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Benjamin Katz
The Adaptation of Trauma Therapies
for use with Children and
Adolescents Diagnosed on the
Autism Spectrum: A Qualitative
Study

ABSTRACT

This exploratory study was undertaken to explore the issue of the treatment of trauma in children and adolescents with an Autism Spectrum Disorder diagnosis. Specifically this study sought to explore two specific questions: are there any specific modalities of treatment that are best suited for treating trauma in children and adolescents with a diagnosis on the Autism Spectrum, and are there any patterns in the kinds of adaptations to treatment that need to be made to make treatment effective across different kinds of therapeutic interventions?

Using semi-structured interviews with seven licensed clinicians who have treated trauma in children and adolescents with a diagnosis on the Autism Spectrum, the study found no clear results in terms of identifying a better-identified modality of treatment. However, several patterns did emerge in the kinds of adaptations to treatment that needed to be made across various modalities of treatment for the interventions to yield positive results.

The study concluded that increases in clinicians attention to meeting the specific needs of the individual client with respect to his or her cognitive and developmental levels as well as social and interpersonal functioning was of the utmost importance if there was to be success in treatment. Similarly this work was to be supplemented with increased support and work with the parents and or care givers of each individual client.

THE ADAPTATION OF TRAUMA THERAPIES FOR USE WITH
CHILDREN AND ADOLESCENTS DIAGNOSED ON THE
AUTISM SPECTRUM:
A QUALITATIVE STUDY

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social work.

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CHAPTER I

Introduction

During the last few years there has been a dramatic surge in the number children being diagnosed with Autism Spectrum Disorders (ASDs). This cluster of diagnoses includes: Asperger's Syndrome, Autistic Disorder/Autism, and Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS). The Centers for Disease Control as of March 2012, estimates that one in 88 children in the United States have been identified as having a disorder on the Autism Spectrum. With this in mind, a great deal of research has been done. At this point though, research has only focused on two main points: 1) identifying the etiology of ASDs and 2) behavior management or social skills training.

In the United States and around the world greater attention has been placed on individuals who have been exposed to trauma. Previous research has focused on the role of therapy in the treatment of trauma as diagnosis rates have continued to climb. Much of this recent trauma research, especially in the United States, has come in the wake of two decades long wars in Iraq and Afghanistan. Furthermore, researchers have focused primarily on treating adults, often times veterans of these recent conflicts. However, as a function of this increased focus on trauma as a category of clinical work, a great deal more work has been conducted with children and adolescents in mind as well.

Unfortunately, there has been little research conducted that examines the treatment of those diagnosed with an Autism Spectrum Disorder who have also been exposed to some kind of trauma (Focht-New, Barol, Clements, & Miliken, 2008). It was not until the last few years that individuals with Autism Spectrum Disorders or the broader category of individuals with developmental disabilities were considered to be

appropriate candidates for counseling or psychotherapy, a belief that it still widely held by clinicians (Barol & Seubert, 2010). As a function of these significant shortcomings, we, as practitioners, do not yet know how best to provide treatment to this population. That being said, the few studies conducted thus far have shown that these clients can benefit greatly from treatment and positive results are feasible (Barol & Seubert, 2010; Fletcher, 1993). Thus, the question for this study is: When providing treatment to a child or adolescent with a diagnosis on the Autism Spectrum with a history of traumatic experiences is/are there any modalities of treatment that are better indicated for this kind of work? Further, are there any patterns to the kinds of adaptations made to specific treatment interventions that enable treatment to be effective?

Seven clinicians who have had experience treating individuals for trauma who also have a diagnosis on the Autism Spectrum were interviewed. These clinicians will be subjected to a semi-structured, open-ended interview in order to gather in-depth narrative data about their treatment strategies.

Findings from this research will primarily be geared towards informing clinicians working in the areas of treatment for individuals with trauma or with a diagnosis of Autism Spectrum Disorder and on how to focus their treatment interventions. However, this information will also be relevant for identified patients, family members and caregivers of individuals with an Autism Spectrum Disorder, if they are in need of treatment. This information will help these individuals in finding a clinician or treatment setting to best meet their specific needs.

CHAPTER II

Literature Review

To begin this exploration, researchers must first develop an understanding of what both Autism Spectrum disorders (ASD), and trauma are as pathologies. Researchers must also gain perspective on how traumatic responses may differ in individuals diagnosed with an Autism Spectrum Disorder as compared to their neuro-typical peers.

Additionally, the prevalence of traumatic experiences and responses between individuals with an ASD and neuro-typical peers will be explored. This review of the literature will indicate whether there is an actual need for this research to be done or if it is even relevant. Finally, given an understanding drawn from the needs and possible limitations of individuals with an ASD, I will describe several methods of treatment plans that seem to be indicated for use in this kind of work. These methods will be selected from current treatment practices that have evidence to suggest their effectiveness in working separately with treating individuals diagnosed with an Autism Spectrum Disorder or the treatment of symptoms related to a traumatic response.

Autism Spectrum disorders and trauma, as they relate to this study will be defined. Furthermore, the way in which both interact in an individual as compared to in isolation will also be illustrated. Similarly evidence that highlights the rates of trauma for children and adolescents with an ASD diagnosis will also be presented. This data will not only underscore the significance of the need for effective trauma treatment to be available for these individuals, but when combined with a proper clinical understanding of each category, may provide insight into what differences this kind of treatment might require. This will be followed by an exploration of several different current treatment

models that could be implemented for this dually diagnosed population. Limitations of the current research will also be discussed, as well as a brief discussion about what it all means for this study.

Operationalizing Autism Spectrum Disorders and Trauma/Traumatic Responses

Autism Spectrum Disorders

As a function of this study, it is critical for any research being conducted to be clear about the diagnostic category (ies) that correctly describes this population. Unfortunately, accurate diagnoses are now somewhat murkier given the mental health field's current transition to the new Diagnostic and Statistics Manual V (DSM V) (American Psychiatric Association, 2013). In the new manual the three originally separate diagnoses of Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder NOS from the previous DSM-IV-Text Revision, are now under a singular umbrella diagnosis - Autism Spectrum Disorder. This new diagnostic category has made further distinctions based on the level of severity. These levels of severity take into account factors such as difficulty with social communication, restricted interests, repetitive behaviors, and amount of support needed (American Psychiatric Association, 2013, p. 50-59). As such, this study will only focus on individuals with one of the four specific recognized diagnoses; Autistic Disorder, Asperger's Syndrome, Pervasive Developmental Disorder NOS, or Autism Spectrum Disorder (as per the new DSM-V diagnostic criteria). The current study being conducted includes diagnoses from both diagnostic manuals, the DSM-IV-TR and DSM-V due to the concurrent timing of the research and transition in diagnostic instrumentation.

We can begin to look at the features and symptomology that need to be taken into account when working with the Autism Spectrum Disorder (ASD) population. Roth, Hoekstra, Pasco and Watson (2010) provide a very solid beginning framework for understanding current and historical constructs of ASDs, general discussions of symptom presentation, and ideas/insights around clinical interventions. The key symptoms illuminated by Roth, et al., are described as developmental delays that are connected with significant social, communication and behavioral disruptions. Other features include difficulty with sensory integration (either dulled or hypersensitive), difficulty with fine and gross motor coordination, and repetitive behavior. However, another significant factor addressed by Roth et al., (2010) is the etiological nature of ASDs. The current understanding within the medical and mental health fields is that the disorder is present at birth and is consistent throughout the individual's life. Furthermore, the major areas of deficits are centered on social and relational processing.

In regards to social and relational processing, there are many concerns about verbal processing including difficulty with literal versus non-literal speech and a concept known as *Theory of Mind*. Theory of Mind refers to the difficulty or inability individuals have with the ability to attribute, “mental states to themselves or others, and that this deficit is expressed as a failure to take other's mental states into account,” (Kaland, Callesen, Moller-Nielsen, Mortensen & Smith, 2008, p. 1112). In the same study, Kaland et al. (2008) looked at 21 children and adolescents diagnosed with Asperger's Disorder and 20 neuro-typical peers to assess differences in their ability to perform on “Theory of Mind” tasks. Kaland, et al. (2008) found that participants with Asperger's performed significantly lower than their peers on all tasks. Another

significant feature that is common in individuals diagnosed with an ASD is difficulty with understanding literal versus non-literal or metaphorical speech (e.g. turns-of-phrase or sarcasm) (Roth et al. 2010; Nicholson, Irwin & Dwivedi, 2010). These deficits can lead to feelings of alienation and isolation as well as do not mesh well with traditional methods of talk therapy. Roth et al. (2010) also state that current research indicates a more medical/biological basis for these disorders, which is yet to be identified.

Trauma and Traumatic Responses

With this understanding of what Autism Spectrum Disorders are and how they impact the social functioning of individuals with these diagnoses, we must also gain a similar perspective on how to define traumatic responses. That being said, although we needed to be much more specific in the operationalization of what an Autism Spectrum Disorder is for the purposes of this study, our criteria for trauma can and should be more flexible. This is because of several factors. One example involves the decision of whether or not to require clients of the participants to have a full PTSD diagnosis. To require these clients to have had both an ASD diagnosis and PTSD diagnosis would be a highly limiting factor in finding participants with the relevant clinical experience. As will be discussed later, there is also a great deal of difference in the way in which traumatic events are perceived/experienced by individuals with a diagnosis of ASD. Similarly there are also significant differences in the kinds of events that can potentially be interpreted as traumatic. With that in mind, the most important factor is that there needs to be some kind of identifiable traumatic experience that warrants treatment. At this point there does not seem to be a need to limit the scope further, in terms of only looking at community/interpersonal violence, physical/sexual abuse, collective trauma,

etc. In fact, as Saul, Grant and Carter (2008), showed by interviewing 1,581 adolescents between the ages of 12 and 17, the current diagnostic criteria for PTSD within the DSM-IV-TR does not adequately encompass the expression of a traumatic stress response in adolescents. However, this still begs the question of what constitutes trauma, and how does it impact the individuals affected by it.

Nicholson, Irwin, and Dwivedi (2010) in *Children and Adolescents in Trauma: Creative Therapeutic Approaches* describe trauma as:

Trauma is an experience that breaks into and breaks down the individual's physical and psychological capacity to cope with the surrounding world. The usual mechanisms that we have to manage ordinary stress, pain or discomfort, do not work once the experience goes beyond a certain critical depth. Once this level of impingement is reached auto-physiological responses take over and conscious efforts to manage become less effective. To make this clearer, we can see the same mechanism occurring when a physical injury is suffered and the bodily defenses intended to deal with the injury cannot cope and in turn further afflict the sufferer (p. 30).

With this definition we can begin to understand that although everyone has negative or adverse experiences throughout their lives, not all of them are considered traumatic.

Experiences only become traumatic when the individual's internal ability to cope with and respond to those events becomes overloaded, or as Herman (1997) states, "traumatic reactions occur when action is of no avail," (p 34). This idea also raises the question of how the lowered threshold for becoming overwhelmed makes the ASD population more susceptible to trauma. Robin Shapiro (2005) explicitly addresses this issue by exploring the differences between "Trauma" and "trauma". Big "T" or major trauma connects to the kinds of experiences that most individuals would generally acknowledge as being traumatic, such as being the victim of interpersonal violence, or abuse, as well as other larger scale events including natural disasters and large scale community violence.

