

AUTISTIC AUTHORS' NARRATIVES OF TRAUMA AND RESILIENCE: A
QUALITATIVE ANALYSIS

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ABSTRACT

AUTISTIC AUTHORS' NARRATIVES OF TRAUMA AND RESILIENCE: A QUALITATIVE ANALYSIS

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This qualitative dissertation investigates current research gaps regarding autistic individuals' experience of trauma and resilience in the face of adversity. Specifically, it conceptualizes trauma and resilience through a neurodiverse lens, through identifying themes in memoirs written by five autistic authors related to trauma, potentially traumatic events, resiliency, and posttraumatic growth. Through Interpretive Phenomenological Analysis, I identified individual, interpersonal, and societal factors impacting the memoirists experiences of trauma, through the identification of 11 superordinate themes. Prominent themes at the individual level included self-acceptance and emotion regulation promoting resilience. At the contextual level, sensory processing and uncertainty coincided with experiences of trauma. At the interpersonal level, many memoirists describe interpersonal traumas, including mutual misunderstanding between themselves and others. Finally, at the societal level, themes across the memoirs point to the importance of mental health professional training and awareness regarding autism and expanding our understanding of traumatic experiences. Thus, I propose a sociocultural approach for conceptualizing how autism and trauma intersect. Based on this approach, I advocate for systemic-level changes, community, contextual, and individual interventions to support the resiliency of autistic individuals. This dissertation is available in open access at AURA (<https://aura.antioch.edu>) and OhioLINK ETD Center (<https://etd.ohiolink.edu>).

Keywords: Autism, resiliency, trauma, adverse childhood experiences, posttraumatic growth, neurodiversity, neurodivergence

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CHAPTER I: INTRODUCTION

Current estimates by the Center for Disease Control (CDC) suggest that 1 in 54 children in the United States meets diagnostic criteria for autism spectrum disorder (ASD; Maenner et al., 2020). Autism, defined by medical and psychological diagnoses as a neurodevelopmental disorder, impacts each autistic individual differently and is often accompanied with comorbid mental health diagnoses (American Psychiatric Association [APA], 2013). Central to the APA's diagnostic criteria for autism is difference in social interaction and communication, and a pattern of restricted interests, behaviors, or activities. Despite the growing number of autistic individuals, there has been little investigation into their experience of stress, trauma, potentially traumatic events, and factors that contribute to their resiliency (Hoover, 2015; Kerns et al., 2015; van Steensel et al., 2011).

Efforts to measure traumatic impact in a diverse population of autistic individuals have yielded inconsistent data. Across studies, rates of PTSD in autistic participants range from 0%, to 5.9%, to 17.4 % (de Bruin et al., 2007; Mehtar & Mukaddes, 2011; Storch et al., 2013). Notably, a growing body of literature suggests that autistic individuals may experience more potential stressors than their neurotypical peers and evince hardier resiliency in the face of these stressors (Berg et al., 2016; Kerns et al., 2017; Rigles, 2017). Current explorations tend toward quantitative reports relying on clinical diagnoses. There are few first-hand accounts of autistic individuals describing their own experience of potentially traumatic events (Hoover, 2015; Kerns et al., 2015; van Steensel et al., 2011). In this dissertation, I engage in a qualitative analysis of published memoirs written by autistic authors about traumatic experiences they have endured in order to understand their lived experience of stressful and traumatic events and the resulting sequelae, including their resiliency and description of post-traumatic growth.

CHAPTER II: LITERATURE REVIEW

Transformative Framework

This research is based on the transformative framework, which asserts that knowledge is constructed and reflects the current power dynamics within society (Creswell & Poth, 2018). From this perspective researchers work to construct knowledge to improve society, particularly for marginalized and oppressed groups to question, if not disrupt, the status quo. Transformative research and evaluation employ intentional inclusion of those largely discriminated against based on dimensions such as gender, race or ethnicity, disability, social class, age, sexual orientation, and religion (Mertens, 2009, p. 14). To construct knowledge that may better the lived experience for those with marginalized identities, researchers are encouraged to hold an agenda for reform, as well as amplify the voices of the research participants (Creswell & Poth, 2018). Central to transformative research is the belief that the immense strength of communities and groups addressing oppressive systems calls for inquiry into resilience as well as perceived problems (Mertens, 2009). While this this dissertation does not engage participants directly in the inquiry, it provides a first step for future collaborative research with autistic individuals.

Identity-First Language

People use a variety of language to identify autistic individuals depending on multiple complex factors (Kenny et al., 2016). Currently there exists controversy regarding using person-first language (i.e., a person with Autism) versus identity-first language (i.e., autistic individual; Brown, 2011; Sinclair, 1999; Vivanti, 2020). Proponents of both sides recognize the importance of language and its impact on societal attitudes. Regarding disability status, proponents of person-first language argue that in general putting the noun before identifying

characteristics may emphasize the value and worth of an individual person and reduce bias regarding disabilities (APA, 2021; Dunn & Andrews, 2015).

Conversely, identity-first language proponents argue that using person-first language may perpetuate stigma (Gernsbacher, 2017). Autistic self-advocates and scholars theorize that person-first language may imply that autism is undesirable and/or lesser than other neurotypical presentations. This may perpetuate negative connotations, bias, and assumptions regarding autism spectrum. Additionally, autistic self-advocates argue that autism is a part of their identity, and not something that can be separated from who they are (Brown, 2011; Sinclair, 1999). A study of United Kingdom adults found that most autistic adults and family members and friends of autistic people preferred the term “autistic,” (Kenny et al., 2016). Vivanti (2020) urges others to be flexible and defer to the preference of the individual. When the preference may be unknown, they urge consideration of the historical agendas related to person-first and identity-first language, as well as the priorities and experiences of the autistic community (Vivanti, 2020). Similarly, APA (2020) guidelines encourage using the preference of self-advocacy groups or other stakeholders when determining which language to use. For the purposes of this research, while acknowledging the current controversy, I will use identity-first language, except when referring to individuals who provide other preferred language.

Autism Spectrum and Neurodiversity

The APA diagnostic criteria for ASD highlights a persistent deficit in social communication and social interaction, as well as restricted and/or repetitive behaviors, activities, or interests (APA, 2013, p. 50). In addition, these criteria must be present early in the individual’s development, though diagnostic criteria may not be fully met until the individual reaches a point when the social demands placed on them exceed their capacity. While the list of

characteristics or behaviors considered to be a result of autism have often changed in the last 80 years, criteria describing differences in social communication and interaction and a pattern of restricted or repetitive behaviors have remained fairly constant (National Research Council, 2001). In the last decade, studies estimate that there are 52 million autistic people around the world (Baxter et al., 2015). Estimates by the Center for Disease Control (CDC) theorize that 1 in 54 children in the United States meet diagnostic criteria for ASD (Maenner et al., 2020). Autistic individuals experience a range of presentations that may vary from requiring very limited or no support to requiring very substantial support in various areas of functioning. Additionally, autism presents a spectrum of cognitive, social, and emotional differences that make each individual's experience unique (APA, 2013).

History of Autism and Asperger's Syndrome

The term "autism" was first used by Swiss psychologist Eugene Bleuler. In his 1916 published work, *Lehrbuch der Psychiatrie* (Textbook of Psychiatry), he used the term to describe patients who appeared to lose touch with reality and seemed unable to communicate with others in the traditional ways (Bleuler, 1934; Greydanus & Toledo-Pereyra, 2012). At the time, Bleuler used the term to describe symptoms of another term he introduced: schizophrenia. In the first edition of APA's DSM, Autism was initially included as a form of childhood schizophrenia (APA, 1952). Autism was first separated from schizophrenia by Leo Kanner, an American psychiatrist, in his study, "Autistic Disturbances of Affective Contact," published in 1943 (Kanner, 1943). In his observation of several families and their children, he identified key characteristics which the children appeared to share amongst themselves and differentiated them from the schizophrenia diagnosis. These traits included a preference for solitary activity, rigidity, a preference for routine and sameness, repetitiousness, and obsessiveness. Kanner (1943)

proposed that the children participating in his study demonstrated, “pure-culture examples of inborn autistic disturbances of affective contact” (p. 250). Autism was not officially separated from schizophrenia until 1980 in the DSM-III, when it was included in a new class of disorders called Pervasive Developmental Disorders (APA, 1980; Volkmar et al., 1992). At the time it was referred to as “infantile autism.” It received this label due to Kanner’s original descriptions that asserted autism was present from birth (Gengoux, 2013). There are autistic children who may experience a plateau or regression in their development; while the exact etiology remains unknown it is theorized that most individuals are born autistic.

Criteria offered for infantile autism in the DSM-III were criticized, as they did not appear to accurately describe developmental changes within the diagnosis (Volkmar et al., 1992). When the DSM-III was revised, the diagnosis was changed to autism spectrum disorder (APA, 1987) to account for the broad developmental presentation of autistic individuals. In the next edition, DSM IV, Asperger’s Syndrome was added as a subtype under the autism spectrum (APA, 1994; Barahona-Corrêa & Filipe, 2016) before being eliminated 20 years later in the DSM-5.

