## THE LIVED EXPERIENCES OF TRAUMA IN AUTISTIC ADULTS: A THEMATIC ANALYSIS

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DOCTOR OF PHILOSOPHY

by

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#### THE LIVED EXPERIENCES OF TRAUMA IN AUTISTIC ADULTS: A THEMATIC ANALYSIS

This dissertation, by Briana Trageser, has been approved by the committee members identified below who recommend that it be accepted by the faculty of Antioch University Seattle in partial fulfillment of requirements for the degree of

#### DOCTOR OF PHILOSOPHY

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#### ABSTRACT

#### THE LIVED EXPERIENCES OF TRAUMA IN AUTISTIC ADULTS: A THEMATIC ANALYSIS

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A qualitative research study focused on Autistic adults explored the lived experiences of trauma. Participants included Autistic adults who have either been professionally diagnosed with Autism Spectrum Disorder or who self-identify as Autistic. Data was collected through a survey with 12 open-ended questions. A thematic analysis revealed six themes: (a) adverse childhood experiences, (b) exposure to violence and loss, (c) difficulty relating to others, (d) complex mind and sensory experiences, (e) medical and mental health challenges, and (f) autistic identity. The themes revealed instances of Autistic people experiencing trauma in ways that differ and vary in clinical presentation from their neurotypical counterparts. Implications and recommendations for professional counseling and counselor education are discussed based on these findings. This dissertation is available in open access at AURA (https://aura.antioch.edu) and OhioLINK ETD Center (https://etd.ohiolink.edu).

*Keywords*: Autism/Autistic/Autism Spectrum Disorder, trauma, Posttraumatic Stress Disorder/PTSD

### Dedication

To Brendan, Kyle, and Tessa,

Who have inspired me in more ways than you will ever know,

And to those who continue to seek healing, self-understanding, and personal growth,

May this work contribute to a brighter, more hopeful, and inclusive future for all.

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#### **CHAPTER I: INTRODUCTION**

#### **Statement of the Problem**

According to the U.S. Department of Veterans Affairs (2022), approximately six out of 100 people (6%) will develop post-traumatic stress disorder (PTSD) at some point in their lives due to exposure to traumatic events. Trauma is defined as the emotional or psychological response to a deeply distressing event or situation, and rates of reported trauma continue to grow among the general population, with approximately 70% of individuals experiencing at least one traumatic event at some point in their lifetimes (The Mental Health Coalition, 2024). Comorbidity of a trauma-related disorder, such as PTSD and other disorders, is approximately 80% (Creamer et al., 2001). People typically develop PTSD shortly after exposure to a traumatic event, and it can occur at any age and to any demographic (U.S. Department of Veterans Affairs, 2022).

People with Autism Spectrum Disorder (ASD) are significantly more likely to report symptoms of PTSD than the general population, with estimated rates of 32–45% (Rumball, 2022). Trauma, which has been described as a "psychological injury," is experienced in different ways among different people, may be acute or chronic in its lasting effects, and due to the vulnerability and risk factors associated with ASD, such as social naivete, communication deficits, and potentially intellectual disability, Autistic individuals are significantly more likely to experience traumatic events and situations than their typically developing peers (Kerns et al., 2015). Oftentimes, however, experiences of trauma and PTSD are overlooked in people with ASD due to difficulties in self-identifying and showing empathy in a way that is conducive to counseling interventions (Hume & Burgess, 2021). The lack of recognition of trauma in Autistic people is likely due to overlap in the presentation of symptoms, and thus, little is known about the effectiveness of therapeutic interventions for people with co-occurring Autism and trauma (Lobregt-van Buuren et al., 2021). However, one study that specifically looked at the prevalence of trauma-related disorders in Autistic adults found that adults with Autism are four times more likely to have PTSD than their non-Autistic counterparts (Griffiths et al., 2019). Another study found that utilizing traditional DSM-5 diagnostic criteria for PTSD yielded only a small number of participants with probable PTSD (4.9%). In comparison, the PCL-5 indicated a much higher rate of probable PTSD (20.4%), and almost all participants (98.06%) indicated through the interview process that they had experienced at least one identified traumatic event (Haruvi-Lamdan et al., 2019). Acknowledging and understanding communication differences and casting a wider view of what constitutes a traumatic experience may assist in the recognition of trauma in Autistic adults is a newly developing focus in the literature, and it presents curiosity as to the experience that Autistic adults with a history of trauma have had in the counseling setting with symptom recognition, appropriate diagnosis, and effective treatment.

People with ASD are presumably experiencing traumatic events at alarming rates as compared to the general population (Rumball, 2022). However, the link between Autism and trauma has been largely ignored in research. Because of this, there are currently no specific modalities that are recommended as treatment interventions for those experiencing this comorbidity (Haruvi-Lamdan et al., 2018). Autism Spectrum Disorder is a vulnerability marker for PTSD, and yet, few studies exist that identify treatment options for these individuals, and there are even more significant gaps in research for adults (versus children or adolescents) and for those who are identified as cognitively lower functioning (Haruvi-Lamdan et al., 2018). Additionally, Autistic people are at an increased risk of experiencing repeated traumas throughout their lifetimes (Hoover, 2015). It has also been found that Autistic people are at significant risk of experiencing victimization-related traumas by those close to them (Pearson et al., 2023). There are widespread gaps in the literature about what types of treatments may be effective, even though it has been recognized that Autistic people are vulnerable and at high risk for traumatic events (Lobregt-van Buuren et al., 2021).

When examining reported traumatic events among people with ASD, it is likely that the experience of trauma and trauma-related disorders may go unrecognized because of differences in perceptions of what constitutes a traumatic event in a neurotypical person versus an Autistic person (Lobregt-van Buuren et al., 2021). Differences in how diagnostic criteria for PTSD are applied and recognized in symptom presentation may contribute to the vast difference between self-reported incidences of trauma and diagnoseable experiences of trauma or a trauma-related disorder (Haruvi-Lamdan et al., 2019). Autistic adults are generally exposed to more traumatic events than non-Autistic adults due to being more vulnerable to negative life experiences such as bullying and loss of employment. However, the traumas may not be identified or seen as in need of treatment due to the individuals' cognitive impairments, executive functioning challenges, and/or difficulty relating to others and the environment (Lobregt-van Buuren et al., 2021). Additionally, these types of traumas may simply be minimized or dismissed by professionals and others. However, it has been found that Autistic individuals experience more PTSD symptoms, with particular emphasis on re-experiencing traumatic experiences and hyper-arousal related to traumatic events and triggers, as compared to typical adults. This indicates that those with Autism Spectrum Disorder have increased vulnerability as compared to their typical peers due to reduced social skills, more frequent social stressors, and a higher degree of exposure to traumatic events (Haruvi-Lamdan et al., 2020).

Given the suspected high prevalence of PTSD in Autistic people, there is a severe lack of information on effective treatment interventions for this identified demographic group. At this time, there are not specific treatment recommendations for Autistic people who are experiencing symptoms of trauma (Haruvi-Lamdan et al., 2018). Some research recommends that Autistic people may require differently structured sessions, a longer or shorter duration depending on attention, ability to communicate at their own pace, and additional processing time in the counseling setting (Rumball, 2022). Given this information, it would benefit the Autistic population to identify the lived experiences of those who have self-identified traumatic experiences to obtain insight into the situations, symptoms, and challenges that this particular demographic has faced so that treatment recommendations can more appropriately be developed and applied.

The goal of this study is to better understand the lived experiences of Autistic adults as they describe situations, events, and/or stimuli that have been self-identified as traumatic for them with the intention of bringing awareness to the presumed high prevalence of trauma in the Autistic community that often goes under-recognized and therefore under-treated. Engaging in research on the identified topic could help those with Autism have a voice in expressing their lived experiences with trauma, which could subsequently add to counseling practitioners' abilities to recognize symptom presentation outside of traditional diagnostic assessment and criteria and ultimately more effectively treat these individuals. Benefits of this study include gaining a more in-depth understanding of and expanding recognition of Autistic peoples' experiences with trauma, and providing insight and recommendations for practitioners to better recognize symptoms, explore potential strategies and interventions for treatment.

#### **Theoretical or Conceptual Framework**

Neuroscience is the study of the nervous system concerning biological bases of consciousness, perception, memory, and learning, which links our observations about cognitive behavior with the actual physical processes that support such behavior (Oktar, 2006). Bringing together a scientific approach and insight into how the brain works with behavioral observation has allowed for tremendous innovations in the field of counseling, specifically in the area of trauma-informed care and the link with biological responses (Jones-Smith, 2020). Trauma symptoms and PTSD can cause changes in brain development, reactivity, and treatment approaches often center around how to create change in neurological connections that have been created through traumatic stress (Bremner, 2006). ASD, which is typically considered a neurodevelopmental disorder or neurotype, has neurological components that contribute to the symptoms and presentation of the condition (Parellada et al., 2014). Acknowledging differences in experiences, such as the experience of traumatic events, due to differences in neurotype is important. There is a significant lack of information on the experience of and effective interventions for those with ASD and trauma, however, effects of the conditions, both separately and comorbidly, are often theorized through a neuroscience lens.

#### **Statement of Purpose**

The purpose of this study will be to obtain information about the lived experiences of adults with Autism Spectrum Disorder (ASD) to determine their perceptions of experiences of trauma and traumatic events to better identify, diagnose, and treat trauma symptoms and trauma-related disorders such as Posttraumatic Stress Disorder (PTSD). Throughout this study, the terms Autism Spectrum Disorder, Autism, and Autistic are used interchangeably. This researcher has found that among Autistic communities, there are varying preferences for the type of language utilized to identify this demographic. So, in an attempt to be respectful of all identification and identity preferences, variants of the term are utilized.

#### **Research Questions**

The first research question is: What are the lived experiences of trauma in Autistic adults? The second research question is: What themes emerge in Autistic adults' self-identified experiences of trauma?

#### Significance of the Study

The purpose of this qualitative study is to examine the lived experiences of Autistic adults and their perceptions of self-identified trauma in order to expand knowledge about identifying, diagnosing, and treating trauma symptoms and trauma-related disorders such as PTSD so these individuals can be better served in counseling settings. This study aims to address the limited research in recognizing and identifying the experience of trauma in Autistic people, as well as in having reliable and adequate treatment interventions that are known to be effective with this particular demographic. If more information can be obtained about how Autistic adults experience trauma and what themes are present in the experience of trauma in Autistic individuals, then effective treatment interventions may be more readily identified and offered by counselors. ASD is a vulnerability marker for PTSD and other trauma-related disorders. Yet, few studies exist in identifying treatment options for these individuals, with even more significant gaps in research for adults (versus children or adolescents) and for those who are identified as cognitively lower functioning (Haruvi-Lamdan et al., 2018). Trauma and PTSD are often overlooked in people with ASD due to difficulties in self-identifying and showing empathy in a way that is conducive to counseling interventions (Hume & Burgess, 2021). While many known interventions have been proven to be effective for the treatment of PTSD, Autistic

people have often been historically excluded from research studies (Lobregt-van Buuren et al., 2021). Improved recognition of trauma symptoms could be of assistance in closing this gap.

The Autistic community is underrepresented in the current literature when it comes to identifying the prevalence of trauma and trauma-related disorders. However, one study identified that Autistic people are significantly more likely to report symptoms of PTSD than the general population, with estimated rates of 32-45% (Rumball, 2022). One study that specifically looked at the prevalence of PTSD in Autistic adults found that adults with Autism are four times more likely to have PTSD than their non-Autistic counterparts (Griffiths et al., 2019). A study published the next year indicated that PTSD symptoms are significantly more present in Autistic adults (32%) than typical adults (4%) and that Autistic individuals reported more PTSD symptoms, with particular emphasis on re-experiencing traumatic experiences and hyper-arousal related to traumatic events and triggers as compared to typical adults (Haruvi-Lamdan et al., 2020). Another study yielded results of at least one self-identified experience of trauma in Autistic adults at a whopping 98% (Haruvi-Lamdan et al., 2019). Given this information, there is presumably a disconnect between how symptoms are being reported by Autistic clients and how they are being perceived and conceptualized by practicing counselors. Therefore, it is important to continue to learn more about the experience of trauma as it relates to those with Autism so that counselors can better identify and subsequently treat symptoms as they present.

Often, Autistic people are exposed to a number of risk factors and have additional challenges such as difficulty explaining their emotional state, a lack of social support, overwhelming or upsetting sensory experiences, interpersonal traumas, high distress around transitions/life changes, social difficulties, and other events related to mental health such as high rates of job loss and poverty (Rumball, 2022). Many Autistic people lose trust in others over the

course of their lifetimes due to chronic invalidation and stigma because of their differences (Gates, 2019). Thus, Autistic people may require a different approach to therapy than other groups. Keeping in mind that differences in distress tolerance, sensory experiences, communication, and processing time are essential for many Autistic people to feel relaxed enough to engage in an activity such as counseling (Rumball, 2022). Additionally, a lifetime of potentially feeling judged, dismissed, and misunderstood can interfere with the ability to respond to traditional interventions (Gates, 2019).

Trauma symptoms may be overlooked in people with ASD due to difficulties in self-identifying and showing empathy in a way that is conducive to counseling interventions (Hume & Burgess, 2021). The lack of recognition and underdiagnosis of PTSD in Autistic people is likely due to overlap in presentation of symptoms between the two disorders, and thus, little is known about the effectiveness of therapeutic interventions for people with comorbid ASD and PTSD (Lobregt-van Buuren et al., 2021). Additionally, Autistic people are often victims of succumbing to masking their Autistic traits in social situations to appear neuro-normative, and this occurs most frequently with individuals who have already experienced frequent and ongoing bullying and social rejection and can lead to burnout and other risk factors (Henry Ford Health Staff, 2023). It has been found that many Autistic people normalize being harmed by someone they know. Because it happens to them so frequently throughout their lives, masking of autistic traits occurs in order to maintain a sense of safety. However, this comes at the cost of being exhausted with potential for burnout for the individual, adding another layer of complexity to these issues (Pearson et al., 2023). Continued research on this topic could assist in the professional development of counselors to be more adept at identifying traumatic experiences in Autistic individuals, which in turn could hopefully lead to a decrease in masking if proper intervention and treatment are more accessible.

#### **Definition of Terms and Operationalized Constructs**

Autism Spectrum Disorder (ASD) is defined as a developmental and neurological condition that is attributed to differences in the brain and is characterized by challenges with social interaction, communication, repetitive behaviors, and sensory differences (American Psychiatric Association, 2022). The terms "Autism" and "Autistic" are used interchangeably with Autism Spectrum Disorder. Trauma is described as the emotional or psychological response to a deeply distressing event or situation (The Mental Health Coalition, 2024). Furthermore, Posttraumatic Stress Disorder (PTSD) is identified as a psychiatric condition that can develop after exposure to a traumatic event, and includes symptoms of four identified categories: intrusion, avoidance, alterations in cognition and mood, and alterations in arousal and reactivity (American Psychiatric Association, 2022).

#### **Assumptions and Limitations**

It is assumed that this study could yield information and themes on the lived experiences of Autistic adults and their experiences of trauma. Though it is recognized that trauma is not always well understood by clinical providers, and may not be consistently identifiable. Plus, participants may not realize or may minimize that they have experienced traumatic events. Additionally, participants in this study must have a certain level of cognitive and intellectual ability, energy stamina, and ability to follow written instructions, which may be limiting, unreasonable, or exclusionary to some Autistic people.

#### **CHAPTER II: LITERATURE REVIEW**

#### Introduction to the Literature Review

The following topics are addressed as part of the literature review: background literature on the theoretical orientation of neuroscience, early research on the relationship between Autistic traits and trauma, literature exploring the co-occurrence of Autism with PTSD and Trauma-Related Disorders, research focused on identifying sources of trauma and associated factors in Autistic individuals and their caregivers or families, and lastly, the recent emergence of mental health studies focused on centering Autistic voices. Keywords searched include: Autism/Autistic/Autism Spectrum Disorder, trauma, Posttraumatic Stress Disorder/PTSD.

#### **Theoretical Orientation**

Neuroscience, the study of the nervous system, focuses on how the brain and body create consciousness, perception, memory, and learning, and connects what is observed about how people think and behave with the physical processes happening in the brain and nervous system that make those behaviors possible (Oktar, 2006). One article displayed that there are many ways that advances in neuroscience are contributing to a better understanding of counseling from a transdiagnostic developmental perspective (Gonçalves & Perrone-McGovern, 2014). Recent advances in neuroscience have greatly improved our understanding of how the brain and behavior are connected. Neuroscience can help us better understand our clients by looking at their development from a broader, more integrated perspective. It is suggested that neuroscience can and should be more heavily utilized in future research on both the process and outcomes of therapy and can be applied to studying the effects of different counseling approaches. Various factors, such as negative experiences (like emotional neglect or stress) and positive ones (like nurturing care or a rich environment), can impact mental health. These factors affect key

psychological processes, such as the ability to focus, adapt to new situations, learn from rewards, regulate emotions, and understand oneself and others. These processes, in turn, influence different brain networks involved in attention, motivation, emotional regulation, and social understanding. Ultimately, these brain functions shape a person's cognitive abilities, social skills, emotional well-being, sense of identity, and career development (Gonçalves & Perrone-McGovern, 2014).