Conversely small “t” traumas refer to more common, more innocuous but non-the-less upsetting experiences. Specifically, they are things that would not be generally categorized as “traumatic” by society at large. Examples of small “t” traumas include being the victim of teasing or bullying, relational losses through more natural life patterns (not sudden and unexpected events), feeling othered, and unresolved conflict, just to name a few. However, for individuals with developmental disabilities, small “t” traumas are equally important. Because of the differences in cognitive patterns for ASD individuals, these kinds of events and interactions are just as easily stored within their minds in dysfunctional ways leading to similar kinds of emotional wounding. An example of this could be the way staff at a school responds to a child having a “meltdown”. Specifically, being restrained or secluded can be experienced as a trauma, something that happens with startling frequency. In fact, during the 2012-2013 school year, in the state of Connecticut alone there were 33,000 incidents where restraint or seclusion were used, 378 of which resulted in injuries according to a report from the state’s Board of Education (2014). The same report showed that over 40% of the students who were subject to restraint and/or seclusion were diagnosed with an Autism Spectrum Disorder, and that the vast majority of students who experienced these interventions did so multiple times over the course of the year. Specifically, 40 students experienced seclusion or restraint more than 100 times, while 11 students had between 300 and 900 incidents. It should be noted that these specific figures do not identify whether or not the identified students were also diagnosed with an ASD or not.

The significance of this data lies in the idea that often times neuro-typical children are able to process and understand the consequences of their behavior. Children with a

diagnosis on the Autism Spectrum, however, might not be able to integrate the experienced restraint and seclusion as part of a larger incident, thus encoding it as a traumatic event, e.g. a small “t” trauma. However, without an understanding of how these children and adolescents encode traumatic memories, we as typically functioning individuals would likely be quick to discount these experiences as being traumatic. A deeper and detailed understanding of how children with an ASD encode experiences could also include other negative interactions these children face daily such as bullying, and physical discipline (spanking).

Herman (1997) describes three overarching symptomologies that are indicative of a response to trauma; hyperarousal, intrusion, and constriction or disassociation. Symptoms of *hyperarousal* were first noted in veterans after World War I with hyperalertness, startle reactions, irritability, sleep problems and psychosomatic complaints, which led to later ideas that in the wake of traumatic experiences, “the human system of self-preservation seems to go onto permanent alert, as if the danger might return at any moment,” (Herman, 1997, p 35). *Intrusion* is characterized by the impingement of thoughts related to the trauma long after the danger has passed, both during consciousness (flashbacks) and while asleep as nightmares. Although both hyperarousal and impingement may seem to be self-protective in their intent, by encouraging the victim to be ever-vigilant about future traumas, these symptom clusters actually serve to continue the cycle of trauma and further aggravate the post-traumatic syndrome (Herman, 1997). The third cluster of symptomology has to do with *constriction or disassociation*. In a state of duress a person’s self-defense systems may completely shut down. “The helpless person escapes from her situation not by action in

the real world but rather by altering her state of consciousness,” (Herman, 1997, p 42). Simply, when presented with a situation that would otherwise evoke a fight or flight response, the person does neither, and instead retreats internally and becomes frozen, much like a deer caught in headlights. In this state, the victim’s, “perceptions may be numbed or distorted, with partial anesthesia,” or “the person may feel as though the event is not happening to her, as though she is observing from outside her body,” (Herman, 1997, p 43). In this state, as with hypnosis, there is a suspension of voluntary action, initiative and judgment, subjective detachment/calm, altered states of perception (enhanced or dulled), and distortions of reality (depersonalization, derealization, sense of time) (Hilgard, 1977). Finally as Nicholson, Irwin, and Dwivedi (2010) wrote, trauma often is cyclical in nature and our inability to cope can often lead to further suffering.

Although the symptomology of trauma can vary greatly from person to person, Jonkman, Verlinden, Bolle, Boer & Lindauer (2013) state that common reactions to trauma in children present in the form of school difficulties, anxiety/depressive disorders, hyper-vigilance/alertness, enuresis, aggression, attachment, emotional/behavioral regulation, flashbacks, sleep disturbances and a decrease in their ability to recognize cues to other dangers. These symptoms clearly parallel Herman’s (1997) three-trauma symptomology clusters of hyperarousal, intrusion, and constriction and expand through the illustration of more external behavioral symptoms. Jonkman, et al., (2013) developed this list after examining the responses of 256 children (between seven and 18 years old) to both single event traumas (83 children), and multiple traumas or ongoing maltreatment (173 children) after they had been referred to the trauma unit at a child and adolescent psychiatric institution.

With this understanding of how trauma presents in children and adolescents and given that the core symptoms and difficulties for individuals with an Autism Spectrum Disorder center around social processing and communication, it seems appropriate to explore methods of treatment that would be less verbally oriented. Therefore an exploration of current trauma therapies that fit this category would appear to be a sound place to begin this search. However, we must also gain perspective on the prevalence of traumatic experiences for individuals on the Autism Spectrum.

Trauma in Youth Diagnosed with an Autism Spectrum Disorder

Research over the last two decades has shown that individuals with developmental disabilities are as much as 10 times more likely to be exposed to some kind of trauma, as compared to their typically functioning peers (Focht-New, Barol, Clements, and Miliken, 2008; Goldson, 2002; Sobsey & Doe, 1991). With that in mind, a significant number of perpetrations go unreported, and even fewer are ever follow-up because prosecutors are often reluctant to pursue a case that relies on an individual with a developmental disability to provide testimony (Boch-New, Barol, Clements & Miliken, 2008; Department of Justice, 2002; Petersilia, Foote, & Crowell, 2001). Furthermore, several studies report that not only are there a large number of undocumented incidents, but that the number of unreported cases actually is larger than the number of those reported across the entire population (Austin, 2006; Sharples, 2008). Given the verbal and social limitations of individuals with Autism Spectrum Disorders, one would expect that the number of undocumented/unreported cases of trauma is even higher in this population. Similarly due to social constructs around what may be considered “traumatic” what elicits a trauma response in a child/adolescent an ASD may not be

viewed as such by adults involved in the child's life or society at large. This again raises the importance of acknowledging the impact of small "t" traumatic events. Additionally, these studies focus solely on incidents of interpersonal and individual trauma (abuse, neglect, injuries, etc.) but fail to account for more global or regional traumatic experiences such as natural disasters/war and events like the attacks on September 11, 2001 or the school shootings in Newtown, CT.

Beyond the issue of the prevalence, the issue of if/how individuals with Autism Spectrum Disorders are impacted by traumatic experiences, as compared to their neuro-typical peers must be understood. In a study of 22 male adolescents meeting the diagnostic criteria for an ASD by Sutton et al. (2010) found statistically significant differences in the amount and type of symptoms in response to traumatic events. Findings showed that these ASD individuals exhibited both more aggressive and depressive symptoms when compared to their peers in the same comparative study. The study specifically looked at male adolescents being adjudicated for delinquent sexual offenses who had been subsequently ordered into treatment. The results also showed that the participants with an ASD diagnosis exhibited higher rates of depressive symptoms in response neglectful parenting and previous traumatic experiences.

Mehtar and Mukaddes (2011) conducted a study in Turkey in order to determine if there were any differences in the ways individuals with an Autism Spectrum Disorder experienced trauma when compared to their neuro-typical peers. To answer that, they explored prevalence rates and types of traumatic experiences for 69 regular child/adolescent clients (53 male and 16 female between the ages of 6 and 18) at an area Autism clinic over the course of 12 years. Mehtar and Mukaddes found that rates of

sexual/physical abuse in those with ASD were lower than the general population. Conversely, they did identify that individuals with an Autism Spectrum Diagnosis were far more likely to have witnessed or been a victim of an accident/disaster. Mehtar and Mukaddes also found that PTSD rates were higher in females with ASD, which indicates that females with a diagnosis on the Autism Spectrum who had concurrent trauma histories were more likely to develop Post-Traumatic Stress Disorder, or trauma related symptoms when compared to their male peers (Mehtar & Mukaddes, 2011). Although their evidence contradicts that of Focht-New and Barol et.al (2008) in terms of the rates of traumatic experiences for individuals with Autism Spectrum Disorders, it is significant in showing the differences in how these two populations are effected.

Modalities of Treatment

In the initial review of literature for this study, researchers sought to identify specific modalities of treatment being used with both populations - children and adolescents with trauma, as well as children and adolescents with a diagnosis on the Autism Spectrum. Through this review several treatment modalities were identified as being suited for use with both of these populations separately. Specifically, Eye Movement Desensitization and Reprocessing (EMDR), Equine Assisted Therapy (EAT), the Neurosequential Model of Treatment (NMT), and Trauma Focused – Cognitive Behavioral Therapy (TF-CBT), were all identified as early as modalities of treatment that would be worth exploring in this study.

Eye Movement Desensitization and Reprocessing (EMDR)

Eye Movement Desensitization and Reprocessing (EMDR) has shown some success in the treatment of individuals with either trauma or Autism Spectrum Disorders.

Developed by Francine Shapiro Ph.D. in the late 1980's and early 1990's, EMDR is an eight-phase structured treatment approach to trauma that has been shown to be equally, if not more, effective than other evidence based treatment practices such as Trauma Focused-Cognitive Behavioral Therapy (Shapiro, 2012). With evidence from over two-dozen randomized controlled trials, EMDR was shown to consistently have positive effects when working with trauma victims, and when only looking at the eye movement component of treatment, 20 more randomized control trials showed similar positive effects (Shapiro, 2012). Adler-Tapia (2009) also showed evidence specifically indicating that EMDR was an effective treatment intervention for children with histories of trauma in a study with 10 participants between 12 and 17 years old. Furthermore, the author also discussed differences in the application of EMDR with children versus adults.

EMDR is grounded in the Adaptive Information Processing model, which posits that our brains typically process information in adaptive healthy manners that lead to learning and the relief of emotional distress. However, when presented with traumatic experiences this information is not fully processed (Shapiro, 2002). This incompletely processed information is then stored with any distorted thoughts or perceptions also experienced at the time of the event. For example, after being attacked from behind, a person may be hypersensitive to being approached from behind, leading a friendly tap on the shoulder to re-activate the same fears and cognitions associated with the initial assault.

“It is hypothesized that the eye movement and other dual-attention stimuli,” (Shapiro & Maxfield, 2002, p. 935) used in EMDR such as auditory and kinetic stimuli enhance information processing. When combined with other guided work, this stimulus

allows the brain to reprocess specific traumatic memories more effectively and enable the brain to heal itself; much in the same the body heals itself after an injury.

Barol and Seubert (2010) found that EMDR was effective in reducing aggressive and challenging behaviors in individuals with intellectual and developmental disabilities. One major emphasis in the practice of EMDR with children and adolescents with developmental disabilities lays in the importance of increasing affect awareness and psycho-education (Shapiro, 2005). Although this is important with all participants receiving EMDR, it is especially so with this population. Without the ability to identify and express specific emotional states associated with specific events (in this case the traumatic experience) the client and clinician are unable to explore the trauma, thus impacting the effectiveness of the treatment. Shapiro (2005) also emphasizes the importance of communication with individuals in the client's life as they often live in much more interdependent family and community systems due to the breadth of the challenges the individuals may face as functions of their diagnoses. Similarly communication is also increasingly important in the therapeutic relationship, with specific regard to language and non-verbal forms of expression as this relates to issues and difficulties connected with having poor *theory of mind*. "For instance," Shapiro (2005) notes, "facial, body, and word-for-word mirroring enhance self- and other-awareness in clients, subsequently leading to more interactive functions and behaviors."