The Asperger’s diagnosis has an interesting and salient history. In 1944 Hans Asperger, an Austrian pediatrician, identified a group of boys with high intelligence, obsessive interests, and atypical ways of interacting socially (Asperger, 1991; Greydanus & Toledo-Pereyra, 2012). Asperger referred to children with these commonalities as “autistic psychopaths” (Asperger, 1991). Then, in 1981 Lorna Wing, an English psychiatrist, proposed “Asperger’s Syndrome” as a separate diagnosis, or subgroup of, Kanner’s description of autism (Bernardo & Carlos, 2016; Wing, 1981). Asperger’s Syndrome was included in the fourth edition of the Diagnostic and Statistical Manual (DSM-IV) in 1994 when the diagnostic criteria for autism was broadened to include a spectrum of diagnoses (APA, 1994; Barahona-Corrêa & Filipe, 2016). However,

controversy regarding the DSM classification of Asperger's Syndrome led to its exclusion in the DSM-5 published in 2013 (APA, 2013). Those who opposed the separation of Asperger's Syndrome from autism argued that it was indistinguishable from autism criteria, and that the definition of Asperger's Syndrome was overly restrictive (Klin et al., 2005).

In addition, recent research has suggested that Hans Asperger assisted and supported Nazi euthanasia initiatives, leading some to question whether his name should be included in the diagnostic label (Hudson, 2019). The loss of the clinical diagnosis did not, however, erase the group of individuals who identify with the label and associated experiences. There continue to be communities centered around having Asperger's or being an "Aspie." While some welcomed the dissolution of the boundary between Asperger's and Autism, others were distressed by the erasure of their identity by the DSM committee; they also feared this change would create new barriers to receiving necessary supports (Jones, 2020).

Autism and Intersecting Identities

Much like the current controversy facing the diagnosis and definition of autism, early research intended to define the disorder has been criticized for its lack of inclusivity. Two foundational researchers, Kanner and Asperger, studied participant samples that consisted mostly of white Anglo male children and their families (Asperger, 1991; Dyches et al., 2004; Kanner, 1943). Further, Kanner described parents of autistic children as more likely to be in a higher socioeconomic class (Kanner, 1943; Sanua, 1987). Such research bias calls into question the generalizability of early findings across race, ethnicity, culture, gender, and socioeconomic status. In fact, Dyches et al. (2004) argue that the homogeneity of early samples has continued to skew our current understanding of autism.

In keeping with recommendations put forth by the APA (2017), an individual should be understood from the perspective of intersectionality. In taking an intersectional approach, understanding of all individuals, including Autistic individuals, should account for their diverse identities and incorporate cultural, economic, structural, and social contexts which impact these identities. The early foundational research leaves much to be desired and understood regarding the experience of non-white, non-male, and lower socioeconomic status autistic people (Dyches et al., 2004; Sanua, 1987).

Socioeconomic Status. Historical research exploring the relationship between an autism diagnosis and socioeconomic status (SES) suggested that autistic children were more likely than allistic (or, not autistic) children to have parents with higher SES (Kanner, 1943; Sanua, 1987). More recently, some, but not all studies note a similar pattern (e.g., Dickerson et al., 2017; Durkin et al., 2017). However, this finding has been challenged by other explorations that find no such link (e.g., Delobel-Ayoub et al., 2015; Rai et al., 2012). In fact, Rai et al. (2012) found in their exploration of the Swedish-based population that *lower* SES was associated with increased likelihood of an autism diagnosis. In a related exploration, Delobel-Ayoub et al. (2015) found lower SES only correlated with higher prevalence of autism and co-occurring intellectual disabilities; notably, they found no difference in SES of autistic individuals without intellectual disabilities.

The relationship between autism and SES remains unclear. Indeed, Durkin et al. (2017) hypothesize that a greater prevalence of autistic children from higher SES families could be due to those families having more access to resources. Families with the financial means may be more likely to have their children diagnosed accurately—and deemed acceptable for inclusion in research. Indeed, Durkin and colleagues acknowledge their data comes only from individuals

identified through comprehensive developmental assessments or special education services; they have no way of accounting for possible under-identification of low SES children. It is likely that varying findings indicate underestimation of autism in lower SES families and communities (Durkin et al., 2017; Rai et al., 2012).

Race and Ethnicity. Regarding differences in race and ethnicity amongst the autistic community, studies in the United States have generally found prevalence rates to be highest among white families (Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators & CDC, 2014; Durkin et al., 2017). Previous studies of prevalence suggest that non-Hispanic white children are more likely to be autistic compared to non-Hispanic Black and Hispanic children (Durkin et al., 2017). Additionally, Non-Hispanic Black children showed higher rates than Hispanic children and estimates for Asian and Pacific Islander children were highly variable, from 3.0 per 1,000 to 21.0 per 1,000 (Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators & CDC, 2014). However, similarly to studies investigating SES, some researchers point to potential underdiagnosis in non-white individuals (Durkin et al., 2017; Mandell et al., 2009).

In one study supporting the underreporting hypothesis, Mandell et al. (2009), collected data on children who met their surveillance criteria for autism, and found that only 58% of those children had documentation of their autism in their educational records. Specifically, they found that children who were Black, Indigenous, and People of Color (BIPOC) were less likely than white children to have documentation of a diagnoses of autism despite meeting their surveillance criteria (p. 496). Thus, possible racial/ethnic disparities in special education eligibility determination for autism spectrum may further indicate that BIPOC children with ASD face additional barriers to school-based accommodations and equitable access to education.

Sex and Gender Identity. This pattern of suspected underestimation of autism continues when applied to gender identity. While autistic individuals may be any sex, it appears to be much more commonly diagnosed in males (APA, 2013). Some researchers hypothesize this is due to early underrepresentation of other sexes in studies of autism and assert this has led to a male-biased understanding of autism. Indeed, research conducted by Kreiser and White (2014) suggest that autistic females may present with differing characteristics within the diagnostic criteria when compared to autistic males. For example, when matched for intelligence quotient and age, autistic females demonstrated greater skills in social communication and greater sensory issues than autistic males (Lai et al., 2011). It has also been suggested that autistic females engage in more “camouflaging” behaviors to visibly present with less autistic traits or behaviors (Hull et al., 2019). Lastly, studies have shown that autistic people are more likely to have more diverse gender identities when compared to allistic people, but the research in this area is currently small though growing (Cooper et al., 2018).

Neurodiversity, Autism, and Medical Models of Diagnosis

Neurodiversity. The term neurodiversity, “refers to the neurological constellation of different neurological types, which can be delineated according to a trait or set of traits” (Paletta, 2013, p. 42). Its beginnings can be traced back to civil and human rights movements in the 1990s, and essentially refers to the acknowledgement and celebration of the diversity of human brains (Masataka, 2017; Walker, 2014). This notion of neurodiversity has been used in autistic communities where it has gained significant traction in recent years as part of the burgeoning disability rights movement. The concept of neurodiversity has grown to include other neurodevelopmental differences such as intellectual disabilities, Attention Deficit/Hyperactivity Disorder (ADHD), learning disabilities, Tourette’s Syndrome, epilepsy, and bipolar disorder

(Fenton & Krahn, 2007; Mastaka, 2017). Individuals who fall under these categories, and others who are not considered “neurotypical” can be referred to as neurodivergent. As the neurodiversity paradigm is central to this dissertation, I use neurotypical and neurodivergent throughout in this manner. Additionally, it is important to note that the term neurotypical differs from allistic, which refers specifically to those who are not autistic.

Medical Model and Autism Diagnosis. The neurodiversity perspective was initially intended to oppose the focus on “symptoms” and “deficits” of neurodivergent individuals in the medical model. Instead, proponents of neurodiversity seek to acknowledge strengths and suggest that the identified “symptoms” or “deficits” are better understood as a natural variation in brain functioning and behavior inherent in the heterogeneity of species (Mastaka, 2017; Ortega, 2009; Runswick-Cole, 2014). From a social justice perspective, the neurodiversity movement seeks to promote rights and prevent discrimination against people who are neurodivergent or not “neurotypical.”

However, this perspective also bears critical scrutiny. For example, Ortega (2009) writes, “To those for whom autism is a disease (primarily caused by genetic and neurobiological factors), the anti-cure and pro-neurodiversity positions not only contradict their claims, but also insult the suffering of patient and their families” (p. 429).

In addition, there are significant pragmatic objections to moving entirely away from the medical model. For example, an autism diagnosis is still essential for schools to provide special education services and for health insurance companies to cover therapy and support for autistic children and disability benefits such as housing and employment support. In any event, in recent years, perspectives on autism and neurodiversity have broadened and become less polarized. Opinions amongst families, caregivers, supporters, and autistic individuals on neurodiversity are

now more nuanced and complex; the autism diagnosis covers a broad spectrum of individuals and behaviors (Ortega, 2009).

Autism and Optimal Outcome. Georgiades and Kasari (2018) propose an optimal outcome paradigm in response to concerns on both sides of the debate. Traditionally optimal outcomes were essentially measured against “neurotypical” expectations, and one’s ability to meet goals set by evaluators or professionals. However, to reflect the heterogenous experience of autistic individuals, Georgiades and Kasari (2018) suggest a broader definition of optimal outcome to better align with the neurodiversity paradigm. Optimal outcomes, from this perspective, are based on goals identified by autistic individuals and their families, and progress is measured based on the individuals’ personal history. Similarly, assessment, services, and interventions can be described accordingly, to match this collaborative and individualized approach that accounts for the diverse experiences and goals of autistic individuals.

