

2019

CONSIDERING TRAUMA IN AUTISM SPECTRUM DISORDER DIAGNOSTIC EVALUATIONS IN CHILDREN: A QUALITATIVE INQUIRY

Kaitlyn Page Ahlers
University of Montana - Missoula

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CONSIDERING TRAUMA IN AUTISM SPECTRUM DISORDER DIAGNOSTIC
EVALUATIONS IN CHILDREN: A QUALITATIVE INQUIRY

By

KAITLYN PAGE AHLERS

M.A., University of Montana, Missoula, MT, 2016
B.S., Boston College, Chestnut Hill, MA, 2012

Dissertation

presented in partial fulfillment of the requirements
for the degree of

Doctor of Philosophy
in Clinical Psychology

The University of Montana
Missoula, MT

August 2019

Approved by:

Scott Whittenburg
Graduate School Dean

Anisa Goforth, Chair
Psychology

Christine Fiore
Psychology

Cameo Stanick
Psychology

Jacqueline Brown
Psychology

Lindsey Nichols
Counselor Education

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

Ahlers, Kaitlyn, M.A., August 2019

Clinical Psychology

Chairperson: Anisa Goforth, Ph.D.

The pervasiveness of trauma exposure and potential effects on children's development and both proximal and future health outcomes are well established in the research literature. Importantly, there is increasing recognition that children with disabilities, including autism spectrum disorder (ASD), might be at heightened risk for trauma exposure and trauma-related health outcomes. However, there is a paucity of research on trauma-informed practices with children with ASD, specifically the assessment methods used to evaluate for the presence of trauma exposure and trauma-related sequelae. While there are guidelines for the diagnostic assessment of ASD, there are no known established guidelines or research regarding trauma assessment in children being evaluated for ASD. The purpose of this project was to use qualitative research methodology to explore whether (and if so, how) trauma exposure and trauma-related sequelae are evaluated during ASD diagnostic evaluations through interviewing psychologists who conduct multidisciplinary ASD diagnostic evaluations. This project also sought to determine what factors might affect the likelihood that trauma assessment is integrated into the ASD diagnostic process. While the majority of participants identified that they considered trauma during ASD diagnostic evaluations, most engaged in trauma screening and referred out for additional evaluation to aid in differential diagnosis. Commonly identified barriers to engaging in trauma assessment ranged from individual (e.g., knowledge) to clinic (e.g., available resources) to system (e.g., the diagnostic system) level factors. In order to increase the use of trauma assessment by psychologists in ASD diagnostic clinics, adaptations across each of these levels will be needed.

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Acknowledgements

I am greatly appreciative of my dissertation committee for their time and contributions to this project. Drs. Anisa Goforth, Cameo Stanick, Jacquie Brown, Chris Fiore, and Lindsey Nichols were each instrumental to the conceptualization, planning, and execution of this project. Special thanks to Dr. Lindsey Nichols for her consultation and sharing of her qualitative research expertise. I am also immensely grateful for my dissertation chair, Dr. Anisa Goforth, and her willingness to guide and mentor me throughout the evolution of this project as well as for Dr. Cameo Stanick, who provided mentorship, knowledge, and support from afar. Additionally, this project would not have been possible without Dr. Heather Halko and Lacey DeSalles, who graciously offered their time and insights to this project. A special thank you to Drs. Terisa Gabrielsen, Brandon Rennie, and Connor Kerns who contributed their expertise and helped me shape and refine my research questions and methodology. And a final thank you to the thirteen participants who generously took time out of their busy schedules to share their perspectives and have open conversations about their experiences conducting ASD diagnostic evaluations.

Lastly, the biggest thank you is to my family, especially my parents and Jeff, for their unwavering and constant support, patience, and encouragement throughout my many years of educational pursuits.

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CHAPTER 1

INTRODUCTION

It is well established in the research literature that a significant proportion (approximately two in three children) will experience at least one traumatic event before they reach 18 years of age (Copeland, Keeler, Angold, & Costello, 2007; Finkelhor, Ormrod, & Turner, 2007; McLaughlin et al., 2013). While not all children will experience trauma-related sequelae, the prevalence of trauma exposure is particularly concerning given the potential adverse effects on children's development (Dorsey et al., 2017). Although trauma exposure goes by many different names (e.g., adverse childhood experiences, major/significant life events, traumatic events), regardless of the terminology, trauma has been shown to have pervasive effects on children's cognitive, emotional, physical, and social development, which can significantly affect their immediate and lifelong health (Dorsey et al., 2017; Loeb, Stettler, Gavila, Stein, & Chinitz, 2011; Taylor & Gotham, 2016). Specifically, childhood trauma exposure is associated with the development of posttraumatic stress disorder (PTSD) and other negative mental health outcomes (e.g., mood problems, disruptive behavior), high-risk behaviors in adolescence and adulthood (e.g., delinquency, substance abuse), disease in adulthood (e.g., cancer, heart disease), and reduced life expectancy (Brown et al., 2009; Copeland et al., 2007; Felitti et al., 1998; Layne et al., 2014).

The high prevalence of trauma exposure and trauma-related sequelae indicates a need for all systems that serve children to be "trauma informed," meaning that the pervasiveness of trauma is recognized from the individual- to the systems-level (Keesler, 2014; Ko et al., 2008). Therefore, knowledge of traumatic events and trauma-related outcomes and how to assess and intervene for both is essential in many settings that serve children. While there has been

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increasing recognition of the importance of trauma-informed systems, there has been surprisingly limited research on trauma-informed practices with children with disabilities, specifically autism spectrum disorder (ASD). Indeed, the current research is limited to preliminary investigations of prevalence rates of exposure to childhood adversity and trauma-related sequelae in children with ASD and a hypothetical model outlining the potential relationship between trauma and ASD (Kerns, Newschaffer, & Berkowitz, 2015).

Although the research is limited, researchers have suggested that children on the autism spectrum are at heightened risk for both trauma exposure and trauma-related outcomes (e.g., PTSD, mood disorders; Berg, Shiu, Acharya, Stolbach, & Msall, 2016; Mehtar & Mukaddes, 2011; Taylor & Gotham, 2016). Researchers have noted that there are unique factors associated with ASD that may increase risk for trauma exposure (e.g., social skill deficits, high parenting stress) and trauma-related sequelae (Chan & Lam, 2016; Pfeffer, 2016). Importantly, one of the proposed risk factors for trauma-related symptoms for children with ASD is insufficient trauma screening and assessment practices (Keesler, 2014). Unfortunately, there are no known evidence-based assessment (EBA) tools designed specifically for use with children with ASD who were exposed to trauma (Brenner, Pan, Mazefsky, Smith, & Gabriels, 2017).

Diagnostic evaluations for ASD are considered to be a complex process, as the majority of children on the autism spectrum are also diagnosed with a comorbid condition (e.g., intellectual disability, language disorder, accompanying genetic/medical condition; psychiatric comorbidity; American Psychiatric Association [APA], 2013; Levy et al., 2010). While there are established practice parameters for the diagnostic assessment of ASD (e.g., Filipek et al., 2000), there are no known established, empirical guidelines or research regarding how, or even whether, children with ASD are assessed for trauma exposure and trauma-related sequelae. Preliminary

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recommendations have been published by the National Child Traumatic Stress Network (NCTSN; Charlton, Kliethermes, Tallant, Taverne, & Tishelman, 2004) and a recent book chapter from Prock and Fogler (2018) includes considerations for clinicians. Briggs and colleagues (2013) suggested that clinical assessment procedures in any setting should be adapted to gather a systematic and comprehensive trauma history when children are being evaluated for emotional and behavioral concerns. Early detection of exposure to childhood adversity and associated symptoms would benefit children with ASD who have been exposed to trauma and would enable better (i.e., more accurate and valid) diagnosis of children with ASD (Mehtar & Mukaddes, 2011). It is important that symptoms related to ASD, psychological disorders (e.g., PTSD), or an interaction of multiple disorders are parsed out during the diagnostic process to ensure that appropriate treatment referrals and recommendations are made (Keesler, 2014).

Given the paucity of research on trauma in children with ASD, the purpose of this project was to use a qualitative research methodology to explore whether (and if so, how) trauma exposure and trauma-related sequelae, including PTSD, are evaluated during diagnostic evaluations for ASD. While preliminary research suggests that EBA practices are infrequently used with typically developing children (Jensen-Doss & Hawley, 2010; Whiteside, Sattler, Hathaway, & Douglas, 2016), there is no known research on trauma assessment practices in children being evaluated for ASD. This project also sought to determine what factors might increase or decrease the likelihood that trauma assessment practices are integrated into the ASD diagnostic process. An implementation science lens was applied to help understand and organize the various factors that affect the use of trauma assessment on ASD diagnostic teams.

The majority of participants in the current study indicated that they consider trauma during their ASD diagnostic evaluations through trauma screening. Psychologists in this study

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indicated a clear need for the integration of trauma assessment into ASD diagnostic evaluations; however, a range of factors related to the individual providers, the clinics, and the broader context (e.g., the diagnostic system, needs of the children being evaluated) affected the feasibility with which participants could use trauma assessment practices. As psychologists in ASD diagnostic clinics appear appropriately situated to integrate trauma assessment into their evaluations should trauma exposure be endorsed, it is important to address the factors that influenced participants' use of trauma assessment practices.

CHAPTER 2

LITERATURE REVIEW

The purpose of this study was to better understand the process by which trauma exposure and trauma-related pathology are assessed during diagnostic evaluations for ASD. Specifically, it is important to understand whether trauma is being assessed both during the initial diagnostic evaluation for children suspected of ASD and also during future re-evaluations for children who have already received an ASD diagnosis but are being evaluated again (i.e., to clarify diagnosis, including to rule in/out psychiatric comorbidity). Both trauma and ASD, as well as common assessment practices and guidelines for each, will be reviewed. Additionally, while there is a paucity of research on the transactional relationship between trauma and ASD, preliminary findings on the unique risk factors that might contribute to elevated rates of trauma exposure and trauma-related sequelae in children with ASD will be explored. Lastly, it is important to understand potential barriers to the study of factors that influence assessment practices.

Trauma and the Assessment of Trauma Exposure and Related Pathology

Trauma is defined as resulting from an event, or series of events, that is experienced by an individual as harmful or threatening and also has immediate and/or lasting adverse effects on an individual's functioning and well being (Spinazzola et al., 2005; Substance Abuse and Mental Health Services Administration [SAMHSA], 2014). Importantly, the event(s) may be acute (i.e., an isolated, single occurrence, such as a motor vehicle accident) or chronic (e.g., witnessing recurring domestic violence in the home) in nature. *Trauma* and *traumatic event(s)*, however, are terms that are often used interchangeably and have many varying definitions in the field of trauma (SAMHSA, 2014). The same event may be experienced as traumatic for one individual but not for another as a result of possible differences in an individual's appraisal of the event

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(SAMHSA, 2014). Therefore, the term *potentially traumatic event* (PTE) typically refers to an event that might reasonably be considered a trauma (e.g., physical abuse), though whether or not the event is experienced as traumatic varies by individual (Kerns et al., 2015).

While many children and adolescents are resilient and exhibit limited difficulties associated with trauma exposure, others may experience a wide range of effects, from mild to more profound, on their social, emotional, cognitive, academic, or other areas of functioning (Dorsey et al., 2017; Perfect, Turley, Carlson, Yohanna, & Pfenninger Saint Gilles, 2016). *Traumatic stress*, “a persistent disturbance of mood, arousal, and behavior following a traumatic event” (Kerns et al., 2015, p. 3475), is one of the most recognized and researched responses following exposure to a traumatic event (Dorsey et al., 2017). *Posttraumatic stress disorder* (PTSD) is a specific set of traumatic stress symptoms defined in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; APA, 2013). PTSD is characterized by the presence of recurring trauma reminders, avoidance of trauma-related reminders, changes in mood or cognitions, and changes in arousal and reactivity (e.g., hypervigilance) that persist for more than one month (APA, 2013).

A DSM-5 diagnosis of PTSD requires exposure to one or more traumatic event, outlined in Criterion A in the diagnostic criteria (APA, 2013). In the DSM-5, the definition of a traumatic event is “exposure to actual or threatened death, serious injury, or sexual violence” through directly experiencing the event, witnessing the event, learning the event occurred to a close family member or friend, or experiencing repeated or extreme exposure to aversive details of the event (APA, 2013, p. 271). The DSM-5 offers some examples of events that would qualify as a Criterion A traumatic event, such as threatened/actual physical assault or sexual violence, being kidnapped, or natural or human-made disasters (APA, 2013). While the DSM-5 added a subtype

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of the PTSD diagnosis for children age six and younger that has been shown to identify significantly more cases of PTSD in young children (Scheeringa, Myers, Putnam, & Zeanah, 2012), Criterion A is more restricted for this subtype, as it does not include exposure to aversive details (APA, 2013; McDonald, 2016).

Trauma beyond the DSM-5. Importantly, researchers have criticized the current DSM-5 definition of a traumatic event for not being broad enough, especially for children and adolescents, as a growing number of researchers have demonstrated that many events which youth may consider traumatic are not included in Criterion A (D'Andrea, Ford, Stolbach, Spinazzola, & van der Kolk, 2012; McDonald, 2016; Taylor & Weems, 2009). In the seminal Adverse Childhood Experiences (ACE) Study conducted by Felitti and colleagues (1998), the researchers explored the long-term effects of adverse childhood experiences on a number of health outcomes in adults. Although the researchers did not explicitly define ACEs as traumatic events or assess for PTSD specifically, they assessed the participants for some events that would be considered traumatic using the current DSM-5 definition (e.g., sexual abuse) and others that would not (e.g., living with a household member with an alcohol use problem; McDonald, 2016). In recent years, researchers have continued to recognize the importance of investigating the effects of exposure to a broader range of PTEs, such as community or school violence and traumatic loss, separation, or bereavement, which may or may not be considered Criterion A traumatic events (Greeson et al., 2014; Layne et al., 2014). For instance, there has been heavy debate as to whether bullying and peer victimization, particularly non-physical forms of bullying such as relational bullying, qualify as Criterion A stressors, as there is preliminary evidence associating peer victimization with PTSD (Litman et al., 2015; Mynard, Joseph, & Alexander, 2000; Nielsen, Tangen, Idsoe, Matthiesen, & Magerøy 2015).

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Not only has there been a push for a broader definition of PTSD Criterion A but researchers have also noted that the remaining symptom criteria for PTSD are not the only potential effects of trauma (Copeland et al., 2007; McDonald, 2016; van der Kolk, 2005). Researchers have suggested that the traditional PTSD diagnosis fails to capture the symptoms of children and adolescents who often experience multiple forms of abuse/victimization on frequent occasions, which is most commonly referred to as complex or interpersonal trauma (Cook et al., 2005; D'Andrea et al., 2012; Denton, Frogley, Jackson, John, & Querstret, 2017; Spinazzola et al., 2005; van der Kolk, 2005). *Complex trauma* refers to the “experience of multiple, chronic, and prolonged, developmentally adverse traumatic events” that usually begin early in life and are most often interpersonal in nature (van der Kolk, 2005, p. 402), such as chronic physical, sexual, or verbal abuse, emotional neglect, and community violence (Spinazzola et al., 2005). A growing number of researchers have suggested that the sequelae of complex or interpersonal trauma might necessitate a new psychiatric diagnosis given that affected children often experience difficulties beyond the symptoms captured by PTSD (D'Andrea et al., 2012; Spinazzola et al., 2005). As a result, van der Kolk (2005) proposed a new diagnosis, developmental trauma disorder (DTD), for inclusion in the DSM-5 to better embody the symptoms of children exposed to complex trauma, though it ultimately was not included given an inadequate amount of evidence at the time (McDonald, 2016).

Ultimately, it is important to consider that experiences of childhood adversity may not be fully captured by the DSM-5 symptom criteria for PTSD. Specifically, there may be a broader range of PTEs than would qualify as Criterion A stressors that vary based on an individual's appraisal and reaction to the event(s) (Kerns et al., 2015). In fact, researchers demonstrated in a sample of young adults that participants who selected a non-Criterion A event as the worst event

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they have experienced sometimes reported significantly higher levels of PTSD symptoms associated with that non-Criterion A event than those who selected Criterion A events (Gold, Marx, Soler-Baillo, & Sloan, 2005; Dewey & Schulberg, 2013). Further, as demonstrated by the growing empirical support for a DTD diagnosis (e.g., McDonald, Rostad, & Borntrager, 2014; Stolbach et al., 2013) and the evidence for a range of symptom presentations in children and adolescents who have been exposed to trauma (D'Andrea et al., 2012; Spinazzola et al., 2005), it is important to recognize that trauma symptomatology profiles may extend beyond the DSM-5 PTSD symptom criteria. Therefore, while researchers continue to group children who experience trauma under an “all-encompassing trauma label,” with limited consideration of the qualitatively different outcomes associated with differences in type, frequency, or developmental context within which the trauma occurred, there is likely more nuance that warrants continued exploration (Denton et al., 2017, p. 279).

Prevalence of trauma exposure & trauma-related sequelae. Epidemiological data suggest that nearly two-thirds of children in the United States will experience at least one traumatic event prior to 18 years of age (Copeland et al., 2007; Finkelhor et al., 2007; McLaughlin et al., 2013). Copeland and colleagues (2007) found that in a community-based sample of children and adolescents, 30.8% of participants reported exposure to one traumatic event and 37% reported exposure to multiple events by age 16 using the DSM-IV diagnostic criteria. Of particular importance, 21.9% of children and adolescents who experienced trauma exposure reported significant impairment, and 49.6% of those with two or more exposures endorsed impairment (Copeland et al., 2007). Further, in a population-based sample of adolescents, McLaughlin and colleagues (2013) demonstrated that 61.8% experienced at least one lifetime PTE, with 18.6% experiencing three or more. The researchers assessed trauma

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exposure using the DSM-IV diagnostic criteria, though they allowed participants to include PTEs not explicitly included on their predefined list (McLaughlin et al., 2013).

Along the same lines, researchers used data from the Developmental Victimization Survey, a nationally representative sample of children between the ages of 2 and 17 in the United States, to demonstrate that 71% experienced victimization and of those children and adolescents, 69% experienced at least one additional type of victimization (Finkelhor et al., 2007). Finkelhor and colleagues (2007) used the Juvenile Victimization Questionnaire (JVQ), which included exposure to a wider range of PTEs, such as bullying victimization. A later study used an enhanced version of JVQ, which covered 54 forms of PTEs broken into six general categories, including sexual assault, child maltreatment, Internet victimization, peer and sibling victimization, conventional crime, and witnessing and indirect victimization (Finkelhor, Turner, Shattuck, & Hamby, 2013). Finkelhor and colleagues (2013) examined updated data from the second wave of the National Survey of Children's Exposure to Violence and concluded that their findings reinforced the results from previous studies, which demonstrated that children and adolescents are often exposed to violence, crime, and abuse throughout childhood and adolescence (Finkelhor et al., 2013). Importantly, Finkelhor and colleagues (2013) noted that 11% of their sample had six or more direct victimizations (not including witnessing events) in a single year.

Given the pervasiveness of trauma exposure, it is important to understand the potential effects on the development and functioning of children and adolescents. As was previously mentioned, although not all children who are exposed to trauma will develop symptoms, a variety of short- and long-term trauma-related sequelae have been identified in the research literature (Dorsey et al., 2017). Importantly, exposure to trauma can influence optimal brain

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development and contribute to changes in brain structures and systems that are fundamental to affect, arousal, behavioral regulation, executive functioning, and memory, thus creating potential vulnerability for later psychiatric and somatic illness (Kerns et al., 2015).

While posttraumatic stress symptoms, potentially meeting the diagnostic threshold for PTSD, are not the most common outcome, PTSD is the most researched response following exposure to a traumatic event (Dorsey et al., 2017). Population-based studies (e.g., Kilpatrick et al., 2003; McLaughlin et al., 2013) indicate that approximately 7% of girls and 3-4% of boys will develop PTSD following a traumatic event in childhood or adolescence (Dorsey et al., 2017). However, researchers have noted wide variations in prevalence estimates, and Copeland and colleagues (2007) found that many more children and adolescents may be more likely to display subclinical posttraumatic stress symptom levels (i.e., symptoms are present but not sufficient for a PTSD diagnosis).

Alisic and colleagues (2014) suggested that the wide variability in PTSD prevalence estimates is likely a result of moderator variables (i.e., variables that affect the direction and/or strength of the relation, in this case, between a traumatic event and PTSD; Baron & Kenny, 1986). Therefore, in their meta-analysis (72 studies) the researchers not only examined the overall PTSD prevalence rate but also looked at variations in prevalence due to different moderator variables (Alisic et al., 2014). In a sample of 3,563 children and adolescents between 2 and 17 years of age, approximately one in six (15.9%) met diagnostic criteria for PTSD following exposure to a DSM-IV or DSM-5 trauma. Alisic and colleagues (2014) noted significant variation in this prevalence rate depending on the type of trauma; for instance, the rate of PTSD following an interpersonal trauma was 25.2% as opposed to 9.7% following a non-interpersonal trauma. Consistent with past findings (e.g., Hanson et al., 2008; Kilpatrick et al.,

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2003), they also found that girls were at higher risk for PTSD than boys. While not investigated by Alisic and colleagues (2014), other researchers have observed an additional moderator affecting PTSD prevalence rates in children and adolescents. Specifically, the risk of developing PTSD appears to be higher in those who have experienced complex as opposed to single-incident trauma (33-75% risk vs. 10-20% risk, respectively; Ford & Courtois, 2009). While PTSD is a potential outcome associated with trauma exposure, it is not the only outcome, and it often co-occurs with additional short- and/or long-term mental and physical health outcomes.

Notably, for children and adolescents exposed to trauma, as stated by D'Andrea and colleagues (2012), "comorbidity seems to be the rule, rather than the exception" (p. 188). For instance, in a longitudinal study of a large community sample of children through middle childhood to adolescence, 40% of children who have been exposed to trauma had at least one other mood, anxiety, or disruptive behavior disorder diagnosis (Copeland et al., 2007). Further, this relationship was exacerbated by exposure to increasing numbers of traumatic events, and children with a trauma history had almost double the rates of psychiatric disorders of those without a trauma history (Copeland et al., 2007; D'Andrea et al., 2012). Consistent with the findings by Copeland and colleagues (2007), a number of researchers have established that exposure to multiple or repeated traumas (i.e., complex trauma) in childhood can not only result in more severe outcomes than the sequelae of single incident trauma but, as mentioned previously, can also lead to qualitatively different symptoms in affective and interpersonal domains (e.g., difficulty with self-regulation and functional deficits in attachment, anxiety, mood, eating, substance use, attention and concentration, impulse control, somatization, and academic performance; Cloitre et al., 2009; D'Andrea et al., 2012; Spinazzola et al., 2005). As children with complex trauma histories typically meet the diagnostic criteria for a number of

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both internalizing and externalizing psychological disorders, researchers have suggested that van der Kolk's (2005) DTD would better capture these children's symptoms and improve treatment outcomes (D'Andrea et al., 2012; Denton et al., 2017).

Lastly, as has been documented in the ACE studies for more than a decade, the associations between trauma exposure in childhood and poor health outcomes in adulthood are well established (Greeson et al., 2014). Through retrospective studies with adults who were exposed to childhood adversity, researchers conducting ACE studies have consistently reported links between exposure to PTEs in childhood and leading causes of death in adulthood (Layne et al., 2014). For instance, researchers have reported dose-response relationships between the total number of ACEs and adult psychiatric symptoms and disorders (e.g., depression, alcohol-related disorders, anxiety), the adoption of health risk behaviors (e.g., physical inactivity), disease (e.g., cancer, chronic lung disease, heart disease), and reduced life expectancy (Brown et al., 2009; Felitti et al., 1998; Greeson et al., 2014; Layne et al., 2014).

Recently, researchers have built on the ACE studies to examine more proximal sequelae of trauma earlier in life (e.g., during adolescence) to better understand potential impairments and health risk behaviors. For instance, in a sample of children from the NCTSN Core Data Set, Layne and colleagues (2014) reported significant associations between childhood adversity and high-risk behaviors in adolescence, such as delinquency, impaired attachment, substance abuse, and sexual promiscuity. Further, consistent with the earlier ACE studies, each additional type of trauma and loss significantly increased the odds ratio (from 6% to 22%) for high-risk behavior and/or functional impairment (Layne et al., 2014). Another group of researchers also found a significant dose-response relationship between total number of trauma type exposures and both externalizing (e.g., aggressive, attention, emotionally reactive, rule breaking, and social

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problems) and internalizing (e.g., anxious/depressed, somatic complaints, thought problems, and withdrawn/depressed) problems in a large clinic-referred sample of children and adolescents (Greeson et al., 2014). Overall, the robust findings from the adult retrospective studies, such as Felitti and colleagues' (1998) original ACE study and subsequent follow-up studies (e.g., Brown et al., 2009), in addition to more recent studies examining more proximal health outcomes (e.g., Greeson et al., 2014; Layne et al., 2014) provide strong evidence for a link between cumulative exposure to trauma in childhood and a wide range of future physical and mental health difficulties in adolescence and into adulthood.

Trauma assessment. Psychological assessment is a fundamental component of identifying and then effectively meeting and addressing the needs of children who have been exposed to trauma (Kisiel, Conradi, Fehrenbach, Torgersen, & Briggs, 2014). Importantly, trauma assessment is distinct and more comprehensive than trauma screening (Kisiel et al., 2014). Trauma screening tools are most commonly used for identification purposes (i.e., to detect exposure to PTEs and/or possible traumatic stress symptoms) whereas trauma assessment refers to the comprehensive process of exploring the range of PTEs experienced by children and the areas of their functioning that might have been affected by that exposure (Kisiel et al., 2014). Trained mental health providers most commonly conduct trauma assessments, and they use the assessment to determine whether the child has experienced PTEs and, if so, whether clinically significant symptoms of traumatic stress are present and if there are any associated effects on the child's functioning (Kisiel et al., 2014). The established literature base that trauma exposure in childhood can be linked to a wide array of adverse developmental, biological, psychological, health, and social sequelae has contributed to recognition of the value of conducting comprehensive trauma history assessments in children (Pynoos et al., 2014). Briggs and

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colleagues (2013) indicated further that the consistent research findings demonstrating the pervasiveness of trauma exposure and related outcomes support the need for trauma assessment procedures that systematically explore the trauma types, frequency, developmental periods, and density of exposure to trauma and trauma-related symptoms/outcomes.

Kisiel and colleagues (2014) described that an ideal trauma assessment includes the following components: clinical interview, use of objective and psychometrically valid measures, behavioral observation of the child, and contact with important individuals within the child's life (e.g., family members, other providers, teachers). Along the same lines, Milne and Collin-Vézina (2015) suggested that trauma assessments should gather data from a number of sources and integrate the use of both standardized measures and clinical interviews. Further, researchers underscored the importance of not only assessing for symptoms of PTSD but also evaluating broader traumatic stress reactions, such as symptoms of complex trauma (Kisiel et al., 2014). Kisiel and colleagues (2014) added that the goals of trauma assessment extend beyond gathering information about trauma history, symptoms, and the effects on functioning to reach a diagnosis. Trauma assessment should also identify the strengths of children and their families, summarize the assessment information in a meaningful way to inform treatment planning, and include a collaborative sharing of feedback through engagement of children and their families in the assessment process (Kisiel et al., 2014).

Layne, Kaplow, and Youngstrom (2017) applied the principles of evidence-based assessment (EBA), which is a rigorous and practical approach to using assessment tools to guide diagnosis and treatment planning, to trauma assessment (Layne et al., 2017). Layne and colleagues (2017) described that the components of EBA include 1) selecting the most appropriate assessment tools for the clinical questions, 2) gathering the best available data using

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the assessment tools, and 3) “judiciously applying assessment data to make informed clinical decisions about individual patients” (p. 69). They divided the EBA process into stages to be applied to the psychological assessment of children with trauma exposure.

Layne and colleagues (2017) posited that it is important for clinicians to have knowledge of the developmental epidemiology of both prevalence rates and approximate age of initial onset for different types of trauma to ensure that clinicians are asking about PTEs that are most relevant to the child they are assessing. This can guide the use of systematic screening tools that include a broad range of types of PTEs (Layne et al., 2017). Measures that assess child trauma history typically ask about the child’s exposure to a range of PTEs and may incorporate questions about the age of exposure and/or frequency (Lang & Connell, 2017). Some measures assess a single type of trauma (e.g., sexual abuse) and others assess a broad range of trauma exposures; for instance, the *Trauma History Profile*, which was adapted from a section of the *UCLA PTSD Reaction Index for DSM-IV* covers 20 trauma types and allows children to identify additional traumatic events (Pynoos et al., 2014; Steinberg, Brymer, Decker, & Pynoos, 2004).

Following the evaluation of trauma history, it is important to examine children’s reactions to PTEs and the existence of clinically significant distress and impairment (Layne et al., 2017). As mentioned previously, given the many areas of functioning that can be affected by exposure to PTEs, it is important to not only assess for posttraumatic stress symptoms but also for a broader array of emotional and behavioral difficulties (Copeland et al., 2007; D’Andrea et al., 2012; Denton et al., 2017). An example of a measure that assesses children’s PTSD or related symptoms is the *Trauma Symptom Checklist for Children* (Briere, 1996). Some measures exist that combine the assessment of trauma history and trauma-related symptoms into one measure, such as the *UCLA PTSD Reaction Index for Children/Adolescents – DSM-5* (Pynoos &

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Steinberg, 2015). Overall, there are a number of instruments that can be used to assess trauma exposure and its consequences in children and adolescents (for reviews, see Courtois & Ford, 2009; Denton et al., 2017; Mash & Barkley, 2007; Nader, 2008; Strand, Sarmiento, & Pasquale, 2005). Also, the NCTSN compiled a *Measures Review Database* (<http://www.nctsnet.org/resources/online-research/measures-review>) for locating measures to be used with children and adolescents who have experienced trauma.

Trauma assessment complications. Despite evidence that a comprehensive assessment of childhood trauma is essential for implementing evidence-based treatments, many clinicians do not systematically screen for trauma as a routine component of their clinical intake process (Pynoos et al., 2014). Further, many commonly used assessment tools do not include trauma, which creates “blind spots” in the detection of trauma exposure and related symptoms, and using standard clinical interviews exclusively is only a moderately accurate approach to identifying trauma (Layne et al., 2017, p. 67). Researchers have suggested that many clinicians adopt a “don’t ask, don’t tell” approach to trauma, and, as a result, they fail to systematically assess for children’s possible exposure to traumatic events (Lieberman, Chu, Van Horn, & Harris, 2011). Further, it has been suggested that clinicians do not assess for trauma out of fear of “retraumatization” and potential harm despite researchers’ findings that asking children about traumatic experiences is unlikely to cause harm or retraumatization and, instead, is more commonly perceived as a positive experience (Milne & Collin-Vézina, 2015). Lastly, as was previously mentioned, popular standardized measures of trauma-related symptoms may be too narrow in scope and fail to capture the pervasive and complex range of problems displayed by children who have experienced complex trauma (Denton et al., 2017).

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Given the prevalence of trauma exposure and trauma-related outcomes, there is growing recognition of the need for all child service systems to be “trauma informed,” meaning that all individuals within a particular system have the knowledge and skills required to identify trauma-exposed children and families and to be equipped to provide further support and resources (Briggs et al., 2013; Ko et al., 2008). Therefore, an understanding of both PTEs and trauma-related outcomes, including PTSD, other psychological disorders, and additional mental and physical health effects, and how to assess children for trauma exposure and outcomes is essential in many settings that serve children. It is particularly important for practitioners engaged in psychological assessment, including assessment for ASD, to be trauma informed.

Autism Spectrum Disorder and the Diagnostic Process

Despite significant heterogeneity in the presentation of ASD, there are common symptom categories that define the disorder (APA, 2013). Key clinical features include impairment in social communication, including deficits in social-emotional reciprocity (i.e., the give-and-take of social interactions), difficulty with nonverbal communication behaviors (e.g., eye contact, body language, gestures), and deficits in developing, maintaining, and understanding relationships (APA, 2013). In addition, restricted and repetitive behaviors (e.g., stereotyped or repetitive movements, echolalia), difficulties with changes in routines, highly restricted interests, and hyper- or hypo-sensitivity to sensory cues are characteristic of ASD (APA, 2013). These clinical features are subsumed in the DSM-5 under the ASD classification, a change from the *DSM, Fourth Edition, Text Revision* (DSM-IV-TR; Volkmar et al., 2014). As there was minimal evidence to support consistent and replicable differences in diagnosis between the pervasive developmental disorders (e.g., autistic disorder, Asperger’s disorder) in the DSM-IV-TR, the DSM-5 transitioned to one diagnosis, ASD (Volkmar et al., 2014).

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Many children with ASD present with accompanying intellectual or language impairment (APA, 2013) and thus potentially meet criteria for intellectual disability (40-50%) or a language disorder (63%; Centers for Disease Control and Prevention, 2014; Levy et al., 2010). Given the considerable variability in symptom type and severity in children with ASD, as described by Huerta and Lord (2012), “the presentation of ASD can range from a child who is nonverbal and unlikely to make social initiations, to a child who is verbally fluent, but overly reliant on previously learned scripts of speech and social behavior” (p. 2). Additional variability and comorbidity in children with ASD includes associated medical or genetic conditions (e.g., epilepsy, Rett syndrome, Fragile X syndrome; APA, 2013). Lastly, a number of researchers have established that psychiatric comorbidity in children with ASD is high (Levy et al., 2010; Leyfer et al., 2006; Simonoff et al., 2008; Skokauskas & Gallagher, 2012). For instance, Simonoff and colleagues (2008) demonstrated that 70.8% of children with ASD had at least one co-occurring psychiatric disorder. Some of the more commonly identified co-occurring conditions include oppositional defiant disorder (ODD), attention-deficit/hyperactivity disorder (ADHD), anxiety disorders (e.g., social anxiety disorder), obsessive-compulsive disorder (OCD), and mood disorders (Levy et al., 2010; Simonoff et al., 2008).

The significant heterogeneity in ASD symptom presentations makes diagnostic decision-making a complex process (Huerta & Lord, 2012). The growing prevalence of ASD (Elsabbaugh et al., 2012), currently estimated at 1 in 59 (Baio et al., 2018), highlights the need for reliable and accurate ASD diagnostic evaluations. Further, timely diagnosis of ASD is important, as early diagnosis allows for access to intensive and ASD-specialized interventions, which contribute to better long-term outcomes for children with ASD (Rutherford et al., 2016). Screening is an important precursor to ASD diagnostic evaluations, as it identifies children with possible ASD

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symptoms who are in need of a more comprehensive evaluation (Volkmar et al., 2014). The current system for identification of children with ASD involves surveillance and screening within primary care settings, followed by referral for a comprehensive ASD evaluation for those determined to be at-risk (Huerta & Lord, 2012; Johnson & Myers, 2007).

There are specific practice parameters for the assessment of ASD that have been published by professionals across multiple disciplines (Ozonoff, Goodlin-Jones, & Solomon, 2005). It is recommended that ASD diagnostic evaluations are multidisciplinary whenever possible, and the multidisciplinary team can include one or more of the following professionals: psychologists, pediatricians/developmental-behavioral pediatricians, neurologists, speech-language pathologists, audiologists, occupational therapists, physical therapists, child psychiatrists, and educators or special educators (Filipek et al., 2000; Ozonoff et al., 2005; Volkmar et al., 2014). Most commonly, multidisciplinary teams include professionals who work in the same clinical practice within a university, medical, or community setting (Steiner, Goldmith, Snow, & Chawarska, 2012).

Ideally, members of a multidisciplinary team utilize EBA strategies relevant to their particular field. For instance, a speech-language pathologist might perform a comprehensive assessment of expressive and receptive language and communication skills, and occupational and physical therapists might evaluate sensory and/or motor difficulties (Filipek et al., 2000; Volkmar et al., 2014). Psychologists frequently utilize cognitive and adaptive behavior assessments to provide an overall estimate of ability (Filipek et al., 2000). While the responsibilities of various members and composition of multidisciplinary ASD diagnostic teams vary across the United States, a multidisciplinary team approach is considered to be the gold standard for ASD diagnosis (Falkmer, Anderson, Falkmer, & Horlin, 2013). Further, two

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particular measures, the *Autism Diagnostic Observation Schedule, Second Edition* (ADOS-2; Lord et al., 2012) and the *Autism Diagnostic Interview-Revised* (ADI-R; Le Couteur, Lord, & Rutter, 2003) are also considered to be gold standard tools that should be integrated with consensus clinical judgment by team members to reach a diagnosis (Falkmer et al., 2013; Ozonoff et al., 2005).