Equine assisted therapy (EAT)

Molly DePrekel's (2012) *Equine Facilitated Psychotherapy for the Treatment of Trauma* provides another possible avenue to explore. Also known as Equine-Assisted Therapy (EAT), the core concept of this treatment modality is its focus on the attachment

and relational attunement between the triad of client, horse, and clinician. Treatment often focuses on the development of skills including but not limited to self-esteem, personal confidence, communication, trust, boundaries, and limit setting (DePrekel, 2012). All of these are skills that often deteriorate in the wake of traumatic events. In a cross sectional study 63 children received an average of 19 equine assisted psychotherapy sessions to address these specific concerns. Schultz, Remick-Barlow & Robbins (2006) looked at changes in the children's Global Assessment of Functioning pre and post intervention and found that there were statistically significant improvements in all participants, and that there was a strong correlation between the amount/number of sessions given and the amount of improvement. Furthermore, analysis showed that the greatest improvements were in the study's youngest participants and individuals with histories of trauma benefited more than individuals without a history of abuse/neglect (Schultz, Remick-Barlow, & Robbins, 2006). DePrekel (2012) also emphasizes interventions such as mindfulness-based stress reduction, yoga, and other body-based anxiety/stress reducing techniques and reducing reliance on more verbal processing in her methodology. Furthermore, equine therapy has also been shown to be an effective treatment modality in working with individuals with autism when working on social and relational skill development (Cavicchi, 2013; Edwards, 2010). Cavicchi (2013) followed five participants between the ages of 12 and 15 (four male and one female) over an eight week course of EAT in which the clients' progress/development in terms of quality and rates of frequency were tracked across social interactions, communication skills, and stereotyped behaviors. Data from the study revealed that at the end of eight weeks, participants engaged in more frequent social interactions with improved quality in those

interactions, and stereotyped behaviors (both motor and verbal/social) were reduced.

Despite statistically significant findings however, the study lacked generalizability due to the small sample size.

Trauma Focused-Cognitive Behavioral Therapy

Trauma Focused-Cognitive Behavioral Therapy (TF-CBT) is considered by some to be, “the gold standard for treating traumatized children,” (Ruben, 2012, p. 121). TF-CBT is a specific variation of Cognitive Behavioral Therapy (CBT), which has also been used as a means of providing treatment to individuals with a diagnosis on the Autism Spectrum. CBT addresses the relationships between thoughts, feelings and actions, and is founded on the idea that through the therapeutic process, dysfunctional thinking patterns can be addressed and corrected thereby reducing their negative impact on the client (National Alliance on Mental Illness, 2012). Furthermore, CBT has been shown to be an effective treatment method for individuals struggling with a wide array of conditions including, but not limited to, depression, anxiety, schizophrenia, as well as other mood, eating, substance abuse, sleep and autism spectrum disorders (National Alliance on Mental Illness, 2012; Sung et al., 2011; Wood et al., 2014). In some cases, CBT has proven as effective as medication in the treatment of depression (National Alliance on Mental Illness, 2012).

In CBT’s use with children who have a diagnosis on the Autism Spectrum, researchers have found a number of patterns in the specific adaptations that need to be made to the standardized treatment model. Atwood and Scarpa (2013) outline a specific series of these adaptations and the rationale for them rooted in the symptomatic features of Autism Spectrum Disorders. Specifically, adaptations must be made to treatment to meet

the interpersonal and social abilities of the individual client on multiple levels as well as being aware of and addressing the sensory and learning needs of the client (Atwood and Scarpa, 2013).

As previously discussed, individuals diagnosed with an ASD have a wide array of presentations and deficits across various social and interpersonal lines. If these issues are not accounted for, the ability of that individual to learn and benefit from what CBT has to offer will be greatly impeded. Atwood and Scarpa (2013, p. 29) discuss the significance of understanding the individual clients learning and sensory needs as a function of simply being able to work with the client. As with any method of teaching it is important to understand how best to communicate information to the learner. Similarly, because individuals with ASDs are prone to various heightened sensitivities (auditory, olfactory, and tactile), when these are not addressed with respect to the therapeutic environment progress will be hindered. These modifications, however, are just a base for the greater adaptations that that are incorporated through the therapeutic process. Atwood and Scarpa (2013) encourage the use of increased visual aids, consistency and certainty with respect to the structure of sessions, incorporating the special interests/talents of the client into the narrative, being more directive, support in building emotional and affective awareness, building social and language/communication skills, the use of workbooks or projects between sessions, and increased work with the parents/caregivers. Visual aids and hands on activities help to make more abstract concepts such as emotions more concrete and help with comprehension (Atwood & Scarpa, 2013, p. 30). Similarly, because children with ASDs tend to be more rigid in their thinking patterns and have difficulty with coming up with alternative solutions to problems Atwood and Scarpa

(2013, p. 32) advise being more directive throughout the process. Because these children tend to seek predictability and sameness in their lives having an increased sense of routine or structure for sessions can be highly beneficial (Atwood and Scarpa, 2013, p. 34). As the DSM-V notes, a key feature of individuals with ASDs is the development of restricted interests or skill sets (American Psychological Association, 2013). When incorporated effectively these interests and skills can be used to increase motivation attention or even help with conceptualization of various themes (Koegel & Koegel, 2006). As with difficulties around understanding emotional and affective states associated with *theory of mind*, children with ASDs often struggle with *alexithymia*, or a “diminished vocabulary to describe the different levels of emotional experience, especially the more subtle or complex emotions,” (Atwood and Scarpa, 2013, p. 35). As such it is increasingly important to provide affective education within the construct of CBT, which can also include facial emotional recognition (Atwood and Scarpa, 2013, p. 35). Furthermore, it becomes incumbent upon clinicians to both help their clients learn communicate those emotions whether through speech or other forms of communication. As an extension of the communication difficulties individuals with ASDs often face, clinicians are often required to help their clients with pragmatic (e.g. reciprocity, limited focus of topic, over/under sharing information, chronology of an event, and inappropriate initiation) and syntactical aspects (e.g. literal vs. figurative language, or intonation/inflection) aspects of language, through being aware of their clients unique language profile (Atwood and Scarpa, 2013, 36). Atwood and Scarpa (2013) also note that workbooks and projects or assignments between sessions can help with making concepts more concrete, and help to generalize and reinforce new skills outside of the

therapy room. Lastly, because parents play a significantly greater role in the lives of children and adolescents with ASDs, as compared to their typically developing peers much greater amounts of time are needed to support and work with parents and caregivers (Reaven & Blakeley-Smith, 2013).

With respect to Trauma Focused-Cognitive Behavioral Therapy, and how it differentiates from traditional Cognitive Behavioral therapy, TF-CBT is specifically geared towards helping, “children, adolescents, and their caregivers overcome trauma-related difficulties,” (Child Welfare Information Gateway, 2012, p. 1). As an iteration of CBT, TF-CBT focuses on addressing the maladaptive beliefs and cognitive distortions that often arise as a result of trauma; a sense of guilt for the victim’s role in the trauma, anger towards caregivers, and feelings of powerlessness, or inferiority (Child Welfare Information Gateway, 2012). Furthermore, the treatment is also designed to aid in the management of the acting out behaviors and mood disturbances that often result from traumatic experiences (Child Welfare Information Gateway, 2012). TF-CBT also explicitly brings parents and caregivers (assuming they are not the source of the trauma) into treatment, and although based on a prescribed 12-18 session model is flexible with respect to the needs of the clients pace (Child Welfare Information Gateway, 2012). Despite CBT, and TF-CBT’s reliance of verbal communication, it seems as if the recommended adaptations from the CBT model can be applied to the Trauma Focused-Cognitive Behavioral Therapy model, TF-CBT could prove to be a very effective model for treating this population.

Neurosequential Model of Treatment

The Neurosequential Model of Treatment (NMT) developed by Bruce Perry (2009) is another modality of treatment worth exploring. Perry's model explores the impact of trauma on an individual from a neurobiological perspective in a similar way to EMDR. Perry's treatment outlines an approach that starts by addressing the "lowest underdeveloped/abnormally functioning set of problems eventually moving up the brain as improvements are seen," (2009, p. 252). NMT involves custom tailored activities/interventions to the individual client that best suit their needs and characteristics. However, these interventions often focus around activities such as drumming, yoga, breathing, etc. and then as the client improves, moving towards more relational skill building. Unfortunately at this point, there is relatively little empirical data to support NMT's efficacy. That being said, because of the specific construct of the treatment model in conjuncture with the overarching symptomology of Autism Spectrum Disorders, NMT appears to be worth exploring as a modality in this study. Specifically, because of NMT's emphasis on physical expression as opposed to verbal communication, it is possible that this could be an effective treatment method with this population.

Limitations of Current Research:

Unfortunately, a number of the previous studies highlight some of the key struggles resulting in the limited amount of research that has been done in this area to date. For example, each of these studies looked at somewhat different populations. Sutton et al. (2010) did look at individuals with Asperger's Syndrome, a recognized diagnosis in the Diagnostic and Statistics Manual-IV-TR (DSM-IV-TR). However, Sutton et al. did include individuals labeled with High-Functioning Autism (HFA), a

diagnosis not recognized in the DSM-IV-TR. This lack of diagnostic clarity makes it difficult to be sure that individual studies are actually conducting research and exploring comparable individuals. Because there is no clear definition of what qualifies someone for a diagnosis of High-Functioning Autism or delineation of what separates someone with a diagnosis of HFA versus Asperger's or Autism it is hard to accurately compare a study containing subjects with an HFA diagnosis to others studies.

Similarly, at the time that Mehtar and Mukaddes (2011) conducted their study, there was no official diagnosis of Autism Spectrum Disorder. This presents the same problem as trying to work with a diagnosis like High-Functioning Autism. Although it is understood colloquially that the three diagnoses mentioned earlier, Autism, Asperger's, and Pervasive Developmental Disorder NOS all fit under the umbrella of Autism Spectrum Disorders, other similar disorders may or may not be included, depending on who is conducting the research. These diagnoses include Fragile X Syndrome, Rett's Disorder, Childhood Disintegrative Disorder, and Prader-Willi Syndrome. Some of these disorders, although similar in presentation, are known to have specific genetic causes, whereas the primary three still have an unknown etiology. However, now with the DSM-V, which began being used in 2013 there is a specific Autism Spectrum Disorder diagnosis, and the three separate diagnosis now no longer exist. Furthermore, a number of these studies looked at individuals with developmental and intellectual disabilities. As a category, Intellectual Disabilities in addition to ASDs can also include or refer to, Cerebral Palsy, Fetal Alcohol/Drug Syndrome, hearing/vision impairments, Tourette Syndrome, and mental retardation just to name a few.