Trauma and Potentially Traumatic Experiences

Like autism, our diagnostic understanding of trauma continues to evolve and change over time. The American Psychological Association provides diagnostic criteria for various trauma- and stressor-related disorders (APA, 2013). However, there exists evidence of potential other diagnoses that are not currently represented in the DSM (Giourou et al., 2018; Herman, 1992; van der Kolk, 2005). Additionally, research exploring the impacts of adversity in childhood consistently finds that the experience of more adverse events increases the likelihood of future negative cognitive, emotional, developmental, medical, and social outcomes (U.S. Department of Health and Human Services [DHHS], 2021).

Trauma- and Stressor-Related Disorders

Based on diagnostic criteria put forth by the most recent version of the DSM, trauma- and stressor-related disorders are diagnosed when there is exposure to a traumatic or stressful event (APA, 2013). For each disorder that falls under this category, traumatic or stressful events are essential to the diagnostic criterion. The diagnoses which fall under this category are reactive attachment disorder, disinhibited social engagement disorder, posttraumatic stress disorder, acute stress disorder, adjustment disorders, other specified trauma- and stressor-related disorder, and unspecified trauma- and stressor-related disorder.

Reactive Attachment Disorder (RAD) and disinhibited social engagement disorder are both diagnosed in children who evidence the diagnostic criteria before the age of five (APA, 2013). Both RAD and disinhibited social engagement disorder require the child to have experienced social neglect, multiple changes in primary caregivers, and early development in settings that limit the chance for the child to form an attachment. The diagnostic difference lies in how the child's symptoms manifest following the early and extreme attachment disruptions. In RAD, the child is emotionally withdrawn from their caregiver and displays persistent social and emotional difficulties. By contrast, disinhibited social engagement disorder results in the child interacting with unfamiliar adults without discrimination, acting overly familiar with unfamiliar adults, and diminished checking in with their adult caregivers, even in unfamiliar settings. In either case, early social neglect and attachment disruption acts as the catalyst for future sequelae (APA, 2013).

Posttraumatic Stress Disorder (PTSD) and acute stress disorder are similar in that both require the exposure to a Potentially Traumatic Event (PTE) as defined by the diagnostic criteria, and specific symptomology resulting from the exposure to that traumatic event (APA, 2013).

The key differentiation between these diagnoses lies in the duration of resulting symptoms following the exposure. PTSD is diagnosed if the symptoms last over one month, whereas in acute stress disorder the symptoms last from three days to one month. Both diagnoses include presence of intrusive symptoms and thoughts, avoidance of stimuli associated with the traumatic event, negative changes to mood and thoughts associated with the event, and changes in arousal and reactivity (APA, 2013). In order to be diagnosed with either based on the criteria, a person must be exposed to a potentially traumatic event, defined as an event in which a person is exposed to death, injury, or sexual violence or was threatened with death, injury, or sexual violence through either direct exposure, witnessing such events in person, having the event happen to a close friend or relative, or through repeated or extreme indirect exposure (APA, 2013).

Diagnostic criteria for adjustment disorders requires that an individual develops emotional or behavioral symptoms as a response to identifiable stressors present in their lives, within three months of the onset of the stressors (APA, 2013). In this case, what those stressors may be is left undefined. Specified and unspecified trauma- and stressor-related disorders diagnostic criteria require that an individual experiences symptoms characteristic of trauma- and stressor-related disorders which cause clinically significant impairment. “Specified” is used when the clinician chooses to share why the individual does not meet the full criteria for another disorder. Unspecified is used when the clinician does not communicate why the individual does not meet full criteria for another disorder (APA, 2013).

Complex PTSD and Developmental Trauma Disorder

Another potential trauma-related disorder that has not yet been included in our evolving diagnostic understanding of trauma is referred to as Complex PTSD (Giourou et al., 2018;

Herman, 1992). Complex PTSD—or complex trauma—is theorized to result from repetitive, cascading, or prolonged stressors stemming from neglect and abuse by caregivers or other responsible adults over the course of infancy and childhood. This traumatic exposure then leads to changes in biological, neurological, psychological, cognitive, and relational functioning over the course of development (Courtois & Ford, 2009). Symptoms theorized to be related to Complex PTSD include traumatic re-experiencing, avoidance, and perceived threat(s), which align with PTSD as outlined above. However, Complex PTSD includes additional symptoms including emotional and biological dysregulation, relational disturbances, negative self-concept, dissociative coping, and somatic problems.

In an attempt to label the experience from a medical perspective, a diagnosis of Complex PTSD was added to the *International Classification of Diseases* (11th ed.; ICD-11). The associated symptoms include difficulties with affect regulation, seeing oneself as worthless, feelings of shame or guilt related to a traumatic event, and difficulties sustaining relationships with others (World Health Organization, 2020). However, this diagnosis has faced criticism due to some overlap with PTSD and with comorbid borderline personality disorder (Jowett et al., 2020).

Because the memoirs used for this dissertation are retrospective narratives of traumatic exposure, multiple accounts describe the sequelae of child abuse and neglect—traumatic exposure uniquely situated in a child’s relationship with caregivers. For this reason, I also included another trauma-diagnosis—Developmental Trauma Disorder (DTD)—that did not make it into the DSM-5 but may be relevant to our understanding of the impact of early trauma on later functioning. DTD encapsulates the biological, social, and psychological impacts of the experience of childhood trauma and extends beyond PTSD in scope and developmental impact (van der Kolk, 2005).

The first criteria, exposure, postulates that DTD occurs when an individual is chronically exposed to one or more forms of interpersonal trauma, such as “abandonment, betrayal, physical assaults, sexual assaults, threats to bodily integrity, coercive practices, emotional abuse, [and] witnessing violence and death” (van der Kolk, 2005, p. 404). Secondly, the individual displays a pattern of dysregulation when triggered by trauma cues. This dysregulation persists and does not reduce even when brought into conscious awareness of the individual. Dysregulation may produce affective, behavioral, cognitive, relational, and somatic changes.

The third criterion of the proposed Developmental Trauma Disorder is that the individual experiences “Persistently altered attributions and expectancies,” (van der Kolk, 2005, p. 404). These may include loss of trust and expectations for being protected by others and social agencies, distrust of caregivers, negative self-attribution, and the belief that one will inevitably be victimized throughout their future. The final criterion requires functional impairment of familial, educational, social/peer, vocational, or legal activities. In sum, developmental trauma can be distinguished from other trauma diagnoses by the childhood experience of multiple, cascading stressful events, and a primary caregiver who is significantly unavailable, unreliable, or unsafe over time. The child’s coping resources are overwhelmed, and they are without an adult to help them manage their stress; indeed, the person who is tasked with protecting them may very well be the source of danger.

Adverse Childhood Experiences

Studies into potential trauma exposure have linked certain early adverse experiences to poor physical, social, and mental health outcomes later in life (U.S. DHHS, 2021; van der Kolk, 2005). For the past 25 years, researchers exploring Adverse Childhood Experiences (ACEs) have examined impacts of childhood abuse and neglect and other household challenges on future

mental and physical health outcomes (Felitti et al., 1998; U.S. DHHS, 2021). Although more recent versions of the measure include social, economic, and community stressors, the original ACEs collected were divided into three subcategories: abuse, household challenges, and neglect. Each of these categories was divided into subcategories. Abuse included physical, sexual, and emotional abuse. Household challenges referred to the existence of the following within the household: violent treatment of mother or stepmother, substance use, mental illness, parental separation or divorce, and an incarcerated household member. Neglect was separated into emotional neglect and physical neglect.

This original study, and those that followed, found that the higher number of types of ACEs a person experienced, the more likely it was that they would have worsened health and wellbeing outcomes over time, resulting in significant physical and emotional illness and even earlier death. Since the initial study, researchers have examined other types of ACEs that appear to increase risk of future negative outcomes (Finklehor et al., 2015). Such experiences include, for example, peer victimization or bullying, isolation and peer rejection, exposure to community violence, the experience of discrimination, living in foster care, and low socioeconomic status (Cronholm et al., 2015; Finklehor et al., 2015).

Evidentiary support for the findings of the initial ACEs study has been robust: the more ACEs in childhood, the higher the risk for negative short-term and long-term impacts on behavior, physical and mental health, and social wellbeing (Dube et al., 2001; Felitti et al., 1998; U.S. DHHS, 2021; Wolitzky-Taylor et al., 2017). Negative mental health outcomes found to be associated with ACEs include substance use and substance use disorder, depression, anxiety, suicidality and suicide, PTSD, and Complex PTSD (U.S. DHHS, 2021; van der Kolk, 2005). In addition, the literature points to the highly interconnected relationship among ACEs. The

experience of one type (e.g., substance use) is significantly associated with the experience of another (e.g., domestic violence; Dong et al., 2004).

