests three central domains of functioning that have been identified for modification of treatment (Hoover et al. in review):

1. Comprehension/Conceptual Understanding. In intellectual disabilities, conceptual functions are affected resulting in limited ability to comprehend, learn, and reason abstractly. Understanding of spoken and written language, and language expression are often under-developed (Schalock et al., 2021). The heritability of ID suggests an increased likelihood that parents and caregivers may also show weaknesses in these areas and may require support for understanding and adhering to treatment (LeHellerd & Steen, 2014). As compared with typically developing children, those with ID may require slowed and repeated presentation and simpler language, with checks for comprehension (Hronis & Kneebone, 2017). Social understanding, practical judgment, and problem-solving may require aid, as well. These must be integrated into trauma treatment to help patients and families maintain safety and apply tools provided in therapy. They may be more successful if introspection is de-emphasized and the focus is placed on skill building (Deblinger et al., 2011).

Some individuals with ID more easily understand concepts presented visually rather than verbally; often a multi-modal presentation of new material, combining verbal, visual, and physical engagement with tasks along with repetition, eases comprehension challenges (Lisle, 2007). Comprehension and communication differences may affect the child's and caregiver's understanding of concepts presented in trauma treatment.

2. Executive Functions and Motivation. Executive function (EF) is defined as meta-level cognitive processing expressed in skills such as attention, planning, self-motivating, initiating and executing behavior, problem-solving, and regulating emotions. On average, those with intellectual disability show relatively under-developed EF compared with typically developing peers, though the patterns of strengths and

weaknesses vary by individual (Spaniol & Danielsson, 2022). In children, degree of EF weakness is correlated with intellectual capacity, and functions such as working memory appear to improve with age and experience (Erostarbe-Perez et al., 2022). The child and caregiver's EF may impact trauma-focused treatment that requires sustained motivation and working memory for psychoeducation and skills training. In ASD particularly, a tendency has been shown for focusing on proximal details rather than distal goals or perspectives, termed the "weak central coherence" model (Olu-Lafe et al., 2014; Happe & Frith, 2006). Those affected by this processing difference may not immediately or consistently grasp the metacognitively-based rationale for engaging in treatment, especially when faced with anxiety-arousing reminders of trauma events. *We see challenges in sustaining motivation for therapy and the ability to persist in difficult treatment as essentially arising from EF.*

Perspective taking, initiation, and sustained motivation are needed to make the most of trauma therapy, and all may need additional supports. Motivational support for both the child and caregiver may be needed to aid engagement in therapy. Extra explanation and demonstration of the reasoning behind systematic desensitization may be helpful. Use of material reinforcers such as points, stickers, and a reward schedule can help children to stay engaged in treatment work. They may only be able to tolerate relatively shorter sessions due to difficulty sustaining treatment interactions (Hronis et al., 2017; Ung et al., 2015).

3. Generalization of Learning. There is much evidence that individuals with ID have greater difficulty, relative to typically developing peers, generalizing in-session learning to situations outside of training, education, and treatment sessions (e.g., Doughty & Kane, 2010; deMarchena et al., 2015). Generalization requires the opportunity to practice a skill or technique in ways that lend themselves to repeating the response after the learning has taken place. Stokes and Baer (1977) famously noted that generalization is a key component of behavioral analysis and that "a therapeutic behavioral change, to be effective, often (not always) must occur over time, persons, and settings, and the effects of the change sometimes should spread to a variety of related behaviors" (p. 350). Such generalization does not occur passively or simply as a result of learning (described by these authors as the "train and hope" model) and must be attended to if gains are to extend beyond the initial training.

In TF-CBT, skills (i.e., relaxation, affect regulation) are learned and practiced to replace traumatic responses with calm and resolution. Clinical experience suggests that therapy patients need help to recognize when to use coping skills in the "real world." For example, after being taught to use sensory calming strategies, a child may not be aware of internal anxiety cues that would signal that it is time to use the strategies. Some teaching methods such as video modeling have been shown to increase generalization, precisely because it aids memory and attention to context (Cullen et al., 2017).

Key Points: Applications of TF-CBT for Children with IDD

- **Comprehension/conceptual understanding, executive functioning and motivation, and generalization of learning are key domains for modification of treatment.**
- **Visual or multi-modal presentation of materials is often warranted.**
- **Supporting executive functions and motivation may be needed.**
- **Generalization of skills development should be emphasized in tailoring treatment.**

Chapter 6: PRACTICE Skills Modifications- The Matrix**Steps of TF-CBT**

The following steps match specific recommendations above with stages of TF-CBT to provide an adapted treatment. Therapists should ask themselves the following questions, answerable based on neuropsychological assessment of the child and informal assessment of the child and caregivers' response to the interventions. At each stage of treatment, therapists can obtain ideas for therapy session materials and resources from the Matrix- Table 6. The reader is referred to Appendix D for a detailed list of assessment questions the therapist can consider at each of the PRACTICE steps, to inform choice of resources and aids for therapy

Table 6: Matrix of TF-CBT Components and Tailoring Suggestions.