Themes in current literature regarding bringing neuroscience into counseling psychology have been explored (Goss, 2016). A systematic review was conducted in which several academic databases were explored, the researchers looked closely at the available papers to identify common themes. PsycINFO, a large database maintained by the American Psychological Association (APA), was utilized, which includes research articles related to psychology and social sciences, and it covered 2,561 journals, including many that publish counseling psychology research, and 217 journals focused on neuroscience. After filtering results to include journals focusing on counseling psychology and neuroscience specifically, researchers ended up reviewing 21 publications and found four main themes: Biopsychosocial Topics (discussions about how biological, psychological, and social factors interact), Neuroscience Education (the role of teaching neuroscience in counseling psychology), Integrating Neuropsychology (how to combine knowledge of brain function with psychological practice), and Implications of Integration (the potential effects and challenges of including neuroscience in counseling). Though there is not a lot of research on this yet, the existing studies show there are many ways neuroscience can be used in clinical practice. The fact that recent publications are discussing these ideas suggests there may be renewed interest in this approach. The main takeaway is that there is a clear opportunity to bring neuroscience (and neuropsychology) into counseling, both in

research and practice, and this can be done specifically by using a biopsychosocial approach, which looks at how biological, psychological, and social factors all interact to shape human experiences and behaviors. Neuroscience can provide solid evidence to back up the work of counseling psychologists, especially those who take a scientist-practitioner approach, meaning they balance both research and clinical practice. This can help them collaborate more effectively with medical professionals, like doctors and neurologists (Goss, 2016).

## Review of Research Literature and Synthesis of the Research Findings Early Research on Autistic Traits and Trauma

One of the first studies of its kind examined the relationship between those with autistic traits in adulthood and experiences of trauma, including childhood abuse, interpersonal victimization, and posttraumatic stress (Roberts et al., 2015). A longitudinal cohort, the Nurses Health Study, was examined to determine the prevalence of childhood abuse, interpersonal victimization, and PTSD symptoms among women with autistic traits to determine if those with autistic traits are at higher risk of developing post-traumatic stress disorder. Participants consisted of 1,077 women who were all mothers and nurses, predominantly White, and who were assessed for the presence of autistic traits utilizing the Social Responsiveness Scale. It was found that levels of autistic traits are associated with a higher likelihood of childhood abuse, interpersonal victimization, trauma, and PTSD. Those women with the highest presence of autistic traits were more likely to have been sexually abused (40.1%), physically and/or emotionally abused (23.9%), mugged (17.1%), pressured into sexual contact (25.4%), and high rates of PTSD symptoms (10.7%) as compared to those with lower levels of autistic traits as well as when compared to those in the general population. Limitations include that while this was a robust participant pool in terms of the longitudinal nature of data collection and participant

commitment and the overall number of participants. The study was conducted on predominantly White nurses who were mothers, and therefore, there is limited generalizability to other demographic groups. Additionally, it was noted that autistic traits are not always measurable or observable by others, and therefore those at higher risk of abuse, victimization, and trauma may not always be identified depending on the presentation of autistic traits (Roberts et al., 2015).

Another study considered the relationship between Autistic traits and mood symptoms and explored this relationship among university students. There was a focus on how Autistic traits present in a comorbid manner with ruminations and trauma-related symptomatology since it is suspected that those with high Autistic traits are more likely to have trauma-related disorders (Dell'Osso et al., 2019). A total of 178 college students (93 males and 85 females) participated through three universities of excellence across Italy. Participants completed The Structured Clinical Interview for DSM-5 (SCID-5), the Adult Autism Subthreshold Spectrum (AdAS Spectrum), the Ruminative Response Scale (RRS), the Trauma and Loss Spectrum (TALS), and the Moods Spectrum (MOODS). When looking at the AdAS scores, it was found that 74.7% of participants were "low scorers," 25.3% were "high scorers," and those in the "high scorer" group consistently scored significantly higher on the RRS, TALS-SR, and MOOD-SR total scores. The measures were intended to identify not only the presence of symptoms but also a spectrum representation of mood symptoms. Essentially, findings indicated that those with higher attributes of Autistic traits were more likely to report higher symptoms of the mood spectrum and, to a lesser extent, higher symptoms of trauma and stressor-related symptoms and rumination. Limitations include a relatively small sample size due to difficulty in recruiting a high-risk population, the acknowledgment of only utilizing self-report measures as opposed to formal diagnosis, and how this can impact findings. More recognition of Autistic traits in young

adults, a risk factor for mood symptomatology, could help prevent chronic psychological distress and improve therapeutic strategies targeted for this population (Dell'Osso et al., 2019).

Previous research has indicated that those with autism have an increased risk of experiencing traumatic events, yet, this topic had been largely unexplored, so one study sought to examine the association between autistic traits, characteristics of autism spectrum disorder, and post-traumatic stress disorder (Haruvi-Lamdan et al., 2019). Participants consisted of 103 college students (48 males, 55 females aged 18–34) who were recruited via ads from various institutions around the country of Israel. The participants had all been associated with varying degrees of autistic traits as a result of The Autism-Spectrum Quotient (AQ) completed interview that included questions about past experiences of traumatic events and the severity of distress that was experienced, as well as the PCL-5, a self-report questionnaire intended to identify symptoms of trauma. Utilizing traditional DSM-5 diagnostic criteria for PTSD yielded only a small number of participants with probable PTSD (4.9%). Meanwhile, utilization of the PCL-5 indicated a much higher rate of probable PTSD (20.4%), and almost all participants (98.06%) indicated through the interview process that they had experienced at least one identified traumatic event. Gender differences were found in that males reported more traumatic events (9.33 events) in their lifetimes than females (6.83 events) and males also scored higher on the AQ on average (17.79) than females (15.2). Results found positive associations between those with autistic traits and three of the four identified clusters; intrusion, negative alterations of cognitions and mood, and alterations in arousal and reactivity, with only the cluster of avoidance not having an association. Of those most highly affected by self-reported autistic traits, as indicated by the highest AQ scores, there was a significant increase in hyperarousal symptoms indicated. This association between autistic traits and trauma symptoms is likely due to vulnerability factors that

are more prevalent in the identified demographic group, such as increased victimization and social and cognitive impairments. Recommendations include conducting future studies to further examine the relationship between autistic traits and trauma or PTSD, as well as studies that focus on differences in experiences of trauma among those with high autistic traits versus low autistic traits and differences among gender. Limitations include the participant pool of college students and the reliance on self-report measures, so it is recommended that wider scale studies be conducted in the future as there appears to be a strong relationship between Autism and PTSD. Additionally, the authors indicated that diagnostic criteria for PTSD are limiting in nature and perhaps should be re-evaluated, especially when looking at the experiences of those with autistic traits (Haruvi-Lamdan et al., 2019).

# The Exploration of the Co-Occurrence of Autism with PTSD and Trauma-Related Disorders

A detailed systematic review of studies focusing on the relationship between Posttraumatic Stress Disorder (PTSD) and Autism Spectrum Disorder (ASD) was conducted to determine themes in assessment, presentation, rates, and treatment outcomes (Rumball, 2019). Twenty-four studies met the criteria for the study that were found through the following databases: Web of Science, Medline, Psychinfo, Pubmed, Embase, and PILOTS. Several terms were utilized to search for studies, including but not limited to autism, Asperger's, Pervasive developmental disorder, and PTSD. Additionally, while it has been found that Autistic people have experienced self-identified traumas at a high rate, this analysis focused on only one diagnostic criterion for PTSD. Published studies ranging from 1980–2017 focused on the assessment, rates, and/or treatment of individuals with ASD and PTSD were summarized utilizing a narrative analysis. Findings indicate that while the analysis was not limited to specific demographic limitations, literature on Autistic people tends to focus more on children and adolescents than adults, so this is where the most significant findings were discovered. A theme that emerged was that the most common traumatic event reported was the experience of abuse or assault (60%), as well as common themes of oppositional behavioral issues, exacerbation of ASD features, and functional impairments among those in the studies. Findings suggest that PTSD in children and adolescents is prominent in those with co-occurring ASD at a similar or greater rate than their non-ASD counterparts. While current assessments for PTSD can be effective with the ASD demographic, this has yet to be fully determined due to a lack of research on the topic. There was not enough information to gain an understanding regarding assessment or outcome measures. It is recommended that more research be conducted to gain a better understanding of PTSD in Autistic adults, as well as variances based on gender and other characteristics. Additionally, it is recommended that future research focus on assessment and treatment strategies and outcomes to better differentiate between PTSD and ASD presentations (Rumball, 2019).

One study examined exposure to traumatic events and symptoms of PTSD in Autistic adults as compared to typically developing adults (Haruvi-Lamdan et al., 2020). Participants consisted of 50 adults (25 autistic adults and 25 typical adults) with comparable groups regarding age and gender. Participants were asked to report on a variety of measures, including a socio-economic background questionnaire, a traumatic life events questionnaire, the PCL-5 to identify symptoms of PTSD as indicated in the DSM-5, and the Autism-Spectrum Quotient (AQ) to screen for Autism Spectrum Disorder characteristics. Participants reported specifically on PTSD symptoms related to their most distressing event and on social and non-social traumatic life events. Results indicated that PTSD symptoms are significantly more present in Autistic adults (32%) than in "typical" adults (4%). It was found that Autistic individuals reported more PTSD symptoms, with particular emphasis on re-experiencing trauma and hyper-arousal related to traumatic events and triggers, as compared to typical adults. Generally, Autistic participants reported a higher frequency of negative life events than typical adults, and these were often reported to be social events, especially for Autistic females. Plus, 60% of Autistic people chose a social event as their most distressing event versus only 20% of typical adults, indicating a high degree of social trauma among the Autism population. Results indicate that those with Autism Spectrum Disorder have increased vulnerability as compared to their typical peers due to poorer social skills, more frequent social stressors, and a higher degree of exposure to traumatic events. The study reveals that negative social events create significant emotional distress and are cumulative for those with ASD as they are reported to be experienced in a chronic and continuous fashion, which takes a toll and leads to ongoing stress and social difficulties. Limitations include a limited sample of participants in terms of age and a lack of recognition of comorbid diagnoses outside of ASD and PTSD. Future studies could be more expansive in terms of participants' age, gender, and other identifying characteristics, as well as examining the role of trauma and possible PTSD in different contexts for Autistic people (Haruvi-Lamdan et al., 2020).

Another study was determined to better understand predictors of trauma exposure and diagnoses for children with Autism Spectrum Disorder (ASD) and Developmental Disorders (DD) due to these predictors being difficult to identify and poorly understood in these populations because of differences and impairments in communication, behavior, and functioning (Hoch & Youssef, 2020). The current study examined 7,695 child and adolescent clients at a community mental health clinic that focuses on serving those with Autism and

neurodevelopmental disorders by comparing exposure to potentially traumatic events, negative life events, and trauma-related diagnoses between children with ASD, children with DD, and children with other mental health conditions. Evaluations, diagnostic interviews, and an array of assessment tools, such as the Child Behavior Checklist (CBL) and Vineland Adaptive Behavior Scales-3 (VABS), were utilized and analyzed to gather information from de-identified client data. Trauma was reported in 50.6% of clients in the comparison group, 40.3% of children with DD, and 23.5% of children with ASD, and a trauma-related disorder was found to be much less likely to be diagnosed in those with DD or ASD. However, experiences of negative life events were similar across the board, in 78.9% of the comparison group, 78.8% of those with DD, and 75.4% of those with ASD. These findings indicate that trauma is likely to be more challenging for providers to identify in those with DD or ASD because of difficulty differentiating trauma symptoms from these presentations. Another factor could be related to differences in parent reporting in that trauma was underreported by caregivers of those with DD or ASD because they may have lacked awareness that a potentially traumatic event had occurred, or underestimate the toll that an event had on the child. Results suggest the development and use of screening questions tailored to the identified groups that may be utilized across demographics would be helpful in determining trauma exposure and symptom presentation. Additionally, specific tools that focus on deterioration in social, language, and adaptive functioning as indicators of trauma would be helpful in better identifying the experience of traumatic events in those with ASD or DD. Other recommendations include continuing to explore appropriate interventions for trauma, especially for those with ASD or DD, as treatments typically utilized for the general population may or may not be appropriate or effective for the identified group (Hoch & Youssef, 2020).

Diagnostic clarity was the focus of one study in which researchers set out to explore the nature of traumas experienced by Autistic adults and how self-reported experiences of traumas are consistent or inconsistent with the DSM-5 definition of Posttraumatic Stress Disorder (PTSD) to determine the prevalence and significance of atypical traumatic symptoms and experiences in the adult Autistic population (Rumball et al., 2020). Participants included 59 adults (36 female, 23 male, aged 19-67 years) with Autism Spectrum Disorder (ASD). Participants completed a series of online questionnaires that focused on their experiences with traumas and related mental health symptoms and conditions. Findings indicated 33 participants reported traumatic events that met criteria for the DSM-5 definition of PTSD, and 35 participants reported experiencing a traumatic event that did not qualify for a PTSD diagnosis. It was found that Autistic adults exposed to self-reported traumas had an increased risk for developing PTSD as compared to the general population, and a wider range of events and situations tended to be named as traumatic for those with ASD as compared to what might typically be considered as typical. It was found that 40% of Autistic adults reported probable PTSD symptoms within the last month, with over 60% experiencing a probable PTSD event at some point during their lifetimes. These findings indicated that Autistic individuals are at a higher risk for experiencing trauma, and therefore, should be assessed for trauma. It is assumed that due to the differences in perception of what constitutes a traumatic event for Autistic adults as compared with the general population, many Autistic adults may have PTSD symptoms that go unreported and unrecognized. Recommendations include broadening and encouraging the use of self-report measures for individuals with ASD due to misconceptions and misunderstandings of the complexity of traumas for Autistic individuals. Additionally, more research on this topic that includes in-depth interviews, additional assessment measures, and the development of

assessments specifically geared towards the Autistic population is recommended (Rumball et al., 2020).

The presentation of Posttraumatic Stress Disorder (PTSD) in children with Autism was examined as it relates to social challenges to which the Autistic population is especially vulnerable, specifically bullying (Bitsika & Sharpley, 2021). Participants consisted of 71 boys with Autism (age 7–18 years, average age 11.63 years) who completed the Child and Adolescent Symptom Inventory (CASI-4R), focusing on their experiences with being the victims of bullying at school, coping strategies that they have developed to deal with the experiences of being bullied, and self-evaluations of their experiences of bullying and coping strategies as related to criteria for PTSD. In addition to self-reported assessments, the boys' mothers also completed severity ratings for Autism diagnostic criteria for their sons. Results found that over 80% of this demographic had been bullied, and significant relationships were found between the experience of being bullied and PTSD symptoms. The experience of being bullied and the mother reported severity of social interaction challenges, and an inverse relationship between coping strategies and score on the PTSD symptom scale were also reported. These results indicate that the Autistic population is at high risk of bullying and, ultimately, of PTSD and other trauma-related disorders due to their vulnerability in social contexts. However, the development and application of coping strategies can help alleviate some of these effects. Limitations include the inclusion of only males for this study who could be described as mildly impaired, so it would be beneficial for future research to explore this topic further as it relates to females and those who are more functionally impaired. Additionally, further exploring the frequency and severity of bullying as a predictor of PTSD in the Autistic population would be beneficial to help support more robust anti-bullying efforts in schools (Bitsika & Sharpley, 2021).

It has been well established that those with Autism are at an increased risk of exposure to trauma, thus, the purpose of the next study was to explore the rates of trauma exposure and Posttraumatic Stress Disorder (PTSD) and the role of cumulative trauma exposure and memory as risk factors for PTSD in adults with self-reported Autism Spectrum Disorder (ASD) versus those who are identified as typically developing (TD; Rumball et al., 2021). Assessments of self-reported frequency of trauma exposure with the Life Events Checklist (LEC), PTSD symptomatology with the Posttraumatic Stress Checklist (PCL-5), and memory with the Everyday Memory Questionnaire (EMQ-R) and the Behavior Rating Inventory of Executive Function (BRIEF-A) were utilized. The Autism Quotient (AQ) was also administered to confirm those with self-diagnosed ASD. Participants included 38 Autistic adults (age 18-68 years) and 44 typically developing adults (age 19-57 years), and these participants completed the identified assessment tools. A quantitative analysis was performed to compare the groups on trauma exposure, PTSD symptoms, and memory variables. Results indicated that trauma exposure and PTSD symptomatology were significantly higher in the ASD group as compared to the TD group, with noticeable differences in working memory and everyday memory, and a cumulative effect of trauma exposure on PTSD symptom severity was found only in the ASD group. In the ASD group, specific traumas that were most present were physical assault and uncomfortable sexual experiences, as opposed to the TD group findings of sudden unexpected death of a loved one as the primary identified trauma. It was also found that probable PTSD following trauma exposure was 47% in the ASD group as compared to only 5% in the TD group. These findings indicate the need for trauma and PTSD screenings for adults with ASD, noting that cumulative trauma and memory deficits may work to increase the prevalence of PTSD in those with ASD. It is recommended that future studies build upon the interpretation of trauma in ASD individuals

and continue to identify additional risk factors for trauma events and PTSD in ASD adults. It is also recommended that there are considerations in modifying traditional assessments for identifying traumatic events due to the differences in experiences among those with ASD as opposed to the general population (Rumball et al., 2021).