Conceptualizing potential traumatic exposure through the lens of ACEs provides a quantifiable metric for investigating the number of potentially traumatic experiences a person has faced as well as a context for understanding the significance of their resiliency and growth following such exposure (Felitti et al., 1998; U.S. DHHS, 2021). In addition, the list of ACEs broadens the original definition of a potentially traumatic event (PTE) beyond current diagnostic criteria. Like traditional PTEs, ACEs have the potential to negatively impact the wellbeing of individuals. Traumatic exposures have a deleterious impact on development even if they fall short of the DSM-5 criteria for PTSD or another trauma- or stressor-related disorder. In particular, and for the purposes of this dissertation, ACEs may be a more accurate indicator of traumatic exposure than traditional diagnostic interviews. Thus, including ACEs into our understanding of the lives of autistic and other neurodivergent individuals may create a fuller picture regarding their experience of trauma, which may not be fully captured by current understandings of PTEs (Corbett et al., 2009; Gillott & Standen, 2007).

Resilience and Posttraumatic Growth (PTG)

Resilience. While initially viewed as an individual characteristic, resilience may more accurately be described as a dynamic and systemic process impacted by individual, familial, and cultural factors (Benzies & Mychasiuk, 2009; Rutter, 2006; Ungar, 2015). Rutter (2006) offers a definition of resilience inclusive of systemic considerations: “[A]n interactive concept that refers to a relative resistance to environmental risk experiences, or the overcoming of stress or adversity” (p. 1). From this perspective, resilience relies on individual, contextual, and cultural factors, and the dynamic interaction between each over time (Ungar, 2015).

Ungar (2015) proposes three domains required for assessing resilience in children. First, the child must be exposed to adversity. Second, there must be a presence of resilience following adversity. The third proposed domain includes consideration of temporal and cultural dimensions. On an individual level, factors theorized to impact resiliency include temperament, cognitive structures, good physical health, sense of control, belief-systems, feelings of empowerment, and ability to self-regulate (Benzies & Mychasiuk, 2009; Ungar, 2015). In addition, Ungar (2015) asserts that specific characteristics of adverse experience(s) also impact the likelihood of resilience. These characteristics include, “severity, chronicity, ecological complexity, attributions of causality, and the cultural and contextual relevance of the factors that influence children’s experience of their exposure to risk” (Ungar, 2015, p. 5). Importantly, at the contextual level, a child’s likelihood of experiencing resilience is based on their families’ and communities’ capacity to help children cope with exposure to adverse experiences. An ACE is significantly less likely to become traumatic if the child has adequate support for managing it.

Regarding families, studies suggest that increased resiliency is related to positive dynamics of family structure, stability of intimate partners, family cohesion, supportive parent-child interaction, stimulating environment, social support, the supportive engagement of family of origin, stable and adequate income, and secure housing (Benzies & Mychasiuk, 2009; Ungar, 2015). At the community level, factors related to increased resiliency include involvement in the community, peer acceptance, supportive mentors, safe neighborhoods, access to quality schools and childcare, and access to quality health care.

Lai and Szatmari (2019) advocate for using a social-ecological perspective framework for understanding the experience of resilience for autistic individuals and their families. Employing this understanding of resilience may be particularly salient following exposure to traumatic and

adverse events; the socio-ecological framework considers access to resources and structural barriers that may prevent individuals from succeeding following exposure to adversity, broadening the context for understanding resilience beyond a focus just on individual factors (Ungar, 2015).

Posttraumatic Growth (PTG). Research has sought to investigate individuals experiencing positive changes—beyond resiliency—after an adverse experience. In their model of posttraumatic growth (PTG), Calhoun and Tedeschi (2006) propose that PTG occurs when, after experiencing trauma, an individual appears to grow in various domains. They identify these domains as: spiritual change, appreciation of life, relating to others, new possibilities, and personal strength. In addition, Calhoun and Tedeschi (2006) identify the role of individual and sociocultural factors in the likelihood an individual exhibits PTG.

Sociocultural PTG Factors. Sociocultural factors considered to contribute to the likelihood of PTG may be labeled either distal or proximal (Calhoun & Tedeschi, 2006). Distal sociocultural factors refer to broad cultural themes across larger societies or geographic areas. This includes for example the influence of cultural and societal values or narratives. Calhoun and Tedeschi (2006) point to the influence of cultural and societal narratives on how an individual sees and internalizes experiences, including traumatic and stressful events. Proximate sociocultural elements refer to smaller communities, social networks, and people with whom the individual directly interacts. How the phenomenon of trauma is spoken about by these close others is theorized to influence the way in which an individual understands their traumatic experience. In addition, assumptions or bias held by these close others regarding trauma and trauma sequelae also impact the individuals' understanding of their traumatic experience (Calhoun & Tedeschi, 2006).

Individual PTG factors. In relation to sociocultural factors, individual factors are also theorized to influence the likelihood an individual will experience PTG following a potentially traumatic experience (Calhoun & Tedeschi, 2006). Further impacted by the interaction of these factors with sociocultural factors is how the individual engages cognitively with their traumatic experience, and their use of self-disclosure. Calhoun and Tedeschi (2006) refer to the process of cognitive engagement as rumination. They propose rumination directly following the traumatic incident is intrusive and automatic. However, over time, they theorize this rumination may become more deliberate, and may positively impact PTG when the individual's rumination supports them in making meaning of the traumatic experience (Calhoun & Tedeschi, 2006).

While there is no proposed theory or model for understanding autistic individuals experience of PTG, like Ungar's (2015) social-ecological understanding of resilience, the model presented by Calhoun and Tedeschi (2006) presents a similar socio-ecologically informed framework for understanding the phenomenon. By applying this understanding of both resiliency and PTG to the experience of autistic individuals, I suggest a multidimensional and systemic understanding of the experience of autistic individuals following exposure to adverse and potentially traumatic experiences.

Review of the Literature on Autistic Individuals' Experience of Trauma and Resilience

There is limited research on prevalence rates or autistic individuals' experience of trauma and trauma-related sequelae (Hoover, 2015; Kerns et al., 2015; van Steensel et al., 2011). In their meta-analysis of the literature related to autistic children and adolescents and anxiety disorders, van Steensel and colleagues (2011) identified two studies that provided prevalence rates of PTSD in their Autistic participants. In the first study cited, Mehtar and Mukaddes (2011) found in their sample of 69 Autistic children, 17.4% met diagnostic criteria for PTSD. In the second

study reviewed, out of 94 children with Pervasive Developmental Disorder, not otherwise specified (PDD-NOS), de Bruin et al. (2007) found no cases of comorbid PTSD.

Results from a related, more recent exploration of suicidality predictors among autistic youth, researchers concluded that 5.9% of their 102 autistic participants presented with comorbid PTSD (Storch et al., 2013). While these differences may in part be explained by varying sample sizes, sampling methodologies, and differences in measures and definitions of both autism and PTSD, the discrepancy in findings as well as the lack of research still leave much unanswered regarding the prevalence rates of traumatic experiences and PTSD for autistic individuals.

Since autistic individuals may process information and communicate distress in atypical ways, traditional methods of data collection may be insufficient for ascertaining accurate prevalence rates. For example, what is considered a traumatic or potentially traumatic event as defined by the APA diagnostic criteria may not be fully representative of neurodivergent individuals' experiences of stress and trauma (Corbett et al., 2009; Gillott & Standen, 2007). Researchers have theorized that the diverse presentations of autism may include cognitive components that could increase risk for autistic individuals developing trauma-related sequelae, as well as require specialized intervention (Hughes et al., 1994; Kerns et al., 2015; Orsmond et al., 2004; Samson, Hardan, et al., 2015; Samson, Wells, et al., 2015; Sullivan & Knutson 2000). And while we know relatively little about the prevalence or traumatic impact of traumatic exposure among autistic individuals, there is even less research exploring their resiliency, protective factors, and posttraumatic growth following PTEs and ACEs (Lai & Szatmari, 2019; Szatmari, 2018).

Potentially Traumatic Events and Adverse Childhood Experiences

Researchers suggest that autistic children and adolescents may be exposed to more ACEs and PTEs, such as maltreatment, abuse, neglect, and peer victimization, than their allistic peers (Kerns et al., 2015; Sullivan & Knutson, 2000). In their research, Sullivan and Knutson (2000) defined maltreatment as incidents of physical, emotional, and sexual abuse, and neglect. They found that youth with intellectual and developmental diagnoses were more likely to be maltreated than their peers without such diagnoses, and these youth were more likely to endure multiple episodes, rather than a single episode of maltreatment. Additionally, autistic children and adolescents may be twice as likely to be the victims of bullying, or peer victimization (Cappadocia et al., 2012). Bullying refers to hostile or aggressive action taken against one child by another, characterized by a power differential. Autistic youth who were younger and had greater difficulty communicating in ways that others understand were found to be more at risk for being the target of bullying and being victimized, which is further associated with increased comorbidity related to mental health (Cappadocia et al., 2012).

There has been growing investigation in the past several years regarding the impact of ACEs for autistic individuals (e.g., Berg et al., 2016; Kerns et al., 2017; Rigles, 2017). In one study, Kerns et al. (2017) found that the autistic children in their sample encountered on average more ACEs compared to allistic children, and the difference was particularly pronounced in families with lower incomes than in those with higher incomes. This supports general findings that people in lower income brackets are more likely to experience more ACEs (Conroy et al., 2010). It also coincides with the findings of Berg et al. (2016). Their sample consisted of allistic and autistic children based on care-giver reports, and their research suggested that reportedly autistic children were at increased risk of experiencing between 1–3 ACEs. When the researchers

controlled for the variables of poverty and residential disadvantage, they found the autistic children to be more likely to be exposed to four or more ACEs (Berg et al., 2016).