	Comprehension	Executive Function	Generalization
Psychoeducation and Parenting Skills	<ul style="list-style-type: none"> • Use visual aids to orient to treatment structure and expectations. • Employ Picture Exchange Communication System (PECS) or other language aid including augmentative and alternative communication devices (AAC). • Outline “Rules for Therapy” using simplified language. • Use developmentally appropriate books and games as comprehension aids (e.g., A Terrible Thing Happened, ‘Please Tell’ for sexual abuse, ‘Something is Wrong at My House’ for domestic violence, ‘Invisible String’ for traumatic loss, ‘Maybe Day’ for foster placement, What Do You Know?). • Introduce and use consistent trauma-related language, use of a table of language differences by cognitive level and corresponding vignettes. • Use concrete, visual examples for types of trauma and symptoms. 	<ul style="list-style-type: none"> • Use visual aids to orient to treatment structure and expectations. • Outline “Rules for Therapy” using simplified language. • Use preferred characters to illustrate symptoms. • Include caregivers’ input on how best to tailor treatment to their child. • Include caregivers’ input on how best to tailor treatment to their child. 	<ul style="list-style-type: none"> • Consider referral to parent support group or individual therapy for caregivers. • Provide psychoeducation about traumatic stress responses at different developmental levels to caregivers and others who help with the child’s care. • Incorporate structured behavioral assessments and interventions (e.g., Functional Behavioral Assessment) in parent training. • Use reward and tracking charts that can be shared by home, school, and other team members. • Provide psychoeducation about social skills. • For caregivers, provide psychoeducation on the interaction of the child’s diagnoses and symptoms (e.g., autism and PTSD).

<ul style="list-style-type: none">• Flash cards for key concepts (i.e., “trauma,” “reminders,” etc.).		
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	Comprehension	Executive Function	Generalization
Relaxation	<ul style="list-style-type: none"> • Use comprehension and engagement aids (“pizza breathing;” “hot air balloon” breathing). • Employ visual imagery/imaginal relaxation. • Deep breathing with concrete means (e.g., using bubbles). • Make a concrete toolkit of relaxation skills (e.g., Calm Box). • Use sensory objects (e.g., bubbles, bubble wrap) to promote relaxation. • Utilize where possible, yoga instruction and practice • Use structured worksheets, like “Schedule for Calming and/or Relaxing Activities.”⁴ 	<ul style="list-style-type: none"> • Teach muscle relaxation using preferred characters (e.g., Buzz Lightyear and Woody, Sesame Street Elmo, “Head, Shoulders, Knees and Toes” song). • Incorporate child’s related interests as ways to relax (e.g., drawing, playing games with caregivers or family members). • Make a toolkit of learned relaxation skills (e.g., Calm Caddy⁵). • Include strategies the parent identifies to work for the child. • Create a reward system for using relaxation strategies. 	<ul style="list-style-type: none"> • Involve caregivers and other important models in practice of relaxation skills. • Use structured worksheets in session and at home or other settings, like “Schedule for Calming and/or Relaxing Activities.”⁵ • Use sensory supports that can be employed in multiple settings (e.g., fidget toys). • Encourage and prompt at-home practice.

	Comprehension	Executive Function	Generalization
Affective Modulation	<ul style="list-style-type: none"> • Use apps or computer programs for learning emotion facial expressions (e.g., Emotional ABCs⁷; Feelu: Emotions & Mindfulness⁸; I Can Special Needs Learning-Feelings⁹). • Use structured worksheets to learn about emotions (e.g., “Words for Worry Word Search”⁴). • Use visual representations for emotions (e.g., emojis, Zones of Regulation⁵, Feeling Thermometers⁴, videos such as Inside Out film clips). • Use fill-in-the-blank scripts to improve communication skills. • Use videos to model emotions and coping strategies. 	<ul style="list-style-type: none"> • Use pictures of preferred characters or interactive activities (e.g., charades, music) to teach the emotions. • Use preferred subjects as metaphor for feelings (e.g., types of weather). • Use preferred subjects as a story to explore feelings (e.g., for airplanes, people’s emotions at the airport) • Charts and rewards for managing difficult feelings. • Power Cards¹¹ to foster identification with preferred characters modulating feelings. 	<ul style="list-style-type: none"> • Use caregivers and other important people in role plays. • Provide visual aids of emotions and affect ratings of family to be used at home. • Encourage caregivers and other important people to use the same simplified language to discuss emotions. • Create a concrete toolkit or box of coping skills to be used at home. • SPACE (Supportive Parenting for Anxious Childhood Emotions¹⁰) anxiety treatment for parents.