A case study was conducted that provided insight and perspective into the experience of an Autistic adult with intellectual disability with a history of trauma to gain more in depth understanding around the manifestations and trajectories of PTSD symptoms in those with comorbid Autism and intellectual disability (Kildahl & Jorstad, 2022). Given the unique needs and experiences of those with Autism and intellectual disability, it is suspected that these individuals are at risk for enduring different and often more severe types of traumas than the general population, and therefore, it is important to better understand how trauma and potentially PTSD manifests in order to better equip service professionals and mental health providers in identifying signs and symptoms in this group. A case study was initiated on a middle-aged (50s) man under guardianship who had been recently referred to a specialized psychiatric program for those with Autism and intellectual disability due to challenging behavioral issues and avoidance. Observational data, interviews with the man's family and caregivers, and a comprehensive medical and developmental review were collected. Through this data collection, it was found that the man had experienced multiple instances of exposure to traumatic events, including scalding by a caregiver and physical coercion by caregivers and hospital staff. After these events, the man developed severe symptoms such as phobias, avoidance, aggressive behaviors, agitation, and sleep disturbance; all symptoms that are consistent with PTSD presentation. Interventions were subsequently provided after the data collection and diagnostic determination, and with the incorporation of trauma-informed practices, have contributed to positive outcomes. Prior to this

study and subsequent intervention, behavioral techniques such as exposure strategies were utilized, which only seemed to increase distress and symptom presentation. While this study yields beneficial information for the determination of PTSD symptom presentation in an adult with Autism and intellectual disability, as well as favorable outcomes related to trauma-informed interventions, the primary limitation of this study is that it is a single case study and therefore limited in its ability to be generalizable to the greater demographic. It is recommended that future studies expand on this research to support better recognition and understanding of trauma in those with Autism and intellectual disability (Kildahl & Jorstad, 2022).

Due to the recognition of the relationship between Autism and trauma and the lack of current research specifically on this age group, one study focused on identifying the experiences of trauma symptoms in middle and older age Autistic adults (Stewart et al., 2022). Adults aged 50 and older were surveyed about their current and childhood socio-communicative difficulties characteristic of Autism as part of the PROTECT study, a large-scale study of 20,220 individuals. According to the results, 1.2% of the PROTECT participants reported a high degree of Autistic traits (n = 251), and data was explored with age- and sex-matched older adults' reports of lifetime traumatic experiences and current symptoms of PTSD, anxiety, and depression. Findings indicated that 30% of those with high Autistic traits, compared to 8% of the comparison older adult group, reported severe trauma in childhood and/or adulthood (physical, emotional, and/or sexual trauma), along with elevated presence of PTSD symptoms and also a significantly greater impact of reported PTSD symptoms for those with high Autistic traits. Results indicate that high Autistic traits indicate a higher likelihood of experiencing trauma as well as a greater impact of traumas experienced across the lifespan. This study only included those with Autistic traits, so recommendations include more extensive research in future studies

examining those who have been professionally diagnosed with Autism to determine whether the pattern is similar, as suspected (Stewart et al., 2022).

The COVID-19 pandemic brought a lot of trauma-related symptoms to light, and one study explored Autism Spectrum Disorder (ASD) with PTSD-related symptoms during and after the COVID-19 pandemic to determine if there is an association between these variables when pathogen threat-related traumatic situations are present (Zhao et al., 2022). Participants consisted of 696 individuals (379 females; average age 22.78) who completed questionnaires that assessed their degree of Autistic traits, presence and severity of COVID-19 related PTSD symptoms, and anxiety sensitivity. Results indicated that those with higher levels of Autistic traits showed higher levels of COVID-19 related PTSD symptoms and higher anxiety sensitivity. This was especially true among women in the participant pool. The findings display the importance of recognizing how trauma manifests in Autistic people, and that females with high Autistic traits were more vulnerable to pandemic-related stressors and anxiety. The findings suggest that interventions typically utilized to address anxiety symptoms may be helpful in relieving trauma-related symptoms in this scenario, such as cognitive behavioral therapy. Future recommendations include continuing to explore the relationship between Autistic traits and trauma, as well as continued assessment of the role of sex differences in Autism and other symptom presentations (Zhao et al., 2022).

Given the high risk of victimization, particularly sexual abuse and violence, against these individuals, one study examined the prevalence of Posttraumatic Stress Disorder (PTSD) in Autistic adults with co-occurring intellectual disability through a cross-sectional study to determine if recognition of trauma-related disorders is underrepresented in this population (Kildahl & Helverschou, 2024). Participants consisted of 88 Autistic adults, 26 females and 62 males aged 15–68 years, with co-occurring intellectual disability referred for mental health assessment as part of a longitudinal study, the Autism, Intellectual Disabilities, Mental Illness Study (AUP). It was found that 34.1% of this sample had experienced violence, 17% had experienced sexual abuse, and 6.8% had experienced both violence and sexual abuse, however, only 3.4% of these individuals were diagnosed with PTSD, suggesting possible underrepresentation of this condition in the sample. Many participants were diagnosed with other mental health conditions, such as anxiety disorders, which suggest that there may be underrecognition of trauma symptoms in this demographic and/or the criteria for a diagnosis of PTSD is not representative of this demographic's presentation of trauma symptoms. It is also noted that the level of intellectual disability (mild, moderate, or severe/profound) may play a role in diagnostic accuracy, although, a somewhat surprising result from this study was that all of the participants who were diagnosed with PTSD had severe/profound intellectual disabilities. This could be attributed to these individuals being more vulnerable to traumatic experiences and likely have experienced more significant and/or repeated violence and abuse. Since this study was conducted utilizing data that was longitudinal in nature, causal interpretations are not possible. It is recommended that future studies explore this demographic to learn more about how trauma manifests in Autistic adults with intellectual disability and to better explore utilization of the diagnosis of PTSD in the identified population (Kildahl & Helverschou, 2024).

Another study aimed to look at potential variables to help explain why PTSD is underrecognized and, therefore, underdiagnosed in autistic adults, even though this group is at high risk for experiencing trauma and post-traumatic stress (Reuben et al., 2024). This study explored differences between self-reported PTSD symptomatology and predictors of a professional diagnosis in adults with self-reported autism. Participants consisted of 677 self-identified autistic adults who all completed an online survey that included demographic information, mental health symptoms, and history of trauma. The researchers utilized T-tests and chi-squares to compare subgroups (PTSD+ for self-screened positive PTSD, and Diagnosis+ for professional diagnosis), and logistic regression was utilized to predict diagnosis status. It was found that those who screened positive for PTSD were more likely to be female or a gender minority, of older age, unemployed or on disability, and have lower functional impairment and increased posttraumatic stress and co-morbid conditions; these characteristics also predicted more formal diagnosis of PTSD by professionals. Whereas cisgender men and those who are employed with generally lower functional impairment were less likely to be identified as having PTSD by self-report and by professionals, which could indicate a lower recognition of symptoms in this subgroup due to gender stereotypes. Additionally, autistic adults with a very high degree of functional impairment have increased difficulty obtaining a PTSD diagnosis and thus receiving appropriate treatment. It is recommended that these factors are taken into consideration when assessing autistic adults, given the high likelihood of having had one or more traumatic experiences. As autistic cisgender men were found to have the largest diagnostic gap between symptom presentation and professional PTSD diagnosis, special consideration should be paid to this demographic. Many autistic adults screen positive for PTSD but have never and may never be formally diagnosed, which can add to barriers to trauma-informed care and treatment (Reuben et al., 2024).

# Identification of Trauma and Associated Factors in Autistic Individuals and Their

## **Caregivers or Families**

Some studies have sought to identify the experiences of trauma as well as factors such as risk in the autistic population. One study intended to gain a more extensive understanding of the

lived experiences of Posttraumatic Stress Disorder (PTSD) in Autistic adults who also have a comorbid intellectual disability through the lens of mental health professionals in terms of identification and understanding of the condition in this population (Kildahl et al., 2020). A phenomenological analysis was utilized to explore the experiences of PTSD in the identified group by interviewing 18 mental health clinicians (14 female, 4 male) who regularly work with those who have comorbid Autism Spectrum Disorder (ASD) and intellectual disabilities (ID). Results indicated that causes and expressions of PTSD are often different in those with ASD and ID, and there are additional challenges in identification of trauma symptoms in this group as compared to the general population. "If we do not look for it, we do not see it" the title of this article and a direct quote from one of the participants, is representative of how clinicians who participated in this study described their experience with identifying potential traumatic events and trauma-related symptoms and disorders in those with ASD and ID. Furthermore, this is due to how the detection of trauma is more challenging due to differences in communication, thought processes, understanding, and general intellectual functioning. Those with ASD and ID often display deterioration of functioning, changes in language or behavior, social withdrawal, and aggressive or self-injurious behavior can be indicators of trauma. Additionally, it is suggested that a wider range of causation should be considered when determining events that may be experienced as traumatic by the identified population. It is recommended that thorough, multidimensional assessments with a trauma-specific focus are developed and utilized for the identified group, and that interviews with families, caregivers, and other sources close to individuals be sought out and taken into consideration when exploring a potential trauma history. Additionally, it is recommended that clinicians ask specific questions about trauma, otherwise, it is likely to go unidentified (Kildahl et al., 2020).

Another article from 2020 determined the frequency of assessment, screening, and treatment of trauma-related symptoms in a group of youth patients with Autism Spectrum Disorder (ASD) and examined the providers' perceptions of the need for and barriers to trauma-related services (Kerns et al., 2020). Participants consisted of 673 community based ASD providers who had participated in the 2017 Usual Care in Autism Survey (UCAS), which was designed to assess usual care among children, adolescents, and young adults with ASD among community providers. It was found that over 50% of providers reported some level of screening and treatment of trauma-related symptoms for youth with ASD; 70% of providers informally inquired about trauma-related symptoms, but only 10% universally screened for them. The type and depth of screening and assessment varied among providers in terms of discipline, setting, amount of interaction with the patient, and years of experience with ASD, as well as by patient sex, ethnicity, and socioeconomic status. Findings indicate that more structured trauma screening is a needed service in community clinics, as well as specific provider training on assessing and treating trauma-related symptoms, especially efforts tailored for those with ASD. Providers indicated that it is strongly believed that more extensive training and resources around trauma assessment, symptom recognition, and treatment geared toward working with clients with ASD are needed (Kerns et al., 2020).

A risk factor related to trauma is increased suicidality. Therefore, one study focused on gaining further insight into the Interpersonal Theory of Suicide and whether or not it informs an enhanced understanding of the high rates of suicidality in Autistic adults through specific traits (Pelton et al., 2020). Suicidality occurs at a significantly higher rate among autistic individuals than in the general population. While there is still a lack of clarity as to why this is, it is hypothesized that this is due to more frequent and severe risk factors such as traumas, masking,

and coping without support. The Interpersonal Theory of Suicide, a highly cited theory of suicide, proposes that there are three proximal risk factors for suicidality: strong feelings of thwarted belonging, perceived burdensomeness, and suicidal capability (the body's change in pain and fear systems in response to lifelong traumas). The current study assessed a total of 695 participants (64.6% female, mean age 41.9, age range 18–73) among two groups, one of Autistic adults and one of non-Autistic adults, to explore the topics of thwarted belonging and perceived burden (measured by the Interpersonal Needs Questionnaire 10; INQ-10), autistic traits (measured by the Autistic Quotient Short Form; AQ-S), suicidal capability (measured by the Acquired Capability for Suicide Scale-Fearlessness of Death; ACSS- FAD), traumatic life events (measured by the Vulnerability Experience Quotient; VEQ), and lifetime suicidal thoughts and behaviors (measured by the Suicide Behaviours Questionnaire-Revised; SBQ-R). Findings indicated that autistic traits influence suicidality through thwarted belonging and burdensomeness in both groups. These findings were consistent with the literature reporting higher rates of suicidality in Autistic versus non-Autistic adults. Additionally, Autistic people indicated significantly higher rates of traumatic events than their non-Autistic counterparts. Trauma was significantly associated with lifetime suicidality. It is recommended that future research explore the importance of promoting self-worth and social inclusion for suicide prevention in autistic individuals and how these are experienced in the autistic population. Additionally, it is recommended that future research establish specific models of suicide assessment and intervention that are specifically tailored to autistic people (Pelton et al., 2020).

Medical trauma, specifically, was the focus of one study (McLaughlin et al., 2021). The specific care needs of adult trauma patients who have autism spectrum disorder (ASD) were explored, as it was previously suspected based on prior research that injured adults with ASD

would have increased needs when it comes to clinical care, such as longer stays, higher mortality rates, and more complications as compared to those without ASD. Additionally, it is suspected that adults with ASD are at a higher risk of injury and physical trauma in general. A total of 185 injury patients with ASD (81.1% were male) were matched to 370 controls. Researchers worked with the Pennsylvania Trauma Systems Foundation's (PTSF) statewide database and the Pennsylvania Trauma Outcomes Study (PTOS) to identify patients of at least 18 years of age with an identified Autism Spectrum Disorder (Autism, Asperger's, or Pervasive Developmental Disorder) who had been admitted to a Level I or Level II trauma center in Pennsylvania and had endured a stay greater than 48 hours between the years of 2010–2018. It was found that adult patients with ASD did indeed typically have more needs, including more intubations, lengthier hospital stays, and a higher chance of being discharged to a skilled nursing facility as opposed to going home. It was also found that adults with ASD are more likely to be injured than their non-ASD counterparts in their own homes (30.3% versus 22.3%) or at a residential facility (20.3% versus 1.9%) and more often experience being struck as pedestrians (12.5% versus 3.3%). Differences in mortality, complication, imaging, and operation rates were not observed. Overall, it was found that adults with ASD typically stayed approximately 3.13 days of hospital stay as compared to the control population. It is recommended that future studies are conducted that focus on identifying factors that contribute to the identified disparities for adults with ASD when injured. Additionally, it is recommended that care teams and medical personnel receive additional support around engaging in proactive, collaborative efforts to improve the experience of adult trauma patients with ASD (McLaughlin et al., 2021).

Assessing trauma utilizing traditional methods may present challenges for autistic people. Therefore, the purpose of one study was to identify questionnaires that are typically used to identify trauma symptoms (focusing on emotional dysregulation and interpersonal difficulties) in the general population and evaluate their psychometric properties to determine what types of measures may be most appropriate to adapt for autistic people with mild intellectual disability and a trauma-related mental health condition given the specific needs of this demographic (Wigham et al., 2021). Autistic people with mild intellectual disabilities are likely to have experienced social and relational challenges and interpersonal conflict, as well as difficulty managing emotional responses, making them vulnerable to experiences of trauma. The researchers searched several databases for studies focusing on complex trauma interventions in the general population (adults age 19 and older) and then applied a filter to assess the psychometric tools utilized in the identified studies and evaluated them with the consensus based standards for the selection of health based measurement instruments (COSMIN) checklist. Of the five studies initially identified for complex trauma interventions, 33 articles were examined on their psychometric properties, with, ultimately, the strongest psychometric evidence present for the Emotion Regulation Questionnaire (ERQ) and the Difficulties in Emotion Regulation Scale (DERS). As it has been identified that autistic people, with a focus on those with mild intellectual disability, tend to have difficulties with emotion regulation and interpersonal challenges, these two questionnaires may be appropriate to consider adapting specifically for the autistic population to more effectively identify the presence of a trauma-related mental health condition. As trauma-informed care is limited for autistic people with intellectual disabilities, continued efforts are needed to better identify this group's experiences of trauma as well as trauma-related interventions. Recommendations include continuing to explore current trauma questionnaires and assessments to determine appropriateness for the autistic population, as well as moving forward with the current findings of this study, adapting the identified measures, and

evaluating the effectiveness of doing so with autistic people with intellectual disabilities. Additionally, looking at the appropriateness of measures with respect to age, gender, and cultural background will be a necessary step in future research (Wigham et al., 2021).

Trauma may not only be experienced at the individual level but at a familial systemic level as well. The purpose of one study was to gain further understanding of complex trauma in families that have a child or adult with a learning disability and/or autism since it has long been clinically suspected that such families have a high prevalence of complex post-traumatic stress disorder due to chronic exposure to stress and risk factors (Blackman et al., 2022). As compared to families with typically developing children, families with children or adults who have learning disabilities and/or who are autistic tend to experience additional challenges, including a lack of social, financial, and communal support, which oftentimes are associated with increased risk factors for individual and familial stress. Six families were identified as participants, all of whom had a child or young adult (over age 16 years) in the home with learning disabilities and/or autism, parents between the ages of 30–50, and resided in England. All the families were referred to the study because they were identified as needing additional support by their respective professional networks. The families were interviewed multiple times by psychotherapists over 12 weeks to determine if any themes around trauma were present, and three main themes were identified: how trauma happens in families, the impact of trauma, and the nature of support and intervention. Many of the interviews revealed that the participants had experienced many situations in which they were met with a lack of support and understanding by professionals around their child's needs, that it is difficult to cope with feelings of failure as parents around meeting their child's needs, and that the parents themselves were often going through periods of crises alongside their children. These findings suggest that families with high support needs often feel excluded, disempowered, misunderstood, and isolated. Recommendations include increasing awareness among medical and mental health professionals at identified critical points of high stress: birth, diagnosis, transition to adulthood, and adulthood when parents are aging so that the families' needs can be better met proactively. Additional recommendations include future studies focusing on the needs of caregivers and families of those with learning disabilities and/or autism (Blackman et al., 2022).