Implications for Research and Summary

Given this study's operationalized understanding of Autism Spectrum Disorders and trauma, we can begin to explore how therapies have been or might be adapted further to best suit the needs of an already marginalized and vulnerable population. Although two of these interventions (EMDR, and EAT) have been successfully used with both individuals diagnosed with an Autism Spectrum Disorder or a history of trauma, neither has looked at their effectiveness at treating individuals who are on the Autism Spectrum *and* have a history of trauma. However, it stands to reason that this work is already being done to some degree in clinical settings as there are certainly children diagnosed with an Autism Spectrum Disorder who are seeking treatment for a history of trauma. As such, gathering information about current practices is warranted.

CHAPTER III

Methodology

This study was an attempt to examine the implementation and effectiveness of current treatment modalities for trauma in individuals with a diagnosis of an Autism Spectrum Disorder. In this study, the research questions being posed were: 1) Are there any current treatment interventions that are best indicated for the treatment of trauma for children and adolescents diagnosed on the Autism Spectrum? And 2) what, if any, patterns there are in the kinds of adaptations that need to be made in treatment to make the therapy effective?

With this in mind, and in reflecting on the lack of information provided by previous studies, the major objective of this study was to identify any specific modalities of treatment that would best be indicated for use in the treatment of trauma with individuals diagnosed on the Autism Spectrum. Secondary to identifying specific modalities of treatment, it appeared pertinent to explore whether or not there were any overarching trends in terms of the adaptations made to treatment interventions for this specific kind of work. Given that much of the research conducted by this point in time appears to be very disjointed across trauma interventions and treatment for individuals with Autism Spectrum Disorders, an examination of the work currently being done in the field was indicated. In order to accomplish that goal, a qualitative approach based on interviews with open-ended questions was best suited to exploring these issues.

Research Design

The qualitative design of the study afforded the opportunity to gain a moderate amount of insight into a wide array of treatment modalities, further establishing a basic

assessment of the effectiveness of participant's clinical practice. As Engel and Schutt (2013) note, qualitative designs are optimal for developing and "explanation, description, or evaluation," of "what is actually happening in the real world," (p. 21). In this case the aim was to see what is and is not working in the treatment of trauma for individuals diagnosed with an Autism Spectrum Disorder. Finally, results from this kind of study might be sufficient to support or contradict some of the assumptions about what makes certain interventions effective when working with this population.

Data were collected through interviews with clinicians who practice each of these modalities of treatment and across various clinical settings (private practice, agency settings, etc.). The primary objective was to determine whether the participants (the clinicians) have had any success/difficulties in providing treatment to clients diagnosed with an Autism Spectrum Disorder and a history of trauma. All interviews were conducted with the same basic format and set of questions. However, based on specific responses, follow up questions (probes) were asked for further clarification. For example, because the data were collected from clinicians in the field, they were able provide insight into how treatment gets applied practically on a regular basis when compared to a textbook treatment model. The interview format has three primary sections: 1) demographic data about the participant, 2) categorical information about the participants past clients and clinical practice and 3) questions about the participants conducting trauma work with children and adolescents diagnosed on the Autism Spectrum. A copy of the interview framework can be found in appendix B.

The initial plan for the study was to have all interviews be conducted in person, limiting the participant pool to the same geographical area as the researcher. Early

examination illuminated two potential limitations. The first concern centered on the ability to recruit enough participants with the requisite clinical experience necessary for participation in the same geographic area as the researcher. This limitation was addressed by making the decision to open up the possibility to use video conferencing. Using the internet to conduct the interviews enabled the researcher to draw upon participants from around the country. The second concern came in the lack of ability to objectively assess/compare the effectiveness of various interventions.

Other concerns included the potential for sampling biases based on the low numbers of clinicians doing this kind of work. Furthermore, some biases may have been less detectable in terms of participant's assessment of their work due to the relatively limited access to services amongst impoverished or marginalized groups. One specific example of this appears in the exploration of equine therapy as a treatment model given the demographic breakdowns of populations who live in places that might have access to the physical space required for equine therapy, e.g. urban/rural populations. Additional concerns exist around rates of over/under diagnosis for individuals with Autism Spectrum Disorders based on racial and financial lines that could be linked to issues of access to services. Despite these concerns, these are not necessarily issues that would explicitly be of concern to this study. This is because the study is specifically looking at the clinical decisions around intervention based on experience, as opposed to issues of access. However, these are issues, which should be addressed, in future research, and similar questions need to be asked about cultural/ethnic differences in terms of treatment applications for this population as well as potential differences in symptom presentation.

Sample

Although the population being studied was children and adolescents with a diagnosis on the Autism Spectrum and the effectiveness of their treatment for trauma, the participants were actually clinicians who worked with the ASD population. This is because the subject of the study centers on the clinical interventions used in treatment and not actual recipients of treatment. Similarly, because the target population is highly vulnerable, it seemed inappropriate at this time to use them as participants given the greatly limited amount of data at this point in time. Ideal recruitment for the study was between 12 and 15 participants.

As previously stated, there are several therapeutic modalities that have been shown to be effective when working with populations similar to that which is being studied (individuals with an ASD or other similar diagnosis, individuals with trauma/PTSD, adolescents with Developmental Disabilities, etc.). These indicated modalities include, Equine Therapy, EMDR, and TF-CBT. Practitioners conducting these types of treatment were sought out for participation. Additionally, to avoid biases, clinicians providing treatment through other modalities were also sought out as participants. Furthermore, attempts were made to identify multiple clinicians, practicing each identified modality of treatment to participate, to further reduce biases in the final pool of data. With multiple clinicians drawing from each modality of treatment there is more balance and input in the resulting data.

To avoid theoretical biases and concerns around ability to gather a reasonable sample size, participants were included/excluded based on their training background or field of practice. Specifically, participants with backgrounds in psychology, social work,

marriage and family therapy and other clinical backgrounds were sought out for participation. However, to ensure as much possible efficacy in the treatment being explored, all participating clinicians were required to have some kind of state licensure to practice in their given clinical field.

Nonprobability sampling was used to recruit participants and included a blend of availability, purposive and snowball sampling methods. Because the study required participants with certain expertise in terms of their clinical work and experience (e.g. a specific theoretical framework and experience working with individuals diagnosed on the Autism Spectrum with trauma backgrounds), sampling began with web searches and referrals to clinicians working in each of the given styles of treatment. These clinicians were then contacted by phone or email (a copy of the recruitment form letter can be seen in Appendix A) to determine if they possessed the relevant experience necessary, and were interested in participating. Furthermore, various organizations, agencies and associations dedicated to work related to the population being studied were contacted to find participants. Examples include: Autism Speaks, the Connecticut Autism Resource Center, and the National Child Traumatic Stress Network.

Finally, snowball-sampling methods were also used. Specifically, at the end of every interview, participants were asked for if they knew any other clinicians doing work that connects to this study. Participants were also asked if they had any ideas for other treatment modalities not yet being explored in this study.

Attempts were made to assess for the representativeness of the sample population by looking at the demographic information about participants as compared with that of the larger clinician population. Specifically, it is important to note whether or not the

participants in this study are representative of the greater population of treatment providers and clinicians. This information could be useful in assessing whether or not any further research needs to be done along the lines of characteristics of treatment providers. Although some analysis was done to look for any trends along these lines, those results are secondary to the subject of the study. As such, participants were not included or excluded based on those demographics (e.g. age, gender, theoretical and educational background, credentialing, or race). Furthermore, it would be impossible to tell how an individual clinician's demographics would impact the treatment they have provided to their clients.

With regards to participant inclusion/exclusion criteria, there were only four criteria. The first criterion was whether or not the participant possessed some kind of state licensure to operate as a clinician in their area. Secondly, over the course of their clinical practice, the participant must have treated at least one child or adolescent with a diagnosis on the Autism Spectrum for some kind of trauma. Third, the participant must have been able and willing to meet for an interview lasting approximately one hour, whether in person or via a video conferencing system. Finally, the potential participant needed to be willing to have that interview be accompanied by an audio recording for subsequent transcription and data analysis by the researcher.

Recruitment Challenges

With over 50 potential participants being directly contacted by phone or email, and many more through referrals and word of mouth, only seven participants were successfully recruited and interviewed for the study, well below the initially expected N of 12-15. Complications arose early, and several challenges emerged in terms of where

recruitment attempts fell through. The most common reason clinicians did not participate was due to a lack of clinical experience working with the population being studied.

Whether these clinicians had never explicitly treated trauma in children and adolescents with an ASD diagnosis or had never seen a client with the conditions co-occurring is unclear. Based on some conversations with clinicians it is entirely possible that they had worked with children or adolescents with a trauma background and an ASD diagnosis but they were only treated for one of the two diagnoses.

Other clinicians who were contacted did not meet the inclusion criteria of the study. One example of this was that all of the equine therapists who responded to outreach by the researcher were not licensed clinicians. In conversations with these clinicians it was found that in order to perform equine therapy, one is only required to get a certification through an authorized instruction program. As such, the clinician often works in conjunction with a licensed clinician for supervision, but the clinician is not directly involved in treatment. Similarly, many of the clinicians who were contacted based on their specialization in work with children and adolescents with an ASD diagnosis were also not licensed. This was because many had certifications in modalities of treatment such as Applied Behavioral Analysis (ABA) or other similar treatments that do not require state licensure.

Finally, a number of the clinicians who were contacted simply never responded. Two clinicians who had originally agreed to participate in the study eventually were unable to participate due to repeated scheduling conflicts.

Ethics and Safeguards

Ensuring confidentiality

As anonymity is not possible with this kind of study, confidentiality became highly important despite that there being no Health Information Portability and Accountability Act (HIPAA) sensitive information being given or collected. Confidentiality of participants was maintained by not linking the names of participants to any printed materials beyond that of the informed consent documentation (Appendix B), which was kept separate from the transcripts of the interviews. All meetings were held in private settings, whether in person or via video conferencing to prevent any accidental disclosures of confidentiality. Only the researcher, research advisor, and transcriptionists (who also signed confidentiality agreements, Appendix C) had access to audio recordings of the interviews. Furthermore, all recordings have and will only be used for the purposes of completing this research project, and the names of the participants will not be linked to the recordings in any way, unless names are used during the interview process. In this event names and other sensitive information has been scrubbed from the published version of the study. All research materials will be securely stored for a minimum of three years in accordance with federal regulation and/or until they are no longer needed. After that point they will be destroyed. Until that time, all electronically stored data will be password protected and subsequently destroyed.

Risks and benefits

There were no reasonable, foreseeable, or expected, risks associated with participation in this study. As such, no specific supports were prepared in advance. However, in the event of a participant becoming upset or uncomfortable they were encouraged to seek appropriate supports.

No compensation was offered to participants for their participation in the study. Participants in the study were offered no material benefits or compensation for their participation or time. The only benefit to clinicians who participated in the study was the potential to gain additional insight into their clinical work with this population by being asked to reflect on the clinical interventions they have used and the motivation/rational for those clinical decisions.

The potential societal benefits and benefits to the field of social work could come through improved clinical knowledge and improved practice techniques in working with this population. Specifically results from this study could help to guide other clinicians in their work with future clients who fit the subject of this study through improved awareness about more effective treatment practices. Individuals seeking treatment and/or the family members and caregivers of these individuals could benefit through improved knowledge about treatment options. Specifically, treatment seekers could look to clinicians practicing a particular modality of treatment based on the results of the study, or explicitly discuss the kinds of adaptations to interventions that will be required to make treatment effective.