There are common components that appear across published guidelines for the diagnostic evaluation of ASD, including: obtaining a comprehensive history and current information on medical, family, developmental, and behavioral characteristics/functioning; physical examination; behavioral observation; developmental and cognitive testing; and laboratory evaluation (Hansen, Blum, Gaham, Shults, & Committee DBS, 2016). Additionally, the evaluation of children with ASD should include information from multiple sources and contexts, such as measures of parent report, teacher report, and child observation across settings (Ozonoff et al., 2005). Ozonoff and colleagues (2005) emphasized that a high-functioning child with ASD may present as “charming, precocious, and highly intelligent when provided with one-on-one attention and conversational scaffolding from a well-meaning adult professional” whereas the same child may display significantly more symptoms during unstructured play with peers on a playground (p. 525). Further, it is critically important to engage in the process of differential diagnosis and evaluate for the presence of additional behavioral symptoms (e.g., inattention, mood, anxiety, sleep disturbance, aggression, self-injury) beyond those outlined in the DSM-5 criteria for ASD (Ozonoff et al., 2005).

Given the elevated rates of psychological disorders observed in children with ASD it is important to assess for the presence of psychiatric comorbidity during the ASD diagnostic process (Ameis & Szatmari, 2015). This may occur during the initial diagnostic evaluation after

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identification through screening and surveillance or during a re-evaluation for children who have already received an ASD diagnosis. Children with ASD, particularly those who received a diagnosis at an early age (2-3 years) or those who present with significant behavioral disturbances, should be re-evaluated to clarify diagnosis (Filipek et al., 2000; Huerta & Lord, 2012). Ameis and Szatmari (2015) recommended that a comprehensive assessment should include direct observation and a complete clinical history from the patient, family, other providers, and teachers, including specific questions targeting ASD, psychiatric, and medical symptoms and accompanying functional impairment. The aforementioned EBA strategies, including selecting the most appropriate assessment tools and gathering the best available data with those tools (Layne et al., 2017), can be applied to the assessment of psychiatric comorbidity in children with ASD. Specifically, Ameis and Szatmari (2015) added that utilizing a functional behavior assessment, including evaluating the antecedents, behaviors, and consequences of the behaviors of children with ASD might be helpful for clarifying the origin and function of observed psychological symptoms. For instance, if a child is reluctant to engage socially with peers, it is important to distinguish whether this behavior might be associated with ASD-related social skill deficits, anxiety-related fears of being negatively evaluated by peers (i.e., social anxiety), avoidance of a trauma reminder following exposure to bullying or peer victimization (i.e., PTSD), or an interaction of multiple disorders.

Despite the high rates of psychiatric comorbidity in children with ASD, there are relatively few tools to assist clinicians in assessing psychological symptoms (Ameis & Szatmari, 2015). Unfortunately, most EBA tools (e.g., standardized diagnostic interviews, rating scales) to assess for psychological symptoms are not validated for children with ASD (Ameis & Szatmari, 2015). Further, McLeod, Wood, and Klebanoff (2015) noted that the field is just beginning to

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recognize that measures developed for typically developing children in the general clinical population cannot necessarily be applied to children with ASD, as they likely do not have adequate psychometric properties. For instance, Kerns and colleagues (2016) indicated that most anxiety measures examined for use in children with ASD were designed for typically developing children; therefore, their ability to reliably distinguish anxiety and ASD symptoms and to accurately capture differing manifestations of anxiety in children with ASD might be limited. However, while there is no gold standard for the assessment of anxiety disorders in children with ASD, there are several promising diagnostic tools in need of additional research, including the *Anxiety Disorders Interview Schedule* (ADIS; Silverman & Albano, 1996) with Kerns' and colleagues' (2014) *Autism Specific Addendum* (ADIS/ASA; Kerns et al., 2016). Importantly, there are no known evidence-based assessment tools to assess trauma-related sequelae in children with ASD (Brenner et al., 2017).

In addition to measurement-related challenges, Ameis and Szatmari (2015) identified that a significant challenge in assessing psychiatric comorbidity in children with ASD is the symptom overlap between symptoms of ASD and comorbid psychological disorders. For instance, children with PTSD (regardless of whether they have an ASD diagnosis) might struggle with social interactions, engage in repetitive behaviors, and have hypersensitivity to sensory experiences (e.g., loud noises; Brenner et al., 2017). Therefore, it is difficult to distinguish whether symptoms are characteristic of ASD, part of the presentation of a comorbid disorder (e.g., PTSD), or compounded by ASD and a co-occurring condition (Ameis & Szatmari, 2015).

Prock and Fogler (2018) recently published several key considerations with respect to the assessment and treatment of trauma and stressor related disorders (TSRD) in children with co-occurring neurodevelopmental disorders. They cited preliminary guidelines published by the

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NCTSN, which recommended that, given the potential communication difficulties of children with developmental disabilities, a wide range of informants be consulted to gather information, including parents/guardians and school and daycare personnel (Charlton et al., 2004). Prock and Fogler (2018) echoed the other NCTSN guidelines, suggesting to train caregivers on the types of behavioral change that might follow trauma exposure and to adapt assessments by slowing down speech, using simple language, and presenting one concept at a time (Charlton et al., 2004). In particular, Prock and Fogler (2018) highlighted the importance of monitoring children's symptoms over time and obtaining a thorough and chronologic history and timeline to the best of practitioners' abilities. They offered the example of considering even how a child's behavior fluctuates over the course of the evaluation. For instance,

Whereas the child with primary ASD will be consistently socially disconnected during a play-based evaluation like the ADOS-2, and euthymic as long as s/he is left to pursue his/her self-directed interests, the child with primary TSRD will likely have wide fluctuations in social response and affect regulation depending on whether or not s/he has been triggered. (Prock & Fogler, 2018, p. 65).

Prock and Fogler included additional recommendations for the assessment of TSRD in children with neurodevelopmental disorders. They indicated that it is important to establish a sense of trust and safety within evaluations, such that it should simultaneously be communicated that the clinician is ready to listen but also respects the child's autonomy to disclose. Further, they encouraged practitioners to follow up on endorsed items on measures of trauma exposure and traumatic stress symptoms given potential reluctance of children or their families to share the full extent of exposure and/or symptoms.

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ASD assessment complications. Despite the ability to reliably diagnose ASD as early as 24 months of age (Guthrie, Swineford, Nottke, & Wetherby, 2013), researchers have identified a significant delay to ASD diagnosis (Daniels, Halladay, Shih, Elder, & Dawson, 2014). For example, data from the CDC established the median age of ASD diagnosis to be 53 months (Daniels et al., 2014). Substantial wait times for diagnostic evaluations, sometimes as long as six to 12 months or more has resulted in alternative models to diagnosis to maximize efficiency (Swanson et al., 2014). Therefore, although comprehensive multidisciplinary team evaluations conducted in a time-sensitive manner are ideal, they do not always reflect “real-world” practice (Johnson & Myers, 2007; Swanson et al., 2014). Data from the *2011 Survey of Pathways to Diagnosis and Services* indicated that among school-age children (6 to 17 years of age) with ASD, 18.1% received an ASD diagnosis from a multidisciplinary team, with others receiving diagnoses from a specialist doctor (44.1%), psychologist (22.1%), or pediatrician/family provider (15.7%; Child and Adolescent Health Measurement Initiative, 2016).

Given the growing prevalence of ASD and elevated rates of comorbidity, including significant psychiatric comorbidity, it is critically important that ASD diagnostic evaluations are timely, reliable, and accurate. Delayed ASD diagnosis can adversely affect children in a number of ways, including postponing children’s access to needed and beneficial autism-specific early intervention services (McMorris, Cox, Hudon, Liu, & Bebko, 2013) and delaying families’ understanding of their children’s special health care needs (Brett, Warnell, McConachie, & Parr, 2016). However, there are also potentially long-lasting negative consequences as a result of misclassification of ASD (Johnson & Myers, 2007) or failure to recognize a comorbid condition (e.g., PTSD or other trauma-related sequelae), delaying the receipt of appropriate and symptom-focused evidence-based interventions. Therefore, regardless of the model used to conduct ASD

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diagnostic evaluations (e.g., multidisciplinary team, individual provider), it is essential that the evaluation process is comprehensive and accounts for potential comorbidity.

Trauma and Autism Spectrum Disorder

There is limited research on the prevalence of trauma in children with disabilities, and there is even less information about the occurrence of traumatic events among children with ASD (Grayson, Childress, & Baker, 2013). In addition, despite the proliferation of studies on the prevalence and features of PTSD in typically developing children, there is a lack of research on trauma-related sequelae, including PTSD, in children on the autism spectrum (Mehtar & Mukaddes, 2011). Within the past decade it was still widely believed that individuals with developmental disabilities, such as ASD, could not understand or appreciate trauma and loss and, therefore, did not experience related pathology (Focht-New, Clements, Barol, Faulkner, & Service, 2008).

Further, researchers have expressed concern that diagnostic overshadowing might contribute to the limited amount of research dedicated to the intersection of trauma and ASD (Focht-New et al., 2008; Keesler, 2014). Mason and Scior (2004) described diagnostic overshadowing as ignoring and/or misattributing mental health symptoms to a disability, such as ASD. For instance, self-injurious behavior demonstrated by a child with ASD following a PTE may be viewed only within the context of ASD as opposed to considering the behavior as a potential trauma-related symptom (Grayson et al., 2013). Therefore, this may contribute to the paucity of research on the relationship between trauma and trauma-related outcomes and ASD.

Existing framework for the transactional relationship between trauma & ASD. In order to provide a framework for the expansion of research on the intersection of trauma and

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ASD, Kerns and colleagues (2015) proposed an initial model of the transactional relationship between the two (see Figure 1).

Notably, it is likely that the symptoms of ASD affect the experience of trauma at multiple levels. First, symptoms of autism may moderate to what type of PTEs the child is exposed. Autism may also influence the appraisal of PTEs and whether they are experienced as harmful and threatening. Further, both the risk of developing traumatic stress and/or other negative outcomes and the manifestation of trauma-related symptoms/outcomes may be moderated by symptoms of ASD.

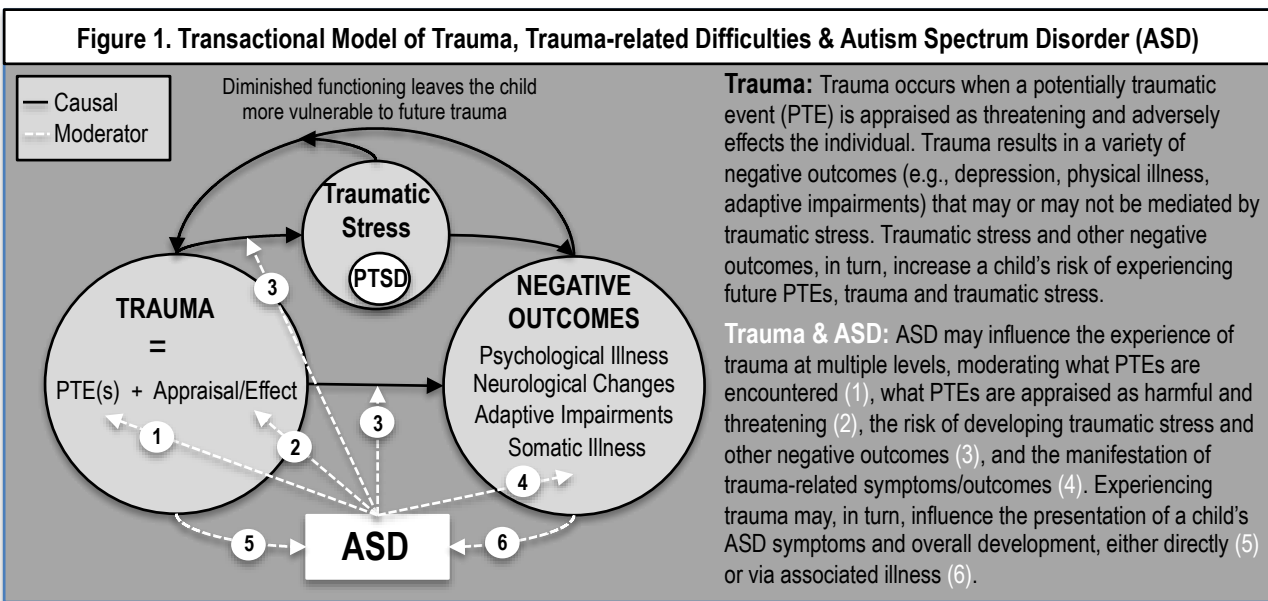


Figure 1. Transactional models of trauma, trauma-related difficulties and ASD. From “Traumatic Childhood Events and Autism Spectrum Disorder,” by C. Kerns, C. Newschaffer, and S. Berkowitz, 2015, *Journal of Autism and Developmental Disorders*, 47, p. 3481. Copyright 2015 by Springer Science and Business Media. Reprinted with permission.

Just as ASD may affect all aspects of how trauma is experienced by children with ASD, importantly, trauma also has the capacity to influence the developmental trajectory of children with ASD. Kerns and colleagues (2015) noted that trauma may affect a child's clinical presentation through new trauma-related symptoms or the exacerbation of existing ASD

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symptoms (e.g., self-injury). This may occur directly or through the development or worsening of associated difficulties (e.g., anxiety disorders, emotion regulation). Existing preliminary research on the intersection of trauma and ASD will be reviewed within the outlined framework proposed by Kerns and colleagues (2015).

ASD as a risk factor for trauma exposure. Researchers in the trauma field have long endeavored to understand what factors might make particular children vulnerable to being exposed to PTEs (Trickey, Siddaway, Meisser-Stedman, Serpell, & Field, 2012). Generally, children are considered to be more vulnerable to trauma exposure, such as maltreatment, than adults given their dependence on others (Turner, Vanderminden, Finkelhor, Hamby & Shattuck, 2011). This is similarly mirrored in the disability literature that suggests adults with disabilities are at a significantly higher risk of trauma exposure due to their necessary relationships with caretakers, etc. (e.g., Nosek, Foley, Hughes, & Howland, 2001). This risk factor may be especially relevant in children with developmental disabilities, as they may be even more dependent and for longer periods of time (Charlton et al., 2004; Pfeffer, 2016).

Two characteristics that have been identified as risk factors for trauma exposure among those with intellectual and developmental disabilities are impaired social skills and communication deficits (Pfeffer, 2016). Social and communication deficits are core features of ASD, which suggests that individuals with ASD may be increasingly vulnerable to exposure to PTEs (Pfeffer, 2016). Children with ASD may be socially naïve and have difficulty communicating their emotional experiences, which may contribute to vulnerability to manipulation and lack of awareness and/or ability to communicate about victimization experiences (Charlton et al., 2004). Researchers have provided further support for this claim, as they demonstrated in a sample drawn from the general population that a “broad autism

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phenotype” (i.e., traits of autism, such as difficulty interpreting social information, deficits in social communication/interactions, repetitive and rigid behaviors) observed in adulthood was associated with elevated prevalence of trauma exposure, specifically physical, emotional, and sexual abuse, and PTSD (Roberts, Koenen, Lyall, Robinson, & Weisskopf, 2015). Further, researchers have consistently identified that cognitive, language, sensory, and motor impairments, all of which are likely in children with ASD, may increase the risk of exposure to maltreatment (Chan & Lam, 2016; Hendricks, Lansford, Deater-Deckard, & Bornstein, 2014). Other researchers have indicated that social skill deficits, social isolation, and desire for friendship and acceptance are risk factors for victimization, specifically bullying by peers and siblings (Little, 2002; Majoko, 2016). Some researchers have gone as far as to say that severe social skill deficits make children with ASD “perfect victims” (Little, 2002, p. 44), though the researcher admitted that victimization could also contribute to greater social skill deficits.

Importantly, Brown and Schormans (2014) provided a reminder to avoid viewing disability as a “problem” and attributing everything to a child’s impairment (in this case, ASD) because there is significantly more to the maltreatment and victimization of children with developmental disabilities than the characteristics of the child and presentation of ASD. Instead, it is important to examine the interaction between the child and their environment; therefore, researchers have conceptualized child maltreatment from an ecological perspective (Algood, Hong, Gourdine, & Williams, 2011; Brown & Schormans, 2014; Fisher, Hodapp, & Dykens, 2008). Citing Belsky’s (1980) ecological approach to child abuse, Fisher and colleagues (2008) offered a theoretical approach to understanding factors that may make children with disabilities more vulnerable to early adverse experiences. As described by Leeb, Bitsko, Merrick, and Armour (2012), child maltreatment stems from the “confluence of multiple, transactional, nested

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forces in which the child, family, community, and culture interact to determine child experiences and outcomes” (p. 10). For instance, the severity of a child’s disability (e.g., challenging behaviors) might interact with parenting stress and social factors (e.g., stigma and discrimination in their community from being viewed as a “bad parent” who cannot manage their child’s behavior) to set the stage for potential maltreatment (Leeb et al., 2012). Therefore, risk factors for exposure to PTEs exist at every level of the ecology, and it is likely that children with ASD, who experience risk in multiple contexts and/or multiple risk factors in a single context, are at greater risk for maltreatment than those who experience fewer risk factors (Leeb et al., 2012).

Beyond the social and communication deficits characteristic of ASD, children on the autism spectrum may have additional characteristics that increase their vulnerability to exposure to PTEs. One researcher examined risk factors for victimization from the perspectives of the parents/caregivers of children with ASD and found that parents reported largely on factors at the child level (Pfeffer, 2014). While a limitation to this study is that parents might not have reported on familial risk factors or those that originated in the home, they identified four key risk factors that they felt contributed to their children’s vulnerability to abuse, neglect, maltreatment, or criminal victimization (Pfeffer, 2014). Parents indicated that their children’s dependence on others for their safety and well-being, lack of trustworthy friends despite strong desire for social acceptance, lack of a sense of danger, often manifesting in trust of strangers, and little or no verbal proficiency were the most evident risk factors for exposure to victimization.

More recently, researchers also used an ecological framework to conceptualize the vulnerability of children with developmental disabilities to sexual abuse (Miller, Pavlik, Kim, & Rogers, 2017). Miller and colleagues (2017) acknowledged that some individual level factors, such as communication delays or dependence on others for support, might affect children’s

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ability to effectively disclose when abuse occurs or lead to confusion about appropriate boundaries and privacy. In addition, the researchers noted that children with developmental disabilities are often taught to be compliant with caregivers' requests (Miller et al., 2017). Further, a lack of sexual education and knowledge of safety skills may increase the risk for sexual victimization among children with developmental disabilities. This may stem from caregivers and service providers overlooking or avoiding the discussion of sexuality and sexual education for children with developmental disabilities. Miller and colleagues (2017) investigated the knowledge of personal safety skills in children with developmental disabilities and found that knowledge deficits were present and that parents perceived that their children did not have the necessary knowledge and skills to keep their bodies safe.

Other community risk factors for sexual abuse outlined by Miller and colleagues (2017), which may be generalized to other forms of victimization, included societal perceptions of individuals with developmental disabilities as vulnerable, unable to disclose abuse, and less likely to be a credible informant of abuse should they disclose. Palusci, Datner, and Wilkins (2015) noted that despite lack of support for this claim, the legal system is hesitant to include children with developmental disabilities as witnesses, as they are viewed as unreliable and unable to provide accurate information, which may result in the discounting of abuse disclosures.

Lastly, various family factors may increase the risk of exposure to PTEs for children with ASD. It is likely that caregivers of children with ASD share many of the same risk factors for perpetrating maltreatment as caregivers of typically developing children (e.g., parental psychiatric disorders, substance use, low levels of education, social isolation, poor parenting skills, financial concerns, parental history of abuse; Fisher et al., 2008; Leeb et al., 2012; Vig & Kaminer, 2002). Some of these risk factors may be even more evident in caregivers of children

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with ASD; for instance, financial concerns may stem from high costs for services as well as lost wages from additional time attending to the child's special health care needs (Grayson et al., 2013). Not only can services be expensive but parents may also confront barriers in obtaining services for their children, which can lead to feelings of social isolation (Grayson et al., 2013).

In addition, researchers have acknowledged the potential role of parenting stress in exposure to maltreatment for children with ASD (Hall-Lande, Hewitt, Mishra, Piescher, & LaLiberte, 2015) given past evidence that parents of children with ASD experience significantly higher levels of parenting stress when compared to parents of both typically developing children and children with other disabilities (Hayes & Watson, 2013). Hibbard and Desch (2007) identified that parents might have heightened levels of stress if they have limited social and community support given the increased levels of supervision and care often necessary for children with disabilities, such as ASD. Further, the behavioral characteristics and associated features of ASD (e.g., communication difficulties, atypical or aggressive behaviors) and potential to be nonresponsive to typical methods of behavioral intervention might contribute to heightened stress levels for parents (Hall-Lande et al., 2015). Rigles (2017) suggested that higher levels of parental stress might manifest in an increased likelihood of exposure to childhood adversity, such as divorce and exposure to violence in the home.

Recently, researchers examined risk factors for harsh discipline by parents of children with ASD through the lens of an ecological perspective (Chan & Lam, 2016). Chan and Lam (2016) investigated risk factors at multiple levels, including characteristics of the child, the parent, the family, and the broader context (e.g., the community). They found that, at the bivariate level, child symptom severity, parenting stress, family economic pressure, and experienced discrimination were positively related to parental psychological aggression, whereas

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only child symptom severity and parenting stress were positively associated with parental physical assault (Chan & Lam, 2016). Parenting stress remained linked to both psychological aggression and physical assault and child symptom severity continued to explain variance in physical assault at the multivariate level.

The effect of ASD on the appraisal of PTEs. ASD might not only affect the types of trauma to which children are exposed, but it also may influence how PTEs are appraised and whether they are experienced as harmful or threatening (Kerns et al., 2015). Specifically, the differences in cognition, perception, sensation, and social awareness characteristic of children with ASD may influence whether PTEs are experience as traumatic (Haruvi-Lamdan, Horesh, & Golan, 2017). While there are no studies to my knowledge that explore the influence of autism on event appraisal, researchers have found that children with ASD experience difficulties with emotion regulation and coping with stress, which may present as emotional meltdowns or outbursts (Mazefsky et al., 2013) and increase the likelihood of children with ASD interpreting events as harmful. Kerns and colleagues (2015) also hypothesized that disturbance in neurobiological substrates of stress in children with ASD (e.g., dysregulation of the limbic-hypothalamic-pituitary-adrenal axis, which underlies the stress response, and an exaggerated cortisol response to new and threatening stimuli) might be associated with increased risk of a stress response to trauma exposure.

Additionally, Kerns and colleagues (2015) cited the growing research literature on the intersection of anxiety disorders and ASD to demonstrate that those with ASD may experience different events as stressful when compared with typically developing individuals. Kerns and colleagues (2014) have labeled these anxiety symptoms as *atypical* or *ambiguous*, which are qualitatively different from the symptoms that are typically seen for traditional anxiety disorder

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categories. For instance, children with ASD may develop specific phobias that have an unusual focus, such as a fear of men with beards (Kerns et al., 2014). This may extrapolate to the development of traumatic stress, such that children with ASD may experience different (or atypical/ambiguous) events or experiences as stressful, harmful, or threatening, though additional research on this topic is clearly needed.

ASD as a risk factor for trauma-related sequelae. Lastly, according to Kerns' and colleagues (2015) proposed model of the transactional relationship between trauma and ASD, both the risk of developing traumatic stress symptoms or other outcomes and the manifestation of these symptoms may be moderated by symptoms of autism. One of the most prominent predictors of traumatic stress symptoms following trauma exposure is a pre-existing psychiatric disorder, especially anxiety (Copeland et al., 2007; Kerns et al., 2015). Researchers have consistently demonstrated high rates of psychiatric comorbidities among individuals with ASD (Levy et al., 2010; Simonoff et al., 2008; Taylor & Gotham, 2016), with an estimated co-occurrence for anxiety disorders of approximately 40%, though rates ranging from 11% and 84% have been identified in community- and clinic-referred samples (van Steensel, Bögels, & Perrin, 2011; White, Oswald, Ollendick, & Scahill, 2009).

Additionally, Kerns and colleagues (2015) noted that additional predictors of traumatic stress are common in children with ASD, including lower IQ, limited social support, and exposure to repeated traumatization. As was previously mentioned, some individuals with ASD experience intellectual disability and language impairment (APA, 2013). Further, findings from the National Longitudinal Transition Study-2 showed elevated levels of social isolation for adolescents with ASD, including lower rates of seeing friends outside of school, rarely/never receiving phone contact from friends, and not being invited to social activities (6%, 84%, and

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50%, respectively; Wagner, Newman, Cameto, Levine, & Marder, 2007). Further, researchers reported that individuals with ASD experience loneliness and that both peer victimization and lack of education of typically developing peers and teachers are factors that contribute to social isolation (Locke, Ishijima, Kasari, & London, 2010; Majoko, 2016). Lastly, the aforementioned risk factors for trauma exposure (e.g., Leeb et al., 2012) and the demonstrated high rates of exposure to PTEs in children with ASD (e.g., Berg et al., 2016; Pfeffer, 2016), may contribute to a heightened risk for exposure to multiple PTEs and resulting traumatic stress symptomatology. Importantly, researchers have established that accumulated exposure to multiple, repeated traumatic events in childhood is associated with increased posttraumatic stress symptom severity and complexity (Briere, Kaltman, & Green, 2008). While this association has not been investigated in children with ASD, it is particularly concerning given the high risk and demonstrated rates of exposure in this population.

Along the same lines, there are concerns that lack of recognition of the effects of exposure to PTEs on symptoms displayed by children with ASD may limit appropriate referrals for trauma treatment (Keesler, 2014). For instance, if trauma-related exposure and/or symptoms, such as an increase in stereotyped or repetitive behaviors, are not recognized as such, then children with ASD might not receive needed support. Diagnostic overshadowing and insufficient trauma screening and assessment in children with ASD can lead to misdiagnosis and/or the receipt of inadequate treatment, potentially resulting in the exacerbation of trauma symptoms or heightened vulnerability to continued trauma exposure and future symptom development (Keesler, 2014).

Lastly, Kerns and colleagues (2015) suggested that both cognitive and psychosocial features of ASD might predispose children with ASD to developing traumatic stress. For

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instance, mental rigidity, differences in information processing, and impaired emotional insight might disrupt their use of adaptive strategies (e.g., cognitive coping), which could increase resiliency following trauma exposure (Kerns et al., 2015). Specifically, children with ASD might get “stuck” ruminating about memories of adverse or stressful events due to their difficulties with shifting attention (Kerns et al., 2015). Further, children with ASD might not develop emotion regulation skills as a result of decreased attention to social cues, which can cause disruptions in learning these skills from others (e.g., via modeling; White et al., 2014). Lastly, children with ASD might not only have difficulty with emotion regulation and but also with identifying or processing those emotions, which might affect their ability to cope with PTEs (Kerns et al., 2015; Mazefsky & White, 2014).

In addition to conferring risk for the development of traumatic stress and other health outcomes, ASD may moderate the way in which trauma-related symptoms and outcomes present (Kerns et al., 2015). Though limited, several researchers have demonstrated that children with ASD present with a varied profile of symptoms associated with trauma exposure (Kerns et al., 2015). For instance, increased academic failure, activity level, disruptive behavior, social isolation, self-injury, stereotypies, and decline in adaptive functioning have been associated with exposure to PTEs in children with ASD (Mandell, Walrath, Manteuffel, Sgro, & Pinto-Martin, 2005; Mehtar & Mukaddes, 2011; Valenti et al., 2012). Further, researchers recently explored the expression of symptoms following physical, sexual, and/or emotional abuse in children with ASD (Brenner et al., 2017). The researchers found that trauma-exposed children with ASD displayed significantly more intrusive thoughts, distressing memories, loss of interest, irritability, and lethargy than those whose caregivers did not report abuse, suggesting that children with ASD experience trauma-related symptoms similar to the DSM-5 diagnostic criteria for PTSD.

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However, the researchers also noted that children who were exposed to trauma displayed behavioral symptomatology that was not directly related to DSM-5 criteria (e.g., increased temper tantrums), suggesting that more research in this area would be beneficial (Brenner et al., 2017).

Trauma exposure and related outcomes in ASD. Most research on exposure to violence and maltreatment in children with disabilities suggests that children with disabilities are at a greater risk for victimization than children without disabilities (Leeb et al., 2012; Turner et al., 2011). However, many of the researchers in this area have combined different forms of disability (e.g., hearing impairment, conduct disorder, physical disabilities, intellectual disability) into a single disability category, have differed on their operationalization of maltreatment or other types of PTEs, and have used a variety of study methods and research samples (Leeb et al., 2012; Turner et al., 2011). As a result, many consider the magnitude of the disparity in exposure to PTEs, such as maltreatment, in children with and without disabilities to be unclear (Leeb et al., 2012).

Sullivan (2009) noted that the various definitions of disability used by researchers have led to a lack of data on the incidence of exposure to violence in children with disabilities. She asserted that it is important to distinguish developmental disabilities from the broader category of disability, as the terms (and definitions) are not interchangeable (Sullivan, 2009). However, given the limited research on the exposure to PTEs in children on the autism spectrum, the broader literature base on the prevalence of trauma exposure in children with disabilities will first be presented.

Trauma exposure and children with disabilities. Jones and colleagues (2012) conducted a relatively recent systematic review and meta-analysis to further explore the prevalence of

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violence experienced by children with disabilities, given results from a past systematic review (Govindshenoy & Spencer, 2007) suggesting a weak association between childhood disability and abuse. In their systematic review and meta-analysis (17 studies: Jones et al., 2012), the researchers concluded that violence is an important problem for children with disabilities. They demonstrated that up to a quarter (27%) of children with disabilities will experience violence in their lifetimes and children with disabilities are three to four times more likely to experience violence than children without disabilities (Jones et al., 2012). The researchers suggested that the lack of clarity evident in past research studies is likely due to wide variation in the characteristics of the studies—a limitation Jones and colleagues (2012) also acknowledged in their own review, as despite finding increased risk for children with disabilities, they noticed significant heterogeneity in their pooled estimates. Ultimately, the findings from this study provide support for earlier researchers' (e.g., Westcott & Jones, 1999) conclusion that children with disabilities are at a heightened risk of violence (Jones et al., 2012).

In an effort to move away from combining types of disabilities and studying disability more broadly, Turner and colleagues (2011) suggested that level of risk for victimization in children with disabilities likely varies by type of disability. The researchers separated children in their study into four major disability categories, including physical disability, internalizing disorders, ADHD, and developmental and learning disorders (Turner et al., 2011). They also grouped victimization into four categories: peer assault/bullying, sexual victimization, maltreatment, and property crime. Turner and colleagues (2011) used data from the National Survey of Children's Exposure to Violence, which included children between 2 and 17 years of age and used an enhanced version of the Juvenile Victimization Questionnaire (i.e., questions about Internet victimization were added). The researchers found that children with emotional and

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behavioral difficulties (e.g., depression, conduct disorder) were most at risk for victimization. Surprisingly, Turner and colleagues (2011) showed that while children with developmental or learning disorders experienced significantly higher rates of property crime than children without these types of disabilities, they were not at increased risk to experience any of the other types of victimization. However, older children (ages 10-17) with more severe disabilities were underrepresented in the sample, as they were unable to complete the self-report interview. The researchers concluded that while children with disabilities, overall, may be vulnerable to victimization, not all types of disability are associated with the same level of risk for victimization (Turner et al., 2011).

Additional research studies using population-based datasets to evaluate the risk of maltreatment in children with disabilities found differing rates of victimization by type of disability (Jaudes & Mackey-Bilaver, 2008; Spencer et al., 2005; Sullivan & Knutson, 2000). Interestingly, consistent with the findings of Turner and colleagues (2011), none of the groups of researchers found increased risk of maltreatment for the children in the disability category containing ASD. However, it is important to note that children with ASD were underrepresented in two of the studies and a consistent finding across the studies was that children with conditions that are commonly comorbid with ASD (e.g., intellectual or learning disabilities and other behavioral/mental health disorders) were at increased risk of maltreatment (Jaudes & Mackey-Bilaver, 2008; Spencer et al., 2005; Sullivan & Knutson, 2000).

Spencer and colleagues (2005) used a 19-year whole-population birth cohort in the United Kingdom to examine the association between disability status and exposure to child maltreatment (i.e., physical abuse, sexual abuse, emotional abuse, neglect). They identified variation in the association based on the type of disability and category of abuse. For instance,

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children with conduct disorder and with moderate/severe learning difficulties were at increased risk in all four abuse categories, and children with non-conduct psychological disorders were at heightened risk in all abuse categories except sexual abuse (Spencer et al., 2005). However, children with autism were not at increased risk of abuse, though no conclusions regarding rates of neglect could be drawn, as the number of children with autism in the sample was too small to analyze the association of autism and neglect.

Further, another study used a population-based dataset to evaluate the risk of maltreatment among children with chronic health conditions and categorized the health conditions into three distinct groups, including chronic physical illnesses (e.g., respiratory diseases), developmental delay and mental retardation, and behavior and mental health conditions (e.g., ADHD; Jaudes & Mackey-Bilaver, 2008). The researchers found that although 4.2% of children with developmental delay and/or mental retardation experienced maltreatment during the first six years of their lives, they faced no increased risk of maltreatment when compared to children without these conditions. Jaudes and Mackey-Bilaver (2008) did find that children with behavioral/mental health problems were at an increased risk of abuse or neglect.

Along the same lines, in a school-based population sample of children the researchers revealed a strong association between maltreatment and type of disability classification (e.g., behavioral disorders, mental retardation, learning disability; Sullivan & Knutson, 2000). For all types of disability classification except autism (though only 0.4% of the sample was identified by a school multidisciplinary team as receiving special education services for the classification of autism), the researchers found that the prevalence rate of maltreatment was 3.4 times greater than the rate of maltreatment in children without an educationally relevant disability. Despite finding the rates of maltreatment for children with autism in special education to be similar to children

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without a disability (approximately 9%), Sullivan and Knutson (2000) acknowledged that their sample size for children with autism was so small that they grouped children with autism with children with behavioral disorders for many of their analyses.

Trauma exposure and children with ASD. There is a small but growing number of researchers who have explored the prevalence of PTEs specifically in children with ASD. In addition to the aforementioned studies that investigated the prevalence of various forms of maltreatment in children with ASD and were limited by a small sample (Spencer et al., 2005; Sullivan & Knutson, 2000), more researchers are recognizing the importance of understanding the occurrence of PTEs in children with autism given their unique risk factors (Leeb et al., 2012). The limited body of research that exists on maltreatment and children with ASD has mixed results, though the majority of preliminary data reveal a heightened risk of maltreatment for children with ASD (Hall-Lande et al., 2015).

Researchers examined the prevalence of physical and sexual abuse and factors associated with abuse among children with ASD served in a community setting (Mandell et al., 2005). Mandell and colleagues found that almost one in five children with ASD (14.1%) and one in six children with ASD (12.2%) experienced physical abuse and sexual abuse, respectively. A small percentage (4.4%) of children with ASD treated in community mental health settings experienced both physical and sexual abuse. Further, the researchers found that children who were sexually abused were more likely than other children to engage in sexually acting out behavior, be sexually abusive towards others, have run away from home, or have made a suicide attempt (Mandell et al., 2005). While the data was based on caregiver report, Mandell and colleagues (2005) suggested that the findings are consistent with research on children in other disability categories, and they highlighted the importance of clinicians attending to the

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psychosocial histories of children on the autism spectrum for past abuse and negative consequences of abuse.

A relatively new avenue of exploration to further elucidate the relationship between child maltreatment and disability has been to use data from child protection agencies (Hall-Lande et al., 2015). Hall-Lande and colleagues (2015) compared the child and family characteristics of children involved in Child Protective Services (CPS) who have ASD, other disabilities, or do not have a disability diagnosis. Most notably, in a sample of 9,536 children, the researchers demonstrated that children with ASD and children with other disabilities were represented at higher rates in the CPS system as compared to children without a disability diagnosis. Hall-Lande and colleagues (2015) concluded that their findings added to those of the broader group of researchers who have established that children with disabilities are at an increased risk of maltreatment when compared to children without disabilities. Further, they found that children with ASD who experienced maltreatment were more likely to have parents with diagnosed mental health conditions and staff at group homes and/or residential facilities was more likely to be the alleged perpetrators of the maltreatment, as compared with children with other disabilities and children without a disability diagnosis.

Another group of researchers recently used data from the child protection system in Australia (Maclean et al., 2017). The researchers conducted a population-based study using data for all children born in Western Australia between 1990 and 2010 and identified separate disability categories, including autism, birth defects/cerebral palsy, Down syndrome, intellectual disability, conduct disorder, and mental/behavioral disorders (Maclean et al., 2017). Out of the cases with substantiated maltreatment allegations, 29% involved a child with a disability, and, overall, there was a threefold increased risk of a substantiated allegation for children with a

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disability compared with children without a disability. Despite overall elevations in rates of maltreatment, there was a significantly lower risk of maltreatment allegations for children with autism, as they only made up 0.7% of maltreatment allegations. Maclean and colleagues (2017) found that risk of maltreatment was highest for children with intellectual disability and then conduct disorder and mental/behavioral disorders. Interestingly, of the children identified with intellectual disability ($n = 8,551$), 62.6% also had at least one of the following: autism, birth defects/cerebral palsy, and/or mental/behavioral disorders. Therefore, despite the lack of an increased risk for a maltreatment allegation in children with autism, the presence of comorbid intellectual disability did increase the likelihood of a maltreatment allegation for children with autism (Maclean et al., 2017).