Studies of family stress not defined as ACEs reveal similar findings: families and caregivers with autistic children have increased likelihood of experiencing family stressors (Berg et al., 2016; Hartley et al., 2010). For example, Hartley et al. (2010) found in their research that parental divorce occurred more often in families with autistic children compared to those with allistic children. This finding was replicated and expanded upon by Berg et al. (2016), who also found autistic youth were more likely to be in families with insufficient income, have a family member with a mental health diagnosis, and experience neighborhood violence.

Potential Risk and Resilience Factors

As mentioned previously, some research suggests traits, expressed to varying degrees, associated with ASD may increase a person's risk for developing PTSD, as well as potentially exacerbate their PTSD symptoms (Hughes et al., 1994; Kerns et al., 2015; Orsmond et al., 2004; Samson, Hardan, et al., 2015; Samson, Wells, et al., 2015; Sullivan & Knutson, 2000). This body of research is challenging to summarize and apply, as autism is not monolithic. Each person that meets criteria for autism may have the associated features at varying levels, creating a wide range of individualized and unique experiences (APA, 2013). In addition, there are multiple comorbid diagnoses that further the variability of each individual experience. Each autistic individual has their own unique traits, experiences, and developmental trajectory. Thus, the following list of potential risk and resiliency factors describes some general potential characteristics of autistic individuals. It is not intended to be applied sweepingly to the autistic community, but rather needs to be considered on a case-by-case basis for applicability to individuals.

Rigidity. ASD diagnostic criteria include reference to decreased mental flexibility, or rigidity, suggesting difficulties in shifting to different thoughts or actions in response to changes in the environment or situation (Hill, 2004). Research has indicated that increased numbers of autistic individuals may display higher rates of rigidity, as compared to allistic individuals, and individuals with other neurodevelopmental disorders (Hughes et al., 1994). Kerns et al. (2015) further hypothesizes that increased rigidity in the face of a traumatic incident may cause individuals to be less likely to shift their thinking from the incident, potentially increasing ruminations, and distress.

Emotion Regulation. Emotion regulation refers to processes employed by individuals to influence which emotions they experience, and when, and how they then express these emotions; such processes may occur automatically or with effort, or be unconscious or conscious (Gross, 1998). Research suggests that some autistic individuals may have increased difficulty with emotion regulation, which may lead to increased experiences of negative emotions such as anxiety and anger (Samson, Wells, et al., 2015). This may also lead to an increased likelihood of trauma-exposed individuals to employ maladaptive strategies including, for example, behavioral outbursts, self-harm, aggression, and repetitive behaviors (Samson, Hardan, et al., 2015). Kerns et al. (2015) make the case that exposure to traumatic events may exacerbate emotional dysregulation already present for autistic individuals.

Social Support. Social support prior to the experience of a traumatic event is considered a protective factor against the development of PTSD, as well as a protective factor that moderates the outcome following exposure to a traumatic event (APA, 2013). A key diagnostic feature of autism includes differences in social interaction and communication compared to allistic individuals. Studies indicate that these differences may contribute to autistic individuals

having less access to social support. While autistic people vary in their communication and interaction skills, desire for intimacy, and attachment security, research indicates that those perceived as having less typical social skills, the less likely they may be to seek out and receive social support of others (Orsmond et al., 2004).

Resiliency and Protective Factors. There exists minimal research regarding the resiliency of autistic individuals (Lai & Szatmari, 2019; Ricles, 2017; Szatmari, 2018). There seems to be a growing body of research regarding the resiliency of families and caregivers of autistic individuals (Szatmari, 2018). For example, Kapp and Brown (2011) found multiple factors in their study of resilience among families with an autistic child which appeared to increase parents and caregivers' abilities to provide an environment to aid in fostering growth for their children. These factors include, for example, emotional, social, and instrumental support for the family, a strong spousal relationship, family activities and routine, gaining knowledge and skills regarding autism in general, accepting the diagnosis of autism, expressed hope and perseverance, families organized to assist each other with daily tasks, good health and wellbeing of the family members, and ability to tend to the needs of individual family members (Kapp & Brown, 2011).

The small body of research regarding resiliency in autistic individuals found that supported employment, inclusive educational environments, inclusion in social and academic activities, and positive parenting increased the likelihood of resiliency (Seltzer et al., 2003; Taylor et al., 2012). In addition, McCrimmon et al. (2016) suggest their research shows increased emotional intelligence and social functioning are related to increased resiliency for autistic individuals. However, these studies defined resiliency as a reduction in "symptoms"

following a diagnosis of autism, rather than a dynamic and socioecological process following traumatic or adverse experiences.

Research regarding resiliency following exposure to PTEs or ACEs for autistic individuals is quite limited. However, the existing literature offers evidence to suggest autistic individuals may show more resiliency in the face of multiple adversities than their allistic counterparts. For example, Ricles (2017) investigation into ACEs, outcomes, and resiliency for autistic individuals found that while exposure to increased ACEs was negatively associated with physical and mental health for their sample of both autistic and allistic participants, it was not negatively associated with resiliency as it was for allistic participants. In other words, the autistic participants appeared more resilient in the face of multiple ACEs compared to the allistic participants. This initial exploration raises many questions yet unanswered about the factors contributing to resiliency following exposure to trauma and adversity for Autistic individuals.

Posttraumatic Growth. Notably, PTG is a newer construct, and as such, has only been applied to autistic individuals and their families in a limited fashion. There are several studies published regarding the posttraumatic growth of family members of autistic individuals (e.g., Phelps et al., 2009; Swaab et al., 2017; Wayment et al., 2019). These studies suggest that it is quite possible that resilient families are more likely to be able to raise resilient autistic children which makes such inquiries worthy of investigation; however, we still have very limited understanding of PTG as it applies to autistic individuals themselves.

Trauma, Resiliency, and Posttraumatic Growth through a Neurodiverse Lens

Interestingly, research suggests autistic youth may develop PTSD symptoms from events that do not currently fit the APA's description of a potentially traumatic event (Corbett et al., 2009; Gillott & Standen, 2007). For example, one study found that autistic children had higher

levels of stress and cortisol, particularly when faced with environmental and daily changes in their routines and activities (Corbett et al., 2009). In a similar vein, Gillott and Standen (2007) compared sources and levels of stress among adults with intellectual disabilities and autistic adults. They found that autistic adults had higher levels of anxiety and stress when faced with change and aversive sensory stimuli. This study theorized that the higher rates of stress and anxiety in the face of events such as change in routine, and exposure to aversive sensory stimuli indicates that some autistic individuals may experience these events and their sequelae in such a way that produces a lasting traumatic effect.

The traditional definitions of what is a PTE may not accurately fit the experience of neurodivergent individuals. For example, researchers theorize changes in routine and activities, and aversive stimuli, may be experienced as traumatic based on high levels of distress they may induce. Therefore, the experience of autistic individuals may not be fully captured by traditional understandings, such as in the DSM-5, of trauma-sequelae and trauma- and stressor-related disorders. Given the lack of consensus on what constitutes a traumatic event for an autistic individual, it is not surprising that there is so little research into either prevalence rates or factors supporting their resiliency and posttraumatic growth.

There is much left to learn about how autistic individuals experience and make sense of traumatic exposure. A first step toward greater understanding is hearing from autistic individuals about their experiences, discovering how they make sense of their own trauma and resilience. Such firsthand accounts of trauma and resilience from neurodivergent narrators may serve to better inform conceptualization of trauma and tailored mental health intervention. Building a neurodiverse narrative regarding resiliency and PTG may further help communities and

clinicians to reduce the impact of potentially traumatic events or adverse experiences for a wider range of individuals, as well as provide new insights into resiliency for all.

Memoirs and Personal Essays as Data

Autobiographical accounts have been used as means to grow research and theory in clinical psychology, developmental psychology, and personality psychology throughout these fields' existence (Habermas & Bluck, 2000; Josselson, 2008). Josselson (2008) writes, "Using narrative studies are growing in popularity as means to understand the personal identity, life course development, and historical world of the narrator" (p. 369). Further, autobiographies and first-person accounts provide insight into the lives of individuals through accessible and public domains (Power et al., 2012). Narrative and autobiographical information can be gained through both verbal and written means. One popularized means of sharing narratives includes writing and publishing memoirs. No matter the method of storytelling, the person sharing their life must construct and interpret their account of their experiences. Beyond the act of re-telling, an individual writing about their life may be simultaneously engaging in a range of organizing activities, such as sharing cultural insights, contributing to their reputation, and justifying perceptions (Smith & Watson, 2013).

Due to the selective nature of memory and motivation of the author, autobiographical narration is never just an objective re-telling of facts, but rather serves as a source of information regarding the individuals' experience, beliefs, and the larger contexts which influence them (Smith & Watson, 2013). Therefore, the primary evidence or data offered from autobiographical writing is the perception and lived experience of the narrator.