This researcher will benefit in two ways. First, completion of this research will meet the graduation requirements of the Masters in Social Work Program. Secondly the

knowledge gained from this research will guide my own future clinical work when working with this highly vulnerable population.

Procedures for withdrawing from the study

All participants were afforded the right not to participate or to withdraw from the study at any time up to 15 June 2014. Refusal to participate or withdrawal from the study did not negatively impact participant in any way. Similarly, participants were able to refuse to answer any single or specific questions being asked throughout the study, for any reason. The only result of a decision to withdraw from the study was for the data collected from their interview to not be used in a final published copy of the research. If participants had questions or concerns they were encouraged to share them with either the researcher or in the case of being uncomfortable addressing said concerns with the researcher they were directed to the Smith College School for Social Work Human Subjects Committee. All of this information was contained within the informed consent documentation that participants were instructed to review and required to sign before participation. A copy of the informed consent can be found in Appendix B.

Data Collection

Once the approval letter from the SCSSW Human Subjects Review Committee was received, data collection began (Appendix D). All data was collected through one-to-one interviews between the researcher and participants. Interviews were conducted in person whenever possible. However, when face-to-face interviews were not possible, due to geographic or other significant circumstances, video conferencing over the internet was used. Phone interviews were not conducted because the hope was to resemble the dynamics of face-to-face interviews as closely as possible. Two recording methods were

employed to collect the qualitative data acquired through the interviews. Hand written notes were taken during the interview to highlight specific or relevant responses. Audio recordings of complete interviews were also made. These interviews were subsequently transcribed, and then reviewed for more thorough data analysis.

Instrument

All participants were asked the same interview questions with the exceptions of specific probe questions relevant to the individual responses of participants (Appendix E). All interview questions were self-developed with the intent of collecting data about three separate aspects of the clinician and their work. As previously stated, the three categories of questions centered around; demographic data about the participant, categorical information about the participants past clients and clinical practice, and lastly questions about the participant's experience conducting trauma work with children and adolescents diagnosed on the autism spectrum. The interview sections were ordered in this fashion for two reasons. First, questions were structured so that they would begin with the least open ended and seemingly easiest to answer flowing into questions that were increasingly more open-ended in nature. It seemed that this might encourage a natural progression that of increasingly broad and deep/introspective answers. Secondly the questions begin with the focus being about the participants themselves, gradually shifting the focus away from them and onto their relevant clinical experiences.

The first section, demographic data about the participants, was collected for a secondary data analysis. Questions asking about the participant's age, gender, racial/ethnic identity, as well as clinical/training background were all asked to assess the representativeness and patterns of the sample population.

- How old are you?
- How do you identify racially?
- What is your gender?
- How long have you been practicing in the field of mental health?
- What is your training/academic background?

In this section, questions also focused on what kind of continuing education the participant seek out?

- “What kinds of, and how much continuing education do you participate in?
- How much of that specifically relates to trauma and or Autism Spectrum Disorders?

This was done to look at possible patterns in the overall clinical focus of the participants practice. Specifically, is the participant heavily focused on the population being studied, or is their relevant clinical experience something they have come across as a function of their clinical history?

The second section of questions was designed to begin to develop a picture of the clinicians overall clinical practice. Participants were asked about the kinds of clients they have come across, as they relate to the subject of the study, as well as the volume of clients they have seen.

- Approximately how many clients have you worked with who had a diagnosis on the Autism Spectrum?
- On average, what was the level of functioning of the clients with an ASD or what was their diagnosis?
 - Autism, Asperger’s, PDD NOS?

- Verbal, non-verbal, social-skill level?
- As part of your (or your agencies) intake/assessment process do you routinely screen for trauma?
- Approximately how many clients have you worked with that were both diagnosed with an Autism Spectrum Disorder and a history of trauma?

The objective here was to begin identifying the scope of the participant's clinical experience working with individuals relevant to the subject of the research; the treatment of trauma for individuals with a diagnosis on the Autism Spectrum. It appeared unreasonable to expect clinicians to remember the exact number of individuals they had come across with specific diagnoses/symptoms relevant to the study so approximations were found to be acceptable.

The final section of questions got to the core of the studies focus; an exploration of clinician's experience treating trauma in children and adolescents with a diagnosis on the autism spectrum. Questions here were designed to center around the patterns and trends clinicians have noted in their practice as well as why. Questions further explored what or why clinicians felt specific interventions were successful. Similarly clinicians were asked about the adaptations they made to given treatment models to make those interventions more successful.

- What kinds of successes have you had using XXmodality of treatmentXX to treat trauma for children on the Autism Spectrum?
- What aspects of this intervention do you feel make it best suited to this type of work?

- Have you had to make any specific adaptations to the XXtreatment modelXX to adapt it for use with individuals diagnosed on the Autism Spectrum? If so, what has been changed? What were the reasons you made for those changes?

Similarly questions here began to explore patterns in the client's responses to treatment interventions. This included asking about outcome data for their clinical work in the form of measures like behavioral charts/scoring systems as well as patterns related identity markers of the clients.

- Have you noticed any differences between age groups in their response to treatment?
 - E.g. do younger or older children respond to the given treatment differently?
- How/Do you address cultural/racial/ethnic differences in your practice?
- Are you collecting any kind of objective outcome data on treatment, like regular behavioral assessments? If so, what is that data revealing about client progress

The final question of every interview was an attempt to seek further input into the study regarding additional modalities of treatment to explore, and request for referrals to find more possible participants.

- Outside of your own clinical practice, do you have any ideas of other modalities of treatment that also might be indicated for work with this population?

Because this interview was developed solely for the purposes of this study by the researcher there is little support the validity and reliability of the interview content. For example due to the conversational nature of the interview and open ended process of it, there can be no way to assure that every participant interpreted the questions the same

way, resulting in the potential for the questions to be answered differently by each of the participants. Similarly because participants with vast differences in clinical experience or focus as it relates to the treatment of trauma with children and adolescents on the Autism Spectrum, there is no way to balance the view of a highly educated and dedicated clinician with that of a clinician who is less inclined to perform this kind of work but still possesses the requisite credentialing and expertise. However, that did not mean that a more experienced or dedicated clinician is always going to perform better than a less experienced clinician, and as such it is unclear as to whether or not that is necessarily relevant to the study.

Similarly because of concerns around participant recruitment, some interviews were conducted in person while others were conducted through video conferencing. It is presumable, but unclear as to whether or not and if so, how much those differences impacted the data collected through the course of the interviews. It should also be noted that although video conferencing systems were used, due to technical difficulties the video function did not work. This resulted in what functionally became phone interviews.

Despite the lack of clear evidence to support the validity and reliability of the data collection method, the methods required for this study is quite different from other experimental methods. This is because the goal of the study was not to establish cause and effect relationships between treatment modalities or interventions and the progress made by clients. Also, the goal was to begin to look for any patterns that might prove to be beneficial when treating children and adolescents diagnosed on the Autism Spectrum for trauma.

Data Analysis

Descriptive statistics were used to analyze and describe pertinent demographic and numerical information collected through the study; age, length and type of practice, numerical information about clinical experience. All interviews were transcribed and data from those interviews were scanned for patterns in themes brought up by participants across various questions to report the qualitative data. Specifically, similarities, as well as differences, in word and phrases were categorized and pulled out to assess the themes brought up by clinicians in their responses. For example, clinicians discussed concepts such as, “developing affective awareness,” “helping to identify emotions,” and “building verbal capacity,” that all referred to phases of treatment centered on increasing the clients ability to understand and discuss their internal affective/emotional states, so that they could be addressed in therapy. Given the limitations of the data set, it still seems likely that there will be patterns in the kinds of adaptations being made to interventions across various treatment models.

CHAPTER IV

Findings

This chapter documents the findings from seven semi-structured interviews with licensed, practicing mental health clinicians who have treated clients diagnosed with an Autism Spectrum Disorder for trauma related symptoms or PTSD. All participating clinicians were familiar with the concepts of “small t” and “big T” trauma. Similarly, clinicians discussed incidents of both kinds of traumatic experiences. The most descriptive and pertinent information emerged from the third section of the study. Specifically, there were patterns that emerged when participants were asked to describe the kinds of adaptations they had to make to their interventions in order for treatment to be effective. It was not surprising to find that the majority of clients that the participants discussed during interviews fit the same overarching demographic patterns; white, middle to upper middle-class, males.

The interview consisted of three specific sections: 1) demographic data about the participant, 2) categorical information about the participant’s past clients and clinical practice and 3) questions about the participant’s trauma work with children and adolescents diagnosed on the Autism Spectrum. Questions from the first two sections were comprised of predominately closed ended questions, yielding mostly quantitative data. Conversely, responses to questions from the third section of the interview were far more qualitative in nature. The quantitative data is presented first and includes the demographics of the sample population and an overview of the types of clinical work

being done by the participants. This data came predominately from the first two sections of the interview seen in Appendix E.

Interview Section 1: Demographic Data about Participants

Of the seven total clinicians who were interviewed five were female (71%), with a mean age of 50. Ages of participants were between 35 and 65, for a median age of 49. All participants identified as Caucasian, with three identifying as Jewish, one Greek, and one Native American. Participants range in length of practice was 12 to 44 years with a mean of 25 years of clinical practice. All participants had established private practices while 3 also worked in other settings, including an agency based Partial Hospitalization Program (PHP) setting, and two graduate level educators teaching in social work programs. Three participants had backgrounds in clinical psychology (two with PhD's and one with a M.A.), three social workers (two with MSW's and one with a PhD), and one was licensed as a psychiatric clinical nurse specialist.

All interviewees engaged in various forms of ongoing continuing education that included various trainings, conferences, and seminars on a wide array of topics. Four participants also engaged in their own academic research and writing. Although all participants reported having received continuing education regarding work with individuals with Autism Spectrum Disorders, none reported that being a major factor in their continuing education, outside of their own academic work. Two participants stated that a focus of their continuing education was centered on trauma.

Interview Section Two: Overview of Participants' Clinical Practice

With regards to the participants' experience working with the population being studied, participants ranged from as few as 10 total clients with an ASD diagnosis up to 100's of clients. Similarly, one participant reported working with as few as a dozen clients who had trauma, as compared to others who had worked with hundreds. One participant reported that over 50% of his clients had experienced some kind of trauma that factored into the treatment. Only two participants reported having more clinical experience working with clients who were diagnosed on the Autism Spectrum as opposed to those who had experienced trauma.

Two participants reported having as few as three clients who had a diagnosis on the Autism Spectrum and were being seen by the participant to address trauma related issues. Conversely, two participants reported having seen as many as 50 clients fitting the same criteria. Of the seven total participants, five had seen 20 or fewer patients meeting the criteria for the study. Of those clients, participants reported that the majority of them were white, and came from middle to upper middle-class families. Clients presented with a wide variety of family make-ups; two parent/single parent households, divorced families, adopted, living in group homes. Participants also reported having worked with clients from a wide age range, from early childhood through young adulthood. Two participants reported that the demographic patterns of their clients were heavily influenced by where they [the clinicians] were working at any given time.

The kinds of trauma clients had experienced, as reported by the participants was as varied as the clients themselves. Some clients had experienced isolated or specific traumas while others had more complex and less isolated traumas. Many of the

participants' clients had experienced significant losses, several experienced physical/sexual abuse or been the victim of violence. Other clients had been witness to violence or conflict in the home, experienced significant bullying, or had poor relationships with their families or caregivers due to issues of mal-attunement. One preteen aged client, discussed by a participant, was involved in a significant car crash during an incident in which he had taken the keys to his caregiver's car and became physically trapped in the car until rescue workers were able to arrive.