<ul style="list-style-type: none">• Employ shared Power Point slides as a visual reminder of skills used-collages of pictures, slogans, etc.	<ul style="list-style-type: none">• Make use of child's special interests as coping skills for feelings (e.g., reading, drawing, gaming).• Use mutual play with caregivers as coping skill (e.g., playing cards, engaging in common interests as distraction or expression modes).	
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	Comprehension	Executive Function	Generalization
Cognitive Coping	<ul style="list-style-type: none"> • Use comics or stories with thought bubbles (e.g., Cartoon Conversations). • Use a simplified worksheet for the cognitive triangle. • Use movement activities (e.g., CBT triangle taped on floor) to illustrate examples. • Play the Triangle of Life⁶ mobile app game. • Use simplified thought challenging (e.g., true vs. not true). • Use general coping thoughts/affirmations child can memorize and say to self in times of stress. 	<ul style="list-style-type: none"> • Involve family members in using the chosen name of the child’s worry. • Use characters to represent simplified cognitive distortions (i.e., Power Cards, SuperFlex). • Utilize games to maintain interest- these could include: the CBT Game (ref), Feelings matching. • Include caregivers in sessions identifying thought distortions and have them model cognitive errors. • Use positive sayings from preferred media as challenges to trauma-related beliefs. • Use movement activities (e.g., CBT triangle taped on floor) to illustrate examples. 	<ul style="list-style-type: none"> • Have caregivers and other important people play the Triangle of Life mobile application game with the child at home, school, and community. • Have caregivers and other important people help label the child’s thoughts at home. • Collaborate with caregivers and other important people to generate coping thoughts that fit the child’s typical concerns. • Involve caregivers and other important people as “co-investigators” to challenge trauma-related beliefs.

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| <ul style="list-style-type: none">• Externalize worries (e.g., “my worries are bothering me;” “my brain lies to me.”).• Use Worry Bugs games and books.^{12, 13, 14}• Garcia-Winner Superflex Model (ref) for identifying cognitive styles (e.g., rigidity, catastrophizing).• Incredible 5-point scale (ref) to introduce cognitive flexibility. | | |
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	Comprehension	Executive Function	Generalization
Trauma Narration and Processing	<ul style="list-style-type: none"> • Collaborate with child on ways to communicate needing a break (e.g., SUDS scale, red zone, break word). • Use a visual cue (e.g., timer, schedule) and concrete parameters (e.g., how many questions you will ask that session) to structure narration. • Audio or video record the narration for the child to have other forms of feedback. • Use visual representations to challenge trauma-related distortions (e.g., lists for “good kids” vs “bad kids,” responsibility pie). • Use metaphors for identified cognitive distortions (e.g., black & white cookie thinking, volcano catastrophic thoughts). • Provide play materials- sand tray, dollhouse, a variety of figures for play narration. Remote play: 	<ul style="list-style-type: none"> • Use preferred objects/activities as immediate rewards. • Provide choices in how to use “cool down” or play or preferred activity time following narration in each session. • Utilize support of caregivers in narration process in order to encourage engagement, reduce anxiety. • Use movement and preferred activities during breaks. • Use positive sayings from preferred media as challenges to trauma-related beliefs. • Use structured worksheets for telling the story (e.g., Beginning, During, and After). 	<ul style="list-style-type: none"> • Provide psychoeducation on to whom and under what conditions to share trauma history. • Prepare caregivers that information may not be objectively and completely accurate, but the child’s perception is most important.

<p>onlinesandtray.com; virtuandsandtray.org</p>	<ul style="list-style-type: none"> • Use a visual cue (e.g., timer, schedule) and concrete parameters (e.g., how many questions you will ask that session) to structure narration. 	
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	Comprehension	Executive Function	Generalization
<p>Conjoint Sessions</p>	<ul style="list-style-type: none"> • Encourage caregivers to use visual aids for their praise (e.g., a large font letter, video format, picture). • Plan a flexible schedule (e.g., longer session time with several built-in breaks) to share the narration. • Encourage caregiver to serve as “interpreter” to facilitate explanations. 	<ul style="list-style-type: none"> • Allow child to pick the format to share the story (e.g., recording of child’s voice, clinician reading aloud). • Reinforce the conjoint narration with preferred activity/object for both caregiver and child (e.g., play). • Use white boards, written timelines, or other visual aids to explain narratives and other family processes. 	<ul style="list-style-type: none"> • Use child’s regulation strategies with caregivers when preparing for conjoint sessions.

In-Vivo Mastery	Comprehension	Executive Function	Generalization
	<ul style="list-style-type: none"> • Provide a concrete visual example of a fear hierarchy (e.g., ladder, mountain). • Incorporate disorder-informed difficulties in the hierarchy. 	<ul style="list-style-type: none"> • Use examples from child’s interests to illustrate fear habituation (e.g., roller coasters, storms, spiders, etc.). • Use preferred objects/activities as immediate rewards or safety features. 	<ul style="list-style-type: none"> • Practice in-vivo mastery in settings beyond those in which the trauma was experienced. • Involve caregivers and other important people in exposures and to facilitate practice across contexts.

	Comprehension	Executive Function	Generalization
Enhancing Safety/Social Skills	<ul style="list-style-type: none"> • Use visuals for safety rules. • Use a hula hoop to teach “hula space” (i.e., personal boundaries). • Use games (e.g., Simon Says) to identify various body parts. • Use structured steps for safety seeking (e.g., No, Go, Tell). • Incorporate social skills training and apply to safety enhancement (e.g., Circles Curriculum⁷). 	<ul style="list-style-type: none"> • Use preferred characters in safety rules and boundaries (Power Cards). • Reward child consistently for use of safe behaviors. 	<ul style="list-style-type: none"> • Actively involve caregivers and other important people (e.g., siblings, teachers) throughout the course of treatment to support skill practice across contexts. • Actively involve other therapists (e.g., occupational, speech) for wraparound care. • Actively involve caregivers and other important people in reinforcing therapy-related behaviors (e.g., engagement, skill practice). • Actively involve caregivers and other important people in role plays and behavioral rehearsals. • Conduct follow-up or booster sessions in-person.