Another study included caregiver reports as a reliable source for participant experience of trauma; the purpose of the study was to explore potential sources of childhood trauma in Autistic adults based on self-reports and reports of their caregivers through a qualitative study (Kerns et al., 2022a). Participants included 14 Autistic adults and 15 caregivers, aged 18–70 years old, with variance in socioeconomic and cultural backgrounds, clinical profiles, adverse experiences, and levels of functioning. Participants completed standard assessments for Autism and traumatic exposures and stress in addition to the interviews. A thematic analysis was conducted, and a wide range of traumatic experiences were identified, ranging from those that are typically identified as traumatic among the general population (such as abuse and social marginalization) to those that are unique to the Autistic population (such as sensory traumas). Themes included physical abuse, emotional abuse, death of a loved one, loved one seriously sick/injured, bullying, and 'other trauma,' which included social exclusion and communication challenges. Results indicated that traumas experienced by Autistic adults are not often captured by standardized measures and, thus, may go unrecognized, undiagnosed, and therefore untreated by professionals. Recommendations mention a dire need for future research to continue to assess what types of traumas are common among Autistic people to assist in more accurately

identifying the experience of Autistic people, which will ultimately aid in developing specific treatment around trauma in Autistic individuals (Kerns et al., 2022a).

Identifying trauma symptoms for autistic individuals can be challenging for professionals in the field. Therefore, the purpose of one study was to gather information on trauma indicators for youth with Autism Spectrum Disorder (ASD) as identified by experts in the field of Autism and/or childhood trauma (Kerns et al., 2022b). Participants consisted of 72 individuals who were identified as experts (professionals in the areas of clinical research, administration, and/or behavioral analysis or mental health providers with 5 years of clinical experience with ASD and/or childhood trauma or more) who could weigh in on traumatic stress symptoms and other trauma indicators in Autistic youth through a 2-round Delphi survey. PTSD symptoms and other trauma indicators were collected and were then rated on importance by the participants to narrow down and determine specific indicators that are likely to predict or be consistent with the experience of PTSD in Autistic youth. Results show 22 of the 48 identified indicators reached consensus (>75% endorsement during round 2), which included intrusions, avoidance of trauma reminders, and negative alterations in mood/cognition and arousal/reactivity. Additionally, factors of increased reliance on others, adaptive and language regressions, self-injurious behaviors, and non-suicidal self-injury were recognized as important indicators as well. Results indicated a need for tailored and developmentally informed assessments for the experience of traumas for youth with Autism, which could improve recognition and diagnostic accuracy. Additionally, sensitivity and awareness of the difference in the presentation of trauma-related symptoms in Autistic youth are important for providers to be aware of, as existing measures for trauma and trauma-related disorders are not inclusive or representative of the specific presentation and needs of this demographic (Kerns et al., 2022b).

One study examined data from several sources utilizing a meta-analysis to provide an overview summary of prevalence rates of victimization among autistic individuals, as well as determine what types of victimization they are most at risk for experiencing (Trundle et al., 2023). It has been established that autistic individuals experience victimization at a higher rate than the general population. Thus, this study focused on determining, through the examination of relevant literature, the prevalence not only for victimization generally but types of victimization in more specific presentations. The meta-analysis was conducted on 34 studies that contained the identified inclusion criteria: quantitative studies, studies involving autistic individuals, and studies that report the prevalence of victimization. Studies focused on both children and adults from clinical and community settings. Findings indicated that throughout the studies, 44% of autistic people were found to have endured victimization, and subgroups identified included bullying (47%), child abuse (16%), sexual victimization (40%), cyberbullying (13%), and 84% for multiple forms of victimization. These findings suggest confirmation that victimization among autistic individuals is high, and while variable across types of victimization, there are many shared traumatic experiences. This study highlights the need for strategies and interventions to reduce and limit incidences of victimization. Recommendations include broadening the studies focusing on types of victimization in autistic people, especially those that have not been as focused in the past, such as child abuse, sexual victimization, and conventional crime, as these areas have not been as extensively studied as bullying (Trundle et al., 2023).

The purpose of the next study was to investigate the experiences of Autistic people as victims of sexual assault and intimate partner violence, as it has been well-established that Autistic people are more likely to be victimized than non-Autistic people (Douglas & Sedgwick, 2024). Participants consisted of 24 Autistic adults ages 25–61 years (6 males, 15 females, and 3

non-binary individuals) who engaged in completing the Autism Quotient (AQ) assessment along with semi-structured online interviews about their firsthand experience with intimate partner violence and/or sexual assault. It was found that nearly all of the participants had experienced repeated incidents of intimate partner violence and sexual assault, regardless of gender, with clear consistencies among these self-reports. A thematic analysis was conducted, and six themes emerged from this data, including experiences of abuse, autism used against you, poor family models, the impact of/on friendships, handling trauma, and recommendations for future practice. It is likely that Autistic people experience similar patterns of abuse to those who are non-Autistic. However, there are attributes unique to Autism that add to the vulnerability of this particular population. It is recommended that future endeavors focus on providing sex education tailored specifically for Autistic people to assist in the recognition of potentially abusive behaviors as well as safety strategies to better equip them in responding to these types of incidents. It is also recommended that future research focus specifically on the lived experiences of Autistic men, non-binary individuals, trans individuals, people of color, and those with co-occurring intellectual disabilities, as these groups are currently underrepresented in the literature (Douglas & Sedgwick, 2024).

Some autistic individuals require a high level of care, which can lead to overwhelm, burnout, and vicarious trauma for those in the helping and supportive roles of these individuals. The purpose of one study was to determine the effectiveness of a reflective supervision group of social care professionals who support autistic adults (Hallinan & McMahon, 2024). During a four-month pilot group experience, six male social care participants who work with Autistic adults in the community engaged in a supervision group to assist them in managing their challenging and complex practice. Given the stress that often comes with caring for Autistic individuals with high support needs, including burnout and vicarious trauma, it was hypothesized that a reflective group experience would help prevent and/or manage these types of symptoms should they arise. A thematic analysis was conducted at the end of the sessions based on the participant's responses to a questionnaire after the final supervision session, and themes found were as follows: increased insight/empathy, experiential learning, enhanced awareness/skills in relational practice, personal resilience, team resilience, and emotional challenges. Findings suggest that reflective supervision can be highly beneficial in increasing resilience, emotional insight, and motivation for those supporting clients with high support needs. Recommendations include the suggestion of group reflective supervision for those working with Autistic individuals because of the high likelihood of these groups increasing empathy, resilience, and improving outcomes when it comes to risk factors for burnout (Hallinan & McMahon, 2024).

Adverse childhood experiences (ACEs) have been well established as indicators of trauma, and one study set out to determine how ACEs affect adults with Autism Spectrum Disorder (ASD) as compared to those who are non-Autistic/with typical development (TD) (Okumura et al., 2024). Participants consisted of 205 high-functioning Autistic adults and 104 typically developing adults. Participants were administered the Childhood Abuse and Trauma Scale, the Japanese version of the Autism-Spectrum Quotient, Conners' Adult ADHD Rating Scale, the Japanese version of the Impact of Event Scale-Revised, and the Japanese version of the Adolescent/Adult Sensory Profile. ACEs were examined in terms of how they associate with ASD core symptom presentation, as well as how they may impact peripheral symptoms such as those typically consistent with ADHD and PTSD, as well as hypersensitivity. Results indicated that ACEs are significantly associated with a higher intensity of ADHD symptoms, PTSD

symptoms, and sensory hypersensitivity independent of ASD diagnosis. Additionally, it was found that core symptoms of ASD were not significantly associated with ACEs. Therefore, it is suggested that ACEs do not exacerbate the core symptoms of ASD as previously hypothesized. Overall, results suggest that early intervention for ACEs in Autistic children will not necessarily improve core symptoms of ASD but could likely have a significant impact on alleviating peripheral symptoms related to ADHD, PTSD, and hypersensitivity. Recommendations include further research to establish causality based on these findings to assist in the application of this information to clinical practice (Okumura et al., 2024).

### The Emergence of Mental Health Studies Centering Autistic Voices

In recent years, there has been a shift in the literature towards centering autistic voices. One study explored the experiences of autistic adults on priorities to address mental health needs, such as what kind of research they feel is needed and what mental health outcomes are important and valuable to them (Benevides et al., 2020). A project team involving autistic and non-autistic members in collaboration with an 18-member community council composed of autistic adults and parents of autistic adults led three activities: two large stakeholder meetings, an online survey, and three face-to-face focus groups for autistic adults. A total of 377 individuals participated in the project's activities over a two-year period, with the majority of participants (n = 297) being either self-diagnosed (n = 54) or formally diagnosed (n = 182) autistic adults. Notable findings among the data collected include a strong desire for autistic-specific research on psychological therapies and trauma-informed care practices, as well as intervention research on the use of medical marijuana to treat mental health symptoms. Across measures, focusing on mental health interventions and outcomes for autistic people in research was identified as a significant area of need, and participants expressed concerns about gaps in current research

related to evidence-based interventions specifically for the identified demographic. It was felt that this study was important due to the significant lack of current research that centers on autistic voices and their experience with mental health, and there is a continued need for more extensive research on this population and their mental health needs and outcomes. Limitations primarily include a limited participant pool, as it would be helpful to reach a wider range of participants in future studies when it comes to age/lifespan, racial and ethnic minorities, and those with varying communication abilities across the spectrum (Benevides et al., 2020).

One study focused on understanding the lived experiences of autistic adults in mid-to-late adulthood who grew up during a time before Autism was as well known in Australia (Lilley et al., 2022). A total of 26 participants who were all born before 1975 (ranging from age 45–72) and who all had a diagnosis after age 35 were interviewed by autistic researchers with a focus on the topics of being different, exploring identity, the suffering self, and being Autistic. Of the participants, 14 were female-identifying, 10 were male-identifying, and one was non-binary identifying. Participants were predominantly White, well-educated, and middle class, and the period of time since formal diagnoses ranged from three months to 10 years. Particular attention was paid to the participant's sense of self. Some of the interviewees' responses indicated that they had experienced trauma, including bullying and sexual abuse, negative self-perception, and suffering due to self-reported experiences of stigma, discrimination, exposure to ableism, and depressive symptoms. For most participants, it was reported that receiving a formal autism diagnosis was positively associated with a greater sense of self and an increased ability to focus on one's strengths and positive attributes. Contrary to previous research, which has indicated that autistic people have challenges in the area of self-awareness, the participants in this study largely exhibited a high degree of self-reflection as well as empowerment around their identities as

autistic people. This study found that many autistic people can engage in deep reflection of their lives and experiences as well as their evolving identity of self. Many participants in this study also indicated that they wished that they had been diagnosed with autism earlier in life. However, it is suspected that they were not due to having average or above-average intelligence and fluent verbal communication skills. Recommendations include conducting additional studies addressing the self-perceptions and experiences of autistic adults to better understand the complexity of the autistic experience (Lilley et al., 2022).

Meltdowns, a commonly noted experience for autistic people, were analyzed in depth in a study that sought to have an enhanced understanding of the lived experience of internalized meltdowns for autistic adults, something that has been rarely explored from the perspective of the autistic adult's point of view (Lewis & Stevens, 2023). There were 32 Autistic adults, all of which identified as Autistic and had experienced a meltdown at some point in their lives. They participated in this study through asynchronous online interviews, of which data were analyzed utilizing a descriptive phenomenological approach. Six themes that captured the experience of Autistic meltdowns were discovered among the data: feeling overwhelmed (by informational, sensory, social, or emotional stressors); experiencing extreme emotions (such as anger, sadness, and fear); losing logic (including challenges with thinking and memory); grasping for self-control (in which participants felt out of touch with themselves); finding a release for emotions (often described as an "explosion" of external behaviors or self-harm); and minimizing social, emotional, or physical harm (by avoiding triggers or self-isolating when possible). These findings provide clarity to some of the common experiences of Autistic people and what encompasses a meltdown beyond external behavioral characteristics. A key takeaway from the study was that meltdowns may serve a functional role in helping Autistic people manage their

emotional experience and in expressing themselves in times of distress. However, several participants also reported feeling out of control and unsafe during these episodes. Feeling overwhelmed was not only a theme found throughout the experience of meltdowns but was often cited as the trigger for a meltdown to start. Recommendations include clinicians focusing on the experience of expressing emotions and being strategic about non-physical forms of energy release during therapy to help self-regulation and maintenance of safety during times of high distress and impending meltdown. Additionally, these findings support additional perspectives around what constitutes "problem behavior" that is often cited in Autistic people and offers alternative ways of looking at these experiences in a way that is supportive and not invalidating (Lewis & Stevens, 2023).

Specific types of traumas were explored per self-report in one study; the purpose was to understand the self-identified impact of interpersonal violence and victimization on autistic adults and also explore interventions that may aid or inhibit recovery efforts as it is suspected that there is a high prevalence of such issues within the autistic community that may lead to poor mental health outcomes for this population (Pearson et al., 2023). A total of 102 participants with ages ranging from 19–73 years from the United States and the United Kingdom completed either an online survey or verbal interview about their personal experiences of interpersonal violence and victimization. Participants with self-identified autism were included in this study, and 80 of the participants reported having been diagnosed with one or more additional medical or psychiatric diagnoses. Utilizing thematic analysis of the reports, four themes were identified, including the expectations of victimization and experiences of othering as expected for those with autism, being part of a neuro-minority including trauma, masking, and burnout, the impact of human injustice, and structural inequality/power dynamics, support, and community. Most participants reported that those who caused harm to them were friends or close family members. However, teachers, classmates, co-workers, and bosses were also common perpetrators. In about half of the reported cases of interpersonal violence or victimization, the perpetrator knew that the victim was autistic. These findings suggest that many autistic people normalize being harmed by someone they know because it happens to them so frequently throughout their lives. Additionally, it can be deduced that autistic people often feel the need to mask their autistic traits to maintain a sense of safety. However, this comes at the cost of being exhausting, with the potential for burnout for the individual. Recommendations include improving training initiatives about the autistic lived experience to professionals (specifically those in mental healthcare and the police force) and reducing systemic inequalities, which will likely reduce barriers to appropriate support and recovery efforts. Additional recommendations include future studies focusing on those who have higher support needs and/or who have experienced institutionalization, as it is suspected that the prevalence of interpersonal violence and victimization is higher for those individuals (Pearson et al., 2023).

## Rationale

The rationale for the current study is primarily due to the severe lack of information on those who have comorbid ASD and trauma or trauma-related disorders, as very little is known about this presentation. Yet, it is estimated that Autistic people suffer from trauma at alarming rates as compared to the general population (Rumball, 2022). Autistic people are often excluded from research, and therefore, there are widespread gaps in the literature about symptom recognition as well as what types of treatment may be effective for this vulnerable and high-risk demographic (Lobregt-van Buuren et al., 2021). Examining the experiences of those with ASD who have experienced one or more traumatic events, along with the notion that individuals with ASD are largely underrepresented in research and without strong ideas of experiences of this demographic or specific evidence-based treatment recommendations, may open doors for clinicians to better recognize trauma in Autistic people and subsequently provide modalities that are likely to result in symptom reduction, and if unfounded, may at least reasonably create more discussion around the need for additional future studies on this topic.

## **CHAPTER III: METHOD**

### **Introduction to the Method**

People with ASD are experiencing traumatic events at high rates as compared to the general population, and the link between Autism and trauma has been largely ignored in research (Haruvi-Lamdan et al., 2018; Rumball, 2020). When examining reported traumatic events among Autistic people, it is likely that the experience of trauma and trauma-related disorders may go unrecognized because of differences in perceptions of what constitutes a traumatic event in a neurotypical person versus an Autistic person (Lobregt-van Buuren et al., 2021). Additionally, the voices of Autistic adults have not been historically considered in the development of counseling interventions. This qualitative research study examines the topics specifically: What is the lived experience of trauma in Autistic adults? What themes emerge in Autistic adults' self-identified experiences of trauma?

### **Study Design**

A thematic analysis was selected as the study design. The participants were invited to participate in a survey that collects information on the unique lived experiences of the identified demographic to identify themes in experiences. Given the lack of current research aimed at identifying the experiences of this demographic, the survey consisted of open-ended questions to identify themes that emerge within the content provided by participants. Thematic analysis is appropriate for this study because it is a flexible method that allows for themes or patterns to emerge from the information gained by the responses of participants, which allows for transparent and systematic reporting of the qualitative data that is obtained (Terry & Hayfield, 2021).

Understanding the conceptual world of a group of people could help to better understand those with comorbid Autism and trauma who have had fewer avenues to communicate their experiences and are largely misunderstood clinically due to differences in sensory, communication, and therefore symptom experience. A thematic analysis study could help the research team, and subsequently, mental health clinicians, to better understand themes related to the experience of the targeted population and, eventually how to develop appropriate interventions based on this knowledge.

## **Study Context**

There is no identified intervention in this study. Informed consent and demographic questions were collected via SurveyMonkey. This qualitative study utilized open-ended questions with responses collected via SurveyMonkey.

## **Participants**

The population is Autistic adults who have experienced one or more traumatic events. A sample of 15–30 participants were recruited. Inclusion criteria consist of English-speaking adults 18 and older in the United States who have been previously diagnosed or self-identified as being Autistic. Participants must be able to complete a 12-item open-ended question survey in a verbal (talk to text) or written (typed) manner. Participants must be able to legally consent on their own behalf to participate in research. Exclusion criteria consist of the following: must not be children under the age of 18, must not identify as neurotypical/non-Autistic, and must not be under legal guardianship. There are no inducements offered for participation in this study.

## **Data Sources**

Once participants have been recruited, they were invited to complete a survey of open-ended questions via a secure link. Informed consent was reviewed. There was a brief demographic questionnaire in which participants were asked to identify their age, gender identity, ethnicity, whether or not they have been professionally diagnosed with Autism Spectrum Disorder or self-identify as Autistic, and the age of professional Autism diagnosis or approximate date of suspected Autism diagnosis (can be self-identified). Information was then provided to the participants about the course of the study. Next, participants completed a 12-item open-ended survey. The open-ended questions are designed to allow for narration and elaboration on the participants' lived experiences of living with Autism and experiences with traumatic events.