More recently, researchers linked children with ASD who were identified through the Autism and Developmental Disabilities Monitoring (ADDM) Network to the records of a state-based child protection agency (Fisher et al., 2018). Consistent with past studies, Fisher and colleagues (2018) found that children with ASD were two and one-half times more likely to be referred to their state's child protection agency than children without ASD. While substantiated maltreatment rates were similar, interestingly, referrals for children with ASD were less likely to be screened in for further action than referrals for children without ASD (62% vs. 91.6%, respectively). Along the same lines, in a different state, another group of researchers utilized ADDM Network data and linked it to their state's Department of Social Services records (McDonnell et al., 2018). While there were some differences amongst subgroups (i.e., children with ASD-only, intellectual disability [ID] only, and ASD+ID), McDonnell and colleagues (2018) similarly concluded that children with ASD and/or ID are a heightened risk for maltreatment.

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Importantly, Jones and colleagues (2012) noted that the focus of the majority of earlier researchers investigating the association between trauma and disability has been exposure to maltreatment (i.e., physical abuse, sexual abuse, emotional/psychological abuse, neglect). They suggested that it is important to recognize that children with disabilities are vulnerable to different types of violence and the extent of PTEs experienced by this population might extend further than maltreatment (e.g., experiencing war/terrorism, school bullying; Jones et al., 2012). Therefore, while it is critical to examine the experiences and effects of maltreatment on children with ASD, it is also essential to explore exposure to a wider range of PTEs, such as accidental injuries, natural disasters, other crime events, and peer victimization, that have been associated with psychological distress and other negative outcomes in typically developing children (Newman, Christopher, & Berry, 2000).

Recently, Pfeffer (2016) explored a broader range of PTEs, including physical abuse, bullying, property crimes, maltreatment, sexual abuse, and witnessed violence, in a national sample of children with ASD between the ages of 5 and 18. The Juvenile Victimization Questionnaire (JVQ), which included questions about 34 different types of victimization, was administered to the caregivers of children with ASD. Pfeffer (2016) demonstrated that more than four in five children with ASD (82.1%) had experienced an incident of victimization within the past year, and of the children who had been victimized, 92% experienced more than one incident of victimization in the past year. Assault and bullying were the most common form of victimization reported in this study, with 84% of caregivers indicating that their child had experienced an incident within their lifetime. Qualitative analyses demonstrated a range in the experiences of assault and bullying by children with ASD, extending from moderate to severe

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forms (e.g., being stuffed into a locker, having clothing pulled down to expose private parts on the playground, being forced to eat dog feces), with the most common being emotional bullying.

Additional forms of victimization measured by the JVQ were also elevated in this sample (Pfeffer, 2016). Almost two-thirds of children with ASD (64.2%) had been the victim of a property crime, such as robbery, theft, or vandalism, in their lifetime, with robbery (i.e., having something taken by force) being the most commonly reported. Parents described that theft (i.e., having something stolen without the use of force) most frequently occurred through manipulation by peers who took advantage of the social deficits evident in children with ASD. While Pfeffer (2016) suggested that maltreatment is likely underreported given that parents were the reporters, 50.4% of study participants were identified as having experienced maltreatment in their lifetimes, with the most common forms being psychological or emotional abuse. Further, 30% of children with ASD in this sample witnessed a criminal event in their lifetime. Lastly, sexual assault was the least commonly reported form of abuse, with 14% experiencing an incident in their lifetime. Importantly, Pfeffer (2016) examined risk ratios and demonstrated that if a child with ASD experienced a victimization incident they were at heightened risk to experience another in the same year, regardless of the form of initial victimization (i.e., property crime, maltreatment).

Notably, Pfeffer (2016) demonstrated that the rates of children with ASD who experienced the types of victimization measured by the JVQ were disproportionately high when compared with past research samples of children without disabilities who had also been administered the JVQ. Specifically, caregivers of children with ASD in this study sample reported significantly higher rates of property crimes, assault, bullying, and maltreatment in their children than were found in the National Survey of Children Exposed to Violence sample

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(NatSCEV; Finklehor, Turner, Ormrod, & Hamby, 2010; Pfeffer, 2016). For instance, whereas 4.2% of the NatSCEV sample identified experiencing physical abuse, 34.4% of the sample of children with ASD reported experiencing physical abuse within the past year (Pfeffer, 2016). The rates of witnessed crimes and sexual assault did not appear to be elevated, though Pfeffer (2016) suggested that the use of proxy reporting by the caregiver might have limited the accuracy of these rates. Regardless, Pfeffer (2016) found that a substantial proportion of children with ASD in this sample experienced increased rates and multiple forms of victimization, highlighting the need for additional research on trauma in children with ASD.

Additional groups of researchers have conducted studies to explore exposure prevalence rates for a broader range of PTEs. For instance, researchers have found that children with ASD are at an increased risk for serious physical injuries, such as poisoning and self-inflicted injuries, when compared to their typically developing peers (Lee, Harrington, Chang, & Connors, 2008). Further, children with ASD also experience more frequent and longer inpatient psychiatric hospitalizations (Lokhandwala, Khanna, & West-Strum, 2012). Lastly, a recent meta-analysis (17 studies) demonstrated that children with ASD are at three times higher risk of experiencing school bullying victimization than their typically developing peers, with a pooled prevalence estimate of 44% (Mañano, Normand, Salvás, Moullec, & Aimé, 2016). Importantly, in a recent review of the literature examining types of trauma exposure and symptoms in children with ASD, Hoover (2015) identified that studies of peer victimization and bullying have been the most prevalent. He noted that while there is variation in prevalence estimates, children with ASD are bullied more frequently than children with other disabilities, children without disabilities, children with ID alone, and their typically developing siblings (Hoover, 2015).

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In a continued attempt to explore exposure to a wider range of PTEs in children on the autism spectrum, researchers have started to investigate the prevalence of adverse childhood experiences (ACEs) in this population (Berg et al., 2016; Kerns, Newschaffer, Berkowitz, & Lee, 2017; Rigles, 2017). While this is a relatively recent and novel avenue of exploration in individuals with ASD, the prevalence of childhood adversity and the effects on physical and mental health outcomes in adulthood have been well documented in the literature (Brown et al., 2009; Felitti et al., 1998). As previously mentioned, ACEs are traumatic early childhood experiences that may or may not be considered a Criterion A traumatic event and include maltreatment as well as other family stressors (e.g., household substance use or mental illness, parental separation/divorce) that have lifelong consequences for an individual's physical and mental health and overall functioning (Felitti et al., 1998).

Both Berg and colleagues (2016) and Rigles (2017) used data from the 2011-2012 National Survey of Children's Health (NSCH) to determine the prevalence of ACEs among children with ASD. A modified form of the CDC-Kaiser ACE scale was developed for the NSCH, which included questions about nine ACEs/PTEs: financial income insufficiency, parental divorce/separation, parental death, parental incarceration, witnessing/experiencing violence in the home or neighborhood, living with someone with mental illness or substance use difficulties, and racial/ethnic discrimination (Berg et al., 2016; Rigles, 2017). After controlling for poverty and residential disadvantage, Berg and colleagues (2016) demonstrated that ASD diagnosis was associated with a moderate (1-3) or severe (≥ 4) ACEs number. Further analysis by Berg and colleagues (2016) at the level of individual ACEs uncovered that children with ASD had significantly higher exposure to income insufficiency, neighborhood violence, parental divorce, mental illness, and substance use.

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In addition to determining the prevalence of ACEs in children with ASD, Rigles (2017) explored the association of experiencing ACEs with physical and mental health and resiliency in children on the autism spectrum. Not only did children with ASD experience significantly more ACEs (also reported by Berg et al., 2016), but they also had significantly lower physical health and significantly increased odds of poor mental health than children without ASD (Rigles, 2017). Because an increase in ACEs was associated with poorer health for all children in the sample (i.e., those with and without ASD) the researcher noted that ACEs do appear to be internalized in children with ASD, as they are for their peers without ASD. Rigles (2017) also found a discrepancy in resiliency between the groups, as children with ASD had significantly lower resiliency compared to children without ASD. Notably, resiliency appeared to function differently in children on the autism spectrum. The researcher had hypothesized that increased ACEs would be associated with decreased resiliency, which would then also be associated with decreased physical and mental health, as is the case in typically developing children. However, instead, Rigles (2017) found that an increase in ACEs did not correspond to a significant change in resiliency for children with ASD. The only experience that was negatively associated with resiliency for children with autism was divorce. Rigles (2017) suggested that perhaps the resiliency of children on the autism spectrum is more affected by events or experiences, such as divorce, that interrupt their regular routine.

Both Berg and colleagues (2016) and Rigles (2017) provided preliminary evidence that disparities exist in ACEs and health outcomes between children with and without ASD (Kerns et al., 2017). Kerns and colleagues (2017) questioned whether differing clinical presentations of ASD might influence the relationship between an autism diagnosis and ACEs. Specifically, as the majority of children with ASD present with co-occurring disorders (e.g., intellectual

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disability, attention and behavior problems, anxiety, and depression; Simonoff et al., 2008), the researchers sought to clarify how a child's clinical presentation might contribute to the relationship between ASD and childhood adversity (Kerns et al., 2017). They were also interested in the role of poverty.

Using data from the 2011-2012 NSCH, Kerns and colleagues (2017) found that the relationship between an ASD diagnosis and exposure to ACEs is likely moderated by family income and is also contingent on co-occurring mental health conditions. Expanding on the findings from Berg and colleagues (2016), the researchers demonstrated that the discrepancy in ACEs between children with ASD and children without ASD is particularly pronounced in lower income families (Kerns et al., 2017). Specifically, they found that while some ACEs (e.g., financial stress, mental illness) were more common in youth with ASD than youth without ASD regardless of income bracket, other ACEs (e.g., exposure to neighborhood violence, drug use, and parental separation/divorce) were only more common for lower income youth with ASD. Further, Kerns and colleagues (2017) revealed that, regardless of the presence of an ASD diagnosis, children with anxiety, depression, attention, and behavior problems were twice as likely to have greater than or equal to two ACEs. Adjusting for intellectual disability did not change the relationship between ACEs and ASD. As a result, the researchers suggested that the co-occurrence of mental health conditions in children with ASD is a potential risk factor for exposure to ACEs in this population. The researchers acknowledged that the cross-sectional nature of their study prevented the assessment of causal relationships, but they hypothesized that the association of mental health concerns and ACEs is likely bidirectional. For instance, exposure to childhood adversity might contribute to the high rate of mental health problems in

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those with ASD and the reverse might also be true (i.e., psychopathology might increase vulnerability to ACEs; Kerns et al., 2017).

In sum, while there is limited research on trauma exposure in children on the autism spectrum, preliminary data suggest that there are unique risk factors for exposure to PTEs for children with ASD (e.g., social and communication deficits, high levels of parenting stress), which is supported by a growing number of studies indicating elevated rates of exposure to PTEs in this population (Berg et al., 2016; Chan & Lam, 2016; Pfeffer, 2016). Importantly, there is no known research regarding how, or even whether, children with ASD are being assessed for exposure to PTEs. Further, it is unclear if children with ASD are being evaluated for exposure to the more “traditionally” research PTEs (e.g., maltreatment) in addition to other events that children with ASD might interpret as traumatic (e.g., peer victimization).

Trauma-related sequelae in children with ASD. Given that children on the autism spectrum are at an increased risk for exposure to PTEs, from various forms of maltreatment to stressful life experiences (e.g., parental separation/divorce), it is important to understand the health implications of this disparity. Specifically, as outlined in the theoretical model by Kerns and colleagues (2015), it is also essential to determine whether and how symptoms of autism affect the risk of developing traumatic stress and/or other negative outcomes.

A paucity of research has targeted both the prevalence and clinical features of PTSD in individuals with ASD (Mehtar & Mukaddes, 2011). Several researchers have documented case reports (e.g., Cook, Kieffer, Charak, & Levant, 1993; del Pilar Trelles Thorne, Khinda, & Coffey, 2015; Howlin & Clements, 1995; McCreary & Thompson, 1999; Ryan, 1994) and attempted to understand traumatic life events and posttraumatic stress reactions experienced by children with ASD. Preliminary evidence from the aforementioned case studies suggests that

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traumatic life experiences can result in a posttraumatic stress response, including PTSD, and other negative outcomes (e.g., self-injurious behavior, mood disturbance) in children with ASD. Surprisingly, Kerns and colleagues (2015) highlighted that many studies examining the psychiatric comorbidity often observed in children with ASD regularly omit trauma-related sequelae and PTSD (e.g., Leyfer et al., 2006; Levy et al., 2010; Simonoff et al., 2008). For instance, only 2 out of 86 prevalence studies in a recent meta-analysis (van Steensel et al., 2011) on anxiety disorders in children with ASD provided data on PTSD (Kerns et al., 2015).

To my knowledge, Mehtar and Mukaddes (2011) were the first and only researchers to examine the relationship between exposure to PTEs and trauma-related sequelae, including PTSD, in children with ASD. Importantly, the researchers explored not only the prevalence of trauma exposure in children with ASD but also the prevalence and presentation of PTSD (Mehtar & Mukaddes, 2011). They administered the *Kiddie Schedule for Affective Disorders and Schizophrenia-Present and Lifetime Version* (K-SADS-PL) PTSD scale to regular attendants of an autism clinic in Istanbul who were between the ages of 6 and 18. Eighteen of the 69 participants (26.1%) identified having a trauma history, including witnessing or being a victim of accidents/disasters or violence, experiencing physical abuse or sexual abuse, or experiencing multiple traumas. Interestingly, 17.4% of the sample, but 67% of participants who endorsed trauma exposure, met full diagnostic criteria for PTSD.

The researchers also explored various symptoms in the trauma-exposed group and assessed the effect of trauma on core symptoms and other behavioral features of autism (Mehtar & Mukaddes, 2011). They found that children with ASD who were exposed to trauma experienced deterioration in social-communication skills; for instance, 88.9% showed regression in social interaction, 66.7% had worsening peer relationships, and 61.1% demonstrated

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deterioration in nonverbal communication skills. Mehtar and Mukaddes (2011) also concluded that behavioral problems might be related to trauma exposure, as 94.4% of the participants with ASD who were exposed to trauma had an increase in aggressiveness, anger outbursts, and distractibility. Further, the researchers identified significant changes in the vast majority of participants in vegetative functions (e.g., sleep disturbances), increases in stereotyped and ritualistic behaviors (e.g., stereotypic movements), and deterioration in self-care skills (e.g., enuresis) as related to trauma exposure.

While limited, other researchers have postulated that exposure to PTEs might contribute to other negative mental health outcomes in children with ASD. For instance, Taylor and Gotham (2016) posited that one contextual factor that has been understudied in children with ASD is trauma. The researchers examined the relationship between cumulative stressful life events, trauma, and co-occurring mood and anxiety problems in transition-age youth (aged 17 to 22) with ASD (Taylor & Gotham, 2016). Using caregiver report, Taylor and Gotham (2016) assessed for 27 PTEs and found that 55.6% of youth experienced at least one life event as traumatic. Further, while a significant number of youth exposed to trauma did not endorse mood symptomatology, co-occurring mood disorders were rarely observed in the absence of an event that was experienced as traumatic. Surprisingly, exposure to events experienced as traumatic was not related to anxiety symptomatology, including PTSD, in this sample. The researchers concluded that youth with ASD might demonstrate resilience following trauma exposure, and it is important to explore what factors may be protective in this population.

Along the same lines, Bliel Walters and colleagues (2013) assessed the association between trauma and depressive symptomatology in youth with ASD. Specifically, the researchers investigated the presence of abuse, neglect, and associated mental health outcomes in

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a highly specific subgroup of adolescents with ASD: adolescents with ASD who were also adjudicated sexual offenders (Bliel Walters et al., 2013). Bliel Walters and colleagues (2013) utilized the *Childhood Trauma Questionnaire* to examine the severity of abuse and neglect among adolescents with ASD as compared to adolescents without ASD, all of whom were adjudicated delinquent to a sexual offense. While there were no statistically significant differences between those with and without ASD on the severity scores for abuse and/or neglect, adolescent sexual offenders with ASD reported a “low/moderate” history of emotional abuse, emotional neglect, and physical neglect, whereas the group without ASD reported “none/minimal.” Most importantly, the researchers found that the adolescent sexual offenders with ASD experienced significantly more depressive symptoms than the group of adolescent sexual offenders without ASD. Therefore, Bliel Walters and colleagues (2013) suggested that while there was not a significant difference in history of abuse or neglect in this subpopulation of adolescents with ASD, the adolescent sexual offenders with ASD who experienced emotional abuse/neglect were at a heightened risk for depressive symptomatology.

Both groups of researchers (i.e., Bliel Walters et al., 2013; Taylor & Gotham, 2016) observed a possible association between trauma exposure and mood symptomatology in youth with ASD. Similarly, Storch and colleagues (2013) investigated the occurrence and features of suicidal thoughts and behaviors in children between the ages of 7 and 16 with ASD and co-occurring anxiety problems. The researchers demonstrated that children with ASD and anxiety displayed similar rates of suicidal thoughts and behaviors to typically developing children without anxiety, with 11% of the sample endorsing suicidality (Storch et al., 2013). Further, also consistent with past research in typically developing children, the presence of clinically

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significant depressive symptoms or comorbid PTSD increased the risk of suicidal thoughts and behaviors in children with ASD and concomitant anxiety.

Interestingly, one group of researchers evaluated changes in a different type of outcome, adaptive behavior, in children with ASD following exposure to a potentially traumatic event, the L'Aquila earthquake in Italy (Valenti et al., 2012). Valenti and colleagues (2012) compared children with ASD who did and did not experience the earthquake on four domains of adaptive behavior (communication, daily living, socialization, and motor skills) using the Italian form of the *Vineland Adaptive Behavior Scales* (VABS). The researchers noted that the children and families who were exposed to the earthquake experienced significant disruptions to routines for over six months following the earthquake. For instance, immediately following the earthquake, the children who were exposed experienced a two-week interruption in their rehabilitation services and a forced relocation to provisional housing. Even six months following the earthquake and an opportunity to return to L'Aquila, the children and families were assigned housing in new locations and the school year began in temporarily buildings (as the original was destroyed in the earthquake). For the children with ASD who were in the non-exposed group, they continued their routine activities following the earthquake.

Valenti and colleagues (2012) found that the adaptive behavior of children with ASD who were exposed to the earthquake decreased in all dimensions examined and was statistically and clinically significant in comparison to the adaptive behavior of children with ASD who were not exposed to the earthquake. For instance, children with ASD in the exposed group experienced a 30% decline in socialization skills six months after baseline (a few days prior to the earthquake). While scores on the socialization scale rose in the subsequent six months, they remained far below baseline (15% decline from pre-earthquake) and those for unexposed

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participants (Valenti et al., 2012). A similar pattern was observed for scores on both the communication and daily living scales (i.e., despite skill recovery between six months and a year following the earthquake, scores remained below baseline and below those of the unexposed group). Valenti and colleagues (2012) concluded that the drastic uncertainty for children with ASD and their families about many significant aspects of their life, including housing, work, health services, environment, and social relationships, likely contributed to the changes in adaptive behavior. While the effects of the earthquake appeared to be significant, the researchers were encouraged by the trends toward recovery of pre-disaster functioning in the group of children with ASD who experienced the earthquake.

Given the dearth of research, the ways in which trauma may contribute to the prevalence of traumatic stress and other health outcomes in children with ASD is poorly understood (Kerns et al., 2015). However, Kerns and colleagues (2015) noted that for children on the autism spectrum to be at heightened risk for almost every other psychiatric comorbidity (e.g., anxiety, depression, ADHD) except PTSD is both puzzling and surprising, especially given the previously described risks for exposure (e.g., Berg et al., 2016; Pfeffer, 2016) and poor coping response (e.g., Brenner et al., 2017) in this population. Given the prevalence of trauma exposure and resulting trauma-related sequelae (Copeland et al., 2007; McLaughlin et al., 2013) and other health outcomes (Felitti et al., 1998) observed in typically developing individuals, it is concerning that trauma exposure, PTSD, and other outcomes should be understudied in those with ASD (Kerns et al., 2015).

Assessment & Implementation Science

One of the biggest potential barriers to understanding the relationship between trauma, its sequelae, and ASD in children is the lack of assessment. Unfortunately, lack of EBA is not a new

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problem. Evidence-based practice (EBP) is usually defined as including both EBA and evidence-based treatment (EBT), though the growing movement pushing for the use of EBPs has largely prioritized EBTs and not EBA (Jensen-Doss & Hawley, 2010). Despite the importance of EBA, many researchers have demonstrated that clinicians are not engaging in assessment practices consistent with the aforementioned principles of EBA, most importantly the use of standardized and psychometrically valid and reliable assessment tools (Jensen-Doss & Hawley, 2010).

Notably, researchers have suggested that a lack of EBA can undermine effective treatment by making it difficult to appropriately integrate research into practice and have all of the necessary information to make informed treatment decisions (Jensen-Doss & Hawley, 2010).

Unfortunately, there has been a paucity of research on barriers to the use of assessment, including EBA.

In addition to the previously mentioned hypotheses as to why clinicians do not regularly include trauma in their assessment practices (e.g., fears of retraumatization, inadequate measures), researchers have recently investigated barriers to the use of EBA specific to anxiety disorders, including PTSD. Researchers conducted a mixed methods study to improve understanding of EBA use for anxiety and the potential barriers to utilizing EBA (Whiteside et al., 2016). They found that less than 10% of clinicians reported frequent use of EBA when assessing their clients for childhood anxiety disorders, though having a PhD in psychology significantly increased the likelihood of EBA practices (e.g., structured interviews, rating scales; Whiteside et al., 2016). The two primary barriers identified to using EBA for anxiety were 1) obstacles to use (e.g., insufficient time, lack of access to materials, lack of training, cost) and 2) negative beliefs about the benefits (e.g., unnecessary for good clinical practice, burdensome to the patient). Unfortunately, the infrequent use of EBA for childhood anxiety was corroborated in

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an additional study analyzing the documentation in medical records (Sattler et al., 2016). In the record review, researchers found that clinicians rarely documented support for their diagnoses using DSM criteria and did not report use of common EBA practices when evaluating childhood anxiety (Sattler et al., 2016).

Despite preliminary evidence that EBA is not a common practice (though psychologists are more likely to engage in EBA than clinicians in other disciplines; Jensen-Doss & Hawley, 2010; Whiteside et al., 2016), there is relatively little information available as to trauma assessment practices, and no data exists regarding the integration of trauma assessment into ASD diagnostic evaluations. As demonstrated by Whiteside and colleagues (2016), there is an overwhelming number of potential factors affecting the use of assessment that can occur at a variety of levels (i.e., individual clinician, organization). Fortunately, a growing field of study in many health disciplines, implementation science, provides a scientific approach to understanding the integration of research findings and EBPs into routine practice (Bauer, Damschroder, Hagedorn, Smith, & Kilbourne, 2015).

Implementation science involves the scientific study of methods that foster the uptake of EBPs, such as assessment, in order to better understand the factors that affect the integration of that practice or innovation (Bauer et al., 2015). Importantly, implementation science not only focuses on the integration of the innovation at the patient level but also at the level of providers, organizations, and policies (Bauer et al., 2015). A purpose of implementation science is to examine the success of an organization's attempts to integrate innovations, such as the implementation of trauma-informed assessment strategies within ASD diagnostic evaluations.

A variety of implementation theories have been described in the research literature with the goal of promoting effective implementation (Damschroder et al., 2009). Damschroder and

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colleagues (2009) recognized considerable overlap in these theories and inconsistency in terminology, and, therefore, sought to create a comprehensive framework that integrated the different concepts. Therefore, they developed the Consolidated Framework for Implementation Research (CFIR), which includes the most common concepts from various implementation theories (Damschroder et al., 2009). The CFIR is recognized as a leading, comprehensive implementation framework for understanding factors that affect the implementation of innovations (Lewis et al., 2015).

Damschroder and colleagues (2009) suggested that the CFIR is a beginning foundation to understanding implementation. The CFIR is comprised of five separate implementation domains (see Appendix A), including *characteristics of the innovation, the outer setting, the inner setting, characteristics of the individual, and the process*, that interact to influence implementation effectiveness (Damschroder et al., 2009). Each domain includes specific implementation constructs, which are the “potential predictors, moderators, and mediators or ‘drivers’” of implementation outcomes (Lewis et al., 2015, p. 3). Therefore, various constructs within the five CFIR domains could affect the use of trauma assessment practices within diagnostic evaluations for ASD. For instance, *characteristics of the innovation* (i.e., trauma assessment practices) may affect whether individual psychologists, the multidisciplinary team, and/or the autism center choose to integrate the innovation into the ASD diagnostic evaluation. Specifically, the *relative advantage* (i.e., the added benefit of using an innovation) of trauma assessment may be relevant. As was noted by Whiteside and colleagues (2016), clinicians may feel that integrating trauma assessment measures into the ASD diagnostic evaluation will not add anything or be particularly useful to their evaluation. Further, an *inner setting* construct, such as *available resources* (i.e., the level of resources needed such as money, physical space, and time), could greatly influence

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whether trauma assessment practices are used. For instance, Whiteside and colleagues (2016) demonstrated that clinicians did not feel they had access to the necessary materials, training in EBA for anxiety assessment, and the necessary time to dedicate to anxiety assessment. Given the aforementioned wait times (Swanson et al., 2014) for ASD diagnostic evaluations, clinicians may feel the pressure to complete the evaluation as efficiently as possible and, therefore, feel that they lack the time to integrate trauma assessment.

Notably, the CFIR can be used to guide and organize understanding of the implementation of a particular innovation, such as the use of trauma assessment within ASD diagnostic evaluations. Researchers have suggested that without a theoretical framework to guide the research process, including data collection, analysis, and interpretation, implementation researchers might inadvertently limit their understanding of determinants of implementation to their own specific context (Kirk et al., 2016). Thus, there has been an increased emphasis on use of theory in implementation research. While no research to date has used the CFIR to examine factors, including facilitators and barriers, to psychologists' implementation of trauma assessment practices within ASD diagnostic evaluations, the CFIR has been used in many qualitative and mixed method studies to evaluate innovation implementation. Specifically, Kirk and colleagues (2016) conducted a recent systematic review to determine the types of research studies that used the CFIR and to examine how the framework has been applied. Following their review of 26 empirical studies that met their study selection criteria, the authors noted that over 70% of the research objectives were to explore practitioners' implementation experiences, including their implementation processes and barriers and facilitators to implementation, and the majority of studies were conducted post-implementation. As a result of their systematic review, Kirk and colleagues (2016) developed a list of recommendations to assist future researchers in

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their application of the CFIR to implementation research. The authors noted that integrating the CFIR throughout the research process, including in data collection efforts, had advantages over using it during data analysis only. They also recommended making use of resources developed by the CFIR team, including a free, publicly accessible qualitative coding manual (<http://www.cfirguide.org/qual.html>). In addition, Kirk and colleagues (2016) recommended considering the relevance of phase of implementation (pre-, during, or post-implementation) and to report how CFIR constructs were selected. Lastly, they noted that incorporating implementation outcomes, such as those outlined by Proctor et al. (2011), would allow for increased identification of how CFIR constructs influence outcomes and under what conditions (Kirk et al., 2016). Given the emphasis on using a theoretical framework in the context of implementation research and the evaluation of the CFIR as one of the leading and most comprehensive frameworks, the current study used the CFIR as a framework for understanding psychologists' use of trauma assessment practices, including the facilitators or barriers that affected the integration of trauma assessment into ASD diagnostic evaluations.

Despite the comprehensiveness of the CFIR, it is limited in that it does not include implementation outcome constructs (Lewis et al., 2015). Implementation outcomes are the effects of dedicated and intentional actions to implement new innovations, and they provide an approach to understanding how well an innovation is implemented (Proctor et al., 2011). Proctor and colleagues (2011) developed the Implementation Outcomes Framework (IOF) to create a working taxonomy and develop the conceptualization of implementation outcomes. The IOF can be combined with the CFIR to capture constructs that are relevant at the start of innovation implementation, throughout the early stages, and those that might contribute to the success of innovation implementation (Lewis et al., 2015).

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The implementation outcomes included in the IOF are *acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, penetration, and sustainability* (see Appendix B; Proctor et al., 2011). Proctor and colleagues (2011) identified that particular implementation outcomes may be more relevant at some phases of implementation process than at others. Given the lack of research on the assessment of trauma in children being evaluated for ASD, it may be likely that ASD diagnostic teams are at an earlier stage in the implementation process. That is, they might not be utilizing trauma assessment or are just beginning to integrate trauma assessment practices. While the trauma assessment practices of ASD diagnostic teams are currently unknown, there are no established empirical guidelines for trauma assessment in children with ASD or even trauma measures that have been adapted, standardized, and normed for children on the autism spectrum (Brenner et al., 2017; Kerns et al., 2015). This suggests that the use of trauma assessment is at the discretion of individual providers or organizations.

Therefore, while all implementation outcomes were added to the CFIR coding guide, it is likely that *adoption* (i.e., the initial attempt to try an innovation) will be most relevant to exploring implementation outcomes as they relate to ASD diagnostic teams' integration of trauma assessment into the diagnostic evaluation. Researchers have noted that *acceptability, appropriateness, and feasibility* are additional IOF constructs that predict *adoption* of an innovation, as they are more salient in earlier implementation stages (Chor, Wisdom, Olin, Hoagwood, & Horwitz, 2015; Proctor et al., 2011). For instance, *appropriateness* refers to the “perceived fit, relevance, or compatibility of the innovation or evidence based practice for a given practice setting, provider, or consumer; and/or perceived fit of the innovation to address a particular issue or problem” (Proctor et al., p. 69). For integrating trauma assessment into ASD diagnostic evaluations, *appropriateness* might refer to the fit between the trauma assessment

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practices and the psychologist or child being evaluated and/or the fit of trauma assessment and the setting in which it is being conducted. For instance, psychologists on ASD diagnostic teams might not feel that trauma assessment is part of the diagnostic evaluation process for ASD.

Notably, in the CFIR and IOF, constructs have equal weight and there are no distinctions as to the valence (positive or negative influence) of each construct (Varsi, Ekstedt, Gammon, & Ruland, 2015). For instance, the construct *available resources* would be applied uniformly to statements regarding having the time to conduct trauma assessment during ASD diagnostic evaluations, as well as statements about not having enough time to include evidence-based trauma assessment practices. Thus, it was important to consider the effect of a construct on implementation and whether constructs were facilitators or barriers of implementation.

Overall, the CFIR and IOF implementation science frameworks were applied during the qualitative coding process to better understand whether psychologists integrated trauma assessment into the ASD diagnostic process and to organize the factors that facilitated or impeded their use of trauma assessment. Both frameworks are considered to be the most comprehensive implementation frameworks and their development through rigorous significant research provides justification for their use (Lewis et al., 2015). Specifically, the CFIR was applied to better understand the characteristics of trauma assessment strategies, the psychologists, and the setting that affected innovation use and whether the various characteristics were facilitators or barriers. Lastly, IOF implementation outcomes (e.g., *appropriateness, acceptability, feasibility*) were relevant to understanding why ASD diagnostic teams did or did not incorporate trauma-informed assessment practices.

Current Study

There were two primary aims in the current study:

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Aim 1. This study explored whether (and, if so, how) psychologists conducting multidisciplinary ASD diagnostic evaluations assessed trauma, specifically trauma exposure and trauma-related symptoms.

Aim 2. This study examined the factors that contributed to the use (or lack of use) of trauma assessment practices, including the facilitators and barriers that affected the integration of trauma assessment into ASD diagnostic evaluations. Despite the elevated rates of exposure to PTEs and trauma-related sequelae in children with ASD, there are currently no known EBA guidelines or tools for trauma assessment in children with ASD (Berg et al., 2016; Brenner et al., 2017). Though there is no research on the use of trauma assessment practices within ASD diagnostic evaluations, there is preliminary research on the infrequent use of EBA practices more generally and the barriers to the use of EBA (Jensen-Doss & Hawley, 2010). Therefore, this study considered whether the factors that affected the integration of trauma assessment into ASD diagnostic evaluations were unique or similar to those found in preliminary studies on the use of EBA (e.g., Whiteside et al., 2016).

CHAPTER 3

METHOD

Overall, the purpose of this project was to explore and increase understanding as to whether (and if so, how) psychologists conducting multidisciplinary ASD diagnostic evaluations assess for the presence of trauma exposure and trauma-related sequelae, including PTSD or other clinical presentations. The integration of trauma assessment in different stages of ASD diagnostic evaluations, including both the initial evaluation for children suspected of ASD and also the re-evaluation process for children who have already received a diagnosis but are being evaluated again, perhaps to clarify diagnosis (i.e., confirm ASD, rule in/out psychiatric comorbidity), was included. Further, this qualitative project sought to determine what factors were facilitators or barriers to including evidence-based assessment of trauma in the ASD diagnostic process. As suggested by Kerns and colleagues (2015), qualitative research is an appropriate starting point for exploring the intersection of trauma and ASD in children, as this is a very novel research area. Specifically, as there is no known research on the assessment of trauma in children being evaluated for ASD, this research project was a qualitative inquiry, as qualitative research allows for greater in-depth understanding (Patton, 2002).

Phase 1: Initial Measure Development

I developed a semi-structured interview protocol to explore psychologists' processes for evaluating trauma exposure and trauma-related sequelae in children being evaluated for a diagnosis of ASD (see Appendix C). The interview protocol also explored psychologists' perspectives on factors that affect the inclusion of trauma in the ASD diagnostic evaluation process. A semi-structured interview that included primarily open-ended questions was used to allow for freedom to discuss and elaborate on interviewees' perspectives and experiences. As

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recommended by Kirk and colleagues (2016), theoretical implementation frameworks (i.e., CFIR and IOF) were used to guide interview development. Specifically, as was previously described, I used the CFIR qualitative interview guide tool (<http://cfirwiki.net/guide/app/index.html>) as a resource to inform question development. Further, published qualitative research that has explored the use of evidence-based assessment for trauma or related disorders (e.g., anxiety disorders; Whiteside et al., 2016) was used to develop the interview protocol. Additionally, published qualitative research using the CFIR framework to assess the implementation of an innovation was also used (e.g., Damschroder & Lowery, 2013). I also reviewed research articles using the CFIR that were identified in the systematic review by Kirk and colleagues (2016) as well as several additional articles published since the review was completed in January 2015 (e.g., Varsi et al., 2015). I reviewed these articles with a particular focus on identifying examples of implementation-related questions.

The primary questions for the semi-structured interview were designed to reflect the overarching aims of this project. Specifically, I asked questions about whether assessment techniques were used to evaluate trauma exposure and/or trauma-related sequelae. If psychologists did incorporate trauma assessment into the ASD diagnostic process, additional topics, including the process and measures used, were discussed. Further, I collected background information about the psychologist and their training as well as their clinic's process by which ASD diagnostic evaluations were conducted, including the way in which psychiatric comorbidity more broadly was assessed.

Additionally, interview questions regarding the adoption of trauma assessment practices as well as facilitators or barriers that affected the use of trauma assessment were included. As the goal of this project was to use a primarily deductive approach but to also allow patterns and

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themes to emerge from the data if they did not fit the existing frameworks (Patton, 2002), the overarching dimensions of the CFIR (e.g., *intervention characteristics*, *inner setting*) were used to guide broad questions about facilitators and barriers. For instance, the qualitative interview gathered information about the *characteristics of individuals* (a CFIR domain) that might have affected psychologists' assessment of trauma. A construct within this domain—*knowledge and beliefs about the innovation*—was explored through broad questions about the psychologists' experiences with trauma and trauma assessment, in order to better understand psychologists' training, knowledge, and attitudes regarding trauma, trauma assessment approaches, and the intersection of trauma and ASD. Further, I asked questions related to the *inner setting* and whether the psychologists and/or the broader organization in which they operated might be willing to include evidence-based trauma assessment in the diagnostic process in the future, as both *tension for change* and *readiness for implementation* (constructs within the *inner setting*) might predict future adoption of trauma assessment in these settings.

Importantly, this interview protocol was created through a two-step process using an expert panel. As recommended by Drum and colleagues (2009), an expert panel was formed by recruiting members who are experts in the components of the study topics, including autism diagnosis, trauma assessment, and implementation science. The expert panel was consulted via email and telephone conversations, depending on the experts' availability. First, the expert panel was used to determine the most important topics about which to ask in the semi-structured interview. I proposed questions derived from the research aims and past research to the expert panel. The expert panel provided feedback on the questions for the interview protocol, including both wording and content, and identified any topics that were missing. Adaptations to the interview protocol were made following this process. Following the initial expert panel process, I

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then presented the revised interview protocol to the panel to obtain final feedback about interview question content and structure. Throughout the interview protocol formulation process, a trained, doctorate-level researcher who specializes in qualitative data collection was consulted.