		<ul style="list-style-type: none">• Teach and encourage use of Social Stories to normalize safe interactions.
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Note. See Therapy Materials for resource citations. These recommendations are based on the literature on adapted CBT for individuals with IDD and clinical experience from the authors (see Hoover et al. in review).

Chapter 7: After TF-CBT: What Next?

While TF-CBT may reduce trauma-specific anxiety and depression, these symptoms may persist and require further treatment after TF-CBT. As previously discussed, youth with ASD and ID may have already been symptomatic and/or diagnosed with other mental health conditions prior to recognizing that trauma was a factor. Trauma can also be a risk factor in developing additional mental health conditions and exacerbate pre-existing symptoms. Common additional diagnoses include generalized anxiety disorder (GAD), social anxiety disorder (SAD), attention deficit hyperactivity disorder (ADHD), and major depressive disorder (MDD). Some children develop obsessive-compulsive disorder (OCD), or trauma might add a subtype (e.g., obsessions of contamination and compulsions of hygiene; self/other harm obsessions with checking/reassurance seeking compulsions) to prior OCD subtypes (e.g., symmetry/ordering/arranging).

Children who have developmental disorders and trauma are at risk for numerous other developmental crises, family stressors, further traumas, and clashes with educational and treatment environments. Following even the most successful TF-CBT treatment, children and families often continue to require therapy to address additional mental health problems and adversities to which IDD may predispose them. As a result, the therapist may feel a pull to provide long-term care for a variety of treatment issues that go well beyond the initial trauma-focused therapy request. What should clinics and providers do in this situation? We recommend four possibilities depending on the nature of clinical needs and providers' availability:

- a. Clarify new treatment goals and continue to provide individual and/or family therapy consistent with the therapist's expertise, availability, and funding for ongoing treatment.
- b. Refer for specialty care to address particular behavioral and emotional treatment needs (see below for interventions specific to diagnoses).
- c. Provide monitoring or refer for episodic care in which patients discharge or pause therapy sessions when current treatment concerns are met, and then return as needed across time and development when issues come up.
- d. Co-treatment may be beneficial when the child requires certain specialty services (e.g., behavioral supports, wraparound care, occupational therapy, speech-language therapy, etc.) and these can be offered in addition to ongoing treatment individual and family work with the primary therapist.

In borrowing from work with adult patients, appropriate treatment goals post-intervention include teaching new cognitive and behavioral skills yet unlearned, teaching compensatory strategies for deficits (core problems of the developmental -condition) that cannot be changed, facilitating self-acceptance, and expanding coping skills to decrease or prevent symptoms of comorbid mental health problems such as anxiety and depression (Gaus, 2018). As discussed earlier, a traditional (CBT) approach shows promise for treating behavioral and emotional disturbance in children who have IDD.

Key Points: Post Trauma Recovery

- Trauma can also be a risk factor in developing additional mental health conditions and exacerbate pre-existing symptoms.
- Children and families affected by IDD often continue to require therapy after completing TF-CBT, to address additional mental health targets and other support needs.
- Establish “postvention” treatment goals or plan for referral/co-treatment in the client’s next phase of care.

Conclusions

This therapy guide is meant to provide the most up-to-date information for adapting TF-CBT for traumatized children with developmental disorders. The suggestions in this guide are based on the small but growing research literature and our own clinical experience. While this work may seem complex in its specialized recommendations, much remains to be researched and written as we move forward with renewed hope and determination to serve children and families. TF-CBT for children with IDD requires flexibility and creativity to customize it for each individual. It is our experience that even children with significant developmental differences can heal from trauma and thereby resume their developmental trajectory. We wish you the best as you press forward in this important work.

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Appendix A: Definitions of Intellectual and Developmental Disabilities

1. For resources and entitlements specified by the Americans with Disability Act of 2000 (PL-106-402), including services through Social Security and state agencies for persons with developmental disabilities, the definition provided above pertains with additional specification that three or more (listed) significant areas of functioning must be affected. For young children up to age 9 the law covers developmental conditions that are likely to result in significant future impairment without services and supports.

2. Educational supports offered by states and local school districts under the federal Individuals with Disabilities Education Act (IDEA) follow the IDEA requirement that a child be assessed as having one of 13 qualifying categories of disabilities (e.g., autism, blind, learning disability) and also offers states the option of including the general category of “developmental delay” for children ages 3 to 9 or any subset of those ages. The disability must have an impact on functioning in the educational setting that is assessed as leading to a need for special education services <https://sites.ed.gov/idea/regs/b/a/300.8> IDEA part C requires states to provide early intervention services for infants and toddlers (birth to 3 years) who have developmental delays or developmental disorders putting them at significant risk of delays (See <https://www.parentcenterhub.org/ei-overview/>).

3. Diagnoses of IDD by medical providers, including mental health providers, generally use the developmental disability categories specified by the diagnostic system of mental disorders of the American Psychiatric Association and by the international classification of disorders. With the publication of the DSM-5 (2013), the American Psychiatric Association changed the umbrella term for the group of disorders originating in the developmental period from developmental disorders to “neurodevelopmental disorders” (see Morris-Rosendahl & Crocq, 2020).