Trauma Narratives

In writing about personal traumatic experiences, authors may experience a shift in their perspective or experience of past trauma (Smith & Watson, 2013). For example, in the analysis of narratives written by Holocaust survivors, Duchin and Wiseman (2019) found that the narratives often contained themes of processing and healing from trauma. Those researchers theorize that in writing about the traumatic events they experience, the narrators may be able to fully process the experience and its memory. Through their stories and writing, the Holocaust survivors were able to show themselves to be not just victims of a traumatic event, but also as complete, resilient, and creative individuals (Smith & Watson, 2013).

The body of literature on autistic individuals' experience of traumatic events and resiliency is small; quantitative research offers scant autobiographical information (Welch et al., 2019). However, memoirs written by autistic individuals may provide means for better understanding their lived experiences. For example, Welch et al. (2019) employ thematic analysis of memoirs written by three autistic individuals whom they describe as “minimally verbal.”

In this study, Welch and colleagues (2019) employed a descriptive qualitative approach while immersing themselves in the firsthand accounts written by the autistic memoirists. The authors describe approaching the study with a broad research question: “What new understanding of autism is presented in the published memoirs of these minimally verbal youths?” (Welch et al., 2019, p. 2309). However, they acknowledge that their own clinical and firsthand experiences caused them to be particularly interested in how the memoirists described their experiences of autism, and how they describe the way they see themselves as perceived by others.

Based on their thematic analysis, Welch et al. (2019) found three themes, as well as one larger theme, across the memoirs. The broader theme found across the narratives was “My Inside and Outside Do Not Match” (p. 2311). This theme was divided into three more specific themes: (1) “Autism Inside My Body,” (2) “Autism Inside My Brain,” and (3) “Autism from the Outside” (Welch et al., 2019, p. 2311). The first theme, “Autism Inside My Body,” encompasses feelings of limited control over starting and stopping their own movement, feelings of detachment from their body, feeling helpless in their own body, and feeling emotional experiences physically. The theme “Autism Inside My Brain” refers to themes of the memoirists comparing their brain function, such as sensory perception and memory, to how they believe allistic individuals’ brains function. Under this theme, the authors identified three shared experiences that occurred for the Autistic memoirists: they acknowledged strengths they had that others did not have, they recognized the difference in their brain function, and they acknowledged they perceived the world differently than others around them. The last theme, “Autism from the Outside” includes descriptions of how these autistic memoirists felt they were perceived by others and their feelings of disconnection with others. Under this category, the autistic memoirists identified feeling embarrassed, wanting to be understood by others, acknowledging how they are perceived by professionals, seeing the impact of their autism on others, and seeing that other people doubt their intelligence. Overall, Welch et al. (2019) found themes that challenged typical academic and clinical conceptualizations of autism and propose further investigation regarding firsthand accounts of autistic individuals’ perspectives.

Knowledge Gap and Research Questions

To begin to fill the gaps in the literature regarding autistic individuals’ first-hand accounts of trauma, stress, resiliency, and growth, the following study uses a qualitative

approach. It employs interpretative phenomenological analysis (IPA) to develop and identify relevant themes in five published memoirs written by autistic authors.

In this dissertation, I address three overarching research questions:

- (1) What themes in the narration of traumatic and stressful events, and resulting sequelae emerge for the authors?
- (2) Does the traditional definition of potentially traumatic events (PTEs) as defined by current diagnostic standards and the adverse child experiences (ACEs) studies accurately capture the range of experience for autistic individuals?
- (3) What themes of resiliency and posttraumatic growth emerge in the authors' narration of their experiences?

CHAPTER III: METHODOLOGY

For this study, I used qualitative research to analyze first person accounts written by autistic memoirists. I employed Interpretative Phenomenological Analysis (IPA) to identify themes in the authors' narration of traumatic and/or potentially traumatic events, the resulting sequelae, resiliency, and posttraumatic growth. The primary sources of data were the published narratives of five authors identified as autistic or as having Asperger's.

Research Design: Interpretive Phenomenological Analysis

This research employed IPA to investigate the lived experience of autistic individuals regarding stress, trauma, resiliency, and posttraumatic growth. IPA researchers use participant first-hand accounts of experiences to gain insight into how the participants make sense of the personal and social world (Creswell & Poth, 2018). IPA assumes that there is a hierarchy of experience. In other words, there is a distinction between everyday experiences and experiences that have been reflected on and become "an experience" which is internalized as part of a person's narrative (Smith et al., 2009). IPA is also based on the assumption that humans are inclined to make sense of such experiences in their reflection. The goal of IPA is to engage with these reflections to gain further insight into individuals' unique experiences and/or understandings of phenomena.

The qualitative inquiry of IPA is informed by three philosophical concepts: phenomenology, hermeneutics, and idiography (Smith et al., 2009). Phenomenology views the individual within the context of their culture, language, and relationships. Therefore, IPA acknowledges each person has unique individualized experiences and perceptions. IPA simultaneously acknowledges that individuals and their perceptions cannot be fully understood

without the rich context in which they came to be. The experience of individuals then may be understood through firsthand accounts of phenomena, in-depth inquiry, and interpretation.

The second concept, hermeneutics, is a theory of interpretation. While research requires steps, hermeneutics acknowledges the process of interpretation and analysis is not linear, and that one may move back and forth in their thinking about data. IPA relies then on the researcher to use hermeneutics to examine and make sense of phenomena. Thirdly, idiography combines a commitment to detail and depth of analysis with a thorough and systematic examination. IPA is, “committed to understanding how particular experimental phenomena have been understood from the perspective of particular people, in a particular context” (Smith et al., 2009, p. 29).

Thus, this approach uses a small and purposeful selection of samples. While it uses small, individualized samples, the goal of IPA is to identify phenomena that may be potentially generalized to similar populations (Henwood & Pidgeon, 1992)—for this research, the population of interest is autistic individuals who have experienced potentially traumatic and stressful life events.

Previous research has used IPA to examine the experience of families with autistic members, and the experience of parents and caregivers of autistic children (Harding et al., 2014; Sopaul, 2019; Zaidman-Zait & Curle, 2018). It has also been employed to examine autistic individuals’ experience of phenomenon (MacLeod, 2019). IPA has been used to glean insight regarding autistic individuals’ perspective on autism in general, diagnosis, assessment, and experience of sexuality (Dewinter et al., 2017; Huws & Jones, 2008; MacLeod, 2019).

Memoirists

Each memoirist selected for this dissertation was assessed to meet criteria for autism spectrum disorder by a mental health professional, as well as self-identified as either autistic or

on the autism spectrum. To avoid incorrect information or assumption, I gathered demographic information based upon what the memoirists wrote about themselves including gender, age, race, and country of origin. Various identities and demographic information provided by each author is as follows.

Ido Kedar wrote his memoir about his experience through adolescence, was born in the United States, identified as male and used he/him pronouns, used assistive technology for verbal and written communication, and published his work in 2012. Jennifer Cook O'Toole wrote her memoir as an adult, was also born in the United States, identified as female and used she/her pronouns, and published her memoir in 2018. Anand Prahlad wrote his memoir as an adult, identified as Black, used he/him and less frequently she/her pronouns, was born in the United States, and published his memoir in 2017. Daniel Tammet published his memoir as an adult in 2006, identified as male and used he/him pronouns, and was born in the United Kingdom. Finally, Donna Williams published her memoir as an adult in 1999, was born in Australia, and identified as female, used she/her pronouns as well as he/him pronouns at times.

Data Collection

Data were gathered from memoirs written by autistic individuals who experienced potentially traumatic and stressful life events. Data were gathered with the following goals: (a) explore themes related to traditionally traumatic and stressful live events, and resulting sequelae, (b) examine events viewed as traumatic and stressful for the authors, and (c) identify themes related to resiliency and posttraumatic growth following the experience of potentially traumatic or stressful life events. The use of this method of data collection was chosen specifically in accordance with the APA's guidelines for research as outlined in the Belmont Report: reduction

of risk to the degree possible to gain necessary information, and in consideration of necessity of human participants altogether (United States, 1978).

Published memoirs and essays offer public and voluntary first-person accounts of Autistic individuals. In addition, they offer already existing accounts of potentially traumatic and stressful events, resiliency, and posttraumatic growth. Therefore, using memoir as data provides an APA-preferred method of gathering information to address the research questions, as well as address gaps in the current literature.

For the purposes of this research, five published works were selected. These memoirs and essays were chosen based on their narration by autistic authors regarding experiences of hardships that may be potentially stressful or traumatic as well as resilience and growth. These memoirs and essays were found through word-of-mouth recommendations by professionals, a published list of book recommendations (Waters, n.d.), and through an online search using the terms “autism,” “autistic,” “memoir,” “trauma,” and “resiliency” in various combinations. For this dissertation, I selected the following published works: *Ido in Autismland: Climbing Out of Autism’s Silent Prison*, by Ido Kedar (2012), *Autism in Heels: The Untold Story of a Female Life on the Spectrum*, by Jennifer Cook O’Toole (2018), *The Secret Life of a Black Aspie*, by Anand Prahlad (2017), *Born on a Blue Day: Inside the Extraordinary Mind of an Autistic Savant* by Daniel Tammet (2006), and *Nobody Nowhere, revised edition*, by Donna Williams (1999). This list may also be found in Appendix A.