## **Open-Ended Survey Questions/Prompts:**

This is a study about trauma as it is experienced in Autistic adults. Please keep in mind the definition of trauma as it relates to this study. Trauma is the emotional or psychological response to a deeply distressing event or situation (The Mental Health Coalition, 2024). The following survey questions were asked as part of the online survey:

- 1. What do you want to tell me about yourself?
- 2. What does it mean to you to be Autistic?
- 3. Please describe traumatic experiences you have endured throughout your lifetime.
- 4. In what ways do you feel your experiences with traumatic events have shaped your behavior or interactions with others or the environment?
- Please describe activities, situations, or environments that you avoid as a result of your trauma.

- 6. What differences have you noticed in how you experience trauma as compared to others?
- 7. How do you feel your Autism impacts your experiences of trauma?
- 8. What role do sensory functions play, if any, in your experiences of trauma?
- 9. What role does routine or structure play, if any, in your experiences of trauma?
- 10. How do you cope with traumatic experiences (in the moment and/or afterward)?
- 11. Can you describe experiences you have had in seeking help from others (personal and/or professional) in dealing with traumatic experiences?
- 12. What advice do you have for other Autistic people who have experienced trauma?

# **Data Collection**

A sample of convenience recruited through various means (Facebook groups, Reddit, LinkedIn, online social groups for Autistic adults, etc.). Participants followed the survey link, completed informed consent, responded to the demographic questions, survey questions and were presented with a debriefing form. No identifying information was collected at any time.

#### **Data Analysis**

The results of this study were determined by thematic analysis. The researcher reviewed the survey answers to try to facilitate understanding by exploring themes for how the participants view their experience of the world. In addition, the researcher met regularly with a research advisor and bracketed personal experiences in order to maintain the integrity of the data. For positionality purposes, it is noteworthy that the researcher and research advisor both have personal and professional experience with autism. The six steps of thematic analysis were utilized, according to Terry and Hayfield (2021) as follows:

- Familiarization with the data: Data was reviewed to allow for a deep understanding of the survey responses by two evaluators.
- Initial coding process: This process involved preliminary labeling of interesting or significant features across the data set and organization of the data into meaningful groups.
- Initial theme generation: Next, the goal was to start grouping codes that are related in some aspect to begin identifying broad patterns.
- 4. Develop and review themes: At this point, preliminary themes were refined to ensure an accurate representation of the data and the emerging patterns.
- Define and name final themes: Next, the aim was to clearly define each theme, specify what the theme captures or represents, and give each theme a unique name.
- 6. Write the report: Finally, a thorough written summary of findings with a detailed narrative of themes with support from the data and in response to the identified research questions.

# **Ethical Considerations**

It is important to acknowledge the American Counseling Association (ACA) Code of Ethics (2014) and the occurrence of participant differences and the uniqueness of demographic groups when it comes to the prevalence of conditions and responsiveness to treatment and research participation. Ensuring that informed consent is provided in a responsible way is essential to any study; with this particular study, and given the identified demographic of individuals with co-occurring ASD and trauma, informed consent was detailed and descriptive in identifying risks to participating in a study about traumatic experiences so participants have adequate information and awareness of the context of the survey questions (ACA, 2014; G.2.a.). When conducting a study that is examining aspects of trauma, it is possible that sharing about trauma may create feelings of discomfort and vulnerability and could potentially even re-traumatize participants during the study. Therefore, this researcher was monitoring these risks closely to ensure that precautions are taken to avoid injury (ACA, 2014; G.1.e.). Additionally, given the notion that this area has been largely underrepresented in research, it is possible that results may be unfavorable. However, there is an obligation to report all results, even those that may be unfavorable (ACA, 2014; G.4.b.).

## **CHAPTER IV: RESULTS**

# **Demographic Information**

Twenty-three participants completed demographic questions and the qualitative survey questions. When asked about their age range, three participants reported being between 18-24 years of age (13%), eight participants reported being between 25-34 years of age (35%), six participants reported being between 35–44 years of age (26%), two participants reported being between 45–54 years of age (8.7%), two participants reported to be between 55–64 years of age (8.7%), and two participants reported to be 65 years of age or older (8.7%). When asked about their Race/Ethnicity, 20 participants reported identifying as White or European American (87%), one participant reported identifying as Hispanic or Latinx/é (4%), one participant reported identifying as White or European American and Hispanic or Latinx/é (4%), and one participant reported identifying as White or European American, Black or African American, Native American or Alaska Native, and Asian or Asian American (4%). When asked about Gender Identity, 10 participants reported identifying as female (43%), nine participants reported identifying as male (39%), three participants reported identifying as non-binary (13%), and one participant reported identifying as a non-binary woman (4%). When asked about whether they were professionally diagnosed with Autism Spectrum Disorder or self-identified as Autistic, 19 participants reported having been professionally diagnosed with Autism Spectrum Disorder (83%), and four participants reported having self-identified as Autistic (17%). When asked about the approximate age of Autism Spectrum Disorder diagnosis or suspected Autism diagnosis (can be self-identified), responses ranged from age 3 years to 72 years, with the vast majority of participants indicating suspected identification or diagnosis occurring in adulthood (age 18 or older; 78%).

# **Factual Reporting of the Project Results**

Data analysis revealed six themes: (a) Adverse Childhood Experiences, (b) Exposure to Violence and Loss, (c) Difficulty Relating to Others, (d) Complex Mind and Sensory Experiences, (e) Medical and Mental Health Challenges, and (f) Autistic Identity. The themes and subthemes are identified in the table below.

# Table 1

Themes	Subthemes
Adverse Childhood Experiences	Family Trauma
	Bullying or Socially Induced Trauma School Experiences
Exposure to Violence and Loss	Death
	Crime
	Domestic Violence
Difficulty Relating to Others	Being Misunderstood
	Self-Isolation
	Pressure to "Mask"
Complex Mind and Sensory Experiences	Sensory Experiences
	Executive Functioning
	Intellect/ High Intelligence/Academic Ability
Medical and Mental Health Challenges	Experience of Diagnosis
	Medical Experiences
	Co-occurring Mental Health Conditions
	Fear and Avoidance
	Therapy Experiences
Autistic Identity	Self-Understanding
	Impact of Trauma as an Autistic Person Autistic Pride

Themes and Subthemes

# **Theme One: Adverse Childhood Experiences**

The first theme focuses on adverse childhood experiences. There are three subthemes: family trauma, bullying or socially induced trauma, and school experiences. The participants' narratives highlight a wide range of adverse experiences throughout childhood and adolescence and the impact these experiences have had on them throughout their lifetimes.

## Family Trauma

Family trauma, such as being a victim of abuse by a trusted caregiver, was a commonly reported experience by participants. "To be abused and neglected by your caretakers, and to be gaslit into believing that what you are receiving is love." The impact can be long-lasting, as one participant highlighted, "I have experienced sexual abuse by at least one family member. Verbal abuse and emotional trauma from Parents. Being kept insular from the world and real-life events, making it difficult to adapt to everyday life." Another participant noted that awareness of their Autism may have made a difference in how the trauma affected them, stating,

My mom was emotional and mentally abusive and was neglectful at the time, and that's caused a lot of trauma, and I feel if I had a more caring attentive parent, I would have been diagnosed as a kid, and I would have gotten help and I would have gotten further in life and its traumatic to always be grieving what could have been.

Several participants shared that they endured multiple types of traumatic experiences throughout their childhoods, such as "Physical abuse, sexual abuse, emotional abuse, physical neglect, emotional neglect, witnessing domestic violence (parents), parental separation or divorce, a household member with substance abuse issues, a household member with mental illness, and a household member who is incarcerated." Participants with a history of family trauma noted how they felt that they must intentionally change their behavior to survive. "I spent so much of my childhood in survival mode that I was oblivious to many things. I often was worried about keeping myself out of trouble with my mother and trying to keep her mood stable, so I never really thought about my own needs apart from trying to have social relationships, which I also struggled greatly with."

# **Bullying or Socially Induced Trauma**

Bullying and socially induced trauma were a major contributing factor to feelings of alienation, exclusion, emotional sensitivity, and vulnerability. Participants shared experiences of being bullied throughout grade school, "I was bullied throughout my entire K-12 education, and although I wasn't bullied my freshman year of college, much of that was reactivated. People would target me for my emotional sensitivity." The lasting impact of social trauma contributed to a lack of friendships and an inability to connect with others. Several participants attributed their social challenges to their communication differences. One participant shared, "I never had friends, I was always bullied or taken advantage of, I got beat up or in altercations for being too honest, it's isolating when you don't know how to communicate with typical people." Another stated, "Throughout my life I was relentlessly bullied for being different. This meant that I was a social outcast." A deep mistrust in others was frequently reported, as one participant stated, "It was distressing as a kid to feel that everyone was potentially dangerous/violent, and thinking that they didn't HAVE to be, but that there seemed to be a kind of poison in everyone's lives." Bullying and socially induced trauma were a common experience that highlighted emotional pain and turmoil due to difficulty forming and maintaining relationships, with many sharing that these challenges began at a young age.

# School Experiences

Educational struggles, misunderstanding of needs, and a desire to escape were frequently reported experiences related to school trauma. One participant explained the difficult dichotomy of having academic strengths paired with learning challenges and the lasting effects of not being provided the proper support in school:

Being gifted and also having learning disabilities in school was traumatizing. Teachers never knew how to help me or even sure if I needed help. When I was younger and even now, I have trouble finding the words to express my needs, and that's traumatizing to me because it's a lifetime of having unmet needs.

Another participant shared how threatening situations at school were confusing and upsetting:

I was going to lunch, and I was shouted at that I shouldn't be out here and then my guidance counselor walked me out of the lunch room and to their offices and locked me in a school suspension room saying there was a shooting threat and I had to wait there and not call anyone. I did call my dad.

Avoidance of school was a common theme, as some participants reported school refusal, and others shared that they ended up needing modified schedules, "I avoided school," and "I had to switch to half days at school not long after, and went fully online the next year."

## Theme Two: Exposure to Violence and Loss

The second theme focuses on exposure to violence and loss. There are three subthemes: death, crime, and domestic violence. This section explores the impact of different aspects of experiences with violence and loss that affect feelings of grief, safety, stability, and emotional well-being.

## Death

Exposure to death, whether it be the loss of a loved one or being witness to a violent death, can create deeply rooted grief, trauma, and a sense of vulnerability. One participant shared the difficult situations surrounding parental death.

I wasn't in my 30s before both my parents passed away. It is likely that I was the last one in my family to see either of my parents alive. I was the one who got the call when my father had passed. He was found dead in a car.

Another participant also highlighted the significant toll parental death took on them, "I had my mom take my dad to the local academic hospital, and he was found to have AIDs and he died after 3 years of dementia, during which time me and my mom were the primary caretakers." Exposure to violent death, such as one participant's account of viewing a friend's suicide, illustrates the severity of some of the death-related trauma that participants experienced, "the brutal suicide of a friend—he poured gasoline on himself and lit himself on fire." Frequent exposure to death was an experience for some, with one participant stating, "I have been to more funerals/ memorials than I have been to weddings, birthday parties and the like combined," highlighting an overwhelming presence of death and loss.

### Crime

Some participants reported exposure to criminal acts as a source of trauma and unrest. This includes personal experience of victimization, as one participant shared, "[I was] a victim of gun violence." Also included are incidents of police violence and the toll that situations around social injustice and brutality can take. One participant shared, "I distinctly remember was me trying to escape the police violence with the rest of the crowd," and Subsequent to being tear gassed, I was additionally maced with pepper spray and was hit in the leg by shrapnel from a police "pepper bomb," fortunately only bruising my leg but tearing up the pants I wore that day. I had chemical burns across my back for several days afterwards.

Another participant reported not being a direct victim of criminal behavior but experiencing a devastating loss and bearing witness to criminal injustice, "My mother was murdered that resulted in a 1st degree murder conviction, and recently, that person who killed my mother was released from jail."

# **Domestic Violence**

Being a victim of domestic violence was a theme throughout adulthood for many participants and often was reported to consist of physical and/or sexual abuse along with emotional and psychological abuse themes. One participant reported being a repeat victim of domestic violence and assault, "I was in a sexually and emotionally abusive relationship for two years from 18–20. I have been sexually assaulted outside of that relationship twice." Another participant echoed the experience of being traumatized by multiple offenders,

I've had relationships with a couple of men who neglected the emotional/social parts of the relationship and would manipulate the way we spent time together so that I didn't

have space to communicate anything I wanted, but they always made space for sex. One participant simply stated the experience of "Domestic violence with an intimate partner," indicating the pain of abuse and neglect within a romantic relationship.

# **Theme Three: Difficulty Relating to Others**

The third theme focuses on difficulty relating to others. There are three subthemes: being misunderstood, self-isolation, and pressure to "mask." Challenges around connecting with others

were a frequent theme among participants. Many participants took the blame for these challenges and shared the lasting toll that feeling different from others has taken on them.

## **Being Misunderstood**

The subtheme of being misunderstood was a common thread throughout the participants' responses. The emotional turmoil that many participants reported experiencing highlights how alienating and lonely it can feel not to be understood by others. Participants stated, "I feel deeply misunderstood. I had felt for a long time that I was different from other people," and, "I thought I was just a weirdo." One participant mentioned that while they have a high degree of emotional experience, they often were treated as if they were incapable of this, "Having empathy but being treated like you don't." Another participant explained,

It [being Autistic] means having a brain that operates differently from 98% of those around me and not being able to share that with them. So they judge me as a poor communicator, friend, and incompetent in many areas—for not being like them.

The lasting emotional effects were frequently reported as well. One participant stated, "I'm exhausted and traumatized and extremely distrustful of others because of the inevitability of how I am perceived and therefore treated. The futility of it all is incredibly demoralizing."

## Self-Isolation

Many participants reported retreating and isolating themselves from others due to their challenges relating to others, many of which were shared to have begun at a young age. One participant emphasized the fear they experience that contributes to their need to self-isolate, "My fears may be greater than they should be. I tend to look behind me a lot as if I am being followed. I say no a great deal more because it is safer. I am shut off towards people." Another

participant discusses how past experiences continue to impact their daily experiences and need to self-isolate,

My experiences made me stay away from people, and I isolate a lot. I have depression because I'm stuck in my mind about the sad things in my life. I'm anxious and often just pace around the house. Being at home, away from people is easier, and that over time has made me a bit bitter. I have a very hard time connecting with people even when I want to. While self-isolation seems to be a common coping mechanism among Autistic adults, other participants reflected on how they wish they didn't feel that they have to protect themselves in this way. One participant stated,

I keep to myself a lot. I'm not as outgoing as I'd like to be. If I sense a red flag in another person, I have a hard time gauging how strong of a response I should have, partly because of hypervigilance and partly because of understanding that I might not be reading what the other person meant within the full social/communicative context, and that leads me to second-guess myself. I often err on the side of caution and overreact to perceived red flags.

Another participant shared, "I tend to very much keep to myself at work and only socialize if someone else initiates it. I don't have a lot of energy to put into assessing whether someone is emotionally safe or not when I know I am not going to be able to detect the cues early on." One participant highlighted the ongoing challenge of assessing social situations and how this has led to the desire to isolate from others and partake in imaginary activities instead, "In the past, I've tried to give people the benefit of the doubt and stayed in harmful situations longer than I needed to be, but it's not that way anymore. I generally coped by retreating to my imagination, semi-escapism."

# Pressure to "Mask"

"Masking," a common experience among those with Autism, is the phenomenon of hiding one's true self and instead representing in a way that is more consistent with how others expect you to be, often in a way that hides perceived deficiencies and is intended to avoid judgment and takes an emotional and psychological toll that is potentially harmful (Cleveland Clinic, 2024). One participant described, "Being autistic is like having your brain on a different wavelength. I think and experience the world differently than most people I know. When talking with neurotypical people, I have to "translate" how I'm speaking in order to fit their conversational expectations." Another participant spoke about the toll that masking takes, "I feel like a shell of a person performing to fit everyone's needs except my own." Another discussed the tendency to contradict natural instincts to fit in with others, "I was forced to suppress my autistic tendencies, so masking is a constant thing. A lot of it is involuntary, but still takes a lot of energy."

## **Theme Four: Complex Mind and Sensory Experiences**

The fourth theme focuses on complex mind and sensory experiences. There are three subthemes: sensory experiences, executive functioning, intellect/high intelligence/academic ability. Heightened and unique sensory perceptions are a commonly reported experience among participants, as are challenges with executive functioning and a complex interplay with high intelligence and intellect.

# Sensory Experiences

Several participants described experiencing overwhelming sensory experiences, including sensitivities so severe that they must rearrange their lives to accommodate their differences in how the world is experienced. One participant highlighted their perceived differences as

compared to others, "I experience everything differently—what I see, what I hear, what I taste, what I touch, what I feel, and what I think. And therefore, I behave differently." Another participant reflected on how overstimulation negatively affects their emotional state, leading to big consequences,

Being overstimulated all the time by lights and sound and sight makes it so much worse to be able to cope with it all, and not being able to communicate my emotions makes it hard for me to have my needs met. I have meltdowns with big outbursts and crying and shutdowns where I go nonverbal and pace and rock.