Appendix B: Individualized Therapy Accommodations Planning Tool

Issues	Strengths in each of the Areas	Age/ Grade Level*	Therapy Accommodations
Language issues	Language strengths		
___ Limited expressive vocabulary			
___ Limited ability to express ideas in words			
___ Speech unclear/hard to understand			
___ Limited receptive vocabulary			
___ Limited understanding of complex language forms (e.g., multi-phrase sentences, etc.)			
___ Limited pragmatic skills (understanding and use of verbal and nonverbal cues for interpersonal communication)			
Cognitive issues	Cognitive strengths		
___ Difficulty with abstract concepts (more difficult than expected for age)			
___ Difficulty with generalizing			
___ Difficulty with immediate memory (e.g., ability to remember multiple instructions)			

<input type="checkbox"/> Difficulty with long-term memory retrieval on demand			
<input type="checkbox"/> Limited attention span for at least some kinds of materials (specify)			
<input type="checkbox"/> Limited visual/spatial skills—may affect organizing of information			
<input type="checkbox"/> Uneven skills (specify—e.g., visual spatial skills much stronger than verbal or the opposite)			
Sensory/motor issues	Visual/spatial & motor strengths		
<input type="checkbox"/> Low vision (for near, far, both?)			
<input type="checkbox"/> Hearing issues (any aids?)			
<input type="checkbox"/> Fine motor issues (e.g., affecting writing, drawing)			
<input type="checkbox"/> Gross motor issues			
<input type="checkbox"/> Sensory sensitivities (specify)			
Academic skills that can impact treatment <input type="checkbox"/> Reading decoding <input type="checkbox"/> Reading comprehension <input type="checkbox"/> Writing skills <input type="checkbox"/> Understanding basic numbers	Academic strengths		

<p style="text-align: center;">Other issues</p> <p>___ Willingness and Motivation</p> <p>___ Obsessive about sameness</p> <p>___ Hyperfocus on</p> <hr/> <p>___ Difficulty with transitions</p> <p>___ Limited emotional coping strategies</p>	<p style="text-align: center;">Special characteristics</p> <p>___ Special interests</p> <p>___ Tends to follow clear routines</p> <p>___ Has mastered coping strategies of</p> <hr/> <p>___ Other</p>	
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*If available

Appendix B (Continued): Individualized Therapy Accommodations Planning Tool

Completed Example

Issues	Strengths in each of the areas	Age/Grade Level*	Therapy Accommodations
Language issues	Language strengths		
X Limited expressive vocabulary	Checks for comprehension (“You said...?”)	4 th or 5 th	<ul style="list-style-type: none"> ·Pt uses drawings to express emotions, situations ·Pt given sufficient time to answer therapist questions and prompts
X Limited ability to express ideas in words	Can express simple, concrete ideas	4 th or 5 th	<ul style="list-style-type: none"> ·Pt uses drawings to express emotions, situations ·Pt asked to point to or circle things when possible ·Therapist writes out pt’s words when necessary
__ Speech unclear/hard to understand	Pt can express himself/articulate		

<p><input checked="" type="checkbox"/> Limited receptive vocabulary</p>	<p>Can learn new words with repetition</p>	<p>4th or 5th</p>	<ul style="list-style-type: none"> ·Therapist carefully selects words to streamline/reduce psychology jargon ·Use of pictures whenever possible instead of/in addition to words ·Use of slides and visuals to present content
<p><input checked="" type="checkbox"/> Limited understanding of complex language forms (e.g., multi-phrase sentences, etc.)</p>	<p>Can understand simple, concrete language</p>	<p>4th or 5th</p>	<ul style="list-style-type: none"> ·Therapist simplifies language in session and on hw ·Therapist matches words and pictures when possible
<p><input checked="" type="checkbox"/> Limited pragmatic skills (understanding and use of verbal and nonverbal cues for interpersonal communication)</p>	<p>Pt understands use of facial expressions in others and in himself but does not often exhibit them</p> <p>Pt is very social – wants friends, wants to treat people kindly</p>	<p>2nd or 3rd</p>	<ul style="list-style-type: none"> ·Therapist constantly reviews and exaggerates own facial expressions when practicing emotion recognition ·Therapist emphasizes behaviors (facial, hand, body expressions) associated with emotions ·Rapport-building emphasized at start of session by spending several sessions with caregiver

			<p>understanding pt's:</p> <ul style="list-style-type: none"> -Interests (including restricted ones) -Strengths -Reward systems already in place -Collaterals involved in care -Preferred mode of communication
Cognitive Processing Issues	Cognitive Processing Strengths		
<p><u>X</u> Difficulty with abstract concepts (more difficult than expected for age)</p>	<p>With repetition, personalization, and simplification, can understand more abstract concepts</p>	<p>3rd or 4th</p>	<ul style="list-style-type: none"> -Slower pacing of treatment to allow for more review of content -Breaking down session content in to smaller, more concrete pieces -Always bringing content back to personal experiences -Review previous session content at start of every session