Phase 2: Interviews of Licensed Psychologists

Inclusion Criteria. Licensed psychologists (ages 18 and above; $N = 13$) who conducted multidisciplinary autism diagnostic evaluations located in centers specializing in the assessment and treatment of ASD (e.g., autism centers for excellence) were recruited for this study using purposeful sampling techniques. Purposeful sampling is a technique for the intentional selection of individuals who can provide the greatest depth of information regarding the phenomenon of study (Palinkas et al., 2015; Patton, 2002). Therefore, for this study, psychologists who were knowledgeable about the diagnostic process for ASD, specifically, the process by which potentially co-occurring conditions (e.g., anxiety disorders, ADHD, traumatic stress or other trauma-related sequelae) were considered, were identified and selected through purposeful sampling. Licensed psychologists of varying genders, ages, races/ethnicities, years of experience, and geographic locations were equally desired as long as they conduct multidisciplinary ASD diagnostic evaluations. Importantly, only psychologists who have completed the necessary requirements for licensure as required by their respective state (e.g., postdoctoral training, passage of the Examination for Professional Practice in Psychology) were included.

Licensed psychologists who conduct multidisciplinary ASD evaluations were recruited using a combination of critical case and snowball sampling techniques. As described by Patton (2002), critical case sampling can be used to determine “if it doesn’t happen there, it won’t happen anywhere” (p. 236). As was previously mentioned, multidisciplinary evaluations are considered the “gold standard” by which ASD is ruled in or out and appropriate diagnosis for

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children suspected of ASD is reached. Initially, the goal was to include only psychologists who conduct multidisciplinary team evaluations; however, through initial recruitment, I realized that clinics varied widely in their approach to performing team-based multidisciplinary evaluations. For example, some clinics included other disciplines at varying time points in the assessment process. Specifically, many organizations do not have professionals from all disciplines participating in a same-day evaluation, and psychologists from different clinics have found various ways to integrate multidisciplinary team data, such as requiring a school-based multidisciplinary evaluation prior to being seen for a clinic evaluation. Thus, psychologists who conducted multidisciplinary evaluations were included in this study; however, some latitude in the method by which the evaluation was multidisciplinary and team-based was permitted. Importantly, given that this is the first study in this area, to my knowledge, psychologists who were engaged in “best practice,” meaning they were located at autism specialty centers (e.g., those located within autism centers for excellence, Autism Treatment Network sites, or nationally ranked children’s hospitals) and conduct multidisciplinary ASD diagnostic evaluations, were targeted for participation.

Further, snowball sampling was used in conjunction with critical case sampling. Snowball sampling is a process by which participant referrals are collected from other psychologists throughout the interviewing process (Patton, 2002). Snowball sampling is a technique by which information-rich participants can be identified through asking people who are “well-situated” in the field (Patton, 2002, p. 237). The first participants were identified through the use of the expert panel, specifically the panel members who are prominent researchers and practitioners in the field of autism diagnosis and practice.

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As described by Patton (2002), unlike in quantitative research, there are no rules for sample size in qualitative research. Patton (2002) indicated that the validity and significance derived from qualitative studies stem more from the richness of information gathered from data sources; therefore, sampling is complete when no new information is being gained from the addition of new research participants. The point at which including new research participants no longer adds new information or themes to the qualitative data is referred to as saturation (Guest, Bunce, & Johnson, 2006). Guest and colleagues (2006) have suggested that saturation can be reached after 12 interviews when there is structure in the interview protocol (i.e., all participants are asked the same questions) and homogeneity in the sample, which is typically true in critical case and snowball sampling. Given that psychologists in this study were all asked similar questions via the semi-structured interview by the same interviewer and the narrow inclusion criteria created a relatively homogenous sample, the current study aimed to recruit between 12 and 15 licensed psychologists who conduct multidisciplinary ASD diagnostic evaluations.

The size of the sample reached 13 individuals, which was determined by saturation of responses; specifically, saturation was reached when the categories, including those that were predetermined from the CFIR and IOF and any that arose inductively, of how and why psychologists use (or do not use) trauma assessment practices became redundant. Data saturation (Guest et al., 2006; Saunders et al., 2018) was determined to be the most appropriate approach to saturation for this study. I did not use a priori thematic saturation, an approach to saturation that is common in deductive studies, because it requires adequate representation of all predetermined codes in the data (Saunders et al., 2018). Given that different CFIR and IOF constructs are relevant at different stages of implementation, it was not expected that participants would reference every construct in both frameworks.

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Participants. Thirteen licensed psychologists who conduct multidisciplinary ASD diagnostic evaluations in autism specialty centers across the United States participated in this study. Interviews ranged from 27 to 82 minutes ($M = 43.46$, $SD = 13.6$), and the median interview length was about 42 minutes. Participants were dispersed geographically with 30.8% ($n = 4$) of participants each in the Northeast, Midwest, and South regions of the United States and only one in the West. Participants ranged in age from 33 to 46 ($M = 38.54$, $SD = 4.18$) and were primarily female (76.9%) and White (84.6%). The majority of participants had a Ph.D. (84.6%; $n = 11$) while the rest had a Psy.D in psychology, and 84.6% of practitioners specialized in Clinical Psychology and were trained in a scientist-practitioner model. Participants varied in their years of experience conducting multidisciplinary ASD diagnostic evaluations in their current setting from several months to 11 years ($M = 4.50$, $SD = 3.43$) with their overall experience conducting these evaluations, including prelicensure, ranging from 3 to 23 years ($M = 10.05$, $SD = 6.41$).

Sixty-nine percent ($n = 9$) of participants presently conduct ASD diagnostic evaluations in an outpatient clinic affiliated with a children's hospital, and the remaining participants (30.8%) described their setting as a university-based clinic. Most participants (84.6%) described over half of their evaluations as initial (first-time) ASD diagnostic evaluations as opposed to re-evaluations, and all participants but one reported that the majority of their assessments are clinical (not research) evaluations. Participants indicated that they conduct the majority of their evaluations with children between ages 5 and 12 and children ages 3 to 5, such that 46.2% ($n = 6$) and 30.8% ($n = 4$) of psychologists conduct over half of their evaluations with children ages 5 to 12 or children ages 3 to 5, respectively. Only four participants perform any percentage of their ASD diagnostic evaluations with individuals 18 years of age and older, and while no participants

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conduct the majority of their evaluations with children birth to three, 61.5% of participants at least conduct some percentage of their evaluations with this age group. See Table 1 for a summary of sociodemographic information.

Measures. Telephone interviews using the semi-structured interview protocol developed and vetted through the expert panel in Phase 1 were conducted. Participants first completed a demographic measure using Qualtrics (online survey software; see Appendix D), including questions about their age, gender, ethnicity, and details about their education and professional training (e.g., clinical vs. school psychology program). They were also asked about the number of years they have conducted ASD diagnostic evaluations, including the number of years in their current setting. They then were contacted for the telephone interview.

Materials and setting. I conducted the telephone interviews in a university research laboratory or private office, which allowed for confidentiality in the data collection process. The telephone interviews were recorded with a digital recorder. Following the completion of the interview, the audio recordings were transferred from the recorder and converted into MP3 files to be stored on password protected, encrypted cloud storage. Transcription was also conducted in a confidential setting, and all identifying information was removed during this process. Qualitative interview data were transcribed verbatim by a research assistant and then reviewed a second time by me. The audio recording was erased from the digital recorder following conversion to an MP3, and it was deleted from the cloud storage following transcription.

Procedure. I contacted participants via email and asked if they would be willing to participate in the study. Snowball sampling was used to disseminate a study flyer (see Appendix E) and recruitment email (see Appendix F) advertising the research study in organizations that met the inclusion criteria. If the participant agreed to engage in the study, they were sent the

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online Qualtrics survey. Following survey completion, they were contacted to schedule a telephone interview at a time and date that was convenient for their schedule. Prior to conducting the interviews, I reviewed informed consent, including the process (e.g., audio-recording, data storage) and potential risks and benefits of the study. Participants were reminded that their participation in the study was voluntary and that all identifying information would be removed from the transcription of the recording. Participants were also asked to review the transcription of the interview electronically and to make clarifications/revisions via “track changes” to ensure that their perspective was captured accurately. Lastly, participants were provided with contact information for my research supervisor and me should they have questions or concerns about the study. Psychologists who participated in telephone interviews received a \$40 Amazon gift card following their transcription review to demonstrate appreciation for their participation. The University of Montana Institutional Review Board reviewed and approved the study protocol.

Researchers’ backgrounds. The research assistants and I, who conducted and coded the qualitative interviews with psychologists, are all members of a university research laboratory focused on the use of culturally responsive evidence-based practices in child psychology. I am an advanced graduate student in a clinical psychology doctoral program, with specialized training in both trauma and autism diagnostic assessment, including ADOS-2 certification, and implementation science. There are two research assistants, one of whom is an advanced graduate student in clinical psychology who has specialized training in trauma, implementation science, and qualitative research. She also has additional training and clinical experience working with children with ASD. Both this graduate student and myself were previously members of a dissemination and implementation science (DIS)-focused research laboratory and have training in and experience using DIS frameworks, including the CFIR and IOF. The second research

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assistant is a graduate student in behavior analysis with a bachelor's degree in psychology and thus completed coursework in clinical psychology, abnormal psychology, and family violence. She has additional training in and experience working with children on the autism spectrum. The advanced graduate student brought extensive experience with implementation science and qualitative research methodology to the study and did not require further training. However, the other research assistant received additional training in both areas to increase the trustworthiness of data analysis. This included the assignment of readings and subsequent discussions with me on an overview of implementation science, research articles establishing relevant implementation frameworks (e.g., CFIR; Damschroder et al., 2009), sample studies using the implementation frameworks (e.g., Varsi et al., 2015), and articles on qualitative methodology, including content analysis. It also included thorough review and discussion of the codebook to answer any questions prior to coding.

Throughout the interview and coding process it was important for the researchers to attend to our potential biases that could have informed our data collection and analysis. Specifically, I am an advanced graduate student in a clinical psychology program that adheres to the scientist-practitioner model of training, which seeks to integrate research and scientific practice. Therefore, I have a strong bias towards the use of practices (i.e., assessment and treatment approaches) that are informed by research data. Further, all researchers are members of a university research lab focused on the application of EBPs. Additionally, I have received extensive training in trauma, including the importance of trauma-informed systems, and I believe that all systems that serve children should be prepared to address and support trauma-exposed children and families. Therefore, it was important for me to not insert my opinion into the interview process, although I experienced the urge to validate participants when they commented

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on the need for trauma assessment practices during ASD diagnostic evaluations. I was mostly successful in refraining from inserting opinions or commentary throughout the interview; however, the conclusion of the interview often prompted questions and discussion by the interviewee about my interest and perspective on the topic as well as my knowledge of any resources. In addition, my training in DIS and past experience with implementation frameworks, including the CFIR and IOF, informs my view of the adoption of EBPs.

Coders were mindful of their biases in the coding process, and I assumed responsibility for attending to and discussing biases in the team meetings. Coders wrote memos and added notes via comments on the interview transcripts to capture both their coding decision-making process and their reactions to the content. These were used during meetings for coding discussions as well as reflection and examination of the researchers' values and biases in order to achieve bracketing.

Data analytic strategy. Frequency and descriptive (e.g., mean, standard deviation) statistics were generated to summarize relevant demographic information. As was previously described, conducting implementation research without a theoretical framework can limit researchers to their specific contexts in which the research was conducted and impede generalization and building on findings across studies (Kirk et al., 2016). According to Varsi and colleagues (2015), implementation research guided by well-established theories, frameworks, and models strengthens “the understanding and explanation of how and why implementation succeeds or fails (e.g., what works, for whom, under what circumstances, and why;” p. 2). Thus, a primarily deductive approach using the CFIR and IOF as coding frameworks was used. Notably, given the lack of prior research on the use of trauma assessment in the diagnostic

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process for children suspected of ASD, this project was also open to an inductive approach, in which patterns and themes emerge from the data (Patton, 2002).

Data was analyzed through directed qualitative content analysis, which is a method that allows for descriptive analysis and results in the identification of core patterns or themes in the data (Patton, 2002). Content analysis is considered to be a “flexible method for analyzing text data” that provides description and understanding of the phenomenon being studied (Hsieh & Shannon, 2005, p. 1277). Content analysis was selected as the primary approach to this project, as its purpose is to organize and extract meaning from the data and draw conclusions (Bengtsson, 2016). Specifically, content analysis seeks to answer questions such as “*what, why, and how*” (Cho & Lee, 2014, p. 6). The common patterns within the data are sought in order to engage in a “sense-making effort” (Patton, 2002, p. 453) to understand and systematically describe the data relevant to the specified research questions (Cho & Lee, 2014). For this project, I sought to describe and better understand the trauma assessment process within ASD diagnostic evaluations. Therefore, I approached the data with a primarily deductive approach that also allowed any “core consistencies and meanings” (Patton, 2002, p. 453) relevant to *how* psychologists are integrating trauma assessment in the ASD diagnostic process and *why* (or *why not*) to emerge from the data. I further explored *what* factors facilitated or impeded the use of trauma assessment, which I viewed through the lens of established implementation science frameworks (e.g., CFIR, IOF). However, any data that did not fit the frameworks was noted and reviewed for fit into alternative categories.

Content analysis was selected as the qualitative approach given its focus on describing and understanding (Patton, 2002). Given the lack of research on the integration of trauma assessment into ASD diagnostic evaluations, it is important that content analysis allows for the

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description of recurring patterns across clinics that engage in multidisciplinary ASD diagnostic evaluations. Grounded theory (Charmaz, 2006) was evaluated as a potential methodological approach for this study, and while there is significant overlap (and resulting confusion) between grounded theory and qualitative content analysis, content analysis was determined to be the best fit for the research questions (Cho & Lee, 2014). Grounded theory is predicated on the generation of theory (Charmaz, 2006), and there are already well-established frameworks to organize the factors that affect the adoption of clinical practices. Importantly, I did not want to try to “reinvent the wheel” regarding facilitators and barriers of the use of innovations. However, given the nascent stage of research on trauma and ASD, I also did not want to limit the potential concepts that could emerge to those within the established implementation science frameworks. Therefore, a primarily deductive approach to content analysis was used for data analysis combined with openness to additional themes that may have arisen inductively from the data.

The transcripts were read through several times for understanding (Bengtsson, 2016). Prior to beginning data analysis a codebook was created from combining the CFIR guide with the implementation outcome definitions from the IOF. Coding with the predetermined codes began following transcription of the interviews and was conducted in chunks (i.e., approximately every four interviews). Data were coded using NVivo 11 or 12 qualitative data analytic software. I coded all interviews, and the research assistants coded about 75% and 25% of the interviews, respectively, so two different researchers coded each interview. All three researchers coded the first interview to establish consistency across coders and met to discuss any discrepancies. Research assistants were instructed to code the smallest possible meaning units (Bengtsson, 2016), such that it was the smallest unit containing relevant insights or information. As described by Bengtsson (2016), each coder examined the interview independently and then met via

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videoconference or telephone to discuss their coding and obtain consensus on any differences. Following a first round of coding, I reviewed the interview transcript to examine the unmarked text to evaluate its relevance to the aims of the study and then presented this information during meetings to discuss whether it fit the existing codebook or required a new category or subcategory. During coding meetings, coders reviewed discrepancies and resolved differences through discussion and negotiation. Following reaching consensus, codes were designated as “facilitators” (i.e., facilitate the use of trauma assessment), “barriers” (i.e., impede the use of trauma assessment), or “neutral” (i.e., do not positively or negatively influence the use of trauma assessment). This process of consensus coding helped to establish increased confidence in interrater agreement (Bradley, Curry, & Devers, 2007), as consensus coding is an established method for achieving reliability and dependability of qualitative data (Palinkas, 2014). Coding decisions were tracked, and the research assistants and I used memos to note decisions made during the consensus coding process.

Notably, in order to attempt to reduce bias in the coding process and increase the trustworthiness of the findings, triangulation procedures were used (Patton, 2002). First, interviewing a broad range of individuals helped to obtain a range of experiences related to the ASD diagnostic process during multidisciplinary evaluations. Sending the transcripts to the interview participants for their review allowed for member checking, which can increase the accuracy and credibility of the data. Ten out of 13 participants returned their transcript and confirmed reading and approving the transcript. Two participants provided additional clarification of their responses. Also, analyst triangulation (i.e., using several different researchers to review and analyze the data) was used throughout the coding process. The coding team met regularly throughout the coding process and worked collaboratively to determine how

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to resolve discrepancies in coding. Progress and results were reviewed throughout the coding process with a trained, doctorate-level researcher who specializes in qualitative data collection.

CHAPTER 4

RESULTS

Consistent with the aims of the study, before considering the constructs associated with the use of trauma assessment within the context of ASD diagnostic evaluations, it was important to first explore whether and, if so, how participants incorporated trauma assessment into their evaluations. Subsequently, factors that influenced the use (or lack of use) of trauma assessment were grouped based on the CFIR and IOF frameworks and then designated as facilitators or barriers of the integration of trauma assessment into ASD diagnostic evaluations. Thus, factors were categorized into the CFIR domains of 1) *process*, 2) *outer setting*, 3) *inner setting*, 4) *characteristics of individual providers*, and 5) *innovation characteristics*. Notably, while participants referred to all five domains of the CFIR, the implementation *process* domain was found to be less pertinent to this study given that participants were either not using trauma assessment practices (and thus were not engaged in an implementation process) or were in the early stages of implementation. Thus, while the *executing* construct in the *process* domain is intended to capture implementation according to a plan, it was used in this study to include the current assessment practices of psychologists conducting ASD diagnostic evaluations. Other *process* constructs will still be discussed below within the *process* domain, although they proved to be less influential than the constructs within other CFIR domains. Similarly, implementation outcomes were categorized according to IOF constructs, and constructs that were related to pre-implementation and the early stages of implementation were more relevant to this study.

See Table 2 for additional coding data for constructs discussed below, including the constructs referenced and the number of participants who predominantly identified the constructs as facilitators and barriers, and Table 3 for sample quotes for each construct.

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Consolidated Framework for Implementation Research (CFIR)

Factors that influenced the integration of trauma assessment practices into ASD diagnostic evaluations were organized using the CFIR framework into the five overarching domains and associated constructs and subconstructs. Although not as comprehensive as trauma assessment, factors that facilitated trauma screening were included. Specifically, participants who engaged in primarily trauma screening were asked about the factors that influenced and affected their current practice, what barriers to conducting in-depth trauma assessment might exist, and what might facilitate more comprehensive trauma assessment in their clinics.

Notably, the vast majority of data fit within the framework as outlined by Damschroder and colleagues (2009). Thus, the CFIR appeared to be a suitable theoretical framework to guide the research process, including data collection and analysis. There was only one subcategory that arose from the data that seemed to fall outside of the CFIR framework, which will be discussed in the *needs and resources* subsection.

Process. The majority of participants did not discuss the process constructs as relevant to their implementation efforts; thus, the 1) *executing* construct was used to capture the current assessment practices of psychologists conducting ASD diagnostic evaluations. There were no other process constructs that were discussed by greater than 50% of participants. However, one subconstruct within the 2) *engaging* construct, a) *external change agent*, will be discussed given that it appeared to be influential for participants who used trauma assessment practices, even as a relatively low-frequency construct.

Executing (referenced 201 times). In addition to exploring the extent to which psychologists conducting multidisciplinary ASD diagnostic evaluations assessed for psychiatric comorbidity more broadly, participants were asked to describe their standard procedure for

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assessing both trauma exposure and symptoms of traumatic stress or other trauma-related sequelae. Twelve out of 13 (92.3%) participants indicated that they evaluated for trauma exposure and trauma-related symptoms in some form. Only one participant described that her ASD diagnostic evaluations contained no assessment of trauma and that her clinic made no attempts to parse out psychiatric comorbidity beyond developmental concerns. While the vast majority of participants described assessing for trauma to some degree, 8 out of 12 reported practices consistent with trauma screening rather than assessment. Trauma screening refers to the process by which exposure to PTEs and/or possible trauma-related symptoms are identified but are not the subject of further comprehensive evaluation. Thus, most participants reported that they screened for trauma exposure and followed up with screening for PTSD symptoms if a PTE was endorsed and then referred out for further evaluation.

Cumulatively, nearly 70% of the sample ($n = 9$) described that it was their and/or their clinic's procedure to refer out for additional evaluation if psychiatric comorbidity, specifically traumatic stress or other trauma-related symptoms, was a concern following a positive screen for exposure and possible trauma symptoms. All participants except one (92.3%) identified that the psychologist was the leader in diagnostic decision-making and, thus, it was the role of the psychologist to assess for psychiatric comorbidity, including trauma.

Participants provided additional details regarding the manner in which trauma screening was conducted. With the exception of the one participant who did not engage in any trauma screening or assessment, the majority of participants indicated that the primary method by which they engaged in trauma screening and/or assessment was through a caregiver interview. Nine out of 12 participants stated that, regardless of any other information obtained, caregivers were always asked trauma exposure screening questions in the context of the psychiatric interview,

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which was conducted by either the psychologist ($n = 8$) or psychiatrist ($n = 1$). For instance, one psychologist described,

Mostly I am asking every family basic questions about, “Has your child ever experienced anything serious or threatening?” And then I give a lot of examples and ask specifics about hurricanes, earthquakes, other natural disasters, sexual abuse, physical assault, substantial teasing or bullying.

The remaining three participants described that they only asked screening questions if the caregiver had endorsed at least one PTE on their intake or demographic form that was completed prior to the evaluation. For example, one participant stated that the intake questionnaire was like a “pre-screening” and that she followed up “based on what the family document[ed];” therefore, she relied “pretty heavily on that intake to clue [her] in to whether [she] needed to specifically ask questions about trauma.”

For the three participants who engaged in more comprehensive trauma assessment, they indicated that the primary method by which they explored trauma-related symptoms further was through the use of measures. Overall, while five of the 13 participants (38.5%) endorsed access to trauma measures, only three (30.8%) of the psychologists described regular measure use. Only one participant described occasional use of an exposure measure (i.e., *NSLIJHS Trauma History Checklist and Interview*; North Shore-Long Island Jewish Health System, Inc., 2006), such that she would only use it if she did not get adequate exposure history from the intake form or a record review. All three participants who indicated that they administered measures to evaluate for trauma symptoms used the *Trauma Symptom Checklist* (TSCC; Briere, 1996) and the *Trauma Symptom Checklist for Young Children* (TSCYC; Briere, 2005). One participant added the *Child*

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PTSD Symptom Scale (CPSS; Foa, Johnson, Feeny, & Treadwell, 2001) in addition to the TSCC or TSCYC to assess trauma symptomatology.

Beyond the intake form, caregiver interview, and/or measure use, participants infrequently obtained other sources of data to supplement their trauma assessment. Specifically, a child interview was not a standard procedure for any of the psychologists, although eight participants (61.5%) referenced it as a potential component of the evaluation. Two psychologists described that for children who were being administered Module 3 of the ADOS-2, they would make use of the “teasing and bullying” question to follow-up with the child about trauma exposure. Other participants ($n = 6$) indicated that conducting a child interview was dependent on the child’s language ability and age. Interviewing the child was also frequently eliminated from the evaluation as described by one participant: “The psychiatric interview with the child during these clinics is an extremely small piece and, quite frankly, may not happen at all.” As an alternative to interviewing the child, one participant described using live video observation in a naturalistic play setting if additional diagnostic clarification was needed. Further, collateral information was not often obtained from the school. While eight participants (61.5%) noted that they had interactions with school professionals, only three participants (23.1%) discussed trauma with school professionals if it seemed relevant and one noted, “If they don’t bring up any concerns, then we wouldn’t typically ask that question about trauma.”

Importantly, all but one of the psychologists interviewed included trauma as a consideration in their ASD diagnostic evaluations. However, the primary method by which trauma was considered was through screening for exposure and then symptoms if at least one PTE was endorsed. The psychologist most commonly performed the screening through the use of an intake form and/or a caregiver interview. Three participants regularly added trauma symptom

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measures if exposure was endorsed; however, this was not the norm among participants. The most commonly used approach to evaluate for trauma was screening for exposure and, if needed, PTSD symptoms, and then referring out for further evaluation. As one participant summarized, “My role is more to assess if the child needs the next step.”

Engaging. As a limited number of participants had active comprehensive trauma assessment practices, only a few participants noted that they made efforts to involve individuals in the implementation of trauma assessment. One low frequency, but seemingly influential, subconstruct of the *engaging* construct that will be discussed is a) *external change agent*.

External change agent (referenced 11 times). Four participants (38.5%) identified individuals who were affiliated with an outside entity that positively influenced their use of trauma assessment. All four of these participants noted that the *external change agent* facilitated their use of trauma assessment practices. One participant described how her clinic’s involvement in a research project with a trauma specialty clinic led to the integration of trauma assessment into the standard caregiver interview in their ASD diagnostic clinic. She explained that “two of [their] psychologists collaborated with [trauma clinic director] over a period of a couple of months at least to determine what was the most appropriate, beneficial, as well as feasible” approach that could work for their clinic. Two additional participants echoed that the collaboration with individuals from a trauma specialty clinic was the impetus for the adoption of trauma assessment practices.

Further, one participant noted that her clinic’s collaboration and eventual hiring of multiple providers from an outside clinic that primarily conducted assessments with children in foster care facilitated increased use of trauma assessment within her clinic; however, it was mostly “luck.” She noted that the ASD clinic did not think, “Oh we’re not assessing trauma very

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well, let's recruit somebody who can." Thus, while the individuals from the external organization influenced the adoption and use of trauma assessment practices, the participant was skeptical that these psychologists were actively engaged and sought out for collaboration for the purpose of influencing the clinic's trauma assessment practices.

Outer Setting. Participants offered numerous statements about how the broader context (i.e., "the economic, political, and social context," p. 5, Damschroder et al., 2009) within which their organization resides affected their use of trauma assessment practices within ASD diagnostic evaluations. The outer setting constructs that were discussed by the majority (greater than 50%) of psychologists included 1) the *needs and resources of those served by the organization*, 2) *cosmopolitanism*, 3) *peer pressure*, and 4) *external policy and incentives*.

Needs and resources of those served by the organization (referenced 147 times). All 13 of the participants (100%) described the extent to which they knew and prioritized the needs of children receiving ASD diagnostic evaluations and their families. When asked if they perceived a need to assess for trauma exposure and trauma symptoms during ASD diagnostic evaluations, 100% of participants said, "Yes," though two stated that it depended on the age or needs of the child. Furthermore, all participants identified ways in which the needs and resources of children and their families both facilitated and impeded their implementation efforts.

Nine participants (69.2%) believed that the need for integration of trauma assessment into ASD diagnostic evaluations outweighed potential barriers, whereas four participants (30.8%) indicated that the needs of the children being evaluated impeded their implementation of trauma assessment. The *needs and resources* construct was referenced the most frequently out of any construct as a factor influencing participants' perspectives and use of trauma assessment in ASD diagnostic evaluations. Given the frequency with which *needs and resources* was referenced,

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statements were further organized into subcategories, which are presented below. Importantly, one subcategory, *symptom overlap*, was considered to be a distinct factor affecting the use of trauma assessment practices that did not entirely fit within the CFIR framework.

Prevalence. Twelve out of 13 participants (92.3%) identified that the prevalence of trauma in children with developmental disabilities was a prominent factor in their views of the needs of the children being evaluated. Ten of 12 psychologists indicated that the higher prevalence of trauma in children with ASD created a need for the innovation, such that they viewed trauma assessment as something that was needed given the population that they served (i.e., children with ASD). As one participant explained:

I think that children with autism and all neurodevelopmental disorders are at a higher risk of trauma. Poor communication, different intellectual functioning, poor perceptions of interpersonal relationships, I think it puts them at risk of experiencing trauma above and beyond maybe a typically developing child.

Four participants discussed the prevalence of trauma within their geographic location as a factor that influenced their view of the need to assess children for trauma. For instance, one participant noted that “about 65% of [their] patients are on Medicaid” and another commented that “the inner city population” served by their organization contributed to their perception of trauma assessment as a needed practice.

Interestingly, out of the 12 participants who discussed prevalence of trauma as a factor that affected their perception of trauma assessment as a needed innovation, four participants made statements describing trauma as a rare occurrence in children with ASD, suggesting a lack of a need for trauma assessment and, thus, potentially impeding their use of trauma assessment practices. One participant identified hearing from a colleague in regards to trauma, “Why? We

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don't ever see that." Other participants noted that other comorbidities occur at higher base rates than trauma exposure and trauma-related symptoms, including one participant who stated, "It's still a fairly low frequency phenomenon, not nonexistent obviously, but when we think about other phenomena, like anxiety or self-injury, those are things that occur at very, very high rates in this population." This was echoed by other participants as well.

Caregivers and family. Participants reported that the needs of the caregivers or families often influenced their perception of the need for trauma assessment and their use of trauma assessment practices. Specifically, participants described that there was a need to assess for trauma in children being evaluated for ASD because, as stated by one participant, "Family functioning in the environment that that child lives in plays a role certainly in their overall level of functioning." Another participant highlighted a need for the assessment of psychiatric comorbidity more broadly, including trauma, because "it's very frustrating for families when you say, 'No, your child doesn't have autism,' and then send them on their merry way without an answer to what's going on."

While several participants identified that the caregivers and/or families of children being evaluated for ASD created a perceived need for trauma assessment, many participants discussed ways in which the caregivers/families were a barrier to their use of trauma assessment practices. Specifically, five participants noted that the willingness of families to discuss trauma, especially if family members were involved, affected their questioning regarding trauma. For instance, one participant noted that family members can "feel defensive," and, therefore, she does not "want to make them put up their guard with [her] when [she has] other questions to go through." Another participant summarized her concern regarding fear of creating a perception of blame in families:

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There's been a big effort in the last decade to move away from models that might ascribe symptoms of autism to family factors. So we've come a long way from the "refrigerator mother" explanation of autism. And so I think within the culture there's some hesitation to ask about factors that may ascribe "blame" to the family system in some way, and I think that sensitivity may contribute to less direct assessment of trauma symptoms.

In addition, several participants highlighted that their consideration of how overwhelming it was for families to receive an ASD diagnosis influenced their assessment of psychiatric comorbidity, including trauma. One participant commented, "It was already so overwhelming to get a new autism diagnosis... They were already hearing a million things, so our philosophy was more let's do one thing at a time."

Child. Many participants also identified that their knowledge of the needs of children being evaluated influenced their use of trauma assessment practices and/or their view that these practices are needed. Specifically, participants indicated that the symptoms displayed by children, children's safety, and the importance of accurate diagnosis created a need for the use of trauma assessment. For instance, if a "child is having difficulty sleeping, difficulty concentrating, those types of things," one participant expressed that it was important to examine what contributed to those symptoms. Another participant added that she had to ensure that "as a mandated reporter that all of the bases are covered and that the child is safe." A different participant echoed that she saw a need for trauma assessment in the children she evaluated for ASD because:

If a child is currently in an abusive environment it's my responsibility to make sure that they're safe... Number two would be to account for any other diagnostic considerations

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that might affect the patient's presentation... almost ruling out any other potential influencing factor that might be contributing to or not to a diagnosis of autism.

Nine participants (69.2%) identified desire for appropriate diagnosis as contributing to their perception of a need for integrating trauma assessment into ASD diagnostic evaluations. They noted that not only is "just getting the right diagnosis" important but also "[trauma] has the ability to really affect a diagnostic decision." Thus, the majority of participants recognized that including trauma in their ASD diagnostic evaluations was important for adequately understanding the child's symptom presentation and reaching a diagnostic conclusion. Six participants (46.2%) added that there was a further need for trauma assessment practices because it allowed for appropriate treatment recommendations. One participant summarized this need for trauma assessment given the need to obtain an accurate diagnosis and link to appropriate treatment services for children being evaluated for ASD:

If you don't understand the context of the child's experience, especially as it relates to trauma, it can lead to misdiagnosis and then you have very inappropriate treatment responses. In the case of comorbidity with ASD you have a significant risk of missing out on connecting the child with appropriate treatment services...So I think that integrating trauma assessment allows better informed treatment recommendations.

While many participants indicated that they perceived a need for trauma assessment given the needs of children being evaluated for ASD, all participants also referenced ways in which the needs of children being evaluated for ASD impeded their implementation efforts. Nine participants (69.2%) described that the needs and abilities of the children being evaluated interfered with their integration of trauma assessment. Specifically, eight participants (61.5%) referenced the diversity in language and communication abilities in children with ASD as a

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barrier to their use of trauma assessment. Other participants added that additional comorbidities, such as intellectual disability, influenced their use of trauma assessment practices, such that, “the level of insight and language of the child may be massive barriers.” One participant noted that characteristics of ASD impeded her use of trauma assessment as children “have a hard time with reporting what they are really experiencing or they already have weaknesses in identifying emotions and thinking processes.” Many of the comments regarding language were also related to psychologists’ views regarding the *adaptability* of trauma assessments and the *feasibility* of conducting trauma assessments during ASD diagnostic evaluations, and additional details are included in those sections.

In addition, along the same lines as the hesitance to integrate trauma assessment practices due to the needs of the caregivers or families, participants reported that their use of trauma assessment was affected by not “want[ing to] get the patient all distraught before they do testing.” One participant described, “I don’t want to put a kid in a situation where they’re revealing details about trauma that then we’re not able to support in a context of that evaluation.” Other psychologists connected the concern regarding the patient’s response to trauma assessment and its relationship to their implementation efforts to the nature of evaluations as short-term, brief relationships. For instance, participants noted, “Without a therapeutic relationship and more in the context of single diagnostic assessment, asking a child really difficult questions can be a challenge,” and “we got a kid who’s coming in to talk to a stranger in a weird clinic.” Additional discussion on this topic will be included in the *feasibility* and *acceptability* subsections.

Symptom overlap (referenced 22 times). *Symptom overlap* was created as a subcategory of the *needs and resources* subconstruct because, while related to *needs and resources*, it also was not completely captured there and appeared to be distinct from the CFIR constructs.

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Symptom overlap was created to include a commonly occurring statement by participants that their ability to integrate trauma assessment into ASD diagnostic evaluations was influenced by the overlap of ASD and trauma symptoms. This was determined to be an *outer setting* domain issue, such that it was not a component of the trauma assessment practices (*innovation characteristics*), individual providers (*characteristics of individuals*), clinic (*inner setting*), or the *process*. While it was the diagnoses assigned to the children being evaluated that influenced the use of trauma assessment, *needs and resources* is not a true fit to capture the degree to which the current diagnostic system struggles to effectively take these comorbidity issues into consideration because it was more about the diagnoses than the patients being evaluated.

Results showed that 69.2% of participants noted that the symptom overlap between ASD and trauma influenced their perception of a need for trauma assessment and/or their integration of trauma assessment practices. Five of the nine participants believed that the symptom overlap created a need to incorporate trauma assessment practices into ASD diagnostic evaluations. One participant pointed out, “You have to really understand there are many, many diagnoses that can be a part of a kid’s presentation when they’re struggling with social communication.” Thus, participants found the diagnostic overlap to be a crucial consideration in their diagnostic process, such that it increased their use of trauma assessment practices. Another participant added,

I think that it [trauma] can so impact a child’s social interactions, social communication, and play behaviors. It has a pervasive impact on a child, just like a neurodevelopmental disorder does. And when you’re looking for core impairments in autism that are different in kids who may just have been exposed to trauma it can look very similar.

While participants identified that the potential overlap in symptoms created a need for the innovation and prompted their use of trauma assessment practices, seven of the nine participants

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who referenced *symptom overlap* also commented on ways in which the overlap impeded their use of trauma assessment. Participants referred to the overshadowing of trauma symptoms given the focus on ASD symptoms. For instance, one participant stated,

If we have a kid who is demonstrating pretty significant behavior concerns that might overshadow some of the internalizing things that are happening. And so we might prioritize these other pieces before we realize, “Oh gosh, some of this might be trauma-related,” especially if nobody is reporting it.

Another participant described that repetitive behaviors may or may not be related to ASD and instead, “they may be related to the fact that the only two toys that child had for two years were these stacking cups and that one car, so then their play looks pretty atypical.”

The issue of symptom overlap was also related to the *available resources* construct, such that participants indicated that there is not a measure that effectively discriminates between ASD and trauma symptoms. This will be discussed further in the *available resources* subsection.