Data Analysis

The data were interpreted using a step-by-step process using IPA to analyze qualitative data, as proposed by Smith et al. (2009) and used previously to identify themes in memoirs written about the experience of sibling death (Neubacher, 2015). IPA requires the following

steps: (a) reading and re-reading, (b) initial noting, (c) developing emergent themes, (d) searching for connections across emergent themes, (e) moving to the next narrative, and finally (f) looking for similar themes across the narratives. With these themes, I sought to capture common threads exploring themes of adversity and resiliency.

Step 1: Reading and Rereading

The first step of IPA requires one to deeply immerse oneself in the data through reading and re-reading (Smith et al., 2009). Therefore, I read each memoir three times while taking note of my first impressions and reactions. The purpose of this stage was to familiarize myself slowly and purposefully with each narrative.

Step 2: Initial Noting

Initial noting “examines the semantic content and language use on a very exploratory level” (Smith et al., 2009, p. 83). Through this process I made initial notes and took exploratory comments on quotes of interest both in the hard copies of the books and in a word document. These comments focused on describing the content of the narrative, identifying conceptual underpinnings of the narrative, and noting specific use of language. The identified passages with their exploratory comments were then transcribed into a data table. Through this process, I sought to become increasingly familiar with the author’s narratives and how they describe and think about potentially traumatic stressors and events, resiliency, and posttraumatic growth.

Step 3: Developing Emergent Themes

In developing the emergent themes, I shifted from the narratives to the exploratory comments. The exploratory comments were analyzed to identify emergent themes. The goal of this process was to summarize the intent of the narratives while maintaining complexity to produce a concise statement, or emergent theme (Smith et al., 2009). These themes therefore

reflected not only the authors' original language, but also my interpretation. Once identified, these emergent themes were recorded into the data table in a separate column alongside the narrative passage and corresponding page number, and the exploratory comments from which they were extrapolated (see Appendix D for an example). Once this process was completed for each memoir, the data were combined into one table for convenience.

Step 4: Searching for Connection Across Emergent Themes

The next step in the IPA process called for the identification of connections across emergent themes, mapping how they may fit together (Smith et al., 2009). Through this process, near identical emergent themes were combined based on linguistic and conceptual similarities (i.e., “constant anxiety,” “frequent anxiety,” and “anxious all the time”). Emergent themes that were not relevant to the research questions were discarded. Once the list of emergent themes was finalized, they were copied from the table and added to a new document that listed the themes in order of their occurrence.

Step 5: Moving to Next Narrative

After completing the first four steps with one memoir, I applied them to the next. Smith et al. (2009) stressed the importance of preserving the individuality of each case, and I used journaling to reflect on potential influences of previous memoirs. The intention of the rigorous step-by-step process was to allow new emergent themes to surface.

Step 6: Looking for Patterns Across Narratives

The final step required that I look across the narratives for themes (Smith et al., 2009). To do so, I printed a physical copy of the document containing the list of emergent themes from each memoir and cut them up. From there, I physically organized and reorganized the emergent themes into groupings based on identified patterns and connections. Through abstraction and

subsumption, these groupings of emergent themes were labeled with superordinate themes. These superordinate themes and emergent themes were then organized into one data table, along with which authors had these themes within the memoir, and the page numbers of the identified examples.

Addressing Subjectivity

The double hermeneutics of the IPA process acknowledges the subjectivity of the analyst (Smith et al., 2009). However, that subjectivity is intended to be both rigorous and systematic. There is a range of approaches IPA researchers may engage in to increase transparency, transferability, and credibility. For the purposes of this dissertation, I engaged in external audits regarding my process and engagement with the data set (Smith et al., 2009). I did so by having a professional review my annotations as they relate to emergent themes, and my emergent themes as they relate to the superordinate themes. Additionally, I kept a research journal as a way of reflecting on my own biases, attitudes, and beliefs regarding the data set (Smith-Sullivan, 2008). Through these practices I sought to account for my own subjectivity as the data analyst.

CHAPTER IV: RESULTS

In this dissertation, I explored the narratives of five autistic authors who detailed their experiences of trauma, adversity, resiliency, and growth within their memoirs. Within the transformative framework, I sought to use pre-existing firsthand accounts to illustrate the intersection of neurodivergent identity, trauma, and resilience. Using Interpretative Phenomenological Analysis (IPA), I sought to answer three overarching research questions: first, what themes in the narration of traumatic and stressful events, and resulting sequelae emerge for the authors? Second, does the traditional definition of potentially traumatic events (PTEs) as defined by current diagnostic standards and the adverse child experiences (ACEs) studies accurately capture the range of experience for autistic individuals? Third, what themes of resiliency and posttraumatic growth emerge in the authors' narration of their experiences? Through this process, I abstracted 11 superordinate themes based on the emergent themes of each memoir. In this section, following a summary of demographic information describing the memoirists, I provide details regarding the creation of each superordinate theme and their emergent themes, and I provide one example for each emergent theme from the memoirs to illustrate the results. Additionally, I include in Appendix E further examples of the emergent themes from other memoirs.

Throughout the analysis process, I focused on themes related to descriptions of traumatic or adverse experiences and their impact, and narratives regarding resilience, ways of coping, and growth following these experiences. This strategy yielded nine prominent themes, occurring in all five narratives (see Table 4.1). In addition, I found two themes that occurred less frequently and offer insight into individualized and unique experiences of trauma, adversity, and resilience.

Table 4.1*Superordinate Themes*

Superordinate Theme	Kedar	O'Toole	Prahlad	Tammet	Williams
Interpersonal Traumatic and Adverse Childhood Experiences	Yes	Yes	Yes	Yes	Yes
Other Interpersonal and Social Experiences Contributing to Distress	Yes	Yes	Yes	Yes	Yes
Other Community and Societal Experiences Contributing to Distress	Yes	Yes	Yes	Yes	Yes
Individual Need in Conflict with Circumstance	Yes	Yes	Yes	Yes	Yes
Negative Impacts on Sense of Self	No	Yes	No	No	Yes
Emotion Dysregulation	Yes	Yes	Yes	No	Yes
Self-Identifying with Trauma-Related Disorders and Sequelae	Yes	Yes	Yes	No	Yes
Environmental Factors Supporting Safety and Comfort	Yes	Yes	Yes	Yes	Yes
Social and Community Factors Supporting Resilience	Yes	Yes	Yes	Yes	Yes
Learning Ways to Regulate	Yes	Yes	Yes	Yes	Yes
Individual Processes Contributing to Resilience	Yes	Yes	Yes	Yes	Yes

Each superordinate theme was abstracted based on the emergent themes present in each memoir. The emergent themes were labeled based upon the authors' language, and they were identified as themes due to the prominence and importance the authors appeared to ascribe to them based upon my immersion in the data through the analytic process. The following table (Table 4.2) provides a list of the emergent themes and the subsuming superordinate theme.

Table 4.2*Superordinate and Emergent Themes*

Superordinate Theme	Emergent Themes
Interpersonal Traumatic and Adverse Childhood Experiences	Experiencing abuse Experiencing sexual assault Manipulation by others Peer victimization and bullying Peer rejection and isolation Interpersonal racism Witnessing abuse in the home
Other Interpersonal and Social Experiences Contributing to Distress	Anxiety with eye contact Fear of others and crowds Fear of being alone or abandoned Masking for social acceptance Misunderstanding others Being misunderstood Invalidation of emotion and experiences Fear of intimacy and vulnerability
Other Community and Societal Experiences Contributing to Distress	Feeling different Professionals misunderstanding or misdiagnosing Masking to navigate societal demands
Individual Processes in Conflict with Context	Intolerance of ambiguity Sensory overwhelm
Negative Impact on Sense of Self	Diminished sense of self Self-blame
Emotion Dysregulation	Emotional overwhelm Frequent anxiety Emotion suppression Self-injurious behavior Emotion regulation and stimming
Self-Identifying with Trauma-Related Disorders and Sequelae	Complex PTSD Hypervigilance Intergenerational racial trauma PTSD from Treatment Re-experiencing Traumatic Events
Environmental Factors Supporting Safety and Comfort	Accommodations/ adaptations for sensory overwhelm

Superordinate Theme	Emergent Themes
Social and Community Factors Supporting Resilience	Listing to and creating music Rules, routine, and repetition Time in Nature Accommodations/adaptations for communication Learning about social intricacies and skills Religious and spiritual beliefs Peer acceptance Supportive and understanding loved ones Supportive and understanding mentors and professionals Sense of community and network of support
Learning Ways Regulate	Knowledge and information gathering Mental preparation and rehearsal Mental distraction Exercise Comfort objects Meditation and breathing practices Sensory input for regulation
Individual Processes Contributing to Resilience	Identifying personal strengths and growth Self-understanding Acceptance of self and experience Autonomy and control Making meaning of experiences Using personal experiences to help others

Superordinate and Emergent Themes

To further illustrate the above superordinate themes, each one is described below, as well as the emergent themes which were combined to create the superordinate theme. In addition, the number of memoirs which included each theme are listed, as well as examples from the data illustrating each emergent theme. For emergent themes which were applicable to more than one memoir, examples from the data for each can be found in Appendix E.