<p><input checked="" type="checkbox"/> Difficulty with generalizing</p>	<p>Pt can offer examples pertaining to his personal life</p>	<p>3rd or 4th</p>	<ul style="list-style-type: none"> ·Therapist reviews hw with pt at start of session and brings his answers into the review of last session, generalizing skills to things that happened to him ·Therapist always ties examples back to things pt has said/experiences he has had
<p><input checked="" type="checkbox"/> Difficulty with immediate memory (e.g., ability to remember multiple instructions)</p>	<p>Pt wants to focus but cannot always do so without prompting</p>	<p>3rd or 4th</p>	<ul style="list-style-type: none"> ·Therapist coaches caregiver how to prompt without nagging ·Therapist breaks instructions down into small pieces, checks for comprehension in between ·Therapist puts everything on slides/visuals when possible and matches verbal language to slide content

<p><u>X</u> Difficulty with long-term memory retrieval on demand</p>	<p>Pt does hw in between sessions, with prompting from caregiver and setting alarm (together with therapist in session)</p>	<p>5th or 6th</p>	<ul style="list-style-type: none"> ·Therapist reviews at start of every session ·HW each week is based directly off of session content (therapist created content specially for pt) ·First pg. of hw is a pictorial summary of session content ·Pt teaches back session content to caregiver at end of every session ·Therapist uses hw responses to check pt's comprehension and know what to emphasize or focus on next
<p><u>X</u> Limited attention span for at least some kinds of materials (specify)</p>	<p>Pt is very motivated to perform well and very responsive to positive reinforcement</p>	<p>3rd or 4th</p>	<ul style="list-style-type: none"> ·Therapist shortened sessions to 30 minutes/week ·Therapist maintains engagement through active learning (games, questions, activities)

<p>__ Limited visual/spatial skills— may affect organizing of information</p>	<p>Area of strength – cognitively and pt's preference</p>	<p>4th or 5th</p>	<ul style="list-style-type: none"> ·All session content is presented visually ·Pt is asked to draw responses whenever possible ·Abstract concepts, chain analyses, cause and effect are explained with diagrams and pictures
<p>_X_ Uneven skills (specify—e.g., visual spatial skills much stronger than verbal or the opposite)</p>	<p>Pt is relatively stronger in visual vs verbal skills</p>	<p>5th or 6th</p>	<ul style="list-style-type: none"> ·Therapist utilizes visual content whenever possible ·Therapist matches verbal words to visual content ·Therapist streamlines and simplifies verbal content/psychological jargon

<p><input checked="" type="checkbox"/> Slowed processing speed or working memory</p>	<p>Pt does process information but needs 30 seconds longer than most to do so</p>	<p>4 or 5 y/o</p>	<ul style="list-style-type: none"> ·Therapist waits 30 seconds after saying something to give pt time to respond ·Therapist allows pt to check for comprehension (“You said...?”) ·Therapist slows pace and rate of speech, uses shorter sentences, and pauses often to allow pt to process ·Therapist talks only 30% of time – pt engaged in activities rest of time
<p>Sensory/motor issues</p>	<p>Visual/spatial & motor strengths</p>		
<p><input type="checkbox"/> Low vision (for near, far, both?)</p>	<p>Intact</p>		
<p><input type="checkbox"/> Hearing issues (any aids?)</p>	<p>Intact</p>		
<p><input type="checkbox"/> Fine motor issues (e.g., affecting writing, drawing)</p>	<p>Intact (immature pencil grasp but readable drawing and writing)</p>		
<p><input type="checkbox"/> Gross motor issues</p>	<p>Intact (poor coordination)</p>		
<p><input type="checkbox"/> Sensory sensitivities (specify)</p>	<p>Not impairing</p>		

<p>Academic skills that can impact treatment</p> <p>___ Reading decoding</p> <p><u>X</u> Reading comprehension</p> <p>___ Writing skills</p> <p>___ Understanding basic numbers</p>	<p>Academic strengths</p> <p>Very hard working</p> <p>Very positive</p>	<p>4th or 5th</p>	<ul style="list-style-type: none"> · Minimal reading comprehension required · Simplification of content across UP sessions · Therapist praises pt's work and effort · Therapist helps caregiver to implement reward systems when needed
<p>Other issues</p> <p><u>X</u> Willingness and Motivation</p> <p>___ Obsessive about sameness</p> <hr/> <p>___ Difficulty with transitions</p> <p><u>X</u> Limited emotional coping strategies (i.e., frustration tolerance)</p>	<p>Special characteristics</p> <p><u>X</u> Special interests</p> <p><u>X</u> Tends to follow clear routines</p> <p>___ Has mastered coping strategies of</p> <hr/> <p><u>X</u> Other Increased engagement of collaterals</p>	<p>3rd or 4th</p>	<ul style="list-style-type: none"> · Likes drawing – therapist and pt draw together every session – pt drawing what happened during situation of high emotional intensity, therapist drawing diagram, etc. · Same routine every session – Review HW, review previous session content, and “Listening Eyes and Ears” · Minimal materials that pt has to read. Most content is visually presented · Therapist engages regularly with: caregiver, sibling, community hab care providers, school social

			worker, psychiatrist day hab workers
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Appendix C: ACCOMMODATIONS CHECKLIST