Cosmopolitanism (referenced 94 times). All 13 participants commented on the extent to which their organization was networked with other organizations. Nine of 13 participants (69.2%) identified that their organizations’ *cosmopolitanism* positively affected their trauma assessment practices. Three participants described engaging in collaboration with a trauma specialty clinic outside of their clinic, which contributed to their use of trauma screening. One participant described that their clinic engaged in “collaboration and coordination with [trauma clinic director] to think through how to best evaluate trauma in kiddos with developmental disabilities and autism.” Other participants outlined affiliations with social services agencies or community-based professionals engaged in trauma-informed care as facilitating their use of trauma assessment practices. One participant highlighted that she has been involved in a

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community action workgroup related to issues faced by children in early childhood, such as poverty and trauma, and she has “been trying to insert disability into those conversations.”

While a number of participants ($n = 7$) reported that they had attended professional meetings or conferences, only two described hearing relevant information that facilitated their integration of trauma assessment practices into ASD diagnostic evaluations. Although one participant noted that the use of trauma assessment within autism evaluations has “definitely been a topic over the past few years,” the other described that “the field is not quite where we need to be in this area, like specifically within individuals with intellectual disabilities or developmental disabilities.” Other participants who attended conferences shared the perspective that they have found useful information on trauma assessment in children being evaluated for ASD to be “very limited.” The few barriers associated with cosmopolitanism that were identified by participants included a lack of connections to outside agencies and also being the only ASD diagnostic clinic in a particular area, such that for one participant her clinic was “the catchment area of like four hours in every direction” as “basically the only diagnostic clinic in [state].”

As was described in the *executing* section, while not designated as a facilitator or a barrier, nine participants discussed being networked with other organizations, such that they referred out for further evaluation if the trauma screening was positive for exposure and potential trauma-related symptoms. Notably, this connection might have affected psychologists’ use of trauma assessment practices, though participants did not endorse it as either a facilitator or barrier to the integration of trauma assessment within ASD diagnostic evaluations.

Peer pressure (referenced 15 times). *Peer pressure* refers to the competitive pressure to implement an innovation, such that the trauma assessment practices of psychologists in their clinics were influenced by the perception that other providers and/or clinics had already

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implemented trauma assessment practices. While 12 out of 13 participants (92.3%) commented on the practices of their peers through response to direct questioning regarding their awareness of the use of trauma assessment during ASD diagnostic evaluations outside of their clinic setting, it was neither a facilitator or barrier of trauma assessment use. Eleven out of 12 participants had no awareness as to what extent other clinics conduct trauma assessment during ASD diagnostic evaluations. One participant guessed,

I do have a sense of what other centers are doing for their diagnostic evaluations and although we haven't spoken directly about trauma assessment, I would guess that means it's because it's not a formal or large part of any of those centers' process.

Thus, *peer pressure* did not seem to be a factor that actively facilitated the use of trauma assessment practices of the psychologists interviewed.

External policy and incentives (referenced 16 times). The external strategies that contribute to the spread of an innovation, such as external mandates, policies and regulations, recommendations and guidelines, are subsumed under the *external policy and incentives* construct. Nine of 13 participants (69.2%) commented on recommendations, mandates, or policies related to evaluating for trauma within the context of ASD diagnostic evaluations that affected their use of trauma assessment practices. Six of these nine participants believed that external policies increased their use of trauma assessment practices, and the primary policy that affected their evaluation of trauma was mandated reporter guidelines. In addition, one participant highlighted that as an ADOS trainer she was pleased that there is a line in the standard set of training slides that “you have to understand the impact of early trauma in the context of an assessment.” Unfortunately, outside of this reference in the ADOS trainer materials and mandated reporter guidelines, participants were asked to what extent they were aware of other

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policies or guidelines that influenced their trauma assessment practices and no participant expressed that their use of assessment was affected by *external policy and incentives*. Two participants noted that billing and reimbursement policies negatively influenced their use of trauma assessment practices. For instance, one participant commented, “we are limited by the insurance companies in terms of what we can bill for, which makes doing a true comprehensive evaluation not possible beyond general screening.”

Characteristics of Individuals. The majority of participants described how their own characteristics either facilitated or impeded their integration of trauma assessment practices into ASD diagnostic evaluations. Fifty percent or more of psychologists referenced 1) *knowledge and beliefs about the innovation* and 2) *self-efficacy*, which will be discussed below.

Knowledge and beliefs about the innovation (referenced 111 times). *Knowledge and beliefs about the innovation* includes psychologists’ familiarity and knowledge about trauma assessment as well as their attitudes and values regarding the integration of trauma assessment into ASD diagnostic evaluations. All 13 of the participants (100%) identified their knowledge and attitudes towards trauma and trauma assessment as important for their ability to successfully integrate trauma assessment into their diagnostic evaluations. Only four of 13 participants (30.8%) had positive attitudes towards assessing trauma in children with ASD and/or believed that their knowledge of trauma and trauma assessment facilitated their use of trauma assessment practices and outweighed any barriers. In contrast, eight of the 13 participants (61.5%) believed that their knowledge of trauma and trauma assessment practices was insufficient and impeded their implementation efforts.

Some of the participants discussed trauma assessment in children being evaluated for ASD as something they personally valued. For instance, one participant stated,

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I think it is too narrow, and maybe this is my background as a social worker too, just to look at autism, even though it is an autism clinic. There are a lot of reasons for a child to present the ways that they do, and so if we are not looking at those factors then I don't think we are doing an adequate job.

On the other hand, one participant noted that trauma can be “sensationalized” by the media, which negatively skews practitioners' attitudes and beliefs towards asking about trauma. She noted hearing from colleagues, “Oh, abuse, I don't want to mess with that. That's scary.”

While participants tended to value incorporating trauma assessment practices into their ASD diagnostic evaluations, only four participants (30.8%) identified past experiences with trauma assessment and/or treatment. Three participants described that their graduate training included more broad-based child clinical or generalist training, and two participants noted that they sought out advanced training through postdoctoral positions in trauma-focused settings. One participant highlighted that she sought out trauma training because it was “a very important add on for someone who already knew she was going to be an autism specialist.” Another participant described that she knows “the DSM inside and out from the foster care work and [she] could just add in this last chapter [neurodevelopmental disorders]. And that has been more helpful than [she] would have anticipated” for her consideration of trauma during ASD evaluations.

Nine of 13 of the psychologists (69.2%) interviewed did not have any (or had only minimal exposure to) training in trauma or trauma assessment and believed that this interfered with their implementation efforts. Specifically, one participant commented, “With all of the evaluation training I don't think trauma ever came up as a consideration.” Other psychologists noted that lack of training and exposure to trauma more broadly was something that they observed in other practitioners in their clinics. One participant described that psychologists

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conducting ASD evaluations “don’t have training in [trauma], they don’t feel comfortable with it, and they want to give it someone else.” Another participant observed, “The people who were doing the evaluations, I felt like they knew that neurodevelopmental chapter of the DSM really, really well but they didn’t know the rest of the book well.”

Some participants who had some exposure to trauma in typically developing children indicated that they did not receive additional “formal training in assessing for trauma for individuals with IDD [intellectual and developmental disabilities].” Further, some participants noted that their colleagues were hesitant to engage in trauma assessment associated with their lack of knowledge. One participant described that when she has tried to encourage others to engage in trauma assessment during ASD diagnostic evaluations she has “had a lot of push back because they’re like, ‘Well what if we find something, what do we do with that?’”

Another participant reflected that the lack of provider knowledge about trauma in children with ASD within the field is a reflection of the state of research more broadly. She commented,

It’s certainly not a part of hotly discussed or widely available resources. So if you look at publications on autism you might see a sprinkling of trauma-related publications, but it’s not something that I think that the field of autism is consuming largely or sort of learning about or focused on broadly.

Similarly, five participants (38.5%) noted that their lack of knowledge of guidelines or measures to differentiate trauma and ASD was a barrier to their use of trauma assessment practices during ASD diagnostic evaluations. One participant stated,

Because I do a lot of assessment and neuropsychological assessment I feel good about tools and instruments that are well normed and proven to be effective at measuring a

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particular skill or trait or characteristic or experience. So my lack of experience there is a big factor.

It is important to note that while participants indicated that they lacked knowledge of recommendations, guidelines, or assessment tools to assist in their evaluations, this information does not necessarily exist and thus will be discussed in the *available resources* subsection.

In addition, six participants (46.2%) described that they identified ASD as a specialty early on and pursued focused ASD training throughout graduate school, predoctoral internship, and/or postdoctoral training. One participant commented, “So me being someone who has got a lot of autism training, I know nothing about trauma.” As was previously mentioned, two of these participants intentionally sought out specialty trauma training. Another participant stated that she made efforts to obtain this knowledge later in her career. She described, “I think that as a licensed psychologist now and given the increased emphasis on this topic I’m trying to seek out more educational experiences around accurate assessment of trauma in this group [children with ASD].” One participant highlighted the lack of integration of trauma training into more focused ASD training as a barrier to the use of trauma assessment in ASD evaluations. She stated,

So if I would have come up like the usual neuropsych training route, I have no clue what the discussion or education of trauma looks like. Just like my training had no autism content. And so it seems a bit ridiculous to me that these programs aren’t overlapping more when we’re seeing the same patient pool.

Self-efficacy (referenced 33 times). Twelve of the 13 participants (92.3%) described their *self-efficacy*, or their individual belief in their capabilities to use trauma assessment practices within ASD diagnostic evaluations, as influential to their implementation efforts. Only

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four of these 12 participants indicated that their *self-efficacy* facilitated their use of trauma assessment practices whereas eight participants identified *self-efficacy* as a barrier.

Specifically, four participants expressed confidence that they could execute the appropriate course of action to integrate trauma assessment practices into ASD diagnostic evaluations. One participant stated that she felt “reasonably well prepared to assess for trauma,” even though it was not something she did every day. Most participants who felt that their self-efficacy contributed to increased confidence in their abilities to use trauma assessment practices cited their past clinical experiences as their primary reason for their confidence. For instance, one participant referenced her time working on “inpatient units where we had kiddos with PTSD on a pretty regular basis” as contributing to her self-efficacy. In addition to the four participants who were confident in their abilities to conduct comprehensive trauma assessment, three additional participants felt prepared to engage in trauma screening. One participant described that she felt “competent to screen for it [trauma] and refer if there [were] significant concerns for a more thorough assessment.” However, she added, “I wouldn't feel competent fully assessing for trauma just given my background and my training.”

Six of 12 participants who described self-efficacy as a factor that influenced their use of trauma assessment practices indicated that they felt unprepared and not confident in their abilities to conduct trauma assessment. Specifically, one participant stated, “I don't think I have that expertise to go deeper even if I'm suspecting it.” Similarly, other participants described that they felt much better prepared to assess for ASD than trauma. For instance, one participant noted, “I feel like I have a better handle on how to assess ASD symptoms, but then not quite the trauma.” Several participants laughed or commented “not very” when asked how prepared they felt to assess trauma. One participant rated her feelings of preparedness at a “one out of 10.”

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Inner Setting. Many participants provided statements regarding the ways in which their clinic setting influenced their use of trauma assessment within ASD diagnostic evaluations. The majority (greater than 50%) of participants referenced 1) *networks and communications*, 2) *implementation climate* subconstructs, 3) *readiness for implementation* subconstructs, and 4) *learning climate*, which will be discussed below.

Networks and communications (referenced 68 times). All 13 of the participants (100%) identified ways in which the networking in their clinics (e.g., meetings) influenced their use of trauma assessment. Twelve out of 13 (92.3%) participants indicated that their *networks and communications* facilitated the integration of trauma assessment into ASD diagnostic evaluations in their clinics. One of the most commonly described aspects of clinics' networks that increased use of trauma assessment was the communication among members of the multidisciplinary team. Ten of 12 participants emphasized that communications between team members facilitated their ability to use trauma assessment practices. For instance, several participants described that other team members would "flag" trauma-related comments made during evaluations and then the psychologist followed up. One participant offered an example,

I feel like my speech pathologists often, if they see the family first, will hear about things like domestic violence. And then they come back to me and say, "Oh [participant name], this is what is going on. You are going to need to ask more questions about that."

Another participant added that the technicians who conducted testing made note of information shared by children being evaluated, such as "So and so hits me," and then the psychologist could "come in and do an interview later to assess for safety and follow up." In addition, several participants described that their clinics had a brief "pre-eval consult" meeting with team

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members or a “staffing sheet” that was completed prior to evaluations, which facilitated communication about potential differential diagnoses and relevant history.

Seven participants identified that the multidisciplinary team also facilitated consideration of trauma as a differential diagnosis. One participant described the discussion that occurred during their team meetings,

Anytime anything came up about social relationships, about communication skills, pretty much any symptom of autism, we would always have multiple people asking like, “How much of that do you think is autism and how much is environmental?” And that was a constant debate.

Further, participants noted that additional clinic meetings, such as case conferences, included discussions of patients that were “tricky” and children who displayed symptoms of ASD and trauma were discussed in these conferences. Ten of 12 participants indicated that they had regular case conferences, though one participant stated that trauma was never a topic. One participant described that the case conferences served to remind practitioners to consider trauma during their ASD diagnostic evaluations. She stated,

Every time we have a presentation or meeting related to a particular topic, whether it’s trauma or another topic, I think it calls our attention back to the importance of screening. And I would guess that probably some of that attention fades over time, as it’s less in the forefront of our minds.

In addition, one participant noted that their meetings also offered opportunities to reinforce patient care and consideration of differential diagnoses, including trauma. She described,

We have a rewards program in place where we write notes to each other on our professionalism, our initiative, and our quality of service, and so we really give feedback

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to each other about things like that. At our meetings we do things like we do shout outs at the beginning of meeting where we kind of brag about somebody else on the team who did something really great to better serve patients.¹

Lastly, participants indicated that their connections to professionals in their clinics, including other psychologists, and the ease with which they could consult facilitated their use of trauma assessment practices. This will be discussed further in the *access to knowledge* subsection.

Implementation Climate. *Implementation climate* includes constructs that are indicative of a shared receptivity to the use of trauma assessment practices, the extent to which trauma assessment was supported within the clinic, and the capacity for the clinic to change. The subconstructs that will be discussed because they were referenced by greater than 50% of participants include a) *tension for change*, b) *compatibility* and c) *relative priority*.

Notably, seven of 13 participants (53.8%) referenced the broader construct of *implementation climate*. Five of those seven participants identified *implementation climate* as a facilitator of their use of trauma assessment practices. Several participants commented that trauma assessment was “definitely something that [was] widely encouraged” in their clinic. In addition, two participants discussed how trauma assessment practices became an expectation in their setting, such that “it is something that we all now routinely assess for.” Another participant stated, “We developed a standard clinical interview form and I think for those [trauma questions] they’re expected to be asked. And then having psychologists and psychiatrists around us who have worked in that field the information it is just expected.”

On the other hand, two participants noted the opposite, including that trauma assessment has not become “part of [the] general routine for what [they] do in the clinic.” Additionally, one

¹ This statement was also coded as fitting in the *organizational incentives and rewards* subconstruct; however, this subconstruct was not included in the study results as only one participant commented on it.

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participant described that she observed a lack of openness by practitioners to evaluating for comorbidity, such as anxiety, in children being evaluated for ASD. She stated, “There were definitely people who really just thought it was part of the autism and not comorbidity, and I think the same would have applied to trauma or reactions to trauma.”

Tension for change (referenced 14 times). Ten of the 13 participants (76.9%) described the degree to which providers within their clinics perceived their clinics’ current practices as needing to change. Only three of 10 participants viewed the current situation in their clinics as intolerable, which facilitated the integration of trauma assessment practices, whereas five participants made statements that indicated a lack of a need for change. Of the participants who identified a need for change, they primarily expressed a desire to “do more” (i.e., expand their use of trauma assessment practices). One participant stated, “I think we can still even do better. I think we could do a lot better.”

However, several participants indicated that while their clinics were open to new ideas, they did not currently see a need to change their procedures and, thus, were not in the process of doing so. Therefore, for the clinics that were not engaged in trauma assessment or that were using brief trauma screening practices, there was a lack of tension to change and adopt more comprehensive trauma assessment. Another participant described that he had not integrated trauma assessment because he had “not seen or heard that [he’s] doing anything poorly or contrary to a standard practice.” Thus, at this time, with the exception of a few participants, *tension for change* was not a factor that actively facilitated the use of trauma assessment practices of the psychologists interviewed.

Compatibility (referenced 19 times). Ten of 13 participants (76.9%) referenced *compatibility*, or the degree of fit between the value psychologists attached to conducting trauma

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assessment within ASD diagnostic evaluations, psychologists' own values, and the fit within the existing clinic workflow. Only two of 10 participants described ways in which they viewed trauma assessment as compatible with their practice and the clinic's existing workflow and, thus, contributed to increased use of trauma assessment. One participant outlined her clinic's approach to differential diagnosis and how trauma was incorporated into that process. She described,

Our process is to put everything on the radar and then you slowly start taking things off as you gather more evidence and some things move closer to your target and some things move farther away. So you just keep gathering data until you're confident with your end result. And for us the way we gather that data in addition to an interview is we add in those measures, so it's just kind of an automatic thing that we do.

She added that trauma "would just automatically go somewhere on that radar," which resulted in consistent integration of trauma assessment into their ASD diagnostic evaluations. Another participant described that in her clinic psychologists were "very much in a really good role to assess for it and intervene and make change for [their] patients," and, thus, trauma assessment fit within their diagnostic processes.

Three participants described that the innovation was just not a fit with their own values and the clinic's workflow and values. Specifically, one participant described that comprehensive trauma assessment did not fit into their clinic's view of a "gold standard" ASD evaluation and, thus, was not compatible. She stated,

If our assessments were shorter we could see more kids, but we wouldn't be doing best practice with our interdisciplinary clinics and the gold standard assessments for autism we want to implement. So we want to see kids more quickly, but if we were to have a more comprehensive, a longer evaluation, we would see fewer kids. And so then they

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wouldn't get seen, they wouldn't get diagnosis they need and then intervention as quickly. I think it's the cost benefit of doing that.

Another participant summarized, "I think it was mostly that we were already doing so much that it was just not what we specialized in, so we just didn't do it. It was more what the focus of the clinic was than anything." Thus, given their clinic's focus on conducting ASD assessment, the additional time and specialization needed to conduct trauma assessment decreased their use of trauma assessment practices.

In addition, five participants offered suggestions for ways in which trauma assessment practices would need to be adapted to be compatible within their clinic. These suggestions for adaptation will be discussed in more detail in the *adaptability* section; however, it is important to note that participants felt that in order for trauma assessment to be used in their clinic there needed to be significant changes to their clinic processes and workflow.

Relative priority (referenced 46 times). Each of the 13 participants (100%) described the importance of the implementation of trauma assessment practices within their clinics. As was already described in the *needs and resources* section, 13 of 13 participants (100%) identified a need to assess for trauma exposure and symptoms during ASD diagnostic evaluations. All 13 participants (100%) also made statements about the importance of incorporating trauma assessment into ASD diagnostic evaluations. Only six of 13 participants (46.2%) identified that the *relative priority* of the innovation facilitated their use of trauma assessment practices. In contrast, five of 13 participants (38.5%) indicated that a lack of prioritization of trauma assessment practices impeded their use, and two participants made an equal number of statements describing *relative priority* as a facilitator and a barrier.

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Participants made a number of statements suggesting a shared perception within their clinics of the importance of utilizing trauma assessment practices. One participant indicated that the value of conducting trauma assessment had been an ongoing discussion. She stated, “Here in our clinic we have been talking about the importance of evaluating trauma in kiddos with ASD for a couple of years.” Other participants emphasized that within their multidisciplinary team, incorporating trauma assessment was valued across providers in psychology and other disciplines. For instance, one participant commented,

The other psychologists that I work with, and for that matter the speech paths too who have sought out some additional information about this, think that it is valuable and important to know whether or not this is a part of what is going on with a child and a family.

In addition, one participant highlighted that the discussion of exposure to PTEs was a priority in their team meetings. She described,

So almost always in the staff meeting we start[ed] with the trauma history of the child or the placement, all of the stuff we found in the record review... We would never skim over that. So that was the most important part.

While many participants commented on the importance of assessing for trauma during ASD diagnostic evaluations in their clinics, others noted that relative to answering the diagnostic question of ASD, evaluating for trauma was not prioritized. Specifically, eight of 13 participants (61.5%) identified that their primary role was to assess for ASD and “the main question for [them was] to answer the diagnostic question, ‘Is it autism or not?’” As a result, participants indicated that this influenced their use of trauma assessment. For instance, one participant stated,

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Our front seat is always autism “yes” or “no.” And so, everything else, the other psychiatric comorbidities, are taking a backseat. They are relevant and important and we want to be able to obtain a full comprehensive view of the child. But our number one priority in these brief evaluations is to try to tease apart whether or not autism is appropriate.

Further, participants noted that they assessed for psychiatric comorbidity, including trauma, only if it did not interfere with their ability to rule in or rule out ASD. As described by one participant, “So if we can assess for any other comorbid diagnoses we try to do that if it’s not at the expense of the primary question of autism.” Another participant noted that sometimes they were unable to administer trauma questionnaires given their prioritization of evaluating for an ASD diagnosis. She explained, “There are a number of questionnaires and interviews our families complete and so it may be prohibitive to give [trauma measures] to everybody since our primary focus is answering the question of autism.” Similarly, the importance of assessing for ASD over trauma was summarized by another participant, “Getting that diagnostic picture completely accurate is less [of a] priority in the autism clinics.”

Readiness for implementation. *Readiness for implementation* includes constructs that are immediate indicators that the clinic and/or psychologists are prepared to integrate trauma assessment practices. The subconstructs of *readiness for implementation* that will be discussed include a) *access to knowledge and information* and b) *available resources*.

Access to knowledge and information (referenced 56 times). Each of the 13 participants (100%) described their ability to access information or training about trauma and trauma assessment as influential to whether they incorporated trauma assessment practices into their ASD diagnostic evaluations. Nine of 13 participants (69.2%) believed they had sufficient access

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to knowledge and information whereas only one participant (7.7%) believed his ability to obtain information about trauma assessment negatively affected his use of trauma assessment practices.

As was already outlined in the *networks and communications* section, many participants described meetings and processes for communication amongst psychologists and providers from various disciplines within their clinics as important for their use of trauma assessment. In addition, as was mentioned in the *cosmopolitanism* section, some participants described ways in which their connections and collaborations with organizations or attendance at professional conferences facilitated their use of trauma assessment practices.

Many of these connections, both within and outside of the organization, created opportunities for participants to access information about trauma and trauma assessment. For instance, two participants noted that, despite their own lack of knowledge and educational training in trauma-informed practices, it was beneficial to have individuals within their clinic that had trauma specialty backgrounds. One participant described their clinic director as a useful source of knowledge and stated, “She has a history of working with children in the foster care system and so I think that definitely plays a role in how we currently perceive trauma and assess for trauma.” Another participant highlighted that if she did have the time to incorporate trauma measures into her ASD diagnostic evaluations she could “likely walk down the hall and ask [her] neuropsych team what they are currently using and what they feel is most appropriate for parent report and is appropriate for child report.”

While the majority of participants felt that they *could* access information regarding trauma and trauma assessment, only four of 13 participants (30.8%) indicated that they had either received or facilitated trainings on using trauma assessment practices in their ASD diagnostic clinics. One additional participant indicated that it would have been possible in her clinic given

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her professional resources, but there were no trainings offered. She described, “I was surrounded by enough experienced clinicians that I could’ve got training in doing that [trauma assessment].” Other participants described their experiences with training and how they accessed information on using trauma assessment. As was previously described in the *external change agent* section, two participants noted that their clinic’s involvement in a research project conducted by a trauma specialty clinic led to the receipt of information on “incorporating the trauma question into [their] interview.” Another participant described that in her clinic they had trained new providers on how “to assess for trauma as well or any other symptoms that come up during the interview.” She elaborated on this process, which included guidance on trauma assessment, and described,

When we get a new provider or postdoc or trainee, there’s this mentorship process. And so they shadow our clinics, I meet with them every week, and I sit down in their clinics when they are doing it on their own. And so part of that mentorship is this process where we talk about like, “Here’s how we have found the best way to address diagnostic differentiation.” And so then they do it that way too.

In addition, one participant described attending a training within her organization specifically on assessing trauma in children with developmental disabilities. Beyond the four participants who described access to trainings on assessing trauma in children being evaluated for ASD, one participant indicated that she has had beneficial training on strategies that facilitated her use of trauma assessment. She stated,

We’ve had a lot of good education on tools about how to ask open-ended questions and nonjudgmental questions regardless of who’s in front of you because you can’t tell by looking at someone whether they are likely to have experienced trauma.

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In contrast, several participants made statements regarding the inadequacy of their access to knowledge and information about assessing for trauma within their clinics. For instance, one participant stated, “There’s nothing, again, these kinds of particular trainings or things that are mandated for understanding trauma as it presents in the DD [developmental disability] population.” Another participant described that how to assess for trauma in children being evaluated for ASD was not a topic covered in their training of new providers. He stated, “So thinking about some of our postdocs now... I’m thinking like, ‘Well, I’m not sure if anybody would have gone over trauma and what trauma might look like in kids, especially kids with autism and who are nonverbal.’”

In addition, as was already described in the *knowledge and beliefs* section, many participants felt that their individual knowledge in trauma assessment and prior training through their educational experiences was lacking and impeded their use of trauma assessment. Further, participants noted that in addition to this lack of foundational individual knowledge, the information that would be beneficial is not yet available in the field (see *available resources* subsection). This sentiment arose in participants’ discussion of their access to knowledge within their clinics as well. One participant commented,

In terms of materials and then resources, like training and good information, I also get mad. I feel like both trauma and autism are areas where there’s so much crap out there, like there’s so much bad stuff for parents and clinicians and everything.

Available resources (referenced 85 times). All 13 participants (100%) described the availability of resources (e.g., time, measures) as highly influential in their ability to integrate trauma assessment into their ASD diagnostic evaluations. Nine of the 13 participants (69.2%) identified that the level of resources within their clinics impeded their use of trauma assessment

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practices whereas only two psychologists (15.4%) felt that the availability of resources was sufficient and facilitated their implementation efforts. Two participants made an equal number of statements describing *available resources* as both a facilitator and a barrier.

The most commonly identified barrier to using trauma assessment practices within the *available resources* subconstruct was time, as it was discussed by 92.3% of participants ($n = 12$). Participants made numerous statements about the limitations on their time and the implications for their use of trauma assessment during their ASD diagnostic evaluations. They identified that their lack of time impeded their ability to use trauma assessment. One participant stated, “It’s really the time constraint... Sometimes you know there is more, but then you really can’t get into it.” Participants also noted that the length and difficulty of ruling in or out a diagnosis of ASD took away from the time that could be allocated to trauma assessment. One participant indicated,

I have a limited amount of time to spend and when you’re doing an ADOS and a full developmental history and you use it to provide feedback in the same visit I don’t always get to go as in depth as I would like to.

Participants identified that this contributed to their need to refer out for additional evaluation, as summarized by one participant, “I will occasionally diagnose PTSD, but that is pretty rare. I am more likely to refer out because I don’t really have time to tease it all apart.” A few participants noted that trauma assessment can also be lengthy and stated, “The criteria for PTSD requires a fair amount of questioning. This would take a fair amount of time to really nail it down.”²

Several participants added that the scheduling of appointments contributed to their time constraint. For instance, one participant described, “Maybe I have an evaluation from 9 to 11, and then I have other clients coming in right at 11.” Relatedly, four participants (30.8%)

² This statement was also coded as fitting in the *complexity* construct within the *innovation characteristics* domain; however, this construct was not included in the study results as it was mentioned infrequently ($n = 2$).

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commented on the demand for ASD diagnostic evaluations and resulting waitlists that contributed to abbreviated evaluation time. One participant summarized,

Anybody's who is doing autism evaluations knows they're in high demand. We're often seeing patients pretty quickly to try and get an evaluation done, given the sort of complexity of autism and developmental symptoms. The time in evaluations can sometimes be too short and so I think that probably influences not to start an evaluation of trauma.

When one participant speculated as to how trauma assessment could be adapted to work in his clinic he stated, "Oof, I don't know. We've got a waitlist that's six to eight months long."

In contrast, the two participants who identified that the resources in their clinics contributed positively to their use of trauma assessment noted that they had more time to dedicate to evaluating for trauma given that they used technicians or trainees (e.g., predoctoral interns, postdoctoral fellows) to complete different parts of the evaluation. One participant noted,

We have a technician model also, so we can do some of the things at the same time. So when I'm doing an interview with a parent, I have a technician who's doing a lot of the testing... So those will happen at the same time, which makes it more efficient.

Additionally, as was described in the *executing* section, only three participants (23.1%) noted that they have access to and make regular use of trauma symptom measures. Two participants (15.4%) indicated that time limitations affected their use of measures, such that they did not use questionnaires given their lack of time. However, seven participants (53.8%) described another reason for lack of measure use, such that there are not existing measures that effectively parse out the symptom overlap between trauma and ASD. Psychologists who had access to measures but elected not to use them described the lack of clinical utility of current

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measures, as they do not reliably differentiate trauma and ASD symptoms, as one of their primary reasons for lack of use. Participants noted that measures of trauma might “automatically elevate because of symptoms of autism” and would go from “normal to extreme really fast.” As explained by one participant,

A lot of those measures, especially rating scales and especially with kids who we knew had trauma, they would elevate those scales even if they had no autism at all. So like not looking at you in the eye, not having a relationship, you know, like those are huge trauma symptoms. And so we couldn't always trust that like the SCQ [Social Communication Questionnaire] or SRS [Social Responsiveness Scale] was actually picking up on autism.

The barrier of the lack of a measure that effectively discriminates between trauma and ASD is related to the issue of *symptom overlap*, which was discussed in the *needs and resources* section. Notably, it is not the “fault” of the clinics that they do not have an assessment tool that addresses the symptom overlap between ASD and trauma. This was summarized by one participant who stated, “I don't think it's a consistent enough message within the autism community yet. And I think if it were that we'd have more reliable resources and more of a standardized way for assessing for trauma.”

Learning climate (referenced 14 times). Ten of 13 participants (76.9%) identified their clinic as a climate in which they felt safe to try new methods and they felt like essential partners in implementation efforts. Of the 10 participants who referenced *learning climate*, nine believed that their clinic was an environment in which they were valued and there was an openness to trying new approaches. When asked if they felt they could try new things in their clinic, nine participants indicated that they can “can try new things pretty easily” as long as they fell within the confines of “positively impact[ing] patient care” and they had the time. While most

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participants identified a positive learning climate, this was noted in response to direct questioning, and it is unclear whether it was a facilitator of trauma assessment use. Thus, *learning climate* was not considered a facilitator of the use of trauma assessment.

Innovation Characteristics. Most of the participants offered comments about how the characteristics of trauma assessment practices either facilitated or interfered with their use of trauma assessment within ASD diagnostic evaluations. The innovation characteristics constructs that were discussed by 50% or more of participants included 1) *adaptability* and 2) *evidence strength and quality*.

Adaptability (referenced 33 times). Ten of 13 participants (69.2%) described how the degree to which the innovation (i.e., trauma assessment practices) was adapted and tailored to their clinics affected their use of trauma assessment during ASD diagnostic evaluations. If participants were not already actively implementing trauma assessment, they were asked to consider in what ways they could adapt trauma assessment practices to work within their contexts. This data was not coded as either facilitators or barriers, as recommended in the CFIR coding guidelines (<https://cfirguide.org/constructs/adaptability/>), which state, “Suggestions for improvement can be captured in this code but should not be included in the rating process.” Thus, this data will be presented in a separate subsection of this construct.

Only two participants believed that the adaptability of trauma assessment practices facilitated their use of the innovation whereas six of the ten participants who referenced *adaptability* indicated that it impeded their use of trauma assessment. One participant highlighted new pilot research on an assessment tool for evaluating trauma in children with ASD that can be used on a tablet or cell phone and includes visual prompts. Another participant described that their clinic’s initial procedure for trauma assessment did not work, so they refined their practices:

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So initially we were going to do a trauma screener that included asking about whether a child had experienced a possibly traumatic event and then included follow-up questions about PTSD symptoms specifically. It was really hard for us to get all of that done, asking all of the follow-up questions, in a timely fashion and in a standardized way. So we decided that it would be feasible for us to ask about traumatic events for every child and have that be standardized, and then from there have each individual clinician determine what follow-up questions were most relevant and appropriate.

As was previously described in the *needs and resources* subsection, eight participants believed that the language and communication abilities were a potential barrier to their ability to use trauma assessment, and there were not effective ways to tailor trauma assessment to meet the needs of these children. For instance, one participant stated, “It’s just really tough to evaluate things like this, any psychiatric symptoms but trauma for sure, in patients who are minimally to nonverbal.” Further, another participant spoke to the challenge of adapting trauma assessment practices for children with varying levels of language. He commented, “In terms of how to assess a child, I don’t know of any way to necessarily add in something for just assessing it with the child directly, especially depending on their language level.”

Suggestions for future adaptation. Seven participants offered suggestions and ideas as to how trauma assessment practices could be adapted to work in their clinics. Two participants hypothesized that adding follow-up questions, for instance to assess trauma-related symptom intensity and frequency, would improve the data they collect and inform appropriate diagnosis. Four additional participants agreed that their clinic could benefit from adapting their trauma assessment practices to obtain more data; however, they suggested that the use of standardized questionnaires/trauma measures would be the best option. One participant proposed, “Perhaps

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having some kind of standardized assessment tool, whether it's a parent-report or a self-report or like a brief semi-structured interview, around trauma that would be specific to ASD, that would be really helpful." Several other participants agreed that the addition of measures would be beneficial, particularly if they could be completed concurrently with other aspects of the assessment process. For instance, one participant suggested,

Parents can fill them out while I'm doing the ADOS with the kid and then I can briefly look through them and it gives me a sense of how to triage my interview questions and where I need to focus my time.

Participants noted that it would be beneficial to have a decision tree or flow chart to indicate "what [to] do if things come up elevated on a screener" so then they know "some very practical things of what might need to be considered or talked about next with the family." One participant cautioned that there are potential barriers to uniform implementation of trauma assessment:

So there would need to be a way to quickly determine whether or not a child or family system warranted more detailed trauma assessment. I think in reality doing a detailed trauma assessment for every patient that comes in the door is unlikely to be successful or adapted to common practice, again because there's so much to attend to in pretty short evaluations.

Evidence Strength & Quality (referenced 13 times). *Evidence strength and quality* was referenced by nine of 13 participants (69.2%), and it was viewed as a factor that positively influenced the use of trauma assessment by all nine of those participants. The psychologists interviewed indicated that they valued using innovations with empirical support and that have been shown in the research literature to produce desired outcomes. Specifically, participants highlighted that they viewed integrating trauma assessment practices into their ASD diagnostic

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evaluations as part of “evidence-based procedures.” One participant commented that the psychologists in her clinic are “trying to do what’s best practice, just like we would do for any other diagnosis that we’re looking for in ASD.”

Notably, as was discussed in the *knowledge and beliefs* and *available resources* sections, many participants did not feel as though they as psychologists, their clinics, or even the field more broadly, had the appropriate resources or knowledge to adequately assess for trauma in children being evaluated for ASD. This was also discussed in the context of the evidence strength of the innovation. For instance, one participant indicated that in his clinic, “The practices are derived from the research on evidence-based assessment for autism. And I guess I’ve not seen trauma taking a front seat in that. So perhaps the literature is just not there.”

Implementation Outcomes Framework (IOF)

As was previously described, implementation outcomes are the effects of implementation efforts, which are important to consider given that they serve as indicators of implementation success and are preconditions for achieving change (Proctor et al., 2011). Thus, the implementation outcome constructs were used to develop a better understanding as to why trauma assessment practices were or were not incorporated into ASD evaluations. As with the CFIR, outcomes that affected the use of both trauma screening and assessment were considered.

Implementation Outcomes. Outcomes that were associated with the integration of trauma assessment practices into ASD diagnostic evaluations were organized using the IOF into the eight implementation outcomes. Greater than 50% of participants discussed implementation outcomes that were most relevant for early stage implementation efforts, including 1) *acceptability*, 2) *appropriateness*, and 3) *feasibility*. The remaining IOF constructs were not discussed by the majority of participants, which was not surprising given that they tend to be

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related to mid or late stage implementation. While 4) *adoption* was not discussed by greater than 50% of participants it will still be discussed below, as it is important to consider the factors that contributed to successful adoption of trauma assessment.

Adoption (referenced 8 times). Only five participants (38.5%) discussed their initial decision to implement trauma assessment practices in their ASD diagnostic evaluations. Four of the five participants described collaborations with clinics outside of their setting (i.e., *cosmopolitanism*) and a particular individual within that setting (i.e., *external change agent*) as critical to their adoption of trauma assessment. As was previously described, three participants described that their clinic's involvement in a research project with a trauma specialty clinic led to the integration of trauma screening within their ASD diagnostic evaluations. In addition, another participant noted that the recruitment and hiring of professionals from an assessment clinic specializing in the assessment of foster care children facilitated their clinic's adoption of trauma assessment. Lastly, one participant described that the expectation in her clinic that trauma assessment was a part of a standard clinical interview (i.e., *implementation climate*) led to the adoption of trauma questions into their caregiver interview.