Interview Section 3: Participants' Clinical Experience Treating Trauma in Clients Diagnosed with an Autism Spectrum Disorder

One original goal of this study was to find and speak to clinicians who were experienced in and predominately practiced only one specific modality of treatment. Specifically, the aim was to speak to clinicians who practiced modalities of treatment including TF-CBT/CBT, Equine Therapy, EMDR, NMT, as well as psychodynamic clinicians. However of the participants, only two explicitly followed a manualized treatment approach; one utilized CBT while another relied heavily on EMDR in their respective practices. However, there were two more clinicians whose clinical work was rooted in one specific modality of treatment - one with CBT and the other EMDR. No clinicians with experience using Equine Therapy or the Neurosequential Model of treatment were found.

Patterns in the adaptations made to treatment interventions

The most pertinent findings for this section center on the kinds of adaptations to treatment being made by clinicians to make their interventions effective. All seven participants reported an explicit need to tailor the work according to the clients' own

pace. Thus, often times the work was slowed down and taken at a much more gradual pace. One participant described this change of pace as:

It's just sort of adjusting my expectations. I'm not expecting too much. And if he can engage in something that's a therapeutic intervention and make use of it... Patients with trauma are very sensitive about this anyway, about not pushing too much. If we've done something that's harder, and then he wants to watch a video for a while without comment or to do some drawing or coloring that may not be specifically on the goal of the therapy, I'm ok to just sort of be with him. I need to not always expect too much from him and recognize that the work that he does do takes a great deal of effort.

Many participants felt similarly and described the overarching difficulties that many individuals with ASDs have with verbal communication and affective awareness as a central reason for the noticeably slowed pace to therapeutic progress. Two participants also noted concerns around physical safety and a drastically increased need to emphasize the rapport-building phase of treatment out of concern that their clients might become physically aggressive when beginning to address trauma history. One participant, who practices EMDR which involved hand-tapping as part of the bi-lateral stimulation component of treatment, described the difficulties and experimentation involved in trying to find both comfortable and physically safe means of performing the treatment.

I had to talk it through with him a few times to even know how he was going to speak about it, what this processing was going to be like, and if he was going to physically act out when the conversation came up with me instigating the conversation versus him just talking about it on the walk. Because he would react – if you brought him something he didn't like, maybe he could react at you. So I was testing a whole bunch of different things leading up to it to see how I could be helpful and how I could understand it.

In this particular situation, the clinician had to be aware of the client's sensory needs as well as the client's propensity for physical aggression. However, what this illustrates is the patterns of reactivity that are very prevalent in both individuals with ASDs as well as those who have experienced a trauma.

All of the participants similarly discussed a slowing of the treatment process due to a need to help increase the “affective awareness” or “emotional intelligence” of the clients they were working with. A feature of Autism Spectrum Disorders is having a difficulty with *Theory of Mind*. If progress is going to be made in therapy, there needs to be some kind of language from which to base that change on, whether that language is verbal or otherwise. Specifically, many clinicians described their experiences educating their clients about basic affective or emotional states. One clinician recounted experiences watching the television show *The Price is Right* and teaching the client to recognize the emotional states of participants. The clinician would then work with the client to help him identify his own internal emotions. Only then was the clinician able to proceed with helping the client to address their difficulties with emotional regulation. Similarly, six clinicians (86%) discussed their use of various kinds of charts or visual aids that depicted the facial expressions associated with various emotions as a means of communicating this information. This aspect of treatment was also very significant for clinicians in helping their clients to “name their experiences,” and “validate their emotions,” according to two participants.

Six respondents (86%) reflected on their consistent need to increase the amount of work being done with the parents/family members/care givers of their clients in therapy. This was done for several reasons. In settings where clinicians were working with less verbal, or lower functioning clients, family involvement was needed so that the clinicians could get a better understanding of what was happening in the clients’ lives. For others, this work was done as a means of capacity building in the parents through psycho-education; teaching the parents about what their child or adolescent is experiencing or

about their diagnosis and specific needs. Similarly, work with the parent is also done because, “it is important to bear in mind that parents need to feel sufficiently emotionally supported in order to best help their children cope,” (Levine & Masotta, 2013, p. 8-9). The thinking was that, if parents are not up to the task of meeting the child’s needs throughout their daily lives overall progress could not be made.

Similar to the use of visual aids and working to build affective awareness, five participants (71%) cited the importance of spending increased time on developing a number of coping skills. Responses included being sensitive to the specific sensory needs of each client. For example, in two cases where clinicians used EMDR, both worked with their clients extensively to find means of engaging in the bi-lateral stimulation component of treatment that was appropriate to the sensory needs of each client. Similarly one clinician who practiced CBT relied on tools such as weighted blankets, or noise cancelling headphones to help clients regulate their moods and meet their own sensory needs.

Responses to specific modalities of treatment

Beyond patterns in the specific kinds of adaptations clinicians were making to their interventions, a number of significant issues were brought up with respect to the use of specific modalities of treatment. One clinician who predominately uses CBT in his work with this population spoke to the concrete nature of the nature of this treatment model. This clinician feels that CBT sits well with the restrictive trends in cognitive processing patterns for individuals with ASDs. However, as the other CBT oriented participants stated about successfully using CBT:

It depends on their readiness and appropriateness for psychotherapy.
Psychotherapy isn’t necessarily a modality for everybody.

Specifically, what they were referring to was the idea that if the client was not functioning at a level high enough to engage in the treatment model, it would obviously not work for them. Conversely, another clinician who does more with using Positive Behavior Supports and Floor Time / Play therapy as her primary interventions stated that:

For the most verbal kids, for high functioning older kids with Asperger's who can access trauma specialists, I would refer them on.

Here again, the idea was that not all clients are appropriate for any given modality of treatment. In this instance though, when the client is functioning at a level high enough to engage with a more trauma-oriented approach it is more pertinent to seek out that specialist as opposed to an ASD specialist.

In speaking with both clinicians who drew most heavily on EMDR for their interventions, both addressed two specific advantages. Specifically, with EMDR one therapist noted:

They [clients] don't necessarily have to talk back to you [the therapist]. They can hold a thought and not necessarily articulate it to you for it to make a difference, whereas a lot of other therapies are more dependent on their whole verbal interaction.

That being said, another clinician noted that EMDR seemed best suited when the trauma being addressed in treatment was a specific incident, and not more complicated or ongoing traumatic experiences.

Unfortunately, no clinicians who practiced Equine Therapy or NMT were successfully recruited for participation in this study. As such, there is no data concerning the effectiveness of those modalities of treatment included in this study.

Response to treatment based on age

Of the seven total participants, most noted no patterns in response to treatment with respect to age. As noted by several clinicians, factors such as developmental functioning were far more important when assessing levels of progress. Specifically, the higher functioning the client, the more likely they were to benefit from treatment. That being said, two clinicians who mostly worked with “higher functioning” clients noted better responses from clients that were between the ages of eight and twelve, or who were “older elementary school aged.” One of these participants theorized that it was likely due to two reasons:

What’s nice is the school age of 8–12 could be a very intense time, but I find that those kids typically do also want to please some adults, and because they want to please and sometimes they’re able to adapt more readily to a structure that they do work well and quickly in therapy.

Once you can name it in a way that works. Obviously with younger kids, you’re working in a much more unconscious way. There’s not as much language, they don’t have the ability to conceptualize so much. But when you hit age eight, you have the ability for abstract concepts comes in in terms of what their brains doing. So once you enter into that zone, in that 8-12 range, you have a lot turning on in the body. So you would have an increased capacity to understand the situation.

Again, these ideas correlate with the appropriateness or the readiness of the client to engage in therapy.

Addressing race, culture, and ethnicity in treatment

Respondents reported very few instances of addressing race and ethnicity throughout the arc of trauma treatment with their clients diagnosed on the Autism Spectrum. One participant noted that,

It’s sad, but it doesn’t typically come up along those lines because it seems like autism trumps everything.

The idea that issues of race, culture, or ethnicity took a backseat to the issues connected to ASDs was a theme that was echoed by other clinicians. This is not to say that clinicians felt that race was not an issue in treatment, but rather that managing the aspects of ASD while trying to do trauma work, complicated treatment to the point that addressing race as well would make treatment that much more difficult. With that in mind, several respondents did discuss their experiences addressing culture and ethnicity with clients. One discussed her experiences advocating for culturally appropriate food for a client after moving into a residential setting to aid with adjustment, while another clinician discussed his experiences helping a family to teach their son about religious practices in the wake of a loss.

Here, it is also significant to note that respondents (who all identified as Caucasian/White) reported mostly having experience treating white clients.

However, three clinicians did note that when working in cross-racial therapeutic dyads, there was a significant increase in work with the parents, specifically around psycho-education. Clinicians talked about addressing cultural barriers related to increasing the family and support system's understanding of the client/child's experience, and how issues such as trauma and ASDs impact the lives of individuals.

Objective outcome data from treatment

Of the seven clinicians interviewed, only one reported having collected any kind of objective outcome data based on her, and her colleagues work using EMDR. Results from the participant's 2010 study showed that EMDR was effective in reducing the aggressive and disruptive behaviors associated with traumatic experiences in individuals with intellectual and developmental disabilities, which included individuals with an ASD.

Other modalities of treatment

When asked about other possible modalities of treatment that should be explored for the ASD/trauma population, participants described several new models. Specifically, two clinicians mentioned Floortime or Theraplay. Two other clinicians who were less experienced with EMDR suggested further exploration into its effectiveness with this treatment population. Conversely two other clinicians suggested looking into CBT, or other “behavioral approaches” in doing this kind of work. Lastly, one participant suggested looking into Occupational & Verbal Therapy, while another proposed using Neurofeedback.

Outside of specific modalities of treatment respondents suggested that models should be, “strengths based” “body based” or “less verbal”. Similarly, it was felt that interventions should utilize increased “imagery” or “visual aids” be sensitive to the sensory needs of each client.

Summary

Major findings from seven interviews with practicing mental health clinicians who have conducted trauma work with individuals diagnosed with an Autism Spectrum Disorder have been presented in this chapter. Significant findings were predominately derived from questions in the third section of the interview. The following chapter will explore the interpretations of those findings as well as compare and contrast significant findings. Additionally, the strengths and limitations of this study will be addressed. Lastly, suggestions for future research will be presented.

CHAPTER V

Discussion

The objective of this study was to explore the issue of the treatment of trauma in children and youth with a diagnosis on the Autism Spectrum. In this study, the research questions being posed were: 1) Are there any current treatment models that are best indicated for the treatment of trauma for children and adolescents diagnosed on the Autism Spectrum? 2) What, if any, patterns are there in the kinds of adaptations that need to be made in treatment to make the therapy effective? Both qualitative and quantitative data were collected through the course of semi-structured interviews with seven licensed mental health clinicians who possessed experience treating children and adolescents with an ASD diagnosis for trauma. Quantitative data was collected to reflect the demographic information about participants as well as get a sense of their experience conducting this kind of clinical work. Qualitative data was collected to develop an understanding of their actual experiences doing this work in the field.