<i>Identify nature of IDD involved (check multiple if pertinent, e.g., ASD and ID)</i>
<input type="checkbox"/> <i>Learning disabled</i>
<input type="checkbox"/> <i>Speech/language impaired</i>
<input type="checkbox"/> <i>Autism spectrum disorder</i>
<input type="checkbox"/> <i>Intellectually disabled</i>
<input type="checkbox"/> <i>Multiple handicap</i>
<input type="checkbox"/> <i>Other (include sensory impairment) _____</i>

ACCOMMODATIONS USED DURING THIS BLOCK OF SESSIONS:

Increased attention to engagement strategies

- More play time
- Use of special interests and/or skills
- Other: _____

Flexible session and treatment length and pacing

- Shorter sessions
- More sessions
- Adjust pacing of content
- Other _____

Adjustment of parental/caregiver involvement

Mechanism:

- Increased time in child session
 - Increase in parent/caregiver sessions or between-session contact

Goal:

- Skill reinforcement
- Help deal with child anxiety
- For interpretation purposes

Adjustment of session content

- Clarifying session structure/aids for marking structure

Strategies for presentation adjusted depending on dd needs:

- Simplify language
- Simplify some content (e.g., choice of PRAC skill strategies)
- Additional comprehension check
- Increased use of visual cues
 - Use of materials/strategies developed for youth with disabilities (e.g., social stories)
 - Building on child's special interests or areas of talent/relative strength^[J3]
- Other _____ (e.g., increased use of technology/apps or materials for younger age)
- Attention to generalization of PRAC skills
- Attention to modality/type of narration based on child's skills
- Other: _____ (includes attention to any sensory issues—e.g., sensory sensitivities of youth with ASD, sensory issues of youth with low vision, hearing impairment, etc.)

Appendix D: Assessment of Adaptive Domains at Each Stage of TF-CBT

Psychoeducation and Caregiver Training- Domain	ASSESS:
Comprehension/Conceptual Understanding	<ul style="list-style-type: none"> • Does the child/caregiver know key terms inherent in this step (e.g., “trauma,” “trigger,” “physical, sexual, psychological abuse,” “rewards and reinforcement”)? • Will the child/caregiver benefit from pictures and other visual and activity-based illustrations of trauma and its effects and parenting skills? • Does the child/caregiver understand the connection between having traumatic experiences and the signs and symptoms present in the child? • Does the child/caregiver understand how the child’s trauma might impact adult caregivers? • Does the child/caregiver have good conceptual connections between descriptions and actual experiences and events (grasping concepts related to trauma and potential feelings, consequences, outcomes, interpersonal implications)? • How much do the participating parents/caregivers know and understand specific behavioral interventions including FBA, use of antecedents, behavioral intervention plans, and social skills training?
Executive Function/Motivation	<ul style="list-style-type: none"> • How willing and motivated are the child/caregiver to engage in therapy with an unfamiliar adult? • How willing is the child to stop, think, and use relaxation skills before, during, or after a stressful trigger? • What is the level of the caregivers’ willingness to change parenting styles if needed?

<p>Generalization of Learning</p>	<ul style="list-style-type: none"> • Are the child/caregiver able to recognize potentially traumatic situations or reminders of past traumas? • Can the child/caregiver remember information that was presented in psycho-education? • How able are caregivers to implement recommendations for parenting skills including tracking, rewarding, and consistency skills?
<p>Relaxation</p>	<p>Assess:</p>
<p>Comprehension/Conceptual Understanding</p>	<ul style="list-style-type: none"> • Does the child/caregiver understand key terms inherent in this step? (e.g., “deep breathing,” “relaxation,” “tense,” “stressed,” and “breath”)? • Are the child/caregiver able to name parts of the body that might experience tension, and identify how tension or body states “feel”? • Will the child/caregiver benefit from pictures and other visual and activity-based illustrations of tension and relaxation? • Does the child/caregiver understand the connection between relaxation and reduced feelings of stress and anxiety?
<p>Executive Function/Motivation</p>	<ul style="list-style-type: none"> • How willing is the caregiver to teach and reinforce relaxation skills at home and in the community? • How willing is the child to stop, think, and use relaxation skills before, during and after a stressful trigger?
<p>Generalization of Learning</p>	<ul style="list-style-type: none"> • Does the child/caregiver have the ability to remember skills taught in session? • Does the child/caregiver have the ability to read cues that it is time to use relaxation? • What is the caregiver’s ability to remember, remind, prompt, carry out

	thoughts-related plans at home and in the community?
Affect Expression and Modulation	Assess:
Comprehension/Conceptual Understanding	<ul style="list-style-type: none"> • Does the child/caregiver understand central key terms including names of feelings (happy, sad, disappointed, scared...)? • Would the child/caregiver be helped by visual illustrations of emotions and emotion management? • How well do the child/caregiver identify feelings in themselves and others? • What is the child/caregiver's understanding of emotional expression, emotional response, body response, and the positive effects of managing one's emotions?
Executive Function/Motivation	<ul style="list-style-type: none"> • How willing are the caregivers to teach and reinforce relaxation skills at home and in the community? • How willing is the child to stop, think, and use relaxation skills before, during, or after a stressful trigger?
Generalization of Learning	<ul style="list-style-type: none"> • How able are the child/caregiver to remember affect regulation skills? • Ability to apply techniques to manage self when they may believe that their response is justified or impossible to manage? • What is the level of the caregivers' ability to remember, remind, prompt, carry out affect regulation plans at home and in the community?
Cognitive Coping	ASSESS:
Comprehension/Conceptual Understanding	<ul style="list-style-type: none"> • Does the child/caregiver understand key terms inherent in this step? ("thoughts vs. feelings," "mind," "brain," "thought glitches," "thought challenging," "negative thoughts," "positive thoughts")