Acceptability (referenced 25 times). Ten of 13 participants (76.9%) referenced *acceptability*, or the perception of trauma assessment as agreeable and satisfactory. *Acceptability* impeded the use of trauma assessment more often than it facilitated its use, as six of 10 participants referred to the *acceptability* of trauma assessment as a barrier. Only two participants indicated that stakeholders' perceptions of trauma assessment positively influenced psychologists' use, whereas two participants made an equal number of statements describing *acceptability* as a facilitator and a barrier.

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Only four participants had positive perceptions of trauma assessment as agreeable and one additional participant called it, “Fine.” These four participants noted that they were “glad” or “happy that it’s pretty consistently part of our radar.” Trauma assessment was also described as “scary” for practitioners. One participant summarized conversations with her colleagues:

Other clinicians I worked with and me when I started, you see something like that pop up on a screener and I think people really struggle with, “Well that’s not my specialty, I’m not a trauma person and I don’t know what to do and I don’t want to get sued. And I don’t want to ruin this kid’s life or make it worse.” And so people are scared.

Another participant expressed dissatisfaction with conducting trauma assessment and stated, “I don’t like it. I don’t like all the questions to result in a PTSD diagnosis in the current DSM. It’s challenging, it’s time consuming, it’s difficult.”

In addition, several participants ($n = 7$) described that the perceptions of the caregivers of children being assessed decreased their use of trauma assessment practices. Specifically, they noted that families’ expectations regarding the reason for the evaluation influenced their perceptions of trauma assessment. For instance, one participant described,

If you came in for a general psychological mental health visit you might expect to talk about it [trauma]. But when people come in for a diagnosis of autism they [caregivers] aren’t always expecting to talk about things like that and sometimes you have to get families around to the idea that this could be really critical to the conceptualization of what’s going on with their kid.

Further, one clinician added that questions about trauma “might inadvertently divert the focus of the evaluation for the families if [she] start[s] with asking questions about past trauma and abuse rather than autism. They may worry the focus isn’t about autism.” Participants also noted that

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trauma assessment was not well-received by caregivers because “a lot of the parents, by the way, thought we were there to take their kids away.” Thus, psychologists expressed it was “difficult sometimes to have conversations with families” given both families’ expectations and fears.

Appropriateness (referenced 81 times). All 13 participants (100%) referenced the *appropriateness* of trauma assessment practices as contributing to their use during ASD diagnostic evaluations. Specifically, nine of 13 participants (69.2%) identified that trauma assessment practices were relevant and fit with the consumers of the innovation (i.e., children with ASD) and/or fit to address a particular issue (e.g., symptom overlap). The majority of issues that contributed to the suitability or relevance of trauma assessment practices were discussed in previous CFIR sections. For instance, as was described in the *needs and resources* section, the majority of participants (53.8%) viewed conducting trauma assessment within ASD diagnostic evaluations as relevant to children being evaluated for ASD given the heightened rates of trauma exposure in children with ASD. One participant highlighted,

The prevalence of adverse experiences is so common that really, even if it’s not trauma, confirmed abuse, or anything, I think that any evaluation for any diagnosis is lacking if you don’t look at that social history and how that impacts the symptoms... you’re losing a lot of information.

In addition, nine participants (69.2%) indicated that the symptom overlap, also discussed within the *needs and resources* section, contributed to trauma assessment practices being suitable and relevant for children being evaluated for ASD. Specifically, participants described that trauma “definitely [has] to be a part of the differential.” One participant stated, “I always say, ‘Is it autism ‘or’ or is it autism ‘and’?’ knowing that those trauma pieces can play a huge role in a child’s social presentation.”

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While only three participants indicated that *appropriateness* impeded their use of trauma assessment more than it facilitated its use, 10 participants (76.9%) identified that it negatively influenced their use of trauma assessment. Many participants connected the *relative priority* of evaluating for trauma during ASD diagnostic evaluations to their use of trauma assessment practices, such that the majority of providers described the assessment of trauma as not their role given their clinic setting. For instance, one participant stated, “My primary goal of my evaluation is to determine whether or not autism is appropriate.” In addition, three participants indicated that their role as assessors precluded them from assessing for trauma and it was not suitable for them as assessors to evaluate for trauma. One participant described,

I know that my role is that I can't really do the follow-up treatments with them, I'm not going to have an ongoing relationship with them, then it becomes more, get the essential information from them, and have all the professionals who can establish ongoing relationships with them really deal with it.

Further, participants added that they did not think that caregivers viewed questions about trauma to be relevant to their children's ASD diagnostic evaluations. One participant stated,

Parents do not necessarily make the link, so it's not an obvious one. Like a lot of time speech is a popular one to make parents think of autism. If the child's speech is really delayed that's a common referral question... But then people do not necessarily think of trauma in the context of autism and how that could play a role.

Feasibility (referenced 46 times). Eleven of 13 participants (84.6%) described the *feasibility*, or the ease by which an innovation can be successfully used within a setting, of implementing trauma assessment within ASD diagnostic evaluations. Ten out of 11 participants indicated that integrating trauma assessment practices into their diagnostic evaluations was not

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feasible, which interfered with innovation use. Most factors that contributed to the lack of feasibility of integrating trauma assessment into ASD diagnostic evaluations were discussed in previous CFIR sections; thus, only a brief summary will be included below.

In particular, participants emphasized that *available resources* issues interfered with the ease with which they were able to implement trauma assessment. Participants associated their lack of time, scheduling constraints, and the unavailability of measures with increased difficulty to integrating trauma assessment practices into ASD diagnostic evaluations. Nine of 11 participants explicitly linked time limitations to the lack of success of implementation efforts. One participant summarized, “One, time, and what we are able to bill for. I don't think we would be able to do both an autism evaluation and a full trauma evaluation.”

Two participants referenced billing limitations and two additional participants referenced the scheduling of back-to-back evaluations as factors that made the use of trauma assessment practices more difficult. For instance, one participant noted,

I am never billing for more than two hours, and it can be quite challenging to get in a good diagnostic interview and an ADOS in two hours... There are certainly times where I have to take three hours and just eat that, but that's my real problem.

Additionally, participants referenced characteristics of the children being evaluated and their families, as was outlined in the *needs and resources* and *adaptability* sections, as factors that decreased the feasibility of assessing for trauma during ASD diagnostic evaluations. Six of nine participants drew the connection between children's variations in language and cognitive abilities and the extent to which using trauma assessment was possible. One participant stated, “I imagine it's very challenging assessing for self-reported trauma in kids who don't have a very good grasp of language.” Further, three participants referenced the hesitation of parents to

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discuss trauma and three additional participants described that sometimes parents did not have information about children's trauma histories, which made assessing for trauma increasingly difficult. One participant indicated, "It's also for kids who have been adopted or are in foster care, it can be tough to get accurate information about what happened, and what was traumatic for the child."

CHAPTER 5

DISCUSSION

The current study investigated the process by which licensed psychologists located in centers specializing in the assessment and treatment of ASD (e.g., autism centers for excellence) assessed for trauma exposure and trauma-related sequelae during multidisciplinary ASD diagnostic evaluations using qualitative research methodology. I used a directed content analysis approach through the application of two comprehensive implementation science frameworks (i.e., CFIR and IOF; Damschroder et al., 2009; Proctor et al., 2011, respectively) that was primarily deductive, but also allowed new categories to arise inductively from the data. This study also examined the factors that contributed to psychologists' use of trauma assessment practices, including whether the factors facilitated or impeded the integration of trauma assessment into their diagnostic evaluations. The findings for each research aim will be discussed below along with limitations of the current study and recommendations for future research.

Trauma Assessment Practices

Overall, most participants reported that they engaged in some level of trauma assessment during their ASD diagnostic evaluations. Given preliminary research findings that children with ASD are at heightened risk for both exposure to PTEs (Berg et al., 2016; McDonnell et al., 2018) and trauma-related outcomes (e.g., PTSD, mood disorders; Mehtar & Mukaddes, 2011; Taylor & Gotham, 2016), this is an important finding. Given robust research evidence that cumulative trauma exposure in childhood contributes to adverse health outcomes (e.g., Brown et al., 2009; Felitti et al., 1998; Layne et al., 2014), early detection of trauma exposure and associated symptoms can help mitigate these effects. Specifically, trauma assessment practices enable more accurate diagnosis and, thus, guide treatment recommendations and referrals (Keesler, 2014;

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Mehtar & Mukaddes, 2011). Further, researchers have recently shown a connection between exposure to ACEs in children with ASD and delays in timing of ASD diagnosis and receipt of treatment (Berg, Acharya, Shiu, & Msall, 2018) as well as unmet healthcare needs (Berg, Shiu, Feinstein, Msall, & Acharya, 2018). Thus, the identification of trauma exposure and trauma-related symptoms is important for both short- and long-term health outcomes.

On the other hand, among those who reported engaging in trauma assessment during their ASD diagnostic evaluations, several of the participants described practices consistent with trauma screening, rather than comprehensive trauma assessment. Screening is distinct from trauma assessment and significantly less comprehensive, as it is primarily used for identification rather than diagnostic purposes (Kisiel et al., 2014). Thus, despite participants reporting that it was the role of the psychologist to assess for psychiatric comorbidity and to take the lead in diagnostic decision-making, they often referred out for further evaluation if they had concerns about psychiatric comorbidity, including PTSD symptoms. There are potential advantages and disadvantages to this procedure. Kisiel and colleagues (2014) recommended that only providers with adequate knowledge and training in assessing for traumatic stress in children engage in comprehensive trauma assessment. Thus, it is appropriate to refer to a trauma specialist if psychologists do not have sufficient training in evidence-based assessment (EBA) for trauma, which, while surprising given their expertise in assessment, was reported by many participants.

Nonetheless, a standard practice of referring out to assess for trauma might not be feasible across the United States, such as in more rural areas that do not have trauma specialty clinics. Moreover, some families wait as long as six to 12 months or more for ASD diagnostic evaluations (Hansen et al., 2016; Swanson et al., 2014). Researchers have found that families report significant levels of dissatisfaction with the ASD diagnostic process associated with the

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length of the diagnostic delay and time to diagnosis (Crane, Chester, Goddard, Henry, & Hill, 2016). Thus, it is possible that after waiting for months to be seen for an ASD diagnostic evaluation, as described by one participant, it might be frustrating to families to be sent “on their merry way without an answer to what’s going on.” Moreover, families might not follow through on the referral for additional evaluation, thus decreasing the likelihood that children receive needed trauma-related evaluation and intervention. As a result, ASD diagnostic evaluations may be an important setting in which EBA for trauma is conducted. However, if psychologists have difficulty integrating trauma assessment practices into their ASD diagnostic evaluations given many of the factors described below, it is essential to ensure that the referral happens and that the burden to pursue additional evaluation does not reside solely with caregivers. Thus, it might be important to consider the role of other multidisciplinary team members, such as care coordinators, who can facilitate follow-up for a more comprehensive trauma assessment.

Participants provided additional information on the process by which they engaged in trauma screening. They rarely utilized an evidence-based screener, and the majority used a caregiver interview to screen for trauma exposure and then trauma symptoms, if needed. Other participants followed up with a caregiver interview only if there was a positive endorsement of trauma exposure on an intake form. Notably, participants rarely obtained collateral information from other sources, including the children themselves, which happened inconsistently due to a number of factors, such as the child’s age, language ability, and time limitations. In addition, only three participants identified that they might discuss trauma with school professionals.

While there are no established, empirical guidelines or practice parameters regarding how children being evaluated for ASD should be assessed for trauma exposure and trauma-related sequelae, there are preliminary recommendations from the NCTSN (Charlton et al., 2004) and a

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recent book chapter with key considerations from Prock and Fogler (2018). Further, there is significantly more information available regarding EBA for trauma in typically developing children (e.g., Kisiel et al., 2014; Layne et al., 2017) and broad-based recommendations for evaluating psychiatric comorbidity in children with ASD (e.g., Ameis & Szatmari, 2015).

Consistent across all of these sources, experts have emphasized that obtaining collateral information and gathering data from a wide range of informants is highly valuable (Charlton et al., 2004; Kisiel et al., 2014). Thus, it is important to consider the factors that interfered with participants' abilities to collect data from multiple informants.

Further, experts recommend that careful attention be given to behavioral observations and fluctuations in symptoms (Kisiel et al., 2014; Prock & Fogler, 2018). While participants obtained a sample of behavior during the ADOS-2 administration, only one psychologist included a behavioral observation with peers as a component of the evaluation to parse out psychiatric comorbidity. In addition, it is a well-established EBA principle that assessments should integrate both standardized measures and clinical interviews, including for trauma assessments (Layne et al., 2017), although there is concern that most EBA tools are not validated for children with ASD, as they might not have adequate psychometric properties (Ameis & Szatmari, 2015; McLeod et al., 2015). Prock and Fogler (2018) added that practitioners should follow up on endorsed items on trauma exposure and symptom measures to obtain clarification. Of the participants who engaged in some form of trauma evaluation, only three reported consistent use of measures (e.g., *Trauma Symptom Checklist for Children*). Participants' infrequent use of measures was related to many factors, which will be discussed below.

Lastly, Kisiel and colleagues (2014) highlighted that it is important to consider broader traumatic stress reactions, such as complex trauma symptoms, rather than focus exclusively on

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PTSD during trauma assessments. Relatedly, Kerns and colleagues (2014) demonstrated that children with ASD might experience qualitatively different anxiety symptoms than those in traditional anxiety disorder diagnostic categories. Thus, while there is preliminary data that children with ASD might present with trauma symptoms consistent with DSM-5 criteria (Brenner et al., 2017), there is not enough research to rule out that traumatic stress might present differently in children with ASD. Therefore, it might be important for clinicians to consider symptoms beyond PTSD diagnostic criteria during their trauma assessments; however, this was not reported by any of the participants.

As described by Layne and colleagues (2017), a comprehensive trauma assessment using structured interviews, standardized measures, and multiple informants for every child who has experienced a PTE is not cost effective and can lead to false positives (i.e., over-diagnosis). Thus, the screening practices adopted by many of the participants are integral components of trauma assessment practices in clinics. However, if psychologists conducting ASD diagnostic evaluations do not go beyond trauma screening and engage in more comprehensive trauma assessment to obtain an accurate diagnostic picture or ensure that these children receive these evaluations elsewhere, this can negatively influence children's health outcomes.

Factors Affecting the Use of Trauma Assessment

In addition to exploring to what extent psychologists assessed for trauma exposure and trauma-related symptoms in children during ASD diagnostic evaluations, this study explored the factors that influenced psychologists' use of trauma assessment practices. I examined not only the factors that contributed to trauma assessment use, but also the valence of those factors (i.e., whether they facilitated or impeded implementation of trauma assessment) through the lens of the CFIR and IOF. Notably, many constructs were simultaneously facilitators and barriers of

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participants' use of trauma assessment practices. Both frameworks were deemed to be a good fit for this study, and there was only one factor (i.e., *symptom overlap*) that appeared to fall outside of the frameworks. Participants reported constructs within all five CFIR domains that influenced their use of trauma assessment. The *process* domain was less relevant, as most participants were in the early stages of implementation. Similarly, the IOF constructs of *acceptability*, *adoption*, *appropriateness*, and *feasibility* were most pertinent given their relevance to early stages of implementation, whereas constructs such as *fidelity* and *sustainability* were not identified as relevant to participants' use of trauma assessment given their applicability to mid to late implementation stages.

Across all participants there was a clear recognition of the need for trauma assessment in children with ASD, as evidenced by the high rate with which participants discussed the *needs and resources* of children being evaluated for ASD. Participants identified numerous reasons that children being evaluated for ASD should be assessed for trauma, including the aforementioned prevalence of trauma exposure and trauma-related symptoms in this population (e.g., Berg et al., 2016; Mehtar & Mukaddes, 2011). Specifically, participants perceived a need for trauma assessment given the prevalence of trauma exposure in children with ASD and/or the prevalence of trauma in their cities. Further, participants emphasized that the need for an accurate diagnosis, including parsing out *symptom overlap* between ASD and trauma, to inform treatment recommendations indicated a need to assess for trauma in children being evaluated for ASD.

Both the perception of a need for trauma assessment practices and the value placed on the use of these practices were evident at the individual provider and clinic (i.e., *inner setting*) levels. Specifically, participants expressed an individual belief that trauma assessment practices were valued (i.e., *knowledge and beliefs*), and many agreed that there was consensus in their clinics

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regarding the importance of using trauma assessment (i.e., *relative priority*) and a shared receptivity to its use (i.e., *implementation climate*). Moreover, a number of participants highlighted that they valued trauma assessment given their preference for innovations with strong *evidence strength and quality*, such that they viewed trauma assessment as “best practice.” Further, many of the reasons that participants valued and viewed trauma assessment as important during ASD diagnostic evaluations were related to the aforementioned *needs and resources of those served*, including getting a “complete picture” of the child. Consistent with participants’ views that trauma assessment was important, they also identified high levels of *appropriateness* for the use of trauma assessment. Specifically, participants viewed assessing for trauma in children being evaluated for ASD as appropriate and relevant. Overall, participants made a strong case for the need, value, and importance of integrating trauma assessment into ASD diagnostic evaluations, and, thus, *needs and resources, knowledge and beliefs, relative priority, implementation climate, evidence strength and quality, and appropriateness* were all considered facilitators (although not exclusively) of participants’ trauma assessment use.

In contrast, while the vast majority of participants believed that trauma assessment was needed and relevant for children being evaluated for ASD, they did not believe that their ASD diagnostic evaluations were the appropriate settings to evaluate for trauma. Thus, participants did not perceive high levels of *appropriateness* or a fit between the innovation (i.e., trauma assessment practices) and the practice setting. Participants primarily cited their perceptions of their roles as the source of this misfit because most participants believed that their primary function during an ASD diagnostic evaluation was to rule in or rule out ASD. Therefore, participants perceived the *relative priority* of assessing for trauma compared to the priority of assessing for ASD as low. Despite participants’ recognition of the importance of parsing out

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psychiatric comorbidity to make accurate and appropriate diagnoses, they reported that their “primary focus [was] to answer the question of autism ‘yes’ or ‘no?’” Thus, while *appropriateness* and *relative priority* were more often rated as facilitators of participants’ trauma assessment use, a number of participants also considered them to be barriers.

Participants indicated that there were a number of factors that contributed to their prioritization of ruling in or ruling out ASD over integrating trauma assessment practices into ASD diagnostic evaluations. Almost all participants who referenced *feasibility* (i.e., the ease with which they could integrate trauma assessment) cited it as a barrier to their use of trauma assessment during ASD diagnostic evaluations. As a result, participants discussed the ways in which they *adapted* their clinics’ trauma assessment practices to be *feasible* and *appropriate* for their practice setting. For instance, as has been discussed, the majority of participants engaged in primarily trauma screening rather than comprehensive trauma assessment. Given a range of factors, such as lack of knowledge, comfort, and time (discussed in more detail below), the use of trauma screening was more *compatible* with their clinic workflow.

Participants’ process of screening for trauma exposure and symptoms, and then referring out for additional evaluation if needed, was facilitated by both the *outer* and *inner* settings. Specifically, participants noted that their connections to external organizations (i.e., *cosmopolitanism*) facilitated the referral for additional evaluation. While participants viewed their connections to external organizations as beneficial and as positively influencing their use of trauma assessment, such that they had places to which children who endorsed trauma exposure and symptoms could be referred, it was likely that this procedure prevented clinics from adopting a more comprehensive trauma assessment process of their own. Consequently, participants who primarily referred their patients to external clinics for additional evaluation did not experience a

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“push” or need to use trauma assessment as a result of their *cosmopolitanism*. Further, the referral connections also potentially contributed to a lack of *tension for change* within the clinic, as most participants reported that they did not see a need to change their current procedures.

Moreover, additional factors from the outer setting, including *peer pressure* and *external policy and incentives*, did not appear to serve as facilitators of the use of trauma assessment practices during ASD diagnostic evaluations. Specifically, almost all participants who commented on the practices of other ASD diagnostic clinics had no awareness regarding the activity of these clinics (i.e., lack of *peer pressure*). Further, outside of mandated reporter guidelines, the majority of participants reported that they were unaware of any policies, recommendations, or guidelines regarding the use of trauma assessment during ASD diagnostic evaluations. Therefore, while *cosmopolitanism*, *peer pressure*, *external policy and incentives*, and *tension for change* did not actively impede the use of trauma assessment practices, they simultaneously did not serve as an impetus for the adoption of trauma assessment practices.

The combination of the lack of an impetus to adopt comprehensive trauma assessment with several factors that decreased the *feasibility* by which participants could integrate trauma assessment into ASD diagnostic evaluations likely impeded implementation. Unfortunately, participants identified a significant number of practical barriers across all CFIR domains, with the exception of the *process* domain, that affected the ease with which they could use trauma assessment practices. Specifically, participants identified ways in which *the needs and resources* of the children being evaluated and their families impeded their use of trauma assessment. For instance, participants noted that variations in the child’s cognitive or language abilities, such as the child being nonverbal, created barriers to using trauma assessment. Participants elaborated that lack of language also contributed to challenges with *adapting* the innovation to children

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being evaluated for ASD. In addition, participants indicated that they were hesitant to use trauma assessment out of fear of causing distress or a sense of blame or guilt in the children or their caregivers. Further, participants noted that caregivers might not find trauma assessment practices to be *acceptable*, given their reasons for having sought an evaluation (i.e., to rule in or out ASD).

Individual characteristics of the participants were an additional factor that impeded the use of trauma assessment practices and made it more difficult (i.e., less *feasible*) for them to integrate these practices into their ASD diagnostic evaluations. Specifically, 69.2% of participants identified that they did not have sufficient *knowledge* from their education and graduate/postgraduate training backgrounds in trauma and trauma assessment. About half of the sample (46.2%) described that they specialized in ASD throughout their psychology training and, thus, unless they intentionally sought out trauma-focused clinical experiences, they did not feel that they had the knowledge to adequately assess for trauma in children being evaluated for ASD. Moreover, the majority of participants expressed a lack of confidence (i.e., *self-efficacy*) in their ability to assess for trauma during ASD diagnostic evaluations. Given that the sample was composed entirely of psychologists, this finding was both surprising and concerning, as the integration of trauma assessment is not only a fundamental component of differential diagnosis but also, as described by participants, needed for children being evaluated for ASD.

Lastly, the most salient barriers that affected the *feasibility* with which participants could integrate trauma assessment practices into ASD diagnostic evaluations were *readiness for implementation* subconstructs, in particular, lack of *available resources*. Most participants noted that lack of time interfered with their use of trauma assessment practices. Specifically, participants described that the amount of time required to conduct a “gold standard” ASD evaluation was prohibitive for then adding comprehensive trauma assessment. Further,

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participants commented on the consecutive scheduling of appointments given lengthy waitlists for ASD diagnostic evaluations as contributing to their “time crunch.” Of note, only five participants had access to trauma measures to evaluate PTSD symptoms and only three of those five participants made use of them. Thus, the majority of participants either did not have or use measures during their ASD diagnostic evaluations and relied on a more time-intensive method (i.e., caregiver interview) for their evaluation of trauma. In addition, several participants identified a lack of *access to knowledge and information* about assessing for trauma in children being evaluated for ASD in their clinics, such that while there were other providers who had trauma-specific knowledge, there were limited trainings in their clinics as to how trauma presents in children with ASD and how to assess for it. Notably, this is related to an *outer setting* issue, which will be discussed below.

In sum, participants identified numerous constructs that were barriers to their use of trauma assessment practices because they made the integration of trauma assessment less *feasible*. Thus, for the reasons outlined above, more participants rated *adaptability, acceptability, knowledge and beliefs, self-efficacy, and available resources* as predominantly barriers to the use of trauma assessment practices during ASD diagnostic evaluations. However, it is important to note that these barriers as well as *access to knowledge and information* (which was predominantly a facilitator of trauma assessment use) concurrently facilitated and interfered with the use of trauma assessment practices. Thus, it was valuable to identify the valence of each of these factors to understand how they influenced participants’ use of trauma assessment.

Only three participants engaged in comprehensive trauma assessment despite all participants recognizing the need and importance, and they did not endorse *feasibility* concerns. For the participants who adopted trauma assessment, a connection with a trauma expert from

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outside of the clinic (*external change agent*) or within the clinic (*access to knowledge and information*) was particularly salient. Further, participants who successfully integrated trauma assessment tended to be those who did not come from the “ASD world” (i.e., completing a graduate program and predoctoral/postdoctoral training exclusively in ASD) and had greater *knowledge* about trauma and, therefore, higher *self-efficacy*. In addition, the clinics in which trauma assessment was effectively integrated had strong *networks and communications*, including designated times for multidisciplinary team meetings and case conferences, and more *available resources*. Of particular importance, all of the participants who adopted trauma assessment practices made use of trauma-specific assessment tools and two described using a technician model for test administration, which freed up additional time for the psychologists.

Symptom Overlap and the Diagnostic System. Participants reported that their ability to integrate trauma assessment practices into ASD diagnostic evaluations was influenced by the *symptom overlap* between trauma and ASD symptoms. Specifically, participants highlighted that children who have been exposed to trauma might display symptoms (e.g., repetitive behaviors, reduced eye contact, difficulties with social interactions) that are associated with ASD. Consistent with the results of this study, researchers have posited that a significant barrier to identifying trauma symptoms in children with ASD is the diagnostic overlap between the DSM-5 criteria for ASD and PTSD (Brenner et al., 2017). Symptom overlap is not an established CFIR or IOF construct, and it was created as a subcategory of *needs and resources* to capture a factor that influenced participants’ use of trauma assessment that was unique to this study.

Participants indicated that the overlap in symptoms associated with ASD and PTSD diagnoses not only created a need to incorporate trauma assessment, thus facilitating its use, but also made it more difficult and less feasible. As was previously described, while the *outer setting*

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construct *needs and resources* captured participants' perception of an increased need for trauma assessment in children being evaluated for ASD given the overlap in symptoms, it failed to capture the problem associated with the diagnostic system.

Notably, the issue of *symptom overlap* and the failure of the diagnostic system to take the comorbidity/overlap into consideration was evident in other comments made by participants that were coded across domains, but should truly be placed within the *outer setting*, as they are a system problem that is outside of the context of the individual ASD diagnostic clinics (i.e., *inner setting*), individual providers (i.e., *characteristics of individuals*), and *innovation characteristics*.

First, participants highlighted that there is a lack of adequate information in the field as to how to assess for trauma in children being evaluated for ASD. Participants noted this at the individual (i.e., *knowledge and beliefs*), clinic (*access to knowledge and information*), and system (*external policy and incentives*) levels. Specifically, there are not any well-established empirical guidelines regarding how to assess for trauma in children being evaluated for ASD. Further, participants indicated that given their value of engaging in best practice (i.e., *evidence strength and quality*), they looked to the literature for guidance; however, the lack of evidence-based guidelines created a barrier to their use of trauma assessment practices.

In addition, participants reported that there is a measurement problem, such that there are not adequate assessment tools available to address the *symptom overlap* between ASD and PTSD. A number of participants further reported that the overlap in symptoms resulted in elevations on commonly used ASD measures, such that children who were truly experiencing symptoms of traumatic stress may have incorrectly appeared, through assessment data, to have ASD. Several participants also noted that there is a need for a measure that is adapted to the needs of children being evaluated for ASD, as some presented with limited language and

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variations in cognitive functioning. Further, as outlined by Kerns and colleagues (2015), it is possible that in addition to affecting the types of trauma to which children are exposed, ASD might influence the appraisal of PTEs and the expression of trauma symptoms following trauma exposure. That is, children with ASD might find different (i.e., atypical) situations or events to be traumatic (Kerns et al., 2015), and children with ASD might display symptoms that are outside of the current PTSD diagnostic criteria (e.g., increased temper tantrums; Brenner et al., 2017). Thus, a measure to assess for trauma in children being evaluated for ASD would need to take *symptom overlap*, *children's needs and resources* (e.g., language level), and potential differences in PTEs and trauma-related symptoms for children with ASD into account.

Ultimately, given the potential overlap in symptoms between ASD and trauma and the resulting lack of consensus in the field as to how to adequately assess for trauma in children being evaluated for ASD, it is striking that the majority of psychologists indicated that their priority is to rule in or rule out an ASD diagnosis. This brings up the question; is it possible to effectively assess for ASD without a comprehensive trauma assessment?

Comparison to Existing Barriers. I considered the results of the current study in relation to the results of a study by Whiteside and colleagues (2016) to explore how the factors that affected the use of trauma assessment during ASD diagnostic evaluations compared to those found in preliminary studies on the use of EBA more broadly. Similar to the findings of Whiteside and colleagues (2016), participants in this study identified many “obstacles to use” of the innovation. Across both studies, participants indicated that insufficient time, lack of access to materials, and unfamiliarity with EBA were barriers to innovation use. Of note, participants in this study did not indicate that costs were prohibitive, though they did identify that billing and insurance company reimbursement restrictions limited their time and how they could use it.

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Interestingly, the studies differed more on the second theme identified by Whiteside and colleagues (2016), which was “negative beliefs.” Specifically, participants in their study made comments that EBA techniques are unhelpful and not needed for good clinical practice. For instance, participants, which included clinicians with both master’s and doctoral degrees, believed interview skills were “sufficient,” although psychologists were less likely to endorse this view (Whiteside et al., 2016, p. 68). This was in contrast to participants in the current study, who identified that trauma assessment practices with high *evidence strength and quality* are needed, valuable, and important. However, both studies noted that barriers to the use of EBA included beliefs that EBA might be burdensome for the patient/family. While significant conclusions cannot be drawn from a comparison with one study, it appeared that the barriers to the use of EBA in this study were comparable to those in the study by Whiteside and colleagues (2016).

One distinction across these two studies, however, was the addition of the *symptom overlap* construct in the present study. Given the nascent state of the research as to how to assess for trauma in children being evaluated for ASD, it is not surprising that this barrier may be more specific to this study. Specifically, accurately differentiating symptoms of trauma from symptoms of ASD is a unique problem that has not yet been addressed adequately in the research literature. However, it is notable that other psychiatric comorbidities (e.g., ADHD, anxiety) have received greater research attention and the development of autism-specific assessment tools (e.g., ADIS/ASA; Kerns et al., 2016). Given the overlap in symptoms, it is even more imperative to be aware of diagnostic overshadowing, such that trauma-related symptoms might be misattributed to ASD symptoms and could contribute to misdiagnosis and, ultimately, inappropriate treatment (Keesler, 2014).

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More broadly, researchers who have conducted recent CFIR studies have started to include valence rating systems to examine which constructs differentiate between high and low levels of implementation (Varsi et al., 2015). Researchers demonstrated that across all three of the studies compared, *needs and resources* and *available resources* were the most commonly cited constructs that differentiated implementation efforts (Varsi et al., 2015). The results of this study provide additional support for the importance of these constructs.

Limitations

There were several limitations of the present study. While researchers have recommended an increased use of theory in all stages of implementation research, including data collection, analysis, and interpretation (Kirk et al., 2016), the use of a directed content analysis with a deductive approach inherently has limitations (Hsieh & Shannon, 2005). For instance, the use of the CFIR to guide the development of the interview protocol could have led to different conversations on factors affecting psychologists' use of trauma assessment practices or different results than if an alternative qualitative research methodology was used, such as grounded theory. To address this limitation, I used open-ended questions and was open to themes that arose inductively from the data outside of the frameworks, as demonstrated by the creation of a new subconstruct (i.e., *symptom overlap*).

Overall, our team found the CFIR and IOF definitions to be adequate and sufficiently comprehensive for coding interview responses; however, the comprehensiveness of the CFIR was also a weakness (Varsi et al., 2015). Specifically, psychologists could not be interviewed about every construct of the CFIR. Therefore, it may be that additional constructs or subconstructs influenced psychologists' use of trauma assessment practices that were not illuminated by this study. Despite this limitation, past CFIR research, an expert panel, and

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consideration of the phase of implementation was used to generate the interview protocol. Further, the interview was designed more broadly and with open-ended questions to allow participants to guide the conversation towards the factors that were most relevant to their use of trauma assessment practices, rather than trying to ask about every CFIR construct.

In addition, there was a lot of double coding between the CFIR and IOF. It is likely that this was related to the phase of implementation of participants, such that the majority were in early stages of implementation, and, therefore, most participants were speaking prospectively rather than retrospectively. Future research that combines these frameworks should seek to further delineate the frameworks, and it might be beneficial to situate the frameworks within a phase model of the implementation process (e.g., the Exploration, Preparation, Implementation, and Sustainment [EPIS] framework; Aarons, Hurlburt, & Horowitz, 2011).

Lastly, while researchers have demonstrated that saturation can be reached after 12 interviews when there is structure and homogeneity in the sample (Guest et al., 2006), the results of the current study might not generalize across all psychologists' who are conducting multidisciplinary ASD diagnostic evaluations in autism specialty centers across the United States. It is possible that psychologists who were more interested in or knowledgeable about evaluating for trauma in ASD diagnostic evaluations elected to participate in this study.

Implications for Future Research

There are a number of avenues for future research given the paucity of studies on trauma in children with ASD. As identified by many of the participants in this study, it is clear that the state of knowledge in the field is presently inadequate. As a result, psychologists do not have the knowledge, training, or tools needed to appropriately parse out psychiatric comorbidity, especially the symptom overlap between ASD and traumatic stress. While some participants in

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this study applied their past trauma-specific training and assessment tools developed for typically developing children to ASD diagnostic evaluations, the majority of psychologists in this study did not feel comfortable or able to conduct comprehensive trauma assessment in children being evaluated for ASD.

Consequently, there is an essential need for continued investigation of the prevalence of trauma in children with ASD (e.g., Berg et al., 2016; McDonnell et al., 2018) and the presentation of trauma-related symptoms in children with ASD (e.g., Brenner et al., 2017). Specifically, epidemiological studies are needed in order to develop an assessment tool that is appropriate for the population, including more information about the types of traumatic events that children with ASD find to be stressful, as well as additional data regarding the presentation of symptoms. The involvement of key stakeholders, including individuals with ASD who have experienced trauma and their families, in this research would be beneficial and provide invaluable information as to the way in which individuals with ASD experience trauma. In addition, as reported by participants in this study, given the symptom overlap between ASD and PTSD, a clear operationalization of traumatic stress symptoms and how they can be differentiated from ASD is crucial.

Community-based participatory research (CBPR) may be a promising methodological approach to not only include people with developmental disabilities as full partners in all phases of research but also to increase the accessibility of an assessment tool to children with ASD and their families (Hughes, Lund, Gabrielli, Powers, & Curry, 2011; Nicolaidis et al., 2015). For instance, the researchers involved with the Partnering with People with Developmental Disabilities to Address Health and Violence study used a CBPR approach to collaboratively select and adapt measures to examine the relationship between violence, disability, and health in

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people with developmental disabilities (Nicolaidis et al., 2015). While the research conducted by this group was with adults with developmental disabilities, their incorporation of adapted measures into an Audio Computer-Assisted Self-Interview (A-CASI; Hughes et al., 2019) might be a useful model for future research exploring exposure to PTEs and associated health outcomes in children with ASD.

Consistent with participants' responses, researchers have identified the lack of an adapted, standardized, and normed trauma measure for children with ASD as a significant barrier to trauma assessment in this population (Brenner et al., 2017; Hoover & Kaufman, 2018; Kerns et al., 2015). Recently, Hoover and Romero (2019) piloted a web-based, self-report trauma assessment tool designed for children with ASD, the *Interactive Trauma Scale* (ITS). They found preliminary evidence of convergent validity with the self- and parent-report versions of a widely disseminated trauma measure, the *UCLA PTSD Reaction Index* (Pynoos & Steinberg, 2015) as well as positive ratings on the ease of use, understanding, and overall acceptability (Hoover & Romero, 2019). Additional research on this measure, including the extent to which it is compatible with the procedures of ASD diagnostic clinics will be important.

In addition, as only one stakeholder group (i.e., psychologists) was interviewed for this study, future research should consider obtaining the perspectives of other key stakeholders regarding their evaluation experiences. While it seemed appropriate to start with psychologists for this study, as they are most likely to engage in the implementation of trauma assessment practices, children (or adults) who have been evaluated for ASD, the caregivers of children who were evaluated, and/or other members of the multidisciplinary team who engage in the assessment of trauma during ASD diagnostic evaluations could offer alternative perspectives as to the factors that facilitate and impede the use of trauma assessment practices.