Attempts were made to interview clinicians practicing across an array of treatment modalities that appeared to be indicated for doing this kind of work, including CBT/TF-CBT, EMDR, Equine Therapy, NMT, as well as clinicians using eclectic or traditional psychodynamic treatment models. Furthermore, over the course of the study, attempts were made seek out other possible treatment modalities for this population..

Throughout the interviews it became clear that the success of treatment centered on two factors: 1) the developmental level/cognitive functioning of the client and 2) the adaptations the clinician made to the treatment to meet the client's individual needs. This chapter reviews the findings in the following order: 1) key findings, reviewing the

participants experiences with treatment and previous literature; 2) implications for social work practice with respect to specific treatment modalities and their success with treating trauma in youth diagnosed with an ASD; 3) strengths and limitations of the study in terms of its design and implementation; 4) recommendations for future research in the area of trauma work with children and adolescents diagnosed on the Autism Spectrum.

Key Findings

Clinicians' experiences with and thoughts on treating youth with an ASD diagnosis as well as traumatic experiences were explored through the course of semi structured interviews. This section compares the most pertinent data collected through those interviews with previous literature, and is reviewed in in the following order: specific modalities of treatment, response based on age, adaptations made to treatment

Specific modalities of treatment

Due to difficulties with the total sample size, little evidence was found to identify whether there may, or may not, be a specific modality of treatment ideal for treating trauma in children and adolescents with a diagnosis on the Autism Spectrum. Reports from clinicians, with some support from the literature, indicate that Eye Movement Desensitization and Reprocessing might be a feasible treatment option when working with relatively lower functioning individuals with a single, specific traumatic incident. This modality is supported given the significantly reduced reliance of verbal communication as a function of the treatment process and its guided reprocessing component of treatment coming from the clinician. Specifically, the aspects of verbal communication that are required for treatment are more incumbent on the clinician rather than the client. However, as per participants' reports, this model did not appear to be as

effective when trying to treat more complex forms of trauma, such as ongoing relational traumas or repeated victimization. Conversely, there is, albeit limited, data indicating that EMDR may be successful in treating these complex traumas when specific adaptations to the EMDR treatment protocol are made (Korn, 2009).

As with EMDR, Trauma Focused, Cognitive Behavioral Therapy appeared to work well, but only under certain circumstances. Beyond the adaptations that clinicians made to the treatment model as a function of meeting the client's individual needs, it did appear that no matter what, clients did need to possess a relatively higher baseline of cognitive and developmental functioning, including the propensity for verbal communication and the ability to mentally grapple with the material contained within the treatment model.

No data was found with respect to Equine Assisted Therapy or the Neurosequential Model of Treatment due to difficulties in finding and recruiting participants. As such, these modalities cannot be ruled as either being effective or ineffective when working with this population at this point in time.

Response to treatment based on age

Two clinicians did note, in their responses, that children in the late elementary to middle school age range did appear to respond better to treatment than others. They cited the idea that children between the ages of eight to twelve, among other reasons, may be more motivated for, or willing to engage in, treatment due to trends in behavioral and social development, as well as an increased ability to engage in higher order and complex thinking. However, what seems more significant in that response, and which falls in line with the other participants' responses, is the significance of the cognitive development of

the individual client. The literature reviewed speaks little to the notion of age and response to treatment. However the responses of the participants stand to reason. If a potential client is not developmentally capable of engaging in the given treatment modality provided by the clinician, the treatment will then be ineffective. For example, if a TF-CBT clinician makes every attempt possible to use and rely upon visual aids when working with a low functioning, non-verbal client, it seems that treatment would not likely be as effective. This is because as a function of TF-CBT verbal communication is still required. That being said, no data was found in the literature to support or deny this claim.

Patterns is adaptations made to treatment

Perhaps the most pertinent findings that emerged from this study are the patterns of adaptations clinicians made to their treatment interventions and models to make treatment effective. In fact the majority of the adaptations the participants discussed through the interviews are directly in line with those that Atwood and Scarpa (2013) proposed in their discussion for using CBT with children and adolescents with High-Functioning Autism Spectrum Disorders. As noted, all seven clinicians who were interviewed discussed the explicit need to adjust their work to the limitations and needs of the client, with specific respect to pacing as well as the interpersonal/social, intellectual, and developmental abilities of the individual. Although it is critical in working with any client to meet them where they are, its significance in working with this population grows exponentially. As such, taking stock of the strengths and deficits/limitations of client should be a key feature in the introductory phases of every treatment relationship, as that information will be critical in guiding all future work to be

done. These adjustments also include being acutely aware of the sensory sensitivities, and restrictive interests prevalent in many children and adolescents with an Autism Spectrum Disorder.

Again both the literature (Atwood & Scarpa, 2013; Cavicchi, 2013; Edwards, 2010; Shapiro, 2005) and 100% of the clinicians who participated in the study discussed incorporating a significant amount of work on the development of social/verbal skills and “affective awareness” or “emotional intelligence”. Here, because an inherent feature of ASDs is a difficulty with features such as *theory of mind* and *alexithymia*, and a key function of trauma therapy is to address the disruptive behaviors and emotional states resulting from the trauma, a solid framework with which to discuss these emotions must be built. Connected heavily to the development of emotional intelligence is the use of language itself, as a means of communication.

As with building the affective awareness of clients, the development of effective coping and mood management skills becomes increasingly important when addressing traumatic incidents with children and adolescents diagnosed with an Autism Spectrum Disorder. Atwood & Scarpa (2013), in conjunction with 71% of the studies participants addressed this need. This is significant in that the act of bringing up and processing traumatic experiences, through the therapeutic process, can be activating to clients, as evidenced by the three clinicians (43%) who reported clients becoming not just triggered, but aggressive during sessions. Furthermore, without developing the skills needed to self-regulate, children and adolescents, particularly those diagnosed on the Autism Spectrum are at increased risk of experiencing further traumatic events such as being restrained or secluded in school (State of Connecticut Board of Education, 2014).

Again, the overwhelming majority of respondents (86%), across all modalities of treatment aligned with the literature (Atwood & Scarpa, 2013; Shapiro, 2005, Barol & Seubert, 2010; DePrekel, 2012; Perry, 2009). Both stressed the importance of increasing the use of visual aids, hands on experiences, or body based work to drastically reduce the need to explicitly rely on verbal communication.

Both the participants (86%) and the literature (Shapiro, 2005; Reaven & Blakeley-Smith, 2013; Atwood & Scarpa, 2013; Child Welfare Information Gateway, 2012; Levine & Masotta, 2013) stressed the need for increased communication, psycho-education, support and work with the parents and caregivers of the children and adolescents seeking treatment. This finding seemed to stem from two interconnected features of children and adolescents with an ASD diagnosis. Because individuals with an ASD have an increased propensity to struggle with accurate communication, these children are immeasurably more dependent on their families and care givers. And, as such, family members are critical in developing accurate understanding of what is happening in the child's world. Similarly, because of the unique and broad ranging features of ASDs clinicians the stress load to families and care givers is extremely high, necessitating a greater need for psycho-education and support.

Implications for Social Work Practice

Given the limited results of this study, the implications social work practice are relatively few. At this point there are no means of determining if any specific modality of treatment might be better suited than another for treating trauma in children and adolescents with a diagnosis on the Autism Spectrum. However, the most relevant implications from the research lie in the specific kinds of adaptations needed to make

treatment effective. The list of adaptations for CBT with children and adolescents diagnosed with HF-ASDs developed by Atwood and Scarpa (2013) appear to be applicable to the treatment of all clients with an ASD diagnosis across all models of treatment. As such, it seems pertinent to note that when working any client with an ASD clinicians should incorporate the following into their treatment: 1) meet and be sensitive to the interpersonal and social abilities of the individual, 2) be aware of and work with the sensory needs and learning profile of the client, 3) increase the use of visual aids or hands of activities, 4) be more directive throughout the treatment process, 5) increase consistency and structure through sessions, 6) find ways to incorporate any special/restricted interests or talents the child possesses into treatment, 7) work on building affective awareness and emotional intelligence to address *theory of mind* and *alexithymia* deficits, 8) help with the development of social and verbal skills including syntactical and pragmatic aspects of communication, 9) whenever possible incorporate workbooks and “homework” assignments between sessions, and 10) increase work with and support of the parents and care givers.

Strengths and Limitations

As a function of the small sample size (seven participants), there are several limitations of this study. Due to such a small sample size, the data garnered through interviews is not enough to be generalizable. Similarly, because clinicians practicing each of the various modalities of treatment previously discussed were not successfully recruited for this study, these results are not representative of the wide array of work being done currently with this population. Time was a significantly limiting factor in the way this study was conducted and contributed significantly to the limited results.

Aspects of this study's operational definition of Autism Spectrum Disorders may have been too broad, thereby obscuring some potential findings. Given the wide array of characteristics exhibited in children and adolescents with ASDs and the various kinds of trauma, there may be no one specific modality of treatment best suited for this work. Specifically, the most appropriate modality of treatment is much more likely to depend on the level of functioning of the individual and may also be impacted by the kind of trauma that child has experienced.

With that in mind however, there was an overwhelming amount of support shown for the specific adaptations to the treatment interventions being used by clinicians across various modalities of treatment. As such, those specific findings do appear to be quite significant.

Recommendations for Future Research

As noted at the beginning of this study, at this point in time there is a significant lack of research being done with respect to the treatment of trauma in children and adolescents with a diagnosis on the Autism Spectrum, and there is much more work to be done. Future research will hopefully not be as time limited, and have much larger sample populations from which to draw upon. Adjustments should also be made to the inclusion criteria for participants, so that clinicians with certifications in specific modalities of treatment, such as Equine Assisted Therapy, can be included.

Based on the results from this study and the responses of the clinicians who participated, there are a number of additional treatment models that should be also examined for their potential use in this kind of work. These treatment models include; Equine Assisted Therapy, the Neurosequential Model of Treatment, Floortime, and

Theraplay. Furthermore there is much more that can be done when exploring the use of TF-CBT, and EMDR when working with this population.

Future studies might benefit from narrowing the scope of client candidates or the kinds of trauma they experienced. Specifically, it may be best to only look at treatment models for youth who meet some kind of pre-determined baseline or range of functioning by the researcher, as opposed to trying to look at the entire spectrum of ASD presentations. Similarly, it might be productive to limit the kinds of traumatic experiences being treated to isolated incidents of trauma versus ongoing complex traumas or even big T versus little t traumas.

As we make steps towards increasing our ability to provide care and treatment for this highly vulnerable population, we may find that a brand new model of treatment should be developed drawing on knowledge of each of these previously examined treatment models. In the end this research was a step toward learning more about the intersectionality of trauma and Autism Spectrum Disorders. It shows that the need is great, but with appropriate and attentive care and the right knowledge base, successes can be made.

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Appendix A

Recruitment Letter

Date: [Insert Date]

Dear [Recipient]:

Hello. My name is Ben Katz and I am a student at the Smith College School for Social Work, working on my Masters in Social Work degree. Currently I am working on conducting research for my thesis as part of my degree requirements. I am contacting you, as I believe you may be an eligible participant in my research, and your knowledge and experience would be greatly beneficial to the work I am conducting.