One participant details the types of sensory experiences that can be particularly difficult for them, emphasizing the challenges of navigating daily life with sensory sensitivities,

Bright lights (especially overhead/fluorescent), loud pop music (I hate it), multiple conversations going on around me so it sounds like I'm in a chicken coop, strong smells (especially perfume and scented body products that make me physically ill), constant interruptions at work with phone calls/people knocking at my door/getting dinged on Teams. Everything is amplified.

Another participant echoes some of these challenges, adding in details of the traumatic impact they have experienced,

Many of my most traumatic events have been meltdowns due to sensory overwhelm coupled with unaccepting family members/relationships. I was always told I was lying about my sensory sensitivities (i.e., "no one else is bothered by this, so just get over yourself"). Lighting has been a constant trigger for meltdowns and therefore, trauma. Trauma around food due to ARFID (being forced to eat through negative sensory experiences, being left at the table overnight because I couldn't finish my plate, tolerating legitimate pain). Sound sensitivity has also greatly contributed to meltdowns over the years, especially coupled with the societal norm that wearing headphones/ear defenders/ear plugs is rude or otherwise unacceptable. My sense of touch has also contributed to overwhelm, i.e., difficulty functioning in an unclean environment, sweaty hands, physical touch from another person (unwanted or otherwise). The combination of sensory sensitivities again makes generally non-traumatic situations traumatic for me. One participant simply sums up their experience of sensory challenges as an ongoing, permanent

part of their life, "My sensory issues are constant, unrelated to events that transpire."

## **Executive Functioning**

Executive functioning, inclusive of the mental processes and skills that are involved in completing tasks, focus and attention, following instructions, and adapting to new situations, was identified as an area of challenge and difference for many participants. One participant shared particular aspects of executive functioning that are challenging, "My therapist said I'm time blind, and I guess my relationship to memories and the past is different. I seem to relive things in more detail than most. I tend to easily trigger." Another participant named how their executive functioning differences negatively impact their ability to process emotions, "I struggle heavily to process feelings. It can take a day or two sometimes before I'm truly able to name what I'm feeling in a given moment." Another participant describes physical experiences related to executive functioning differences,

My brain constantly feels foggy, and my eyes are often unfocused. It's not that I'm blind; my glasses correct my vision to 20/20. It's like I have a light headache at all times, preventing me from concentrating too much that I begin to remember my past again. Additionally, two other participants highlighted both positive and negative aspects of executive functioning differences, with one stating, "I have nearly perfect long-term memory (seems to be autism-related), and it makes it harder to let things go." Another sharing,

Processing definitely both helps and hurts me. It helps because since I don't process all at once, I can focus on the task at hand literally. It hurts because I could be randomly processing something that happened in the past at a bad time/random time long after it happened, and then I have to rehash it and figure it out.

#### Intellect/ High Intelligence/Academic Ability

Many participants reported relative strengths in their intellect, high intelligence, and high academic ability, with one participant stating, "I have been measured in the 97 percentile (twice 20 years apart) in understanding concepts such as philosophy, politics, and religion." However, this theme was sometimes reported along with the negative consequences of intellectual giftedness. One participant reported,

My strengths in pattern recognition, affective empathy (as opposed to cognitive empathy), and problem-solving go unnoticed and unappreciated, but my personal weaknesses are very much noticed. My strengths are a major asset in academic environments, so I always had a source of confidence and belonging until I graduated from college and had to integrate into work environments.

Similarly, one participant shared,

Unlike most people, my Asperger's is why I have a high IQ (140; tested twice). I think, though, that my IQ leads me to feeling boredom in reaction to things I don't find challenging, and that's probably also why I find friendships boring, as I know all the rules and expectations when it comes to friendships or relationships in general.

Another participant discussed a benefit of being academically gifted is that it provided some protection from social trauma, "I had a reputation for being very intelligent/high achieving, so most people left me alone."

## **Theme Five: Medical and Mental Health Challenges**

The fifth theme focuses on medical and mental health challenges. There are five subthemes: experience of diagnosis, medical experiences, co-occurring mental health conditions, fear and avoidance, and therapy experiences. This theme revolves around the complicated and multifaceted experiences of participants when it comes to accessing medical and psychiatric care, including that of seeking diagnostic clarity, common co-occurring mental health symptoms and conditions, fears and avoidant behaviors that have emerged, and experiences with counseling and therapy services.

## **Experience** of Diagnosis

Seeking an appropriate diagnosis, specifically a diagnosis of Autism, can be liberating and provide a sense of relief, and it can also bring up feelings of fear, stigma, or uncertainty. One participant detailed that they had been diagnosed early in life. However, their parent neglected to share this important information with them, "From a young age, I was diagnosed with Asperger's (alongside other things like apraxia of speech), but my parents opted not to tell me because they thought it would be possible for me to grow up 'normal' anyway." Another participant experienced a diagnosis much later in life and also expressed frustration around not knowing this key piece of information, "I was not diagnosed until earlier this year at the age of 72. That's a lifetime of masking without realizing it and definitely not realizing why I needed to." Misdiagnosis is also an issue that was reported among participants, with one individual stating, "I was diagnosed with ASD and ADHD when I was 29 after many years of being misdiagnosed with depression." When the diagnosis is provided, it can lead to an overload of thoughts and feelings, "It took me 10 days to fully integrate the events of my diagnosis appointment. I have very little ability to remember why I just walked into this room." Some participants also described challenges around not being able to access a diagnostic evaluation due to factors such as financial limitations or a lack of qualified professionals in their insurance network, with one participant voicing, "I feel I can't get the correct help because I haven't been diagnosed."

## Medical Experiences

Many participants described challenges related to experiences with medical professionals and the medical system. One participant detailed a trauma response due to a family member being under medical care and the profound impact that had on the individual, "I have had difficulty with certain medical situations and discussions about palliative care given my dad's situation, but I have not been able to avoid them." Other participants discussed medical trauma related to hospitalization, often due to their own mental health issues. One participant stated their unique and complex challenges with being hospitalized, "I have been hospitalized due to suicidality, which only added to the trauma by having my sensory aids taken away, denying my autonomy, being physically restrained and kept in close proximity to others in distress." Another participant also detailed a negative experience of mental health-related hospitalization,

I spent a night in the psychiatric emergency room, which was deeply traumatizing for me . . . My night in the psychiatric emergency room feels like it has permanently tainted who I am as a person. I feel like I will always carry this terrible secret. I don't tell people because I am afraid that they will think I am a broken person or that I am crazy.

Medical experiences were often reported to have had a lasting impact on the individuals, primarily due to traumatic events and a lack of accessible and sensitive treatment by medical professionals.

## **Co-occurring Mental Health Conditions**

A common theme among participants was the disclosure of co-occurring mental health conditions in addition to Autism. Many participants described these conditions as direct results of their experiences with traumatic events. One participant shared, "My traumatic experiences have made me skeptical of others intentions, added to social avoidance, and given me agoraphobia. C-PTSD has exacerbated my chronic anxiety, led to constant hypervigilance, and complicated my ability to maintain relationships." Several participants named PTSD as a co-occurring condition, "I have autism (formerly Asperger's) and PTSD." Another participant shared their unique situation, "Autism, combined with FAS, meant severe sleep deprivation and mental illness associated with it. The military was the most traumatic, the abuse and not being able to make up sleep. Currently being treated for PTSD." Trauma is also speculated to be a factor for one participant experiencing psychosis, "Developing brief psychotic disorder also gave me traumatic experiences, even though the experiences were only real to me." ADHD was also a frequently mentioned co-occurring diagnosis among participants, with one individual mentioning, "I also have ADHD, which I learned a month before the ASD diagnosis." Participants resonated that having multiple diagnoses and/or co-occurring conditions can complicate symptom presentation and access to appropriate treatment options.

## Fear and Avoidance

A theme seemingly related to medical and mental health challenges is that of fear and avoidance of people, places, things, and situations. These experiences were reported to often exacerbate already challenging symptoms of Autism and trauma. One participant noted, "My trauma has made me feel very averse to taking risks and given me a fear of fear that's particularly bad around bedtime." A participant highlighted the ongoing and ever-present struggle of safety concerns, "I am constantly anxious and evaluating any given situation for potential danger," with another participant stating a similar experience of, "I am super hypervigilant, which is something I am told often." The interplay with other themes, such as self-isolation, is also present, as one participant detailed, "[I] avoid leaving my house as much as possible due to low energy levels and a desire to lessen the statistical probability of experiencing another traumatic event." One participant shared their hesitance to pursue certain kinds of entertainment, "I have avoided certain sad or emotional movies for over a decade and have just started to watch/read more complex stories."

## Therapy Experiences

Therapy and counseling experiences were recounted with both positive and negative responses. One participant highlighted the benefits of engaging in therapy and their progress with emotional wellness and acceptance,

In therapy, I have learned that what I have experienced is, in fact, deeply traumatic, and I am not being overly sensitive or dramatic. I have every right to be angry about the things that have happened to me and the ways that the adults in those situations, many of whom witnessed this behavior, failed me.

Another participant positively stated, "I couldn't recommend therapy highly enough. Even just having an unbiased human to talk to is helpful." Many participants reflected on being in and out of therapy over the course of their lifetimes. One participant recalled mixed experiences in therapy, stating, "When I was a kid, I had a therapist I would see until she called CPS, and my parents removed me from her care. Out of all my therapists, she was the only one I trusted. Before that, I had a therapist who would tell my mom everything I told her." Another participant described negative experiences with therapists since childhood and never really feeling understood by a mental health professional,

Been in and out of therapy since I was 7 years old. No relationship with a therapist lasted for longer than a year, either because they simply could not understand my point of view (as they were allistic and wanted to hold me to an allistic standard) or because they outright lied to me as a minor.

One participant frustratedly shared feelings of invalidation, stating, "You'd be shocked at the number of times I've heard 'well, you don't look autistic!' From licensed therapists." While many participants expressed positivity in reflecting on experiences in therapy, several participants revealed feeling invalidated, disillusioned, and generally that therapy has been ineffective for their particular challenges.

## **Theme Six: Autistic Identity**

The sixth theme focuses on Autistic identity. There are three subthemes: self-understanding, the impact of trauma as an Autistic person, and Autistic pride. Many participants reflected on their Autistic identity positively, highlighting progress in understanding themselves and coming to terms with how their traumatic experiences interplay with their ASD and have shaped their perceptions of the world. Several participants also discuss feeling like they are more significantly impacted by trauma than others, noting key differences in experience due to being Autistic. Some participants take pride in their Autistic identity and embrace their differences.

## Self-Understanding

Participants reflected on what it means to them to be Autistic and how understanding this aspect of identity has been helpful in many ways. One participant reflected,

[To be Autistic] gives me something to call one piece of the puzzle, that is my brain, to better understand what is REALLY happening with me or how I operate. That way it would give me at least a percentage of a chance to either be better prepared/equipped to handle a challenge that would be a seemingly simple event to a Neurotypical.

Another participant compared their differences to technology to highlight their perceived differences from others, stating, "My brain uses a different operating software than the 'neurotypical.' I see the world differently than others." One participant shared that they did not assume Autism for some time, and learning more about it has been helpful in self-understanding, sharing,

Autism was not something I came to right away, though it is becoming increasingly visible in the public eye. It's important to recognize that autism may not always look like we expect, and that how it shapes our responses to trauma may not be immediately obvious.

Other participants noted that they always felt different from others, and having more concrete information about why has aided them in self-acceptance, even though they are suffering because of their differences. One participant stated, "I always felt like something was wrong with me since I could have a conscious thought, and now I know it's autism, but that made me feel suicidal when I just didn't know," with another sharing, "My autism increases my sensitivity to traumatic events. I feel that compared to others that have experienced similar things, I am more affected by them. I am more likely to develop trauma from the same things." Learning more about Autism and how it can present, manifest, and resonate was reported by many participants to be a crucial part of self-understanding and Autistic identity.

#### Impact of Trauma as an Autistic Person

Participants overwhelmingly reported feeling a more significant impact of traumatic events as compared to their perceptions of how their neurotypical counterparts identify and experience trauma. One participant expressed,

The emotional residue tends to stick to me longer. Also, relational trauma takes longer to process because I might not fully understand how someone was using sarcasm or hinting at how they felt until years later, and then I can get past confusion and into the validation that comes from recognizing the true dynamics of the situation.

Another participant shared, "I am more braced for it [trauma], I think. I tend to have an uglier view of the world. I am not sure that helps my processing of it, though." Several participants reflected on their gloomy experiences of perpetual traumatic memories. One participant shared, "[Trauma] feels more permanent. Like it isn't forgettable quite as much as normal people move on from it," and another stated, "[My Autism] probably makes it worse, since I am constantly traumatized. I'm assuming non-autistic people don't have that unless they live in a war zone." Another participant summed up their view on the relationship between Autism and trauma, stating, "Autism exacerbates trauma because: 1, Autism makes it difficult to talk about things to allistics; 2, there is a lot to understand with autism, and it can be difficult to untangle the feelings of autism from the effects of trauma."

#### Autistic Pride

Many participants resonated with taking pride in their Autistic identity and coming to terms with Autism being a core part of who they are. One participant reflected, "I was diagnosed in my early 40s, almost 3 years ago. Still trying to figure my way through with the newest expansion pack that is Autism, but also feel very proud to be Autistic . . . even on the hard days." Another participant mentions a strength of being Autistic, "[My Autism] probably allows me to view events and experiences more logically than others." One participant noticed, "My autism has helped me avoid further trauma by making me dead set on medication maintenance and sobriety almost to the point of those being special interests." Another participant thoroughly explained their experience in taking pride in being Autistic and recognizing both challenges and strengths, sharing,

I think it [Autism] makes me both more resilient but also more reflective. I often find myself wishing I could be less sensitive because I feel like I reflect on things a lot more than other people do, and I get sad thinking about things like wishing that I had a normal mother with a normal happy relationship—despite knowing that will never happen and usually am quite strong about it. I can't help but have my moments where I just feel sad and wish it could be different and I really get stuck ruminating on it sometimes, which I know really does not help anything. On the other hand, like I said above, I can really handle a lot and am not surprised by much, and most of all, I think my processing is slower, so in the moment, I can get through things better, as I am not fully processing in the moment. I just focus on whatever I need to focus on until I can settle and really process my thoughts and feelings.

Participants' understanding and noticing aspects of being Autistic bring a sense of pride, self-awareness, and self-worth.

#### **CHAPTER V: CONCLUSIONS**

#### **Interpretation of Data**

According to the results, there are six themes: (a) Adverse Childhood Experiences, (b) Exposure to Violence and Loss, (c) Difficulty Relating to Others, (d) Complex Mind and Sensory Experiences, (e) Medical and Mental Health Challenges, and (f) Autistic Identity. The themes will be discussed in the context of literature below.

#### **Theory and Research**

The purpose of this qualitative study was to examine the lived experiences of Autistic adults and their perceptions of self-identified trauma to expand knowledge about identifying, diagnosing, and treating trauma symptoms and trauma-related disorders such as PTSD so these individuals can be better served in counseling settings. Given the effect that trauma has on the brain, through a neuroscience theoretical perspective, this work is incredibly important to open up opportunities for exploring proactive measures for at-risk individuals, and developing counseling treatment interventions intended for this specific population. Autistic adults are generally exposed to more traumatic events than non-Autistic adults due to being more vulnerable to negative life experiences such as bullying and loss of employment. However, the traumas may not be identified or seen as in need of treatment due to the individuals' cognitive impairments, executive functioning challenges, and/or difficulty relating to others and the environment (Lobregt-van Buuren et al., 2021). Additionally, applying the neuroscience theory of counseling and the idea that the brain is altered by traumatic experiences is notable when considering how these differences in neurotype may impact risks and needs for Autistic individuals. This study intended to address the presenting problems in that there is a severe lack of research in recognizing and identifying the experience of trauma in Autistic people, as well as in having reliable and adequate treatment interventions that are known to be effective with this particular demographic. More information about how Autistic adults experience trauma and what themes are present in the experience of trauma in Autistic individuals could lead to effective treatment interventions being more readily identified and offered by counselors. ASD, which is typically considered a neurodevelopmental disorder or neurotype, has neurological components that contribute to the symptoms and presentation of the condition, and while there is a significant lack of information on the experience of and effective interventions for those with ASD and trauma, effects of the conditions both separately and comorbidly are often theorized through a neuroscience lens (Parellada et al., 2014). Six themes and 20 subthemes emerged from this research that are invaluable in understanding the lived experiences of trauma in Autistic adults.

## **Theme One: Adverse Childhood Experiences**

Adverse childhood experiences were the most prevalent theme reported by participants. This aligns with existing literature on the importance of recognition of risk factors and trauma indicators in childhood for Autistic individuals. Due to the vulnerability and risk factors associated with ASD, such as social naivete, communication deficits, and potentially intellectual disability, Autistic children are significantly more likely to experience exposure to traumas than their normally developing peers, and in this demographic, traumatic events are not limited to large scale occurrences, but are also likely to present in persistent, daily stressors that take a toll on the individual, such as bullying, peer rejection, confusion with social demands, sensory sensitivities, and punishment of repetitive behaviors (Kerns et al., 2015).