	<ul style="list-style-type: none"> • Will the child/caregiver respond best to verbal explanations, visual illustrations, or a combination of both? • At what level do the child and caregiver understand the connection between thoughts, feelings, and the purposes of cognitive coping? • Child/caregiver’s awareness of their own thoughts • The relationship between thoughts, feelings, and actions • Theory of mind concepts- accuracy of self-reflection about thoughts • Ability to challenge client’s own thought process • Understanding of the thought/reality distinction (i.e., just because we have thoughts does not mean they are “real” or “true”)?
<p>Executive Function/Motivation</p>	<ul style="list-style-type: none"> • How able is the caregiver to teach and reinforce cognitive coping skills at home? • How willing is the child to “stop and think”? • Are there impulse control problems that preclude cognitive reflection in the moment?
<p>Generalization of Learning</p>	<ul style="list-style-type: none"> • Ability to remember skills taught in session • Ability to read cues that it is time to use cognitive techniques • Caregiver’s ability to remember, remind, prompt, carry out thoughts-related plans at home and in the community.
<p>Therapeutic Narration</p>	<p>ASSESS:</p>
<p>Comprehension/Conceptual Understanding</p>	<ul style="list-style-type: none"> • Will the client be better able to complete narration in verbal or visual format? • What kinds of support will the client require to complete a narrative? (translator, keyboard, art materials, breaking task into small pieces, dictating to therapist)

	<ul style="list-style-type: none"> • Is the client able to tell a personal story? • Does the child/caregiver understand the purpose and helpfulness of producing a trauma narrative?
Executive Function/Motivation	<ul style="list-style-type: none"> • Does the caregiver support the idea of narration and encourage the child to do this step-in treatment? • Does the caregiver have personal trauma or other issues that reduce willingness to support or listen to the narrative?
In-Vivo Desensitization	ASSESS:
Comprehension/Conceptual Understanding	<ul style="list-style-type: none"> • Does the child/caregiver understand key terms inherent in this step (e.g., “fear,” “worry,” “anxiety,” “exposure,” “face your fears”)? • Will the child/caregiver best respond to visual explanations, diagrams, prompts? • Does the child/caregiver readily understand the applicability of gradual exposure? • Reality-fantasy distinction? • Difference between thoughts and feelings?
Executive Function/Motivation	<ul style="list-style-type: none"> • Are the child/caregiver able to see the “big picture” about how in-vivo practice might be helpful? • How does the child respond to reinforcers? • How able is the caregiver to reinforce the child’s follow-through on difficult in-vivo practice?
Generalization of Learning	<ul style="list-style-type: none"> • Does the child/caregiver remember to carry out “homework” assignments? • Will the child/caregiver remember and respond to visual schedules, calendars, and prompts?
Conjoint Child-Caregiver Sessions	ASSESS:
Comprehension/Conceptual Understanding	<ul style="list-style-type: none"> • Will the child need help- i.e., extra time, verbal assistance, visual-spatial prompts- to share narration with their caregiver?

	<ul style="list-style-type: none"> • Does the child require the caregiver to “interpret” in order to share information including the narration? • Is the caregiver able to follow along verbally or will they require visual or interpretive aids?
Executive Function/Motivation	<ul style="list-style-type: none"> • Will the child/caregiver benefit from conjoint explanation about purposes and outcomes of narration? • Is the caregiver prepared to provide emotional support and regulate own feelings when the narrative is shared? • Do the child/caregiver need extra support to maintain emotional/behavioral regulation in narration?
Generalization of Learning	<ul style="list-style-type: none"> • Will the child/caregiver need guidance for when and where to share the narrative outside of therapy sessions?
Enhancing Safety Skills	ASSESS:
Comprehension/Conceptual Understanding	<ul style="list-style-type: none"> • Does the child/caregiver understand key words inherent in this step (e.g., “safe,” “tell someone,” “danger,” “boundaries,” etc.)? • Are the child/caregiver able to read written safety signals in the environment (stop signs...)? • Will these child/caregivers remember and respond to visual schedules, calendars, reminders, prompts? • Are the child/caregiver able to recognize unsafe environments (e.g., situations in which re-victimization might occur) and the difference between safe and unsafe? • Does the child/caregiver recognize the need to promote safety? • Does the child/caregiver expose themselves to unsafe situations through behavior? • Are the child/caregiver able to anticipate possible unsafe situations before they have happened? • Able to identify safe and unsafe people?

Executive Function/Motivation	<ul style="list-style-type: none">• Does the child/caregiver believe that it is important to maintain safety?• How motivated are the child/caregiver to improve their situation or their child's situation?
Generalization of Learning	<ul style="list-style-type: none">• Does the child/caregiver remember psycho-education?• Will the child/caregiver make use of charts and reminders?• Will the client recognize situations outside of therapy that require the use of coping skills?