As part of my degree I am interested in exploring treatment interventions for trauma in youth with a diagnosis on the Autism Spectrum. Despite the immense amounts of research being done in the field on either trauma or autism spectrum disorders, very little appears to be being done on the overlap in populations. Through my research, I am hoping to see if there are any specific methodologies that appear to be better implicated for work with this highly vulnerable population, thereby reducing some of the gaps in treatment.

If this topic sounds appealing or interesting to you and you are willing to participate it would be greatly appreciated. In order to participate you must be a state board licensed clinician. However, specific training background does not matter (e.g.; social work, psychology, marriage and family therapy, counseling). You must have experience working with individuals who have a diagnosis on the Autism Spectrum (Asperger's Disorder, Autism, Pervasive Developmental Disorder NOS) and a history of traumatic experiences. However a diagnosis for the trauma such as PTSD is not required. Further, treatment of the trauma must have been a factor in the treatment.

Participation will only involve one interview, which will last approximately one hour. During the interview, you will be asked to reflect on your experiences working with individuals in this population, the interventions you used, and the challenges and successes you had.

If you believe you would qualify to participate in this study and would like the opportunity, or would like more information, please contact me by phone or email, as listed above. Thank you for your time.

Sincerely,

Ben Katz

MSW Student, Smith College School for Social Work

Appendix B

Informed Consent Form:



**Consent to Participate in a Research Study
Smith College School for Social Work • Northampton, MA**

.....

Title of Study: Treating Trauma in Children and Adolescents on the Autism Spectrum: A Qualitative Study

Investigator(s): Ben Katz, Smith College School for Social Work, phone number

.....

Introduction

- You are being asked to be in a research study about the adaptation of trauma therapies for use with children and adolescents diagnosed on the Autism Spectrum with trauma histories. Specifically I am looking to see if there are any modalities of treatment that are best indicated for use with this population given their increased vulnerability and specific social deficits/limitations.
- You were selected as a possible participant because you are a practicing licensed clinician who has experience working with this very specific population.
- I ask that you read this form and please feel free to ask any questions that you may have, before agreeing to be in the study.

Purpose of Study

- The purpose of the study is the purpose of this study is to identify any specific modalities of treatment that would best be indicated for use when working with children and adolescents diagnosed with an Autism Spectrum Disorder (ASD) with a co-occurring trauma history. Specifically a number of different modalities of treatment have been show to be effective when working with either individuals seeking treatment for trauma or ASDs separately, but none have been looked at when the two features present together. For example, EMDR has been show to be effective in work with individuals with PTSD and also in work with individuals with an ASD. However, no research has been conducted on whether or not EMDR is effective when working with individuals with an ASD and comorbid PTSD (or trauma symptoms).
- This study is being conducted as a research requirement for *my masters in social work degree*.
- Ultimately, this research may be published or presented at professional conferences.

Description of the Study Procedures

- Participants will be asked to participate in an interview with the researcher. Questions will encourage the clinician to reflect on their past work with clients meeting the criteria of the

study and assess the effectiveness of their treatment interventions. These questions will focus on what aspects of their interventions with clients they found successful and unsuccessful, what adaptations were made to the treatments to meet the needs of the clients, and how they assessed the effectiveness of their interventions. The researcher will also collect demographic information about the clinician including information about age, race, gender, training/background, experience (years of total experience, and experience with this specific population), and theoretical orientation.

- The interactions between the researcher and participants will be limited to the interview and communication involved in recruitment and coordination to complete the study. Interviews will take between 45 minutes and 1 hour.

Risks/Discomforts of Being in this Study

- There are no reasonable foreseeable (or expected) risks.

Benefits of Being in the Study

- The possible benefits of participation are from gaining potential insight into your work. Through the reflection and analysis of the data collected, participants could potentially improve the quality of their work with future clients.
- The benefits to social work/society are: Society and the social work field could benefit from this study through better informed clinical practice in the realm of trauma treatment for individuals diagnosed on the Autism Spectrum. Furthermore, individuals seeking treatment, as well as the parents and caregivers of these individuals will benefit through improved awareness of more effective treatment practices.

Confidentiality

- Your participation will be kept confidential. Confidentiality will be maintained by not linking names to any printed materials. Meetings will be held in private settings to prevent accidental disclosures of confidentiality, and only the researcher, research advisor, and participant will know the details of the meeting. Only the researcher, research advisor, and possible transcriptionists (who will also sign confidentiality agreements) will have access to audio recordings of interviews. Recordings will not be used for any purposes other than the completion of this research project, and names of participants will not be used during interviews.
- All research materials including recordings, transcriptions, analyses and consent/assent documents will be stored in a secure location for three years according to federal regulations. In the event that materials are needed beyond this period, they will be kept secured until no longer needed, and then destroyed. All electronically stored data will be password protected during the storage period. We will not include any information in any report we may publish that would make it possible to identify you.

Payments/gift

- You will not receive any financial payment for your participation.

Right to Refuse or Withdraw

- The decision to participate in this study is entirely up to you. You may refuse to take part in the study *at any time* (up to the date noted below) without affecting your relationship with the researchers of this study or Smith College. Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled. You have the right not to answer any single question, as well as to withdraw completely up to the point noted below. If you choose to withdraw, I will not use any of your information collected for

this study. You must notify me of your decision to withdraw by email or phone by 15 June, 2014. After that date, your information will be part of the thesis, dissertation or final report.

Right to Ask Questions and Report Concerns

- You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, Ben Katz at bkatz@smith.edu or by telephone at phone number. If you would like a summary of the study results, one will be sent to you once the study is completed. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

Consent

- Your signature below indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above. You will be given a signed and dated copy of this form to keep.

.....

Name of Participant (print): _____

Signature of Participant: _____ Date: _____

Signature of Researcher(s): _____ Date: _____

I agree to be audio taped for this interview:

Name of Participant (print): _____

Signature of Participant: _____ Date: _____

Signature of Researcher(s): _____ Date: _____

Appendix C

Transcriber Confidentiality

Professional Transcriber's Assurance of Research Confidentiality

STATEMENT OF POLICY:

This thesis project is firmly committed to the principle that research confidentiality must be protected. This principle holds whether or not any specific guarantee of confidentiality was given by respondents at the time of the interview. When guarantees have been given, they may impose additional requirements which are to be adhered to strictly.

PROCEDURES FOR MAINTAINING CONFIDENTIALITY:

1. All volunteer and professional transcribers for this project shall sign this assurance of confidentiality.
2. A volunteer, or professional transcriber should be aware that the identity of participants in research studies is confidential information, as are identifying information about participants and individual responses to questions. Depending on the study, the organizations participating in the study, the geographical location of the study, the method of participant recruitment, the subject matter of the study, and the hypotheses being tested may also be confidential information. Specific research findings and conclusions are also usually confidential until they have been published or presented in public.

It is incumbent on volunteers and professional transcribers to treat information from and about research as privileged information, to be aware of what is confidential in regard to specific studies on which they work or about which they have knowledge, and to preserve the confidentiality of this information. Types of situations where confidentiality can often be compromised include conversations with friends and relatives, conversations with professional colleagues outside the project team, conversations with reporters and the media, and in the use of consultants for computer programs and data analysis.

3. Unless specifically instructed otherwise, a volunteer or professional transcriber upon encountering a respondent or information pertaining to a respondent that s/he knows personally, shall not disclose any knowledge of the respondent or any information pertaining to the respondent's testimony or his participation in this thesis project. In other words, volunteer and professional transcribers should not reveal any information or knowledge about or pertaining to a respondent's participation in this project.

4. Data containing personal identifiers shall be kept in a locked container or a locked room when not being used each working day in routine activities. Reasonable caution shall be exercised in limiting access to data to only those persons who are working on this thesis project and who have been instructed in the applicable confidentiality requirements for the project.

5. The researcher for this project, Ben Katz shall be responsible for ensuring that all volunteer and professional transcribers involved in handling data are instructed in these procedures, have signed this pledge, and comply with these procedures throughout the duration of the project. At the end of the project, Ben Katz shall arrange for proper storage or disposition of data, in accordance with federal guidelines and Human Subjects Review Committee policies at the Smith College School for Social Work.

7. Ben Katz must ensure that procedures are established in this study to inform each respondent of the authority for the study, the purpose and use of the study, the voluntary nature of the study (where applicable), and the effects on the respondents, if any, of not responding.

PLEDGE

I hereby certify that I have carefully read and will cooperate fully with the above procedures. I will maintain the confidentiality of confidential information from all studies with which I have involvement. I will not discuss, disclose, disseminate, or provide access to such information, except directly to the researcher, Ben Katz for this project. I understand that violation of this pledge is sufficient grounds for disciplinary action, including termination of professional or volunteer services with the project, and may make me subject to criminal or civil penalties. I give my personal pledge that I shall abide by this assurance of confidentiality.

_____ Signature

_____ Date

_____ Ben Katz, Researcher

_____ Date

Appendix D

Human Subjects Review Board Approval Letter



School for Social Work
Smith College
Northampton, Massachusetts

01063

T (413) 585-7950 F (413)
585-7994

February 4, 2014

Benjamin Katz

Dear Ben,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,



Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Charlotte Zeller, Research Advisor

Appendix E

Interview Guide

- **DEMOGRAPHICS OF PARTICIPANTS**

- How old are you?
- How do you identify racially/ethnically?
- What is your gender?
- How long have you been practicing in the field of mental health?
- What is your current professional title and how long have you held it?
- What kind of setting do you practice in?
 - Agency/Office, client homes, school, other community setting, other?
 - Profit/Non-Profit
- What is your training / academic background?
- What kind of professional licensure do you hold?

- **QUESTIONS ABOUT PARTICIPANTS CLIENTS**

- Approximately how many clients have you worked with who had a diagnosis on the Autism Spectrum?
- On average, what was the level of functioning of the clients with an ASD or what was their diagnosis?
 - Autism, Aspergers, PDD NOS
- verbal, non-verbal, social skill level?
- Do you also work with clients not diagnosed on the Autism Spectrum?
- Approximately how many clients have you treated for trauma related symptoms or PTSD?

- As part of your (or your agencies) intake/assessment process do you routinely screen for trauma?
 - Approximately how many clients have you worked with that were both diagnosed with an Autism Spectrum Disorder and history of trauma?
 - What has been the racial/ethnic/SES level of clients you have served within this population?
 - What kinds of trauma had the clients you were working with been exposed to?
 - Witness to violence/victim of violence/sexual abuse/emotional/community violence/natural disaster?
- **QUESTIONS ABOUT PRACTICE:**
 - Do you have a preferred modality of treatment? If so what is it?
 - What kind of modality specific training did you get and where?
 - In school/seminars/etc.
 - What kinds of successes have you had using XXmodality of treatmentXX to treat trauma for children on the Autism Spectrum?
 - What aspects of this intervention do you feel make it best suited to this type of work?
 - Have you had to make any specific adaptations to the XXtreatment modelXX to adapt it for use with individuals diagnosed on the Autism Spectrum? If so, what has been changed?
 - Have you noticed any differences between age groups in their response to treatment?

- E.g. do younger or older children respond to the given treatment differently?
- How/Do you address cultural/racial/ethnic differences in your practice?

- Are you collecting any kind of objective outcome data on treatment, like regular behavioral assessments? If so, what is that data revealing about client progress?
- Outside of your own clinical practice, do you have any ideas of other modalities of treatment that also might be indicated for work with this population?