## Family Trauma

Overwhelmingly, participants shared deeply painful experiences of abuse and neglect, often at the hands of parents and caregivers, throughout their formative years. Many participants not only shared their experiences of family trauma but also reflected on how these experiences continue to impact them into adulthood. Participants highlighted the burden of responsibility they felt to keep peace in their homes while navigating their own coping and survival mechanisms. Some participants reported feeling challenges deciphering their reality from what they were told by those caring for them, which created feelings of manipulation, fear, and self-doubt. Isolation from others was also frequently shared, which highlights the perpetuation of alienation, poor self-esteem, and challenges with learning healthy and adaptive coping skills. Abuse, assault, and neglect by loved ones were commonly reported occurrences, which are consistent with one recent study that suggested that many autistic people normalize being harmed by someone they know because it happens to them so frequently throughout their lives (Pearson et al., 2023). Another prevalent theme was exposure to a parent or caretaker with severe mental illness and the profound effect this can have on a developing child. These findings indicate that often, Autistic adults have experienced childhoods marked by profound dysfunction in the family system and significant emotional trauma as a result of these experiences, often leading to a constant state of hypervigilance, survival mentality, and poor self-worth.

## **Bullying or Socially Induced Trauma**

Bullying and socially induced trauma emerged strongly through participant responses, with many participants describing significant and ongoing traumatic social interactions throughout childhood and adolescence, leaving many feeling victimized, exploited, and distrusting of others. The common thread among participant responses is feeling misunderstood, being targeted by others for perceived differences, and struggling to form connections with others. Many participant statements were reflective of the deep emotional wounds that bullying can have on an individual and how vulnerable many Autistic individuals feel when around other people, even well into adulthood, due to scars of childhood trauma. Several participants attributed their vulnerability to socially induced trauma to their challenges with communication and misunderstanding of social cues and norms. It has been found in previous research that over 80% of Autistic children and teens had been bullied (Bitsika & Sharpley, 2021). Significant relationships were found between the experience of being bullied and PTSD symptoms, indicating that the Autistic population is at high risk of bullying and ultimately of PTSD and other trauma-related disorders due to their vulnerability in social contexts (Bitsika & Sharpley, 2021). In another study, 60% of Autistic people identified a social event as their most distressing traumatic event versus only 20% of typical adults, indicating the severity and high degree of social trauma among the Autism population (Haruvi-Lamdan et al., 2020).

## School Experiences

A variety of school-related experiences were disclosed by participants, bringing attention to the often difficult, isolating, and confusing moments in Autistic individuals' schooling. Experiencing uncertainty about how to support those with giftedness and learning disabilities was a theme that emerged, with some reporting as much as neglect by teachers throughout formative years. Feelings of powerlessness and fear when under duress during threatening situations at school only led to increased feelings of alienation and loss of control. Several participants reported moving into online or hybrid learning environments during schooling due to repeated and ongoing challenges.

## Theme Two: Exposure to Violence and Loss

The second theme, exposure to violence and loss, includes experiencing death, usually the loss of a loved one, subjection to criminal activity or crime-related situations, and domestic violence in adulthood, typically at the hands of a partner or family member. Participant responses around violence, victimization, and tragedy indicated how these experiences led to psychological harm, hypervigilance, and a negative worldview. Healing from tragic situations is often difficult due to the betrayal, injustice, and emotional injuries indicated in participants' stories.

#### Death

The subtheme of death illustrates the toll of loss, emotionally and psychologically. Shock, grief, and feelings of helplessness were present in participant responses. Loss of close family members, providing end-of-life support and caretaking, and exposure to unexpected and jarring deaths by suicide were reported. Some of the exposure to death was incredibly violent in nature, with participants including horrific details of what they had witnessed. An overshadowing of grief and loss was present for many participants as compared to positive experiences with others throughout their lives, indicating a source of trauma for many Autistic individuals.

### Crime

Exposure to crime and criminal behavior was present in some participant responses and, when shared, were severe in nature. Gun violence, police brutality, and exposure to the murder of a loved one with a lack of ramifications by the justice system are examples of the shocking, violent, traumatic stories that were shared.

## **Domestic Violence**

Abuse within close relationships was reported frequently, indicating a subtheme for domestic violence. This subtheme is indicative of relational abuse endured in adulthood, as opposed to that chronicled in the adverse childhood experiences theme. Participant testimony on this topic often indicated the lasting effects of these experiences, such as negative self-worth, feelings of vulnerability, lack of safety, hypervigilance, and difficulty trusting others. It has been well established in previous literature that Autistic people are more likely to be victimized than non-Autistic people, and this is true for intimate partner violence, with one study indicating that nearly all of the 24 participants had experienced repeated incidents of intimate partner violence and sexual assault, regardless of gender, with clear consistencies among these self-reports presumably due to vulnerability attributes of this demographic (Douglas & Sedgwick, 2024).

## **Theme Three: Difficulty Relating to Others**

The theme of Difficulty Relating to Others represents social challenges that Autistic adults face when trying to connect with others, often exacerbated by internal struggles and external expectations. Participants shared experiences that highlight the loneliness, solitude, confusion, and alienation that they have experienced throughout their lives which they have attributed to differences in relational thinking and behavior and expressing and interpreting social information.

#### **Being Misunderstood**

Many Autistic people describe themselves as a "weirdo" or "alien" and attribute this feeling to being drastically different types of people than the majority. These differences lead to feelings of marginalization and frustration. It may be difficult for neurotypical people to imagine living in a world where they are constantly misunderstood, misrepresented, misinterpreted, and alienated. Still, this reality is all too common for Autistic individuals. The subtheme of being misunderstood is woven throughout several of the other themes and is one of the most prominent themes identified in this study. The chronic experience of being misunderstood is a source of trauma for many Autistic adults. The role of empathy was often mentioned, which is something that is often misunderstood among Autistic people in that it is generally misrepresented that Autistic people do not have empathy, while it is often reported by Autistic people that they have strong empathy. The thought that has been established in a social and cultural context that Autistic people lack empathy has been damaging to this population as it denies them a very human experience, may deny access to an Autism diagnosis, and may underestimate the experiences of trauma and potential PTSD that are common among Autistic people (Hume & Burgess, 2021). These controversial misinterpretations of intentions and emotional states often lead to feeling misunderstood by others.

## Self-Isolation

One aspect of difficulty relating to others is the tendency for Autistic adults to self-isolate from others as a protective measure or due to a lack of confidence in social skills and abilities. Self-isolation tends to occur as a result of past rejection and the fear of future rejection, the sheer energy and related exhaustion of social interaction, or feeling as though others cannot relate to or understand oneself. Self-isolation often appeared in participant responses as a coping mechanism and avoidance technique due to, oftentimes, decades of social challenges and painful interactions with others. Self-isolation consists of physical isolation (retreating at home or in a safe place) and social-emotional isolation (limiting or only engaging in certain types of interactions with others). Sadly, self-isolation only perpetuates the larger theme of having difficulty relating to others. However, responses indicate that many Autistic adults are too traumatized to risk being vulnerable and trusting to others due to the significant social traumas they have endured.

## Pressure to "Mask"

Autistic people engaging in masking to appear neurotypical or meet the expectations of others is a concept that has been known for some time. However, in the context of this study, it is important to note the pressure that some Autistic adults have reported feeling to mask to not only fit in but to protect themselves from others. It can be deduced that autistic people often feel the need to mask their autistic traits to maintain a sense of safety. However, this comes at the cost of being exhausting, with the potential for burnout for the individual (Pearson et al., 2023). Masking, or concealing one's true self by engaging in what are assumed to be socially appropriate behaviors, can take a hefty toll on one's mental health. Autistic burnout, identity confusion, and emotional distress were concepts identified by participants due to the toll that masking has taken on them. Suppressing one's natural tendencies, especially those deemed unacceptable by society, such as stimming, can inhibit one's ability to cope and process in a way that feels safe and comfortable, and therefore, can be traumatic for the Autistic individual feeling pressured to do so.

### **Theme Four: Complex Mind and Sensory Experiences**

A unique attribute of Autistic individuals is that they typically experience complex experiences of their senses and minds. These experiences consist of sensory seeking, sensory avoiding, sensory sensitivities, difficulty with facets of executive functioning, learning disabilities, intellectual disability, and/or intellectual giftedness. It is not uncommon for these physical and cognitive complexities to be dichotomous, even in the same individual (i.e., someone may have both a learning disability and intellectual giftedness). Navigating a world that is not sensitive to these differences can be extremely challenging and even traumatic for Autistic individuals.

## Sensory Experiences

Experiencing sensory stimuli differently than most of the population can lead to a lifetime of feeling overwhelmed, confused, exhausted, or even numbing. For some individuals with Autism, the world may be overstimulating, with sensations such as too loud, too bright, too smelly, or too itchy taking over one's sensory experience and making situations often unpleasant or even distressing. For others, the world may feel dull with little response to certain sensory stimuli. Additionally, some may be in need of sensory experiences to calm or cope, which they may not always have access to in certain settings. This presents very complex situations for many Autistic individuals that can be extremely difficult to navigate and can lead to perpetual feelings of dysregulation and Autistic meltdowns. It is also important to note that while in many instances, sensory experiences alone are the catalyst for trauma responses, it is also extremely common among Autistic adults for sensory sensitivities or overwhelm to exacerbate an already traumatic experience, often creating a more intense, impactful, and lasting reaction and response to traumatic events.

### **Executive Functioning**

Challenges with executive functioning and the associated self-management processes of planning and organizing thoughts, keeping focus, and regulating emotions are common among Autistic adults. Maintaining a daily schedule, staying on task, prioritizing responsibilities, and managing expected tasks can be difficult to initiate or sustain, and these difficulties often conflict with educational and vocational expectations and may even affect areas of life such as relationships, financial independence, and hygiene. Many Autistic people indicate a delay in processing or random processing of past events, which can be particularly challenging to manage when emotions are involved. This type of phenomenon can lead one to relive traumatic experiences in a delayed fashion or at times that are not in alignment with the situation. Additionally, executive functioning challenges can also be associated with somatic symptoms such as headaches.

## Intellect/ High Intelligence/Academic Ability

The cognitive abilities of those with Autism are often underestimated as intellectual strengths may be present that are not consistent with one's other skills and abilities. Again, these individuals face a dichotomous situation; those with high intelligence may be highly regarded, and these identified strengths may serve as protective factors from social targeting. However, it can also lead to feelings of isolation and alienation, and make one a subject of jealousy or negativity. Additionally, some individuals with Autism report that their extreme intellect in a particular subject area or specific mastered skill does not serve them well in the world, as it is too specialized. Being misunderstood is also woven throughout this subtheme, as those with academic strengths or high intelligence may have difficulty connecting with others with similar attributes. Having high intellectual abilities presents very complex challenges for the Autistic individual and can be stigmatizing.

## **Theme Five: Medical and Mental Health Challenges**

Medical and mental health challenges were significant among reported experiences of Autistic adults. Pursuing medical and mental health care tends to be challenging in terms of pursuing and accessing diagnostic evaluation and clarity, feeling unheard or dismissed by medical providers, being misdiagnosed and/or experiencing multiple diagnoses before or along with Autism, and the generation of fear and avoidance of certain places or situations, often as a result of deeply traumatic experiences. Experiences in therapeutic settings are mixed, with some Autistic people having reported a positive experience in counseling and others feeling like engaging in therapy has not been worth their time.

## Experience of Diagnosis

Diagnosis is a complex issue; not being able to access a suspected diagnosis, experiencing misdiagnosis, and/or receiving an appropriate diagnosis can create a myriad of feelings and emotions. The experience of exploring a diagnosis is often a journey, sometimes one that is lifelong. For those with Autism Spectrum Disorder, it can be especially challenging to obtain a professional diagnosis as there are barriers to accessibility, such as a lack of qualified diagnostic providers, long waitlists, and a significant financial burden. Additionally, many people are surprised to find themselves on the self-discovery path of identifying as Autistic, realizing with relief and also frustration that they have been Autistic all along, often after having battled years of being told by medical professionals that they have other medical or mental health conditions instead. One study found that for participants who were middle-aged to older adults, it was reported that receiving a formal autism diagnosis was positively associated with a greater sense of self and an increased ability to focus on one's strengths and positive attributes (Lilley et al., 2022). For many Autistic individuals, especially those with low support needs, misdiagnosis and even dismissiveness are rampant among medical professionals and can even lead to mismanagement of medication. A lack of understanding of Autism among the general population only perpetuates this problem. It adds to the identity confusion that many Autistic adults, especially those who realize they have Autism later in life, are dealing with. Additionally, some individuals may feel shame or embarrassment about being labeled as Autistic.

## Medical Experiences

Individuals with Autism often have difficulty accessing medical care due to a variety of reasons. Having had traumatic previous medical experiences is common among Autistic individuals. This is in alignment with one recent study that found that adult patients with ASD had more needs, including more intubations, lengthier hospital stays, and a higher chance of being discharged to a skilled nursing facility as opposed to going home (McLaughlin et al., 2021). Difficulty navigating healthcare settings due to sensory overload, communication challenges, and the medical system's general lack of trauma-informed Autism-related care are a few reasons why medical trauma is rampant among this population. Additionally, Autistic people are at risk for being admitted for psychiatric care for reasons such as Autistic meltdowns, socially inappropriate behavior, and self-harm or suicidal thoughts or tendencies. Biases about Autism only perpetuate the problem and tend to make seeking even routine medical care quite difficult.

#### **Co-occurring Mental Health Conditions**

Misdiagnosis and the quest for diagnostic clarity are also an applicable concern for co-occurring conditions. Many people with Autism also have other mental health disorders that can complicate their experiences with diagnosis, treatment, and aspects of identity. PTSD was commonly reported by participants as a co-occurring disorder, which is not surprising given the vast literature in support of this notion and the wide array of experiences that attributed to Autistic people's experiences of trauma. Dealing with competing symptoms can also be a challenge, and unpleasant aspects of each condition may be exacerbated when one is triggered.

## Fear and Avoidance

A mental and emotional challenge that became evident in participant responses is that of fear and avoidance of certain people, places, and situations as a result of trauma. Negative experiences, anxiety, social challenges, a history of abuse, and sensory overwhelm are examples of catalysts of fear-based and avoidant behavior. This theme is consistent with that of self-isolation and is weaved throughout many of the other themes. However, it emerged as its own subtheme given the severity of its presentation and level of interference for many Autistic adults.

## **Therapy Experiences**

Reported experiences of therapy and counseling by Autistic adults are mixed, with many positive reflections and experiences of feeling seen and supported, as well as several negative experiences around lack of access to care and challenges with feeling heard or understood by mental health professionals. Many Autistic adults reported feeling validated in the therapeutic setting by their counselors in terms of acknowledging that they have, in fact, experienced traumatic events. Unfortunately, there is still a disparity between mental health counselors' understanding of Autism and Autistic individuals' lived experiences and presentations. This is consistent with much of the literature; one study found through focus groups for Autistic adults that it was felt that there is a significant lack of current research that centers on autistic voices and their experience with mental health. There is a continued need for more extensive research on this population and their specific mental health needs (Benevides et al., 2020). The stigmatization of Autism in therapeutic settings and the lack of recognition of the more nuanced and less visible aspects of Autism by counselors is harmful and invalidating and often leads to a lack of interest in pursuing mental health care. Additionally, access to care can be a barrier for

many, with individuals citing roadblocks in pursuing counseling ranging from a lack of health insurance coverage to a lack of qualified counselors in working with people with Autism and/or trauma.

#### **Theme Six: Autistic Identity**

There has been a shift in recent years to take ownership of Autistic identity, and that shone through in participant responses in this study. Many participants reflected on their Autistic identity in a positive manner, sharing gains they have made in self-understanding and accepting how their experiences of trauma intertwine with aspects unique to the Autistic experience. While it is evident that Autistic individuals tend to feel more affected by traumatic events than they assume others may be by the same or similar events, many take pride in their identity as an Autistic person.

## Self-Understanding

Self-understanding is a complex process, and many participants reported feeling like discovering their Autistic identity helped them better understand aspects of themselves and often led to a greater degree of self-acceptance. Being able to attribute differences in the experience of the world to a difference in how one's brain processes information is an incredibly helpful and important opportunity for introspection. Having an awareness of one's Autism assists in seeking out resources, literature, and support, which can assist individuals in coming to terms with their Autism being a core aspect of who they are and not a problem to be fixed. Additionally, the process of self-understanding can assist in self-advocacy, acceptance of differences, and confidence in unique tendencies and ways of thinking. Many Autistic people reference their brains utilizing a different operating system than others, which displays how they view the variance in taking in and processing information. For those who find out about their Autism later in life, finding out this integral piece of information can be life-changing in explaining how and why they have felt differently and can better prepare and equip them to manage their lives, relationships, and the world around them.

## Impact of Trauma as an Autistic Person

This subtheme speaks to how trauma resonates for those with Autism and how the differences in awareness, perception, and processing affect the extensive impact of traumatic events. While aspects of this theme are present throughout all of the themes identified in this study, it is important to recognize the specific aspects of how trauma manifests itself for Autistic people. Oftentimes, there is a more pessimistic and jaded view of the world, as many Autistic people have experienced multiple traumatic experiences throughout their lives and live in a constant state of anxiety, fear, and hypervigilance. The psychological and emotional impact of wounds that often go unhealed because of a lack of social, familial, and professional support is severe and extensive.

## Autistic Pride

Autistic pride is a concept that encompasses the celebration of Autistic traits and embracing Autism as an integral part of one's identity. Taking pride in one's Autism reduces the stigma associated with Autism and shapes one's Autistic identity to focus on strengths as opposed to perceived deficits, creating a more positive self-image and self-empowerment. Autistic pride also fosters a sense of belonging within the Autistic community; when individuals discover or accept their identity as an Autistic person and connect with others who have had similar experiences, this leads to a sense of belonging and a stronger sense of both individuality and ownership of diversity. This is in alignment with recent research that found that contrary to previous research, which had indicated that Autistic people have challenges in the area of self-awareness, participants largely exhibited a high degree of self-reflection as well as empowerment around their identities as Autistic people, and many Autistic people can engage in deep reflection of their lives and experiences as well as their evolving identity of self (Lilley et al., 2022).