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Further, continued research on the relationship between trauma and ASD is only useful if it can be disseminated and implemented in the settings that serve children being evaluated for ASD. As demonstrated by this study, it is not only important to consider the needs of the children being evaluated for ASD, but it is also important to consider the context of implementation (i.e., *inner setting*) and the characteristics of the individuals engaged in implementation. Given the considerable *available resources* concerns, particularly the lack of time, of psychologists engaged in ASD diagnostic evaluations it will be crucial that innovations are created or adapted with the *feasibility* of use as well as the *compatibility* with the clinic's workflow in mind. Notably, the current study was conducted with psychologists engaged in multidisciplinary ASD diagnostic evaluations in autism specialty centers. Psychologists in autism specialty centers are likely to have higher levels of resources than psychologists conducting ASD diagnostic evaluations in other settings. Therefore, given the relevance of *inner setting* constructs found in this study, it is possible that they will be magnified for providers outside of these settings, who might not have the same level of personnel, assessment tools, or other resources.

Moreover, despite the lack of information in the field more broadly, many participants reported minimal exposure to the discussion of trauma in children with ASD. For those who completed their graduate training in ASD-focused programs, several participants reported that they had to make a concerted effort to seek out trauma training. Given the heightened rates of trauma exposure and trauma-related symptoms in children with ASD, it is important that trauma is integrated into the broader discussion of psychiatric comorbidity in this group starting early on in graduate training. It is concerning that many participants felt that they did not have the requisite training to integrate trauma assessment into ASD diagnostic evaluations, and this is a

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critically important gap to address given that early detection of trauma exposure and associated symptoms can help mitigate adverse health outcomes.

Conclusions

This study is the first to my knowledge to explore the process by which trauma assessment practices are integrated into multidisciplinary ASD diagnostic evaluations. Importantly, psychologists in this study indicated a clear need for the integration of trauma assessment into ASD diagnostic evaluations. However, given the limitations in the field, including a lack of knowledge, training, and assessment tools, it is presently difficult for psychologists to engage in comprehensive trauma assessment practices. In addition, the majority of participants viewed trauma assessment as outside of their purview in ASD diagnostic clinics. It will be critical to make adaptations to this view in order to increase the adoption of trauma assessment practices. Further, while many participants identified that it is appropriate for children being evaluated for ASD to be assessed for trauma, there are a number of factors in the clinic setting, most notably the lack of time, that impeded the use of trauma assessment practices.

It will be important to include considerations of the children being assessed and their families, the providers, the clinic, and the broader context beyond the individual clinics in order to effectively adapt trauma assessment practices to be used in ASD diagnostic evaluations. Given that it does not seem possible to adequately assess for ASD without considering trauma, it is essential for psychologists to consider and prioritize the complete picture of children's functioning to adequately address their needs and foster their future success through accurate diagnosis and appropriate treatment referrals.

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References

- Aarons, G.A., Hurlburt, M., & Horwitz, S.M. (2011). Advancing a conceptual model of evidence-based practice implementation in public service sectors. *Administration and Policy in Mental Health and Mental Health Services Research*, 38(1), 4-23. doi: 10.1007/s10488-010-0327-7
- Algood, C. L., Hong, J. S., Gourdine, R. M., & Williams, A. B. (2011). Maltreatment of children with developmental disabilities: An ecological systems analysis. *Children and Youth Services Review*, 33(7), 1142-1148. doi: 10.1016/j.childyouth.2011.02.003
- Alisic, E., Zalta, A. K., van Wesel, F., Larsen, S. E., Hafstad, G. S., Hassanpour, K., & Smid, G. E. (2014). Rates of post-traumatic stress disorder in trauma-exposed children and adolescents: Meta-analysis. *The British Journal of Psychiatry*, 204(5), 335-340. doi: 10.1192/bjp.bp.113.131227
- Ameis, S. H., & Szatmari, P. (2015). Common psychiatric comorbidities and their assessment. In E. Anagnostou, & J. Brian (Eds.), *Clinician's manual on autism spectrum disorder* (pp. 32, Chapter xvi, 91 Pages). Cham, Switzerland: Springer International Publishing, Cham. doi: 10.1007/978-3-319-03056-2_3
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., . . . Constantino, J. N. (2018). Prevalence of autism spectrum disorder among children aged 8 years - Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014. *MMWR Surveillance Summaries*, 67(6), 1-23. doi: 10.15585/mmwr.ss6706a1

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- Baron, R. M., & Kenny, D. A. (1986). The moderator–mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, *51*(6), 1173-1182. doi: 10.1037/0022-3514.51.6.1173
- Bauer, M.S., Damschroder, L., Hagedorn, H., Smith, J., & Kilbourne, A.M (2015). An introduction to implementation science for the non-specialist. *BMC Psychology*, *3*:32, doi: 10.1186/s40359-015-0089-9.
- Bengtsson, M. (2016). How to plan and perform a qualitative study using content analysis. *NursingPlus Open*, *2*, 8-14. doi: 10.1016/j.npls.2016.01.001
- Belsky, J. (1980). Child maltreatment: An ecological integration. *American Psychologist*, *35*(4), 320-335. doi: 10.1037/0003-066X.35.4.320
- Berg, K. L., Acharya, K., Shiu, C., & Msall, M. E. (2018). Delayed diagnosis and treatment among children with autism who experience adversity. *Journal of Autism and Developmental Disorders*, *48*(1), 45-54. doi: 10.1007/s10803-017-3294-y
- Berg, K. L., Shiu, C., Acharya, K., Stolbach, B. C., & Msall, M. E. (2016). Disparities in adversity among children with autism spectrum disorder: A population-based study. *Developmental Medicine & Child Neurology*, *58*(11), 1124-1131. doi: 10.1111/dmcn.13161
- Berg, K.L., Shiu, C., Feinstein, F.T., Msall, M.E., & Acharya, K. (2018). Adverse childhood experiences are associated with unmet healthcare needs among children with autism spectrum disorder. *The Journal of Pediatrics*, *202*, 258-264. doi: 10.1016/j.jpeds.2018.07.021
- Bleil Walters, J., Hughes, T. L., Sutton, L. R., Marshall, S. N., Crothers, L. M., Lehman, C., . . . Huang, A. (2013). Maltreatment and depression in adolescent sexual offenders with an

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- autism spectrum disorder. *Journal of Child Sexual Abuse: Research, Treatment, & Program Innovations for Victims, Survivors, & Offenders*, 22(1), 72-89. doi: 10.1080/10538712.2013.735357
- Bradley, E. H., Curry, L.A., & Devers, K.J. (2007). Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. *Health Services Research*, 42(4), 1758-1772. doi: 10.1111/j. 475-6773.2006.00684.x
- Brenner, J., Pan, Z., Mazefsky, C., Smith, K. A., & Gabriels, R. (2017). Behavioral symptoms of reported abuse in children and adolescents with autism spectrum disorder in inpatient settings. *Journal of Autism and Developmental Disorders*. doi: 10.1007/s10803-017-3183-4
- Brett, D., Warnell, F., McConachie, H., & Parr, J. R. (2016). Factors affecting age at ASD diagnosis in UK: No evidence that diagnosis age has decreased between 2004 and 2014. *Journal of Autism and Developmental Disorders*, 46(6), 1974-1984. doi:10.1007/s10803-016-2716-6
- Briere, J. (1996). *Trauma symptom checklist for children*. Odessa, FL: Psychological Assessment Resources.
- Briere, J. (2005). *Trauma symptom checklist for young children*. Odessa, FL: Psychological Assessment Resources.
- Briere, J., Kaltman, S., & Green, B. L. (2008). Accumulated childhood trauma and symptom complexity. *Journal of Traumatic Stress*, 21(2), 223-226. doi: 10.1002/jts.20317
- Briggs, E. C., Fairbank, J. A., Greeson, J. K. P., Layne, C. M., Steinberg, A. M., Amaya-Jackson, L. M., . . . Pynoos, R. S. (2013). Links between child and adolescent trauma exposure and

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- service use histories in a national clinic-referred sample. *Psychological Trauma: Theory, Research, Practice, and Policy*, 5(2), 101-109. doi: 10.1037/a0027312
- Brown, D. W., Anda, R. F., Tiemeier, H., Felitti, V. J., Edwards, V. J., Croft, J. B., & Giles, W. H. (2009). Adverse childhood experiences and the risk of premature mortality. *American Journal of Preventive Medicine*, 37(5), 389-396. doi: 10.1016/j.amepre.2009.06.021
- Brown, I., & Schormans, A. F. (2014). Application of quality of life to children with intellectual and developmental disabilities who experience child maltreatment. In R. I. Brown, & R. M. Faragher (Eds.), *Quality of life and intellectual disability: Knowledge application to other social and educational challenges* (pp. 136, Chapter xiii, 349 Pages). Hauppauge, NY, US: Nova Science Publishers, Hauppauge, NY.
- Centers for Disease Control and Prevention. (2014). Prevalence of autism spectrum disorders among children aged 8 years: Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010. *MMWR Surveillance Summaries*, 63, 1–22.
- Chan, K. K. S., & Lam, C. B. (2016). Parental maltreatment of children with autism spectrum disorder: A developmental-ecological analysis. *Research in Autism Spectrum Disorders*, 32, 106-114. doi: 10.1016/j.rasd.2016.09.006
- Charlton, M., Kliethermes, M., Tallant, B., Taverne, A., & Tishelman, A. (2004). *Facts on traumatic stress and children with developmental disabilities*. Retrieved from <http://www.nctsn.org/products/facts-traumatic-stress-and-children-developmental-disabilities-2004>
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: SAGE Publications.

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

The Child and Adolescent Health Measurement Initiative, John Hopkins Bloomberg School of Public Health. (2016). *Experience matters: A view into the health and wellbeing of US*

children and families with autism spectrum disorders (ASD). Retrieved from

<http://childhealthdata.org/docs/default-source/cahmi/asdchartbookfinal.pdf?sfvrsn=2>

Cho, J. Y. & Lee, E-H. (2014). Reducing confusion about grounded theory and qualitative content analysis: Similarities and differences. *The Qualitative Report*, 19(32), 1-20.

Retrieved from <http://www.nova.edu/ssss/QR/QR19/cho64.pdf>

Chor, K. H. B., Wisdom, J. P., Olin, S. S., Hoagwood, K. E., & Horwitz, S. M. (2015). Measures for predictors of innovation adoption. *Administration and Policy in Mental Health and Mental Health Services Research*, 42(5), 545-573. doi: 10.1007/s10488-014-0551-7

Cloitre, M., Stolbach, B. C., Herman, J. L., van der Kolk, B., Pynoos, R., Wang, J., & Petkova, E. (2009). A developmental approach to complex PTSD: Childhood and adult cumulative trauma as predictors of symptom complexity. *Journal of Traumatic Stress*, 22(5), 399-408. doi: 10.1002/jts.20444

Cook, E. H., Kieffer, J. E., Charak, D. A., & Leventhal, B. L. (1993). Case study: Autistic disorder and post-traumatic stress disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 32(6), 1292-1294. doi: 10.1097/00004583-199311000-00025

Cook, A., Spinazzola, J., Ford, J., Lanktree, C., Blaustein, M., Cloitre, M...van der Kolk, B. (2005). Complex trauma in children and adolescents. *Psychiatric Annals*, 35(5), 390-398.

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research 3e: Techniques and procedures for developing grounded theory*. Los Angeles, CA: SAGE Publications.

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- Copeland, W. E., Keeler, G., Angold, A., & Costello, E. J. (2007). Traumatic events and posttraumatic stress in childhood. *Archives of General Psychiatry*, *64*(5), 577-584. doi: 10.1001/archpsyc.64.5.577
- Courtois, C. A., & Ford, J. D. (Eds.). (2009). *Treating complex traumatic stress disorders: An evidence-based guide*. New York, NY: Guilford Press.
- Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. L. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, *20*(2), 153-162. doi: 10.1177/1362361315573636
- D'Andrea, W., Ford, J., Stolbach, B., Spinazzola, J., & van der Kolk, B. A. (2012). Understanding interpersonal trauma in children: Why we need a developmentally appropriate trauma diagnosis. *American Journal of Orthopsychiatry*, *82*(2), 187-200. doi: 10.1111/j.1939-0025.2012.01154.x
- Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: A consolidated framework for advancing implementation science. *Implementation Science*, *4*(50), 1-15. doi: 10.1186/1748-5908-4-50
- Damschroder, L. J., & Lowery, J. C. (2013). Evaluation of a large-scale weight management program using the Consolidated Framework for Implementation Research (CFIR). *Implementation Science*, *8*(1). doi: 10.1186/1748-5908-8-51
- Daniels, A. M., Halladay, A. K., Shih, A., Elder, L. M., & Dawson, G. (2014). Approaches to enhancing the early detection of autism spectrum disorders: A systematic review of the literature. *Journal of the American Academy of Child & Adolescent Psychiatry*, *53*(2), 141-152. doi: 10.1016/j.jaac.2013.11.002

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- del Pilar Trelles Thorne, M., Khinda, N., & Coffey, B. J. (2015). Posttraumatic stress disorder in a child with autism spectrum disorder: Challenges in management. *Journal of Child and Adolescent Psychopharmacology*, 25(6), 514-517.
- Denton, R., Frogley, C., Jackson, S., John, M., & Querstret, D. (2017). The assessment of developmental trauma in children and adolescents: A systematic review. *Clinical Child Psychology and Psychiatry*, 22(2), 260-287. doi: 10.1177/1359104516631607
- Dewey, D., & Schulberg, D. (2013). Criterion A, peritraumatic emotions, and posttraumatic stress disorder. *Traumatology*, 19(4), 323-328. doi: 10.1177/1534765613496650
- Dorsey, S., McLaughlin, K. A., Kerns, S. E. U., Harrison, J. P., Lambert, H. K., Briggs, E. C., . . . Amaya-Jackson, L. (2017). Evidence base update for psychosocial treatments for children and adolescents exposed to traumatic events. *Journal of Clinical Child and Adolescent Psychology*, 46(3), 303-330. doi: 10.1080/15374416.2016.1220309
- Drum, C. E., Peterson, J. J., Culley, C., Krahn, G., Heller, T., Kimpton, T., . . . White, G. W. (2009). Guidelines and criteria for the implementation of community-based health promotion programs for individuals with disabilities. *American Journal of Health Promotion*, 24(2), 93-101. doi: 10.4278/ajhp.090303-CIT-94
- Elsabbaugh, M., Divan, G., Koh, Y.-J., Kim, S., Kauchali, S., Marcin, C., . . . Fombonne, E. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism Research*, 5, 160–179. doi: 10.1002/aur.239
- Falkmer, T., Anderson, K., Falkmer, M., & Horlin, C. (2013). Diagnostic procedures in autism spectrum disorders: A systematic literature review. *European Child & Adolescent Psychiatry*, 22(6), 329-340. doi: 10.1007/s00787-013-0375-0

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

Felitti, V. J., Anda, R. F., Nordenberg, D., Williamson, D. F., Spitz, A. M., Edwards, V., . . .

Marks, J. S. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults: The adverse childhood experiences (ACE) study. *American Journal of Preventive Medicine, 14*(4), 245-258. doi: 10.1016/S0749-3797(98)00017-8

Filipek, P. A., Accardo, P. J., Ashwal, S., Baranek, G. T., Cook, E. H., Jr., Dawson, G., . . .

Volkmar, F. R. (2000). Practice parameter: Screening and diagnosis of autism: Report of the quality standards subcommittee of the American Academy of Neurology and the Child Neurology Society. *Neurology, 55*(4), 468-479. doi: 10.1212/WNL.55.4.468

Finkelhor, D., Ormrod, R. K., & Turner, H. A. (2007). Poly-victimization: A neglected

component in child victimization. *Child Abuse & Neglect, 31*(1), 7-26.

doi:10.1016/j.chiabu.2006.06.008

Finkelhor, D., Turner, H., Ormrod, R., & Hamby, S. L. (2010). Trends in childhood violence and

abuse exposure: Evidence from 2 national surveys. *Archives of Pediatric and Adolescent Medicine, 164*, 238-242.

Finkelhor, D., Turner, H., Shattuck, A., & Hamby, S. (2013). Violence, crime, and abuse

exposure in a national sample of children and youth: An update. *JAMA*

Pediatrics, 167(7), 614-621.

Fisher, M. H., Epstein, R. A., Urbano, R. C., Vehorn, A., Cull, M. J., & Warren, Z. (2018). A

population-based examination of maltreatment referrals and substantiation for children with autism spectrum disorder. *Autism*. doi: 10.1177/1362361318813998

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- Fisher, M. H., Hodapp, R. M., & Dykens, E. M. (2008). Child abuse among children with disabilities: What we know and what we need to know. *International Review of Research in Mental Retardation*, 35, 251-289. doi: 10.1016/S0074-7750(07)35007-6
- Foa, E. B., Johnson, K. M., Feeny, N. C., & Treadwell, K. R. H. (2001). The Child PTSD Symptom Scale: A preliminary examination of its psychometric properties. *Journal of Clinical Child Psychology*, 30(3), 376-384.
- Focht-New, G., Clements, P. T., Barol, B., Faulkner, M. J., & Service, K. P. (2008). Persons with developmental disabilities exposed to interpersonal violence and crime: Strategies and guidance for assessment. *Perspectives in Psychiatric Care*, 44(1), 3-13. doi: 10.1111/j.1744-6163.2008.00142.x
- Ford, J. D., & Courtois, C. A. (2009). Defining and understanding complex trauma and complex traumatic stress disorders. In C. A. Courtois, & J. D. Ford (Eds.), *Treating complex traumatic stress disorders: An evidence-based guide* (pp. 30, Chapter xxi, 468 Pages). New York, NY, US: Guilford Press, New York, NY.
- Gold, S. D., Marx, B. P., Soler-Baillo, J. M., & Sloan, D. M. (2005). Is life stress more traumatic than traumatic stress? *Journal of Anxiety Disorders*, 19(6), 687-698. doi: 10.1016/j.janxdis.2004.06.002
- Govindshenoy, M., & Spencer, N. (2007). Abuse of the disabled child: A systematic review of population-based studies. *Child: Care, Health and Development*, 33(5), 552-558. doi: 10.1111/j.1365-2214.2006.00693.x
- Grayson, J., Childress, A., & Baker, W. (2013). Risk of maltreatment for children with autism spectrum disorder. *Virginia Child Protective Newsletter*, 96(Spring), 1-11.

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

Greeson, J. K. P., Briggs, E. C., Layne, C. M., Belcher, H. M. E., Ostrowski, S. A., Kim, S., . . .

Fairbank, J. A. (2014). Traumatic childhood experiences in the 21st century: Broadening and building on the ACE studies with data from the national child traumatic stress network. *Journal of Interpersonal Violence, 29*(3), 536-556. doi: 10.1177/0886260513505217

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*(1), 59-82. doi: 10.1177/1525822X05279903

Guthrie, W., Swineford, L. B., Nottke, C., & Wetherby, A. M. (2013). Early diagnosis of autism spectrum disorder: Stability and change in clinical diagnosis and symptom presentation. *Journal of Child Psychology and Psychiatry, 54*(5), 582-590.

Hall-Lande, J., Hewitt, A., Mishra, S., Piescher, K., & LaLiberte, T. (2015). Involvement of children with autism spectrum disorder (ASD) in the child protection system. *Focus on Autism and Other Developmental Disabilities, 30*(4), 237-248. doi: 10.1177/1088357614539834

Hansen, R. L., Blum, N. J., Gaham, A., Shults, J. & Committee DBS. (2016). Diagnosis of autism spectrum disorder by developmental-behavioral pediatricians in academic centers: A DBPNet study. *Pediatrics, 137*(S2).

Hanson, R. F., Borntrager, C., Self-Brown, S., Kilpatrick, D. G., Saunders, B. E., Resnick, H. S., & Amstadter, A. (2008). Relations among gender, violence exposure, and mental health: The National Survey of Adolescents. *American Journal of Orthopsychiatry, 78*(3), 313-321. doi: 10.1037/a0014056

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- Haruvi-Lamdan, N., Horesh, D., & Golan, O. (2018). PTSD and autism spectrum disorder: Co-morbidity, gaps in research, and potential shared mechanisms. *Psychological Trauma: Theory, Research, Practice, and Policy*, *10*(3), 290-299. doi: 10.1037/tra0000298
- Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *43*(3), 629-642. doi: 10.1007/s10803-012-1604-y
- Hendricks, C., Lansford, J. E., Deater-Deckard, K., & Bornstein, M. H. (2014). Associations between child disabilities and caregiver discipline and violence in low- and middle-income countries. *Child Development*, *85*(2), 513-531. doi: 10.1111/cdev.12132
- Hibbard, R. A., & Desch, L. W. (2007). Maltreatment of children with disabilities. *Pediatrics*, *119*(5), 1018–1025. doi: 10.1542/peds.2007-0565.
- Hoover, D. W. (2015). The effects of psychological trauma on children with autism spectrum disorders: A research review. *Journal of Autism and Developmental Disorders*, *2*(3), 287-299. doi: 10.1007/s40489-015-0052-y
- Hoover, D. W., & Kaufman, J. (2018). Adverse childhood experiences in children with autism spectrum disorder. *Current Opinion in Psychiatry*, *31*(2), 128-132. doi: 10.1097/YCO.0000000000000390
- Hoover, D. W., & Romero, E. M. G. (2019). The interactive trauma scale: A web-based measure for children with autism. *Journal of Autism and Developmental Disorders*. doi: 10.1007/s10803-018-03864-3

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- Howlin, P., & Clements, J. (1995). Is it possible to assess the impact of abuse on children with pervasive developmental disorders? *Journal of Autism and Developmental Disorders*, 25(4), 337-354. doi: 10.1007/BF02179372
- Hsieh, H., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277-1288. doi: 10.1177/1049732305276687
- Huerta, M. & Lord, C. (2012). Diagnostic evaluation of autism spectrum disorders. *Pediatric Clin North Am*, 59(1), 103-111. doi: 10.1016/j.pcl.2011.10.018.
- Hughes, R. B., Lund, E. M., Gabrielli, J., Powers, L. E., & Curry, M. A. (2011). Prevalence of interpersonal violence against community-living adults with disabilities: A literature review. *Rehabilitation Psychology*, 56(4), 302-319. doi: 10.1037/a0025620
- Hughes, R. B., Robinson-Whelen, S., Raymaker, D., Lund, E. M., Oswald, M., Katz, M., . . . Nicolaidis, C. (2019). The relation of abuse to physical and psychological health in adults with developmental disabilities. *Disability and Health Journal*, 12(2), 227-234. doi: 10.1016/j.dhjo.2018.09.007
- Jaudes, P. K., & Mackey-Bilaver, L. (2008). Do chronic conditions increase young children's risk of being maltreated? *Child Abuse & Neglect*, 32(7), 671-681. doi: 10.1016/j.chiabu.2007.08.007
- Jensen-Doss, A., & Hawley, K. M. (2010). Understanding barriers to evidence-based assessment: Clinician attitudes toward standardized assessment tools. *Journal of Clinical Child and Adolescent Psychology*, 39(6), 885-896. doi: 10.1080/15374416.2010.517169
- Johnson, C. P., & Myers, S. M. (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, 120(5), 1183-1215. doi: 10.1542/peds.2007-2361

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- Jones, L., Bellis, M. A., Wood, S., Hughes, K., McCoy, E., Eckley, L., . . . Officer, A. (2012). Prevalence and risk of violence against children with disabilities: A systematic review and meta-analysis of observational studies. *The Lancet*, *380*(9845), 899-907. doi: 10.1016/S0140-6736(12)60692-8
- Keesler, J. M. (2014). A call for the integration of trauma-informed care among intellectual and developmental disability organizations. *Journal of Policy and Practice in Intellectual Disabilities*, *11*(1), 34-42. doi: 10.1111/jppi.12071
- Kerns, C. M., Kendall, P. C., Berry, L., Souders, M. C., Franklin, M. E., Schultz, R. T., . . . Herrington, J. (2014). Traditional and atypical presentations of anxiety in youth with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *44*, 2851–2861. doi: 10.1007/s10803-014-2141-7
- Kerns, C. M., Newschaffer, C. J., & Berkowitz, S. J. (2015). Traumatic childhood events and autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *45*, 3475–3486. doi: 10.1007/s10803-015-2392-y
- Kerns, C. M., Newschaffer, C. J., Berkowitz, S., & Lee, B. K. (2017). Brief report: Examining the association of autism and adverse childhood experiences in the national survey of children's health: The important role of income and co-occurring mental health conditions. *Journal of Autism and Developmental Disorders*, *47*(7), 2275-2281. doi: 10.1007/s10803-017-3111-7
- Kerns, C. M., Rump, K., Worley, J., Kratz, H., McVey, A., Herrington, J., & Miller, J. (2016). The differential diagnosis of anxiety disorders in cognitively-able youth with autism. *Cognitive and Behavioral Practice*, *23*, 530–547. doi:10.1016/j.cbpra.2015.11.004
- Kilpatrick, D. G., Ruggiero, K. J., Acierno, R., Saunders, B. E., Resnick, H. S., & Best, C. L.

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- (2003). Violence and risk of PTSD, major depression, substance abuse/dependence, and comorbidity: Results from the National Survey of Adolescents. *Journal of Consulting and Clinical Psychology, 71*(4), 692-700. doi:10.1037/0022-006X.71.4.692
- Kirk, M. A., Kelley, C., Yankey, N., Birken, S. A., Abadie, B., & Damschroder, L. (2016). A systematic review of the use of the Consolidated Framework for Implementation Research. *Implementation Science, 11*(1), 72. doi: 10.1186/s13012-016-0437-z
- Kisiel, C., Conradi, L., Fehrenbach, T., Torgersen, E., & Briggs, E. C. (2014). Assessing the effects of trauma in children and adolescents in practice settings. *Child and Adolescent Psychiatric Clinics of North America, 23*(2), 223-242. doi: 10.1016/j.chc.2013.12.007
- Ko, S. J., Ford, J. D., Kassam-Adams, N., Berkowitz, S. J., Wilson, C., Wong, M., . . . Layne, C. M. (2008). Creating trauma-informed systems: Child welfare, education, first responders, health care, juvenile justice. *Professional Psychology: Research and Practice, 39*(4), 396-404. doi: 10.1037/0735-7028.39.4.396
- Lang, J. M., & Connell, C. M. (2017). Development and validation of a brief trauma screening measure for children: The child trauma screen. *Psychological Trauma: Theory, Research, Practice, and Policy, 9*(3), 390-398. doi: 10.1037/tra0000235
- Layne, C. M., Greeson, J. K. P., Ostrowski, S. A., Kim, S., Reading, S., Vivrette, R. L., . . . Pynoos, R. S. (2014). Cumulative trauma exposure and high risk behavior in adolescence: Findings from the National Child Traumatic Stress Network Core Data Set. *Psychological Trauma: Theory, Research, Practice, and Policy, 6*(Suppl 1), S40-S49. doi: 10.1037/a0037799
- Layne, C. M., Kaplow, J. B., & Youngstrom, E. A. (2017). Applying evidence-based assessment to childhood trauma and bereavement: Concepts, principles, and practices. In M. A.

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- Landolt, M. Cloitre & U. Schnyder (Eds.), *Evidence-based treatments for trauma related disorders in children and adolescents* (pp. 96, Chapter xiv, 517 Pages). Cham, Switzerland: Springer International Publishing, Cham. doi: 10.1007/978-3-319-46138-0_4
- Le Couteur, A., Lord, C., & Rutter, M. (2003). *The Autism Diagnostic Interview–Revised (ADI-R)*. Los Angeles, CA: Western Psychological Services.
- Lee, L., Harrington, R. A., Chang, J. J., & Connors, S. L. (2008). Increased risk of injury in children with developmental disabilities. *Research in Developmental Disabilities, 29*(3), 247-255. doi: 10.1016/j.ridd.2007.05.002
- Leeb, R. T., Bitsko, R. H., Merrick, M. T., & Armour, B. S. (2012). Does childhood disability increase risk for child abuse and neglect? *Journal of Mental Health Research in Intellectual Disabilities, 5*(1), 4-31. doi: 10.1080/19315864.2011.608154
- Levy, S. E., Giarelli, E., Lee, L., Schieve, L. A., Kirby, R. S., Cunniff, C., . . . Rice, C. E. (2010). Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the united states. *Journal of Developmental and Behavioral Pediatrics, 31*(4), 267-275. doi: 10.1097/DBP.0b013e3181d5d03b
- Lewis, C. C., Stanick, C. F., Martinez, R. G., Weiner, B. J., Kim, M., Barwick, M., & Comtois, K. A. (2015). The society for implementation research collaboration instrument review project: A methodology to promote rigorous evaluation. *Implementation Science, 10*, 1-18. doi: 10.1186/s13012-014-0193-x
- Leyfer, O. T., Folstein, S. E., Bacalman, S., Davis, N. O., Dinh, E., Morgan, J., . . . Lainhart, J. E. (2006). Comorbid psychiatric disorders in children with autism: Interview

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- development and rates of disorders. *Journal of Autism and Developmental Disorders*, 36(7), 849-861. doi: 10.1007/s10803-006-0123-0
- Lieberman, A. F., Chu, A., Van Horn, P., & Harris, W. W. (2011). Trauma in early childhood: Empirical evidence and clinical implications. *Development and Psychopathology*, 23(2), 397-410. doi: 10.1017/S0954579411000137
- Litman, L., Costantino, G., Waxman, R., Sanabria-Velez, C., Rodriguez-Guzman, V. M., Lampon-Velez, A., . . . Cruz, T. (2015). Relationship between peer victimization and posttraumatic stress among primary school children. *Journal of Traumatic Stress*, 28(4), 348-354. doi: 10.1002/jts.22031
- Little, L. (2002). Middle-class mothers' perceptions of peer and sibling victimization among children with Asperger's syndrome and nonverbal learning disorders. *Issues in Comprehensive Pediatric Nursing*, 25(1), 43-57. doi: 10.1080/014608602753504847
- Locke, J., Ishijima, E. H., Kasari, C., & London, N. (2010). Loneliness, friendship quality and the social networks of adolescents with high-functioning autism in an inclusive school setting. *Journal of Research in Special Educational Needs*, 10, 74-81. doi: 10.1111/j.1471-3802.2010.01148.x
- Loeb, J., Stettler, E. M., Gavila, T., Stein, A., & Chinitz, S. (2011). The Child Behavior Checklist PTSD scale: Screening for PTSD in young children with high exposure to trauma. *Journal of Traumatic Stress*, 24(4), 430-434. doi: 10.1002/jts.20658
- Lokhandwala, T., Khanna, R., & West-Strum, D. (2012). Hospitalization burden among individuals with autism. *Journal of Autism and Developmental Disorders*, 42(1), 95-104. doi: 10.1007/s10803-011-1217-x
- Lord, C., Rutter, M., DiLavore, P. C., Risi, S., Gotham, K., & Bishop, S. L. (2012). *Autism*

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- diagnostic observation schedule, second edition (ADOS-2)*. Torrance, CA: Western Psychological Services.
- Maclean, M.J., Sims, S., Bower, C., Leonard, H., Stanley, F. J., & O'Donnell, M. (2017). Maltreatment risk among children with disabilities. *Pediatrics*, *139*(4). doi: 10.1542/peds.2016-1817
- Maïano, C., Normand, C. L., Salvat, M., Moullec, G., & Aimé, A. (2016). Prevalence of school bullying among youth with autism spectrum disorders: A systematic review and meta-analysis. *Autism Research*, *9*(6), 601-615. doi: 10.1002/aur.1568
- Majoko, T. (2016). Inclusion of children with autism spectrum disorders: Listening and hearing to voices from the grassroots. *Journal of Autism & Developmental Disorders*, *46*, 1429–1440. doi: 10.1007/s10803-015-2685-1.
- Mandell, D. S., Walrath, C. M., Manteuffel, B., Sgro, G., & Pinto-Martin, J. A. (2005). The prevalence and correlates of abuse among children with autism served in comprehensive community-based mental health settings. *Child Abuse & Neglect*, *29*(12), 1359-1372. doi: 10.1016/j.chiabu.2005.06.006
- Mash, E. J., & Barkley, R. (Eds.). (2007). *Assessment of childhood disorders (4th ed.)*. New York, NY: Guilford Press.
- Mason, J., & Scior, K. (2004). 'Diagnostic overshadowing' amongst clinicians working with people with intellectual disabilities in the UK. *Journal of Applied Research in Intellectual Disabilities*, *17*, 85–90. doi: 10.1111/j.1360-2322.2004.00184.x
- Mazefsky, C. A., Herrington, J., Siegel, M., Scarpa, A., Maddox, B. B., Scahill, L., & White, S. W. (2013). The role of emotion regulation in autism spectrum disorder. *Journal of the*

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- American Academy of Child & Adolescent Psychiatry*, 52(7), 679-688. doi:
10.1016/j.jaac.2013.05.006
- Mazefsky, C. A., & White, S. W. (2014). Emotion regulation: Concepts & practice in autism spectrum disorder. *Child and Adolescent Psychiatric Clinics of North America*, 23(1), 15-24. doi: 10.1016/j.chc.2013.07.002
- McCreary, B. D., & Thompson, J. (1999). Psychiatric aspects of sexual abuse involving persons with developmental disabilities. *The Canadian Journal of Psychiatry / La Revue Canadienne De Psychiatrie*, 44(4), 350-355.
- McDonald, M. K. (2016). *A measure development study for youth trauma exposure and developmental trauma disorder* (Doctoral dissertation). Retrieved from PsycINFO. (1825958352; 2016-31156-074).
- McDonald, M., Bortrager, C., & Rostad, W. (2014). Measuring trauma: Considerations for assessing complex and non-traditional trauma for children and adolescents. *Journal of Trauma and Dissociation*, 15, 184-203.
- McDonnell, C.G., Boan, A.D., Bradley, C.C., Seay, K.D., Charles, J.M., & Carpenter, L.A. (2018). Child maltreatment in autism spectrum disorder and intellectual disability: Results from a population-based sample. *Journal of Child Psychology and Psychiatry*. doi: 10.1111/jcpp.12993
- McLaughlin, K. A., Koenen, K. C., Hill, E. D., Petukhova, M., Sampson, N. A., Zaslavsky, A. M., & Kessler, R. C. (2013). Trauma exposure and posttraumatic stress disorder in a national sample of adolescents. *Journal of the American Academy of Child & Adolescent Psychiatry*, 52(8), 815-830. doi: 10.1016/j.jaac.2013.05.011

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- McLeod, B. D., Wood, J. J., & Klebanoff, S. (2015). Advances in evidence-based intervention and assessment practices for youth with an autism spectrum disorder. *Behavior Therapy, 46*(1), 1-6. doi: 10.1016/j.beth.2014.07.004
- McMorris, C. A., Cox, E., Hudson, M., Liu, X., & Bebko, J. M. (2013). The diagnostic process of children with autism spectrum disorder: Implications for early identification and intervention. *Journal on Developmental Disabilities, 19*(2), 42-49.
- Mehtar, M., & Mukaddes, N. M. (2011). Posttraumatic stress disorder in individuals with diagnosis of autistic spectrum disorders. *Research in Autism Spectrum Disorders, 5*(1), 539-546. doi: 10.1016/j.rasd.2010.06.020
- Miller, H. L., Pavlik, K. M., Kim, M. A., & Rogers, K. C. (2017). An exploratory study of the knowledge of personal safety skills among children with developmental disabilities and their parents. *Journal of Applied Research in Intellectual Disabilities, 30*(2), 290-300. doi: 10.1111/jar.12239
- Milne, L., & Collin-Vézina, D. (2015). Assessment of children and youth in child protective services out-of-home care: An overview of trauma measures. *Psychology of Violence, 5*(2), 122-132. doi: 10.1037/a0037865
- Mynard, H., Joseph, S., & Alexander, J. (2000). Peer-victimisation and posttraumatic stress in adolescents. *Personality and Individual Differences, 29*(5), 815-821. doi: 10.1016/S0191-8869(99)00234-2
- Nader, K. (2008). *Understanding and assessing trauma in children and adolescents: Measures, methods, and youth in context*. New York, NY, US: Routledge/Taylor & Francis Group, New York, NY.