## **Limitations and Recommendations**

One limitation of this study is that it focused exclusively on Autistic adults who were able to access and understand written communication, which means that the sample was likely composed of those with relatively low support needs, excluding those with higher support needs, and therefore not fully representative of the broader Autism spectrum. Because of this, this study's findings may not capture the unique experiences, challenges, and voices of those requiring more intensive support, specifically those who have intellectual disabilities and/or difficulties in the area of communication and/or are non-verbal. Although ASD and PTSD have long been linked in the literature, few studies focus on those with higher support needs, especially those who are cognitively lower functioning; this must change to identify treatment options for these individuals in future research (Haruvi-Lamdan et al., 2018). Further research is needed to address this disparity and include a broader range of participants to truly capture the voices of all Autistic people.

Another limitation worth noting related to demographics is the vast number of participants who identified themselves as White or European American as opposed to a more diverse sample of racial and ethnic identities. This limitation is important to consider as it is unknown what kind of information may be discovered among racial and ethnic groups other than White or European Americans and prevents a comprehensive understanding of the needs and issues across these non-White or European American demographics. It is recommended that future studies focus on recruiting participants of diverse racial and ethnic backgrounds to ensure representation for a wider population.

One notable limitation is the fairly low sample size, though the sample was well within the recommended range for a qualitative thematic analysis. While the study did not reach a vast number of people, it did allow for a depth of understanding and richness of data in terms of the narrative responses provided in the open-ended survey format. Another limitation related to the style of the research study is that the researcher could not ask follow-up or clarifying questions about participant responses due to it being a survey method as opposed to an interview. Conducting further trauma research in interview format may also help develop future recommendations and implications for clinical practice due to the ability to ask follow-up and clarifying questions, as well as take note of tone, affect, and other aspects of storytelling that are not always evident in written format. An additional related recommendation for future trauma research is for researchers to screen for trauma in Autistic people by focusing on trauma-informed interviews with emphasis on the identified themes of studies such as this one as opposed to solely relying on the traditional DSM-5 diagnostic criteria or traditional indicators of trauma that have been previously depended upon. Since Autistic individuals often experience trauma in ways that are not aligned with conventional diagnostic frameworks, this approach is essential to furthering the identification, and ultimately treatment, of trauma in Autistic people and may help address the gaps in the research. In time, it is also recommended that research focus on developing screening tools that are tailored and specific to the manifestation and presentation of trauma in Autistic adults.

Lastly, an identified limitation was related to the nature of participant recruitment. The researcher had to pursue Autism-specific spaces (social groups, researchers, non-profits) to

attract study participants. This indicates that Autistic individuals may not have felt safe outside of these spaces to engage in a study on a topic that required vulnerability and also limited the pools from which participants were drawn. It is hoped that with more emphasis on accessible and inclusive research studies, Autistic individuals will have fewer reservations about contributing to research.

## Conclusions

In conclusion, addressing trauma in Autistic adults requires the understanding that trauma presents and manifests differently within this demographic due to unique sensory and neurological experiences. Trauma symptoms have been frequently overlooked, misidentified, and dismissed in Autistic people (Hume & Burgess, 2021). Many takeaways from this study can be applied to the field of counseling in terms of clinical practice, counselor education, and supervision. The most prominent theme noted is how trauma is recognized clinically when considering the voices and lived experiences of Autistic adults. Current diagnostic criteria for trauma-related disorders such as PTSD are limited to a very specific set of symptoms and may not be inclusive of the neurological differences in symptom manifestation present in those with Autism Spectrum Disorder. It is recommended that by utilizing data such as that collected in this study to develop a tool to screen for trauma symptoms that are specific to the types of trauma more likely to be endured by those who are Autistic, this would help identify and eventually more effectively treat, those with Autism who are struggling with trauma symptoms that may fall outside of the scope of current traditional DSM-5 criteria.

Additionally, it should be noted that developing and applying a trauma-informed care framework that is inclusive of all and is rooted in anti-ablest practices should be implemented; counselors must be trained and actively practicing a sensory-sensitive approach and implementing accommodations as needed. Incorporating coursework and clinical skills opportunities around Autism-specific experiences in general, to be inclusive of trauma, is essential to counselor education programs. Educating and training counselors to regularly screen for indicators of trauma that are likely to be present in Autistic adults' histories and current lives, in addition to trauma markers indicated on traditional assessments, is integral. One recent study found that over 50% of providers reported some level of screening and treatment of trauma-related symptoms for youth with ASD; 70% of providers informally inquired about trauma-related symptoms, but only 10% universally screened for them (Kerns et al., 2020). Habitually screening, even when there are no obvious signs of trauma, is crucial when working with those with Autism.

Understanding that Autistic individuals view and experience the world differently than their neurotypical counterparts is essential for counselors to recognize, and unfortunately, many of them are suffering from unresolved and untreated symptoms related to trauma. A strengths-based approach to Autism is essential to help clients tap into their Autistic identity and perhaps even Autistic pride. However, it is important not to lose sight of the extensive challenges and traumatic experiences that most of these individuals have endured and to meet them with kindness, empathic understanding, supportive judgment, and authenticity. Autistic people are at risk of experiencing chronic and repeated traumatic experiences throughout their lifetimes and are generally at a higher risk of experiencing traumatic events and situations (Hoover, 2015; Kerns et al., 2015). It is likely that the experience of trauma and trauma-related disorders in those with ASD go unrecognized because of differences in cognitive, sensory, and/or executive functioning perceptions of what constitutes a traumatic event in a neurotypical person versus an Autistic person (Lobregt-van Buuren et al., 2021). A personalized and holistic approach is essential; treatment options that are not solely talk therapy oriented, such as art, dance, movement, EMDR, and nature-based, may also be appropriate avenues to consider for the Autistic demographic given the self-identified needs and experiences dictated in this study. Utilizing a holistic approach and treating the Autistic individual with particular attention to their strengths, abilities, and needs is integral, as is counseling beyond traditionally offered behavior modification. Additionally, structuring counseling sessions and approaches to be inclusive and adapted to the needs of the client will allow therapeutic treatment to occur. Autistic people may benefit from differently structured counseling sessions, with modifications and accommodations such as a longer or shorter duration depending on attention, the ability to communicate at their own pace, and additional processing time (Rumball, 2022).

Clinician biases should also be addressed and checked to determine implicit bias around ableism, which can negatively impact the clinician-client relationship when working with Autistic clients. Utilizing reflective supervision for those working with Autistic individuals will likely increase empathy, resilience, and perspective-taking, assisting in the relational awareness of practitioners and improving outcomes when it comes to risk factors for clinician burnout (Hallinan & McMahon, 2024).

By integrating trauma-informed techniques and the recommendations and strategies based on the themes identified in this study, counselors can create a welcoming and inclusive environment that fosters healing and empowerment. Counselor educators, supervisors, and researchers must continue to teach, train, educate, and contribute to the field of trauma research for Autistic individuals to ensure that these important voices are thoroughly represented. As we continue to advance our understanding of Autism and trauma, we must, as a field, remain committed to adapting our practices to be accessible to the needs of Autistic individuals, as everyone deserves the opportunity to be heard and to heal.

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## **APPENDIX A: IRB APPROVAL**

Online IRB Application Approved: The Lived Experiences of Trauma in Autistic Adults: A

Thematic Analysis November 14, 2024, 9:00 pm

DISSERTATION Search for all messages with label DISSERTATION Remove label DISSERTATION from this conversation

Thu, Nov 14, 1:00 PM

to kjenkins, me

Dear Briana Trageser,

As Chair of the Institutional Review Board (IRB) for 'Antioch University, I am letting you know that the committee has reviewed your Ethics Application. Based on the information presented in your Ethics Application, your study has been approved.

Renewal is not required, however, any changes in the protocol(s) for this study must be formally requested by submitting a request for amendment from the IRB committee. Any adverse event, should one occur during this study, must be reported immediately to the IRB committee. Please review the IRB forms available for these exceptional circumstances.

Sincerely,

Kalesha Jenkins

## **APPENDIX B: PARTICIPANT RECRUITMENT**

## Social media post:

Attention: Seeking Autistic Adults for Trauma Research Study. Are you self-identified or professionally diagnosed as having Autism Spectrum Disorder (ASD)? Have you experienced at least one traumatic event over the course of your lifetime? Please consider sharing your experiences in an online survey. Follow this link, review the informed consent form, demographic and survey questions:

# https://www.surveymonkey.com/r/autisticadultstraumastudy

# **Email post:**

You are invited to participate in an online survey! The aim of this study is to obtain information about the lived experiences of adults with Autism Spectrum Disorder (ASD) to determine their perceptions of experiences of trauma and traumatic events to better identify, diagnose, and treat trauma symptoms and trauma-related disorders such as Posttraumatic Stress Disorder (PTSD). The criteria to participate include the following:

- Self-identified or professionally diagnosed as having Autism Spectrum Disorder (ASD)
- Experienced one or more traumatic events
- English speaking adults 18 and older in the United States
- Participants must be able to complete a 12-item open-ended question survey in a verbal (talk to text) or written (typed) manner
- Participants must be able to legally consent on their own behalf to participate in research

If you decide to participate, it will take approximately 30-60 minutes. The process will include the following:

- Follow this link to review the informed consent form: https://www.surveymonkey.com/r/autisticadultstraumastudy
- Complete the demographic form
- Complete the open-ended survey questions

# **APPENDIX C: INFORMED CONSENT**

# **RESEARCH STUDY CONSENT FORM:**

You are invited to participate in a research study by Briana Trageser, a doctoral candidate in Counselor Education and Supervision at Antioch University. This form describes the study to help you determine if you are comfortable participating.

# **CRITERIA FOR PARTICIPATION:**

You are invited to participate if you meet the following criteria:

- Self-identified or professionally diagnosed as having Autism Spectrum Disorder (ASD)
- Experienced one or more traumatic events
- English speaking
- Age 18 or older
- In the United States
- Must be able to complete a 12-item open-ended question survey in a verbal (talk to text) or written (typed) manner
- Must be able to legally consent on own behalf to participate in research

If you do not meet these criteria, thank you for your interest. You do not have to proceed further. You may simply close your browser window.

If you do meet these criteria, please continue reading the informed consent form for more information and to participate.

# **STUDY OVERVIEW AND PROCEDURE:**

The purpose of this study will be to obtain information about the lived experiences of adults with Autism Spectrum Disorder (ASD) to determine their perceptions of experiences of trauma and traumatic events to better identify, diagnose, and treat trauma symptoms and trauma-related disorders such as Posttraumatic Stress Disorder (PTSD). Throughout this survey, the terms Autism Spectrum Disorder, Autism, and Autistic will be used interchangeably. This researcher has found that among Autistic communities, there are varying preferences for the type of language utilized to identify this demographic. So, in an attempt to be respectful to identification and identity preferences, variants of the term will be utilized.

There will be a brief demographic survey in which participants are asked to identify their age, gender identity, ethnicity, whether the Autism diagnosis is self-identified or professionally diagnosed, and the age of professional Autism diagnosis or approximate date of suspected Autism diagnosis (can be self-identified). Participants may choose to decline answering whether

or not they are self- or professionally diagnosed. Information will then be provided to the participants about the course of the study.

If consent is provided, participants will continue the survey to complete a 12-item open ended questionnaire. The open ended questions are designed to allow for narration and elaboration on the participants' lived experiences of living with Autism and experiences with traumatic events. This includes an approximate time commitment of 30-60 minutes.

The open-ended survey questions include the following:

This is a study about trauma as it is experienced in Autistic adults. Please keep in mind the definition of trauma as it relates to this study.

*Trauma is the emotional or psychological response to a deeply distressing event or situation* (The Mental Health Coalition, 2024).

- What do you want to tell me about yourself?
- What does it mean to you to be Autistic?
- Please describe traumatic experiences you have endured throughout your lifetime.
- In what ways do you feel your experiences with traumatic events have shaped your behavior or interactions with others or the environment?
- Please describe activities, situations, or environments that you avoid as a result of your trauma.
- What differences have you noticed in how you experience trauma as compared to others?
- How do you feel your Autism impacts your experiences of trauma?
- What role do sensory functions (e.g....) play, if any, in your experiences of trauma?
- What role does routine or structure play, if any, in your experiences of trauma?
- How do you cope with traumatic experiences (in the moment and/or afterward)?
- Can you describe experiences you have had in seeking help from others (personal and/or professional) in dealing with traumatic experiences?
- What advice do you have for other Autistic people who have experienced trauma?

# **RISKS AND BENEFITS OF PARTICIPATION:**

No study is completely risk-free. However, we do not anticipate you will be harmed or distressed during this study. You may stop being in the study at any time if you become uncomfortable.

Occasionally, people who participate in counseling-oriented research find that they would like to seek out mental health care and/or support. For more information, you may want to contact the National Alliance on Mental Illness (NAMI) at: 1-800-950-NAMI (6263).

If you need immediate emotional support, the following resources are available:

• Text HOME to 741-741 for the Crisis Text Line

• Dial 988 for the National Suicide and Crisis Lifeline or go to 988lifeline.org

- · Call 1-877-717-7873 for the PTSD Foundation of America
- Call 1-888-288-4762 Autism Speaks Autism Response Team
- · Call 1-800-662-4357 for the Substance Abuse and Mental Health Service Administration (SAMHSA) Helpline

You should also be aware that there is a small possibility that unauthorized parties could view responses because it is an online survey (e.g., computer hackers because your responses are being entered and stored on a web server).

In terms of benefits, there are no immediate benefits to you from your participation. However, we may learn more about the topic of trauma as experienced by Autistic people. Understanding the conceptual world of a group of people will help to better understand those with comorbid Autism and trauma who have had less avenues to communicate their experiences and are largely misunderstood clinically. This study will assist mental health clinicians in better understanding themes related to the experience of the targeted population and eventually how to develop appropriate interventions based on this knowledge.

# **DATA PRIVACY:**

No identifying information will be asked at any time. Otherwise, IP address collection is turned off and your name will not be requested.

# YOUR RIGHTS AS A PARTICIPANT:

Your participation in this study is voluntary. You can decide not to be in the study at any time and can simply close the browser window. Only completed surveys will be utilized for data analysis. In addition, it is important for you to know that your decision to participate or not to participate will not affect your relations with Antioch University in any way.

# **CONTACT INFORMATION:**

This study has been approved by the Antioch University Institutional Review Board (IRB). If you have ethical concerns about this study or your treatment as a participant, you may contact the chair of the IRB (Melissa Kennedy;) or the researcher.

Researcher: Briana Trageser Email: Research Advisor: Dr. Stephanie Thorson-Olesen Email: If you have questions about or do not understand something in this form, please contact the faculty researcher for additional information. Do not click "next" unless the researcher has answered your questions and you decide that you want to be part of this study.

# **CONSENT TO PARTICIPATION:**

By clicking "next" you agree to the following statements:

- · I have read this form, and I have been able to ask questions about this study.
- · I have not given up my legal rights as a research participant.
- I fit the criteria to participate in this study.
- I voluntarily agree to be in this study.

## **APPENDIX D: DEMOGRAPHIC SURVEY**

Thank you for participating in this study. The following questions are designed to gather general demographic information. Your responses will remain confidential.

- 1. Age
  - a. 18-24
  - b. 25-34
  - c. 35-44
  - d. 45-54
  - e. 55-64
  - f. 65 and older
- 2. Gender Identity
  - a. Male
  - b. Female
  - c. Non-binary
  - d. Other (please specify):
- 3. Race/Ethnicity
  - a. White
  - b. Black or African American
  - c. Hispanic or Latino
  - d. Asian
  - e. Native American or Alaska Native
  - f. Native Hawaiian or Pacific Islander
  - g. Other (please specify):
- 4. My Autism Spectrum Disorder (ASD) is:
  - a. Self-identified
  - b. Professionally diagnosed
  - c. I decline to answer

5. Age of Autism diagnosis or approximate age of suspected Autism diagnosis (can be self-identified) \_\_\_\_\_\_

## **APPENDIX E: SURVEY QUESTIONS**

## The open-ended survey questions include the following:

This is a study about trauma as it is experienced in Autistic adults. Please keep in mind the definition of trauma as it relates to this study.

*Trauma is the emotional or psychological response to a deeply distressing event or situation* (The Mental Health Coalition, 2024).

- What do you want to tell me about yourself?
- What does it mean to you to be Autistic?
- Please describe traumatic (e.g. ...) experiences you have endured throughout your lifetime? If so, please describe.
- In what ways do you feel your experiences with traumatic events have shaped your behavior or interactions with others or the environment?
- Please describe activities, situations, or environments that you avoid as a result of your trauma?
- What differences have you noticed in how you experience trauma as compared to others?
- How do you feel your Autism impacts your experiences of trauma?
- What role do sensory functions (e.g...) play, if any, in your experiences of trauma?
- What role does routine or structure play, if any, in your experiences of trauma?
- How do you cope with traumatic experiences (in the moment and/or afterward)?
- Can you describe experiences you have had in seeking help from others (personal and/or professional) in dealing with traumatic experiences?
- What advice do you have for other Autistic people who have experienced trauma?