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

Newman, E., Christopher, S. R., & Berry, J. O. (2000). Developmental disabilities, trauma exposure, and post-traumatic stress disorder. *Trauma, Violence, and Abuse: A Review Journal*, 1(2), 154-170. doi: 10.1177/1524838000001002003

Nicolaidis, C., Raymaker, D., Katz, M., Oschwald, M., Goe, R., Leotti, S., . . . Powers, L. E. (2015). Community-based participatory research to adapt health measures for use by people with developmental disabilities. *Progress in Community Health Partnerships*, 9(2), 157-170. doi: 10.1353/cpr.2015.0037

Nielsen, M. B., Tangen, T., Idsoe, T., Matthiesen, S. B., & Magerøy, N. (2015). Post-traumatic stress disorder as a consequence of bullying at work and at school. A literature review and meta-analysis. *Aggression and Violent Behavior*, 21, 17-24. doi: 10.1016/j.avb.2015.01.001

Nosek, M. A., Foley, C. C., Hughes, R. B., & Howland, C. A. (2001). Vulnerabilities for abuse among women with disabilities. *Sexuality and Disability*, 19(3), 177-189. doi: 10.1023/A:1013152530758

North Shore-Long Island Jewish Health System, Inc. (2006). NSLIHJS Trauma History Checklist and Interview. Retrieved from <https://www.mc.vanderbilt.edu/coe/tfcbt/workbook/Assessment/NSLIHJS%20Trauma%20History%20Checklist%20and%20Interview.pdf>

Ozonoff, S., Goodlin-Jones, B., & Solomon, M. (2005). Evidence-based assessment of autism spectrum disorders in children and adolescents. *Journal of Clinical Child & Adolescent Psychology*, 34(3), 523-540. doi: 10.1207/s15374424jccp3403_8

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- Palinkas, L. A. (2014). Qualitative and mixed methods in mental health services and implementation research. *Journal of Clinical Child and Adolescent Psychology, 43*(6), 851-861. doi: 10.1080/15374416.2014.910791
- Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research, 42*(5), 533-544. doi: 10.1007/s10488-013-0528-y
- Palusci, V. J., Datner, E., & Wilkins, C. (2015). Developmental disabilities: Abuse and neglect in children and adults. *International Journal of Child Health and Human Development, 8*(4), 407-428.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.
- Perfect, M. M., Turley, M. R., Carlson, J. S., Yohanna, J., & Saint Gilles, M. P. (2016). School-related outcomes of traumatic event exposure and traumatic stress symptoms in students: A systematic review of research from 1990 to 2015. *School Mental Health, 8*(1), 7-43. doi: 10.1007/s12310-016-9175-2
- Pfeffer, R. (2014). Risk and protective factors for the safety of children with autism: A qualitative study of caregivers' perspectives. *Journal of Family Strengths, 14*, Article 21.
- Pfeffer, R. D. (2016). Childhood victimization in a national sample of youth with autism spectrum disorders. *Journal of Policy and Practice in Intellectual Disabilities, 13*(4), 311-319. doi: 10.1111/jppi.12203

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- Prock, L. & Fogler J.M. (2018). Trauma and neurodevelopmental disorder: Assessment, treatment, and triage. In Fogler, J. & Phelps, R. (Eds.), *Trauma, autism, and neurodevelopmental disorders* (pp. 55-71). Springer, Cham.
- Proctor, E., Silmere, H., Raghavan, R., Hovmand, P., Aarons, G., Bunger, A., ... Hensley, M. (2011). Outcomes for implementation research: Conceptual distinctions, measurement challenges, and research agenda. *Administration and Policy in Mental Health and Mental Health Services Research, 38*, 65-76.
- Pynoos, R.S. & Steinberg, A.M. (2015). *UCLA PTSD Reaction Index for Children/Adolescents - DSM-5*. University of California- Los Angeles (UCLA).
- Pynoos, R. S., Steinberg, A. M., Layne, C. M., Liang, L., Vivrette, R. L., Briggs, E. C., . . . Fairbank, J. A. (2014). Modeling constellations of trauma exposure in the National Child Traumatic Stress Network Core Data Set. *Psychological Trauma: Theory, Research, Practice, and Policy, 6*(Suppl 1), S17. doi: 10.1037/a0037767
- Rigles, B. (2017). The relationship between adverse childhood events, resiliency and health among children with autism. *Journal of Autism and Developmental Disorders, 47*(1), 187-202. doi: 10.1007/s10803-016-2905-3
- Roberts, A. L., Koenen, K. C., Lyall, K., Robinson, E. B., & Weisskopf, M. G. (2015). Association of autistic traits in adulthood with childhood abuse, interpersonal victimization, and posttraumatic stress. *Child Abuse & Neglect, 45*, 135-142. doi: 10.1016/j.chiabu.2015.04.010
- Rutherford, M., McKenzie, K., Johnson, T., Catchpole, C., O'Hare, A., McClure, I., . . . Murray, A. (2016). Gender ratio in a clinical population sample, age of diagnosis and duration of

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- assessment in children and adults with autism spectrum disorder. *Autism*, 20(5), 628-634.
doi: 10.1177/1362361315617879
- Ryan, R. (1994). Posttraumatic stress disorder in persons with developmental disabilities. *Community Mental Health Journal*, 30(1), 45-54. doi: 10.1007/BF02188874
- Sattler, A. F., Ale, C. M., Nguyen, K., Gregg, M. S., Geske, J. R., & Whiteside, S. P. H. (2016). Use of evidence-based assessments for childhood anxiety disorders within a regional medical system. *Psychological Services*, 13(4), 411-418. doi: 10.1037/ser0000091
- Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., . . . Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality & Quantity*, 52(4), 1893-1907.
- Scheeringa, M. S., Myers, L., Putnam, F. W., & Zeanah, C. H. (2012). Diagnosing PTSD in early childhood: An empirical assessment of four approaches. *Journal of Traumatic Stress*, 25(4), 359-367. doi: 10.1002/jts.21723
- Silverman, W. K., & Albano, A. M. (1996). *Anxiety disorders interview schedule for DSM-IV: Parent interview schedule*. New York: Oxford University Press.
- Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry*, 47(8), 921-929. doi: 10.1097/CHI.0b013e318179964f
- Skokaуска, N. & Gallagher, L. (2012). Mental health aspects of autism spectrum disorders in children. *Journal of Intellectual Disability Research*, 56(3), 248-257. doi: 10.1111/j.1365-2788.2011.01423.x
- Spencer, N., Devereux, E., Wallace, A., Sundrum, R., Shenoy, M., Bacchus, C., & Logan, S.

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- (2005). Disabling conditions and registration for child abuse and neglect: A population-based study. *Pediatrics*, *116*, 609–613. doi: 10.1542/peds.2004-1882.
- Spinazzola, J., Ford, J. D., Zucker, M., van der Kolk, Bessel A, Silva, S., Smith, S. F., & Blaustein, M. (2005). Survey evaluates complex trauma exposure, outcome, and intervention among children and adolescents. *Psychiatric Annals*, *35*(5), 433-439.
- Steinberg, A. M., Brymer, M., Decker, K., & Pynoos, R. S. (2004). The UCLA PTSD Reaction Index. *Current Psychiatry Reports*, *6*, 96–100. doi: 10.1007/s11920-004-0048-2
- Steiner, A. M., Goldsmith, T. R., Snow, A. V., & Chawarska, K. (2012). Practitioner’s guide to assessment of autism spectrum disorders in infants and toddlers. *Journal of Autism and Developmental Disorders*, *42*(6), 1183-1196. doi: 10.1007/s10803-011-1376-9
- Stolbach, B.C., Minshew, R., Rompala, V., Dominguez, R.Z., Gazibara, T., & Finke, R. (2013). Complex trauma exposure and symptoms in urban traumatized children: A preliminary test of proposed criteria for Developmental Trauma Disorder. *Journal of Traumatic Stress*, *26*, 1-9.
- Storch, E. A., Sulkowski, M. L., Nadeau, J., Lewin, A. B., Arnold, E. B., Mutch, P. J., . . . Murphy, T. K. (2013). The phenomenology and clinical correlates of suicidal thoughts and behaviors in youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *43*(10), 2450-2459. doi: 10.1007/s10803-013-1795-x
- Strand, V. C., Sarmiento, T. L., & Pasquale, L. E. (2005). Assessment and screening tools for trauma in children and adolescents: A review. *Trauma, Violence, & Abuse*, *6*(1), 55-78. doi: 10.1177/1524838004272559

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- Substance Abuse and Mental Health Services Administration. SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach. HHS Publication No. (SMA) 14-4884. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2014.
- Sullivan, P. M. (2009). Violence exposure among children with disabilities. *Clinical Child and Family Psychology Review, 12*(2), 196-216. doi: 10.1007/s10567-009-0056-1
- Sullivan, P. M., & Knutson, J. F. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse & Neglect, 24*(10), 1257-1273. doi: 10.1016/S0145-2134(00)00190-3
- Swanson, A. R., Warren, Z. E., Stone, W. L., Vehorn, A. C., Dohrmann, E., & Humberd, Q. (2014). The diagnosis of autism in community pediatric settings: Does advanced training facilitate practice change? *Autism, 18*(5), 555-561. doi: 10.1177/1362361313481507
- Taylor, J. L., & Gotham, K. O. (2016). Cumulative life events, traumatic experiences, and psychiatric symptomatology in transition-aged youth with autism spectrum disorder. *Journal of Neurodevelopmental Disorders, 8*.
- Taylor, L. K., & Weems, C. F. (2009). What do youth report as a traumatic event? Toward a developmentally informed classification of traumatic stressors. *Psychological Trauma: Theory, Research, Practice, and Policy, 1*(2), 91-106. doi: 10.1037/a0016012
- Trickey, D., Siddaway, A. P., Meiser-Stedman, R., Serpell, L., & Field, A. P. (2012). A meta-analysis of risk factors for post-traumatic stress disorder in children and adolescents. *Clinical Psychology Review, 32*(2), 122-138. doi: 10.1016/j.cpr.2011.12.001
- Turner, H. A., Vanderminden, J., Finkelhor, D., Hamby, S., & Shattuck, A. (2011). Disability and victimization in a national sample of children and youth. *Child Maltreatment, 16*(4), 275-286. doi: 10.1177/1077559511427178

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

Valenti, M., Ciprietti, T., Di Egidio, C., Gabrielli, M., Masedu, F., Tomassini, A. R., & Sorge, G.

(2012). Adaptive response of children and adolescents with autism to the 2009 earthquake in L'Aquila, Italy. *Journal of Autism and Developmental Disorders*, 42(6), 954-960. doi: 10.1007/s10803-011-1323-9

van der Kolk, B. A. (2005). Developmental trauma disorder: Toward a rational diagnosis for children with complex trauma histories. *Psychiatric Annals*, 35(5), 401-408.

van Steensel, F. J. A., Bögels, S. M., & Perrin, S. (2011). Anxiety disorders in children and adolescents with autistic spectrum disorders: A meta-analysis. *Clinical Child and Family Psychology Review*, 14, 302–317. doi: 10.1007/s10567-011-0097-0

Varsi, C., Ekstedt, M., Gammon, D., & Ruland, C. M. (2015). Using the Consolidated Framework for Implementation Research to identify barriers and facilitators for the implementation of an internet-based patient-provider communication service in five settings: A qualitative study. *Journal of Medical Internet Research*, 17(11), e262. doi:10.2196/jmir.5091

Volkmar, F., Siegel, M., Woodbury-Smith, M., King, B., McCracken, J., & State, M. (2014). *Journal of the American Academy of Child & Adolescent Psychiatry*, 53(2), 237-257.

Vig, S., & Kaminer, R. (2002). Maltreatment and developmental disabilities in children. *Journal of Developmental and Physical Disabilities*, 14(4), 371-386. doi: 1020334903216

Wagner, M., Newman, L., Cameto, R., Levine, P., & Marder, C. (2007, August). *Perceptions and expectations of youth with disabilities. A special topic report of findings from the National Longitudinal Transition Study-2 (NLTS2)*. Menlo Park, CA: SRI International.

Retrieved from

http://www.nlts2.org/reports/2007_08/nlts2_report_2007_08_complete.pdf

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- Westcott, H. L., & Jones, D. P. H. (1999). Annotation: The abuse of disabled children. *Journal of Child Psychology and Psychiatry*, 40(4), 497-506. doi: 10.1111/1469-7610.00468
- White, S. W., Mazefsky, C. A., Dichter, G. S., Chiu, P. H., Richey, J. A., & Ollendick, T. H. (2014). Social-cognitive, physiological, and neural mechanisms underlying emotion regulation impairments: Understanding anxiety in autism spectrum disorder. *International Journal of Developmental Neuroscience*, 39, 22-36. doi: 10.1016/j.ijdevneu.2014.05.012
- White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in children and adolescents with autism spectrum disorders. *Clinical Psychology Review*, 29, 216–229. doi: 10.1016/j.cpr.2009.01.003
- Whiteside, S. P. H., Sattler, A. F., Hathaway, J., & Douglas, K. V. (2016). Use of evidence-based assessment for childhood anxiety disorders in community practice. *Journal of Anxiety Disorders*, 39, 65-70. doi: 10.1016/j.janxdis.2016.02.008

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Table 1

Sociodemographic Variables of Participants (N = 13)

Characteristics	Frequency (%)
Gender	
Female	76.9
Male	23.1
Race	
Asian	7.7
Hispanic or Latino/a	7.7
White (non-Hispanic)	84.6
Doctoral Program Subfield	
Clinical	53.8
School	30.8
Combined	15.4
Degree	
PhD	84.6
PsyD	15.4
Doctoral Program Training Model	
Clinical Scientist	22.9
Practitioner-Scholar	35.4
Scientist-Practitioner	10.4
Clinic Location by Region of United States	
Northeast	30.8
Midwest	30.8
South	30.8
West	7.7
Current Clinic Setting	
Children's Hospital: Outpatient Clinic	69.2
University-based Clinic	30.8
Age Group in which Majority of Evaluations Conducted*	
Children Birth to 3	7.7
Children 3-5	30.8
Children 5-12	46.2
Adolescents 12-17	7.7
Past Experience Conducting Multidisciplinary Evaluations	
Yes	76.9
No	23.1

**One participant indicated that their time was split evenly amongst age groups.*

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Table 2

CFIR and IOF Coding Data

Construct	Total References	Number of Participants	Predominant Facilitator	Predominant Barrier
PROCESS				
Executing	201	13	-	-
Engaging				
<i>External Change Agent</i>	11	4	4	0
OUTER SETTING				
Patient Needs & Resources	147	13	9	4
<i>Symptom Overlap</i>	23	9	2	5
Cosmopolitanism	94	13	9	2
Peer Pressure	15	12	-	-
External Policy & Incentives	16	9	6	2
INNER SETTING				
Networks & Communications	68	13	12	1
Implementation Climate	9	7	5	2
<i>Tension for Change</i>	14	10	3	5
<i>Compatibility</i>	23	10	2	3
<i>Relative Priority</i>	46	13	6	5
<i>Learning Climate</i>	16	10	9	1
Readiness for Implementation				
<i>Available Resources</i>	85	13	2	9
<i>Access to Knowledge & Information</i>	56	13	9	1
CHARACTERISTICS OF INDIVIDUALS				
Knowledge & Beliefs about the Innovation	111	13	4	8
Self-efficacy	33	12	4	8
INTERVENTION CHARACTERISTICS				
Adaptability	33	10	2	6
Evidence Strength & Quality	13	9	9	0
IOF CONSTRUCTS				
Adoption	8	5	-	-
Acceptability	25	10	2	6
Appropriateness	81	13	9	3
Feasibility	46	11	0	10

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Table 3

Representative Quotes Related to CFIR and IOR Constructs

Construct	Quote
PROCESS	
Executing	We may start broadly and ask if there are any recent stressors or changes over the years for the child and sometimes parents volunteer things. We may ask directly... “Has the child ever been exposed to any past history of trauma or abuse? Have they ever been inappropriately touched or hurt in any way or not have enough food or not gone to school?” If we have documentation we refer back to the documentation, and say, “We saw this in their history, tell me about that. How is that child doing now? What symptoms do you see currently related to that past trauma?”
Engaging <i>External Change Agent</i>	I think it’s really the collaboration between our clinic and then the other clinic that is more focused on trauma. I think they reached out to us and they introduced their research project and then I think it came from that.
OUTER SETTING	
Patient Needs & Resources	Because we know kids with disabilities are at heightened risk for experiencing trauma and we could potentially get them trauma-focused interventions, which might be more specific than the generalized therapies that they’re getting.
<i>Symptom Overlap</i>	Trauma experiences could mask symptoms of autism. Mask isn’t the right word, but confound is probably a better word. And so, if we are seeing a child who started to develop symptoms possibly consistent with autism, but it correlates with when there were significant stressors in the home, that can make an accurate diagnosis challenging.
Cosmopolitanism	I am very involved in community action, like community action groups and collaborative action networks in our community that are really more focused on promoting family engagement and positive outcomes for kids in early childhood that are not specific to disability. And so there’s a lot of talk about poverty and trauma in those groups because of where we live. And I’ve been trying to insert disability into those conversation
Peer Pressure	I can speak to a handful of clinics—ones that I was formerly in or that I have close friends who are currently working in. And I think it is probably a little bit less standardized than what we do. But from the flip side I think in some of the other clinics that I have previously worked in there is more room to

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explore those issues and determine whether or not PTSD is actually warranted to actually provide more differential diagnosis.

External Policy & Incentives

At the very basic level we certainly think about criteria for things like child neglect and child abuse through our Department of Human Services. So we are all mandatory reporters and are always thinking about those types of issues.

INNER SETTING

Networks & Communications

Sometimes when the trauma is such a pronounced part of the child's history in your case, it makes your diagnosis tricky, so we talk about those cases specifically during case conference.

Implementation Climate

We certainly talk about those issues fairly frequently in clinic meetings, and this is outside of the role of autism when we are just getting to gather as a clinic team. And I know that some of my colleagues have backgrounds in trauma-informed care and that's become a more popular approach used in our hospital system.

Tension for Change

I don't recall anything from those meetings in discussing trauma that has resulted in any significant change in my diagnostic practice. So I guess whatever was discussed only affirmed or confirmed what I'm presently doing.

Compatibility

So I think that we are very much in a really good role to assess for it and intervene and make change for our patients.

Relative Priority

Sometimes we have to know that there are concerns and issues but if we also see symptoms of autism then that's our clinic, that's what we do is assess for autism.

Learning Climate

I think we can try new things here pretty easily. I think that the factors we've said that got in the way, in terms of time, experience and training and all of that are usually the rate limiting factors for trying something new.

Readiness for Implementation

Available Resources

We give a pretty lengthy interview focused on autism symptoms and sometimes that can last about an hour and a half. And we have to also look at test results and create a case conceptualization and give feedback to the families within a four-hour time block for us. So I think time limits our ability to fully flesh out any trauma-related disorder or any other significant concerns.

Access to Knowledge & Information

I am really happy we have our psychiatrist now who we can really pull in. She specializes in trauma and infant mental health, and so we have a real expert on our team who we can use as a resource and I'm thrilled about that.

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CHARACTERISTICS OF INDIVIDUALS

Knowledge & Beliefs about the Innovation

On the flip side of what influences our diagnostic process as well is having psychologists come in who aren't as comfortable with that and who don't know that how those kids might present differently or how they need to ask about those issues because some discrepancies that we might be seeing in direct assessment with the child might be explained by some of those early symptoms or current symptoms or current exposures and experiences that that child is having.

Self-efficacy

I feel prepared to an extent, but then that's where I'm really glad to have colleagues who I can go to and say, "What do you think?" I would say my preparations for trauma is definitely less than my confidence in autism. I

INTERVENTION CHARACTERISTICS

Adaptability

You know the fact that a lot of the kids come in young and so they're not able to always articulate emotional responses to things.

Evidence Strength & Quality

I think it's just part of our standard interview that everybody asks almost every family that comes through because we just view it as best practice.

IOF CONSTRUCTS

Adoption

So in collaboration with him my team of clinical psychologists all decided, yes this is something that we're going to incorporate on a very standardized basis.

Acceptability

I think it's difficult sometimes to have conversations with families about past trauma especially if they were involved in that past trauma in some way and so families can feel defensive.

Appropriateness

I absolutely think given the really high prevalence of trauma histories to whatever degree and the huge overlap between those symptom categories I don't see how you can not consider, if not capital "T" trauma abuse like at least the social history and the environment.

Feasibility

We don't usually have much of an opportunity to go into depth about any of these particular traumatic experiences... Probably one of the failures is that sometimes we get diagnostic visits back to back, so there is a bit of a time crunch.

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Appendix A

Consolidated Framework for Implementation Research (CFIR) Constructs

Construct	Short Description
I. INTERVENTION CHARACTERISTICS	
A Intervention Source	Perception of key stakeholders about whether the intervention is externally or internally developed.
B Evidence Strength & Quality	Stakeholders' perceptions of the quality and validity of evidence supporting the belief that the intervention will have desired outcomes.
C Relative Advantage	Stakeholders' perception of the advantage of implementing the intervention versus an alternative solution.
D Adaptability	The degree to which an intervention can be adapted, tailored, refined, or reinvented to meet local needs.
E Trialability	The ability to test the intervention on a small scale in the organization, and to be able to reverse course (undo implementation) if warranted.
F Complexity	Perceived difficulty of implementation, reflected by duration, scope, radicalness, disruptiveness, centrality, and intricacy and number of steps required to implement.
G Design Quality & Packaging	Perceived excellence in how the intervention is bundled, presented, and assembled.
H Cost	Costs of the intervention and costs associated with implementing the intervention including investment, supply, and opportunity costs.
II. OUTER SETTING	
A Patient Needs & Resources	The extent to which patient needs, as well as barriers and facilitators to meet those needs, are accurately known and prioritized by the organization.
B Cosmopolitanism	The degree to which an organization is networked with other external organizations.
C Peer Pressure	Mimetic or competitive pressure to implement an intervention; typically because most or other key peer or competing organizations have already implemented or are in a bid for a competitive edge.
D External Policy & Incentives	A broad construct that includes external strategies to spread interventions, including policy and regulations (governmental or other central entity), external mandates, recommendations and guidelines, pay-for-performance, collaboratives, and public or benchmark reporting.
III. INNER SETTING	
A Structural Characteristics	The social architecture, age, maturity, and size of an organization.

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B	Networks & Communications	The nature and quality of webs of social networks and the nature and quality of formal and informal communications within an organization.
C	Culture	Norms, values, and basic assumptions of a given organization.
D	Implementation Climate	The absorptive capacity for change, shared receptivity of involved individuals to an intervention, and the extent to which use of that intervention will be rewarded, supported, and expected within their organization.
1	Tension for Change	The degree to which stakeholders perceive the current situation as intolerable or needing change.
2	Compatibility	The degree of tangible fit between meaning and values attached to the intervention by involved individuals, how those align with individuals' own norms, values, and perceived risks and needs, and how the intervention fits with existing workflows and systems.
3	Relative Priority	Individuals' shared perception of the importance of the implementation within the organization.
4	Organizational Incentives & Rewards	Extrinsic incentives such as goal-sharing awards, performance reviews, promotions, and raises in salary, and less tangible incentives such as increased stature or respect.
5	Goals and Feedback	The degree to which goals are clearly communicated, acted upon, and fed back to staff, and alignment of that feedback with goals.
6	Learning Climate	A climate in which: a) leaders express their own fallibility and need for team members' assistance and input; b) team members feel that they are essential, valued, and knowledgeable partners in the change process; c) individuals feel psychologically safe to try new methods; and d) there is sufficient time and space for reflective thinking and evaluation.
E	Readiness for Implementation	Tangible and immediate indicators of organizational commitment to its decision to implement an intervention.
1	Leadership Engagement	Commitment, involvement, and accountability of leaders and managers with the implementation.
2	Available Resources	The level of resources dedicated for implementation and on-going operations, including money, training, education, physical space, and time.
3	Access to Knowledge & Information	Ease of access to digestible information and knowledge about the intervention and how to incorporate it into work tasks.
IV. CHARACTERISTICS OF INDIVIDUALS		
A	Knowledge & Beliefs about the Innovation	Individuals' attitudes toward and value placed on the intervention as well as familiarity with facts, truths, and principles related to the intervention.
B	Self-efficacy	Individual belief in their own capabilities to execute courses of action to achieve implementation goals.
C	Individual Stage of Change	Characterization of the phase an individual is in, as he or she progresses toward skilled, enthusiastic, and sustained use of the

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intervention.

D Individual Identification with Organization

A broad construct related to how individuals perceive the organization, and their relationship and degree of commitment with that organization.

E Other Personal Attributes

A broad construct to include other personal traits such as tolerance of ambiguity, intellectual ability, motivation, values, competence, capacity, and learning style.

V. PROCESS

A Planning

The degree to which a scheme or method of behavior and tasks for implementing an intervention are developed in advance, and the quality of those schemes or methods.

B Engaging

Attracting and involving appropriate individuals in the implementation and use of the intervention through a combined strategy of social marketing, education, role modeling, training, and other similar activities.

1 Opinion Leaders

Individuals in an organization who have formal or informal influence on the attitudes and beliefs of their colleagues with respect to implementing the intervention.

2 Formally Appointed Internal Implementation Leaders

Individuals from within the organization who have been formally appointed with responsibility for implementing an intervention as coordinator, project manager, team leader, or other similar role.

3 Champions

“Individuals who dedicate themselves to supporting, marketing, and ‘driving through’ an [implementation]” [101] (p. 182), overcoming indifference or resistance that the intervention may provoke in an organization.

4 External Change Agents

Individuals who are affiliated with an outside entity who formally influence or facilitate intervention decisions in a desirable direction.

5 Key Stakeholders

Individuals from within the organization that are directly impacted by the innovation, e.g., staff responsible for making referrals to a new program or using a new work process.

6 Innovation Participants

Individuals served by the organization that participate in the innovation, e.g., patients in a prevention program in a hospital.

C Executing

Carrying out or accomplishing the implementation according to plan.

D Reflecting & Evaluating

Quantitative and qualitative feedback about the progress and quality of implementation accompanied with regular personal and team debriefing about progress and experience.

Note. From <http://www.cfirguide.org/constructs.html>

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Appendix B

Implementation Outcomes Framework (IOF)

Construct	Description
Acceptability	Satisfaction with various aspects of the innovation (e.g. content, complexity, comfort, delivery, and credibility)
Adoption	Uptake; utilization; initial implementation; intention to try
Appropriateness	Perceived fit; relevance; compatibility; suitability; usefulness; practicability
Feasibility	Actual fit or utility; suitability for everyday use; practicability
Fidelity	Delivered as intended; adherence; integrity; quality of program delivery
Implementation Cost	Marginal cost; cost-effectiveness; cost-benefit
Penetration	Level of institutionalization? Spread? Service access?
Sustainability	Maintenance; continuation; durability; incorporation; integration; institutionalization; sustained use; routinization

Note. Adapted from “Outcomes for Implementation Research: Conceptual Distinctions, Measurement Challenges, and Research Agenda,” by Proctor, E. et al., 2011, *Administration and Policy in Mental Health and Mental Health Services Research*, 38, p. 68. Open Access.

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Appendix C

Qualitative Interview Guiding Questions

INTRODUCTION SCRIPT:

Thank you for taking the time to talk with me about your process for and perspectives on integrating trauma assessment into autism spectrum disorder diagnostic evaluations. This interview will take about 60 to 90 minutes. I will be asking you questions to learn more about your experiences providing ASD diagnostic evaluations, including assessing for trauma, and what you think about using trauma assessment practices. The information I collect from this interview will be used to better understand the practices of psychologists on multidisciplinary teams across the United States and the current challenges and successes to integrating trauma assessment into the ASD diagnostic process. It will be used to expand knowledge of trauma in children with ASD and to inform future practice recommendations.

The information that you provide during the interview will be kept confidential. That is, I will not link your name or organization with any information I share through publications or presentations. I will also be audiotaping and taking notes to make an accurate record of what is said. The recording will be used to make sure that I correctly capture what you are telling me. The recording will be transcribed, and the transcription will be sent to you via email for your review to ensure that your perspective is captured accurately. When the transcription is done the recording will be destroyed.

There are no right or wrong answers to the questions that I will ask. The most important thing is that you share your honest thoughts and opinions. Do you have any questions about how we will be spending the next 60 to 90 minutes?

As was previously discussed, you will be receiving a \$40 Amazon gift card for your participation. The gift card will be mailed to you following completion of your transcription review.

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MAIN GUIDING QUESTIONS:

- *Background information*
 - I am interested in better understanding to what extent your graduate training, predoctoral internship, and/or postdoctoral training were focused specifically on autism. Tell me about your past training experiences relevant to specializing in autism.
 - What is your role as a psychologist on the multidisciplinary team during the diagnostic process for children referred for an ASD evaluation within your clinic?
 - Tell me about the process by which you decide to further evaluate for psychiatric comorbidity (in children being evaluated for ASD).
 - What does this process look like?
 - What are your past experiences with working with children exposed to trauma or conducting trauma assessment?
 - How do you feel about assessing for trauma in your clinic?
 - PROBE: How prepared do you feel to assess for trauma in children being evaluated for ASD?

- *Topic: Evaluating for Trauma Exposure & Symptoms*
 - Is there a standard procedure for assessing for *trauma exposure* in your diagnostic evaluations for ASD?
 - PROBES:
 - Tell me about the process by which trauma exposure is assessed in your clinic.
 - Whose role is it to assess for trauma exposure during diagnostic evaluations?
 - How are the results communicated to the multidisciplinary team?
 - What measures are used to assess for trauma exposure?
 - What reporters (i.e., child, parent, teacher) are asked about trauma exposure?

 - Is there a standard procedure for assessing for *symptoms of traumatic stress or other trauma-related symptoms* in your diagnostic evaluations for ASD?
 - PROBES:
 - Tell me about the process by which traumatic stress or other trauma-related symptoms are assessed in your clinic.
 - Whose role is it to assess for traumatic stress or other trauma-related symptoms during diagnostic evaluations?
 - How are the results communicated to the multidisciplinary team?
 - What measures are used to assess for trauma symptoms?
 - What reporters (i.e., child, parent, teacher) are asked about the presence of trauma symptoms?

- *Topic: Adoption of Trauma Assessment and Facilitators/Barriers*
 - What influences whether trauma is assessed during the diagnostic process in your clinic?
 - PROBES:

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- Do you think there is a need to assess for trauma exposure and symptoms during ASD diagnostic evaluations? Why or why not?
 - To what extent might trauma assessment take a backseat to other aspects of the diagnostic process in your clinic?
- What do you see as the main challenges to assessing for trauma during ASD diagnostic evaluations?
 - **PROBE:** Do you feel you have sufficient resources, information, and materials to assess for trauma during the diagnostic process? Why or why not?
 - What do you see as the strengths to assessing for trauma during ASD diagnostic evaluations?

If the clinic uses trauma assessment at all:	No trauma assessment practices used:
<ul style="list-style-type: none"> - How did your clinic make the decision to assess for trauma? <ul style="list-style-type: none"> ○ PROBE: Who participated in decision-making process? - Were there decisions made about how to integrate trauma assessment so that it would work effectively in your clinic? <ul style="list-style-type: none"> ○ PROBE: What was the process for deciding whether changes were needed so that you could assess for trauma during evaluations in your clinic? - What is complicated about assessing for trauma during ASD diagnostic evaluations? 	<ul style="list-style-type: none"> - How might trauma assessment practices need to be adapted so they could work effectively in your clinic? - What might be complicated about assessing for trauma during ASD diagnostic evaluations?

- *Topic: Organizational Culture and Climate*
 - How do you think your clinic or organization's culture (general beliefs, assumptions, and values people embrace) affects the use of trauma assessment?
 - To what extent do you feel you can try new things in your clinic?
 - Have you had any meetings within your clinic or organization where you have discussed trauma assessment? How do you believe these meetings have influenced your (or the clinic's) practices or procedures?

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- Have you engaged in any kind of information exchange with others outside your clinic related to trauma assessment? Have you attended any professional meetings or conferences in which trauma assessment during ASD diagnostic evaluations was discussed?
 - PROBE: To what extent are other clinics conducting trauma assessment during ASD diagnostic evaluations?
- Were there any local, state, national, or other policies or guidelines that influence whether you assess for trauma?

ENDING THE INTERVIEW:

Thank you again for taking the time to take part in this important research. I appreciate your time and feedback. Do you have any questions before we end?

After the transcription of this interview, I will send you an email in the next month with a Word document containing the transcript with all identifying information removed. This is for you to review to ensure that you feel that your perspective has been captured accurately. Do you have any questions about this process?

After you review the transcript, I will send the \$40 Amazon gift card to you via mail. Thank you.

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

Appendix D

Demographic Questionnaire

Please complete the following questions to the best of your ability. Following the completion of this survey, you will be contacted via email or phone to schedule a telephone interview. Thank you for your participation.

1. What is your age? _____

2. What is your gender?
 - Male
 - Female
 - Other (self-describe): _____

3. What is your racial group?
 - American Indian/Alaska Native
 - Asian
 - Black or African-American
 - Hispanic or Latino
 - Native Hawaiian or Other Pacific Islander
 - White (non- Hispanic)
 - Other (self-describe): _____

4. What was the designated subfield of your doctoral program in psychology?
 - Clinical
 - Counseling
 - School
 - Combined (specify): _____
 - Other, please specify: _____

5. What degree did you receive?
 - Ph.D.
 - Psy.D.
 - Ed.D.
 - Other, please specify: _____

6. What was your program's training model?
 - Clinical Scientist
 - Practitioner
 - Scholar-Practitioner
 - Practitioner-Scholar

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

- Scientist-Practitioner
 - Other (specify): _____
 - Do not know/remember
7. In what year did you complete licensure requirements and become licensed as a psychologist? _____
8. Where do you perform autism diagnostic evaluations?
- Name of clinic: _____
 - City, State: _____
9. Please select the description that best describes the setting in which you conduct autism evaluations:
- Children's hospital: outpatient clinic
 - Community mental health clinic
 - School
 - University-based clinic
 - Other (specify): _____
10. How many years have you worked in your current location? _____
11. Did you work on a multidisciplinary ASD diagnostic team previously (circle)?
- | | |
|-----|----|
| Yes | No |
|-----|----|
- If yes, how many additional years of experience do you have conducting autism diagnostic evaluations as a part of a multidisciplinary diagnostic team?
_____*
 - i. *Can include pre-licensure experiences (e.g., postdoctoral training)*
12. About what percentage of your autism diagnostic evaluations are conducted for the purpose of:
- _____ Research study
 - _____ Clinical evaluation
 - _____ Other (specify): _____
13. About what percentage of your evaluations are with:
- _____ Children aged birth to 3
 - _____ Children aged 3-5
 - _____ Children aged 5-12
 - _____ Adolescents 12-17
 - _____ Adults aged 18 or older

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

14. About what percentage of your evaluations are:

- _____ An initial (first-time) evaluation
- _____ Re-evaluation for children who have already received a diagnosis

15. What is your preferred method of contact to schedule the telephone interview?

- Email (insert address)
- Telephone (insert phone number)

Appendix E

Recruitment Flyer

**Trauma in Autism Spectrum Disorder Diagnostic
Evaluations Study**
University of Montana



Are you a licensed psychologist who conducts ASD diagnostic evaluations as a member of a multidisciplinary team?

If so, you may be eligible to participate in a research study.

The goals of this study are to:

- Better understand psychologists' experiences assessing for trauma within diagnostic evaluations for ASD
- Better understand the factors that might contribute to assessing for trauma during ASD evaluations

We are looking for **licensed psychologists who are members of multidisciplinary diagnostic teams and primarily conduct ASD evaluations for clinical purposes.**

Eligible participants will complete a **brief (5-10 minute) online survey** and a **1-1.5 hour interview** in which they will be asked to discuss their ASD diagnostic practices. Interviews will be conducted over the phone and audio-recorded.

Participation in this research study is **voluntary**, and your responses will be kept anonymous.

Participants will receive a **\$40 Amazon gift card** for their participation.

Contact kaitlyn1.ahlers@umontana.edu with questions.



The University of Montana IRB	
Expiration Date	3-22-2019
Date Approved	4-18-2018
Chair/Admin	[Signature]

CONSIDERING TRAUMA IN ASD DIAGNOSTIC EVALUATIONS

Appendix F

Recruitment Email

Hello,

I am emailing you to invite you to participate in my dissertation project titled, “Considering Trauma in Autism Spectrum Disorder Diagnostic Evaluations in Children.” Though it is well established that there is a high prevalence of trauma exposure in children across the United States, little is known about the integration of trauma assessment into ASD diagnostic evaluations. Thus, the goal of this qualitative project is to better understand psychologists’ experiences assessing for trauma within ASD diagnostic evaluations and potential challenges. The information I collect will be used to better understand the practices of psychologists on multidisciplinary diagnostic teams across the United States.

My name is Kaitlyn Ahlers, and I am a doctoral candidate in Clinical Psychology at the University of Montana. This dissertation is being conducted under the supervision of Anisa Goforth, PhD (anisa.goforth@mso.umt.edu) and has been approved by the University of Montana Institutional Review Board.

Eligible participants include licensed psychologists who are members of multidisciplinary diagnostic teams located in centers specializing in the assessment and treatment of ASD. Research participation will include the completion of a brief (5-10 minute) online survey to provide demographic information and a follow-up telephone interview (60-90 minutes) to better understand your experiences with ASD diagnostic evaluations. The interview will be audiotaped, transcribed, and sent to you for your review to ensure that your perspective was captured accurately.

Participation is completely voluntary and can be discontinued at any time. **Research participants will receive a \$40 Amazon gift card for their participation in this study.**

By clicking the following link, you will be provided with a brief description of the study, informed consent to participate, and the brief survey: [link to survey]

You can contact me with any questions at kaitlyn1.ahlers@umontana.edu.

Thank you for your time and consideration,
Kaitlyn Ahlers