Interpersonal Traumatic and Adverse Experiences

Under the superordinate theme interpersonal traumatic and adverse experiences, emergent themes were abstracted based on their relation to interpersonal traumatic or adverse experiences in alignment with the APA's (2020) definition of a potentially traumatic event, developmental trauma described by van der Kolk (2005) and adverse childhood experiences defined by the CDC (2020). The descriptions of these experiences are the most prominent themes occurring across narratives based on the frequency of their occurrence. The emergent themes under this superordinate theme are: experiencing physical abuse and neglect, experiencing sexual assault, manipulation by others, peer victimization and bullying, peer rejection and isolation, and interpersonal racism.

Experiencing Abuse. Two of the five authors describe their personal experiences of physical abuse and neglect. The following excerpt from Williams, for example, describes her attempts to communicate her distress to her mother, in response to her withholding food and water as a form of punishment:

I looked at the broken china the floor through a misty wall of tears, and cut lines into my face in anger at the injustice of what had happened. I had cut my cheeks, my forehead and my chin. With nothing to lose, I calmly walked downstairs to make my silent statement. 'Oh my God,' said my mother, like some slow deliberate line from a horror film, 'she's fucking mad.' The look on her face was one of complete shock rather than of concern. I was, by this time, nine years old and very close to being sent to a mental hospital. Inside my head, what I was doing was completely sane. I didn't know how to cry out for understanding. I was lost and trapped, and I was making a statement. I think

my mother at least understood the severity of situation; she gave up on the bread-and-water idea. (Williams, 1999, p. 41)

Williams (1999) used self-harm to express to her mother the impact of the physical neglect, her feelings of being “lost and trapped,” and her “anger at the injustice” (p. 41).

Experiencing Sexual Assault. Two of the five memoirists also depict their experiences of sexual assault. In one example, Prahlad (2017) connects his assault with his autism, noting “beware of ‘firsts’” (pp. 157–158), due to the impact that it could have on him as an autistic man:

Beware of “firsts,” the books say about people on the autism spectrum. They never get past them. I never did. My first lessons were all secrets. The first secret was when I was molested in the barn as a child. The second secret was when I was molested at the doctor’s office. Sometimes, while I was facing the wall or lying face down on the cot with my pants down, waiting to get a shot, the nurse’s hands searched for something under my skin. Her breath changed and she inhaled deeply. The freckles on her arm turned to water and washed over me. The water was warm. Eventually, she turned me around and looked at my body and smoothed the skin of my hips like smoothing out a tablecloth. I could feel her hands and her eyes long after we had left. Even lying in bed, sick, the feelings would come to me. The waves of her freckles would wash over me. (Prahlad, 2017, pp. 157–158)

The level of detail Prahlad provides regarding his assault suggests the vividness of his memory. He identifies re-experiencing the same feelings triggered by being sick, presumably why he was seen by the nurse who assaulted him initially.

Manipulation by Others. This theme was included in one memoir, written by O'Toole. However, it appeared to be a prominent theme that she both labelled as impactful and provided several examples of in her memoir. One person she identified as manipulating her was an ex-boyfriend with whom she had a serious relationship as a young adult. In the following excerpt she detailed an experience this emotional abuse and manipulation:

Many times, he'd jump up in a fury just before I was ready to drift off. I was selfish, he'd yell. A stuck-up bitch. He wanted nothing more to do with me. I begged him not to go, but he always would, my dorm room door slamming behind as he rushed off into the pitch-black New England night. Left behind, alone, I crumbled to the floor. I'd done it again. Why couldn't I just make people happy? Why did I always make them hate me? (O'Toole, 2018, p. 186)

In addition to describing her experience of manipulation in this passage, O'Toole (2018) also described how the interaction was followed by internalized experience of self-blame.

Peer Victimization and Bullying. Two authors provide experiences of victimization and bullying at the hands of their peers. For example, Tammet, in the following passage, recalled one of several instances when he was victimized by his classmates:

I remember watching [a movie] together rocking quietly under the chair. I felt no emotion at all until the end, then all of a sudden it was like a switch was flicked in my head and I suddenly realized I was frightened. Feeling agitated I ran from the class-refusing to return until the television was removed. Thinking back, I can understand why the other children teased me and called me "cry baby." I was nearly seven and none of the other children in the class was the slightest bit upset or frightened by the program. Even so, each week I

was taken to the headmaster's office and allowed to sit and wait while the rest of the class watched the next installment of the series. (Tammet, 2006, p. 52)

In Tammet's (2008) experience of bullying, he reflected on how his difference in reaction to a film led his peers to view him as different, or a "cry baby" (p. 52). He is further separated and isolated from his peers through the results of this incident when he is taken out of the classroom for periods of time.

Peer Rejection and Isolation. Four of the five memoirists included descriptions of their isolation from and rejection by peer groups. For example, Kedar connected his isolation and rejection and resulting emotional pain to his differences from others.

Mostly it's the reaction of others to my flapping that is hard to deal with. It's painful to see people react like I'm so strange to them. If I had another way to release my tension. I hope that writing my feelings to others will let me free myself from flapping's hold response to strong feelings. It's not so pleasant to have everyone perceive my emotions even if I'd like to keep my thoughts to myself. (Kedar, 2012, p. 43)

He, like many of the other authors (see Appendix E), used language synonymous with physical pain to articulate the degree of his distress, and the impact of such experiences.

Interpersonal Racism. Prahlad provides insight into his experience of racial discrimination as a Black man, born in the 1950s in Virginia. In the following passage he describes being the only person of color in a gathering for student-body presidents:

The halls were a buzzing, spastic sea of white bodies. I was feeling lost in the whiteness, in the noise. The brightness of the lights made me dizzy. In the close crowds in the hallways and lobby, I was elbowed and shoved, and sometimes fondled. Curious eyes peered through me, like I was a window. Hostile eyes scowled at me. Soft pink lips spat

“*[racial slur]*,” and sneers and laughter waited around every corner. A girl looked at me and licked her lips, as if I was a piece of candy. I wanted to curl up into a ball. The sounds ripped me from the banks and swept me out into cold waters. And the waters replaced my bones. The waters ate through me. (Prahlad, 2017, p. 113)

Prahlad’s experience of the overt racism of his peers intersects with his senses becoming overwhelmed with the lights, crowds, sights, and noise. He explains in his memoir that he uses language literally, not metaphorically. This interpersonal traumatic experience and the sensory overwhelm intersected and, “ripped [Prahlad] from the banks and [swept] him out to cold waters,” (Prahlad, 2017, p. 113), which illustrates the terror and loss of control in that moment.

Witnessing Abuse in the Home. Williams is the only memoirist to describe witnessing violence occurring in her home. This information may provide greater insight into her individual experiences of trauma and adversity. In the following example, Williams contemplates the impact of this violence on her:

It is hard to say whether the violence of my family made me the way I was. What I do know is that I never replayed their violence over and over in my mind until I was much older. (Williams, 1999, p. 38)

She reflects on her general fear of vulnerability, and rather than say her early experiences caused this fear, she acknowledges the resulting traumatic sequelae that she faced later life as a result.

Other Interpersonal and Social Experiences Contributing to Distress

The emergent themes which make-up this superordinate theme were grouped together based on their shared connection to distress (i.e., fear, anxiety, or discomfort) in the context of interpersonal interactions and relationships beyond what is defined by the models for trauma or adversity put forth in the first superordinate theme. Other interpersonal and social experiences

contributing to distress were a prominent theme that occurred across the five memoirs. The emergent themes comprising this superordinate theme include anxiety with eye contact, fear of others and crowds, fear of being alone or abandoned, masking for social acceptance, misunderstanding others, being misunderstood, invalidation of emotion and experiences and fear of intimacy and vulnerability.

Anxiety with Eye Contact. Kedar is the single memoirist to describe his discomfort when maintaining eye contact with others, illuminating further his individual experiences:

Eye contact is hard because the light reflecting off the eyes is not calming. It's hard to explain because I'm not aware that I don't look at people until someone tells me to look at them. It's a strange habit but I can listen better if I don't look at the person. I can look, but it's not pleasant. In ABA [Applied Behavioral Analysis] I had to look in people's eyes with a timer. It was so torturous I did it, but with terrible anxiety. I can't explain why. It just is that way. (Kedar, 2012, p. 49)

Kedar (2012) reflects on the "terrible anxiety" (p. 49) he endured to meet the expectations of his treatment team.

Fear of Others and Crowds. Two memoirists detailed their fear of other people, and crowds in general. In the following excerpt, Tammet reflected on how this fear in combination with physical discomfort led to him feeling overwhelmed and using self-harm as a way of expressing it:

The day involved crowds of shouting onlookers for such events as the sack and egg and spoon races, and the combination of crowds and noise and quite often summer heat was too much for me. My parents often allowed me to stay at home rather than risk me having a meltdown. If I felt overwhelmed by a situation, I could go very red in the face and hit

the side of my head very hard until it hurt a lot. I would feel such a sense of tension within me that I just had to do something, anything, to let it out. (Tammet, 2006, p. 68)

In this instance of emotional and sensory overwhelm contributed to by crowds, Tammet described how using self-harm relieved the tension within.

Fear of Being Alone or Abandoned. Three of the five memoirists alluded to their fears of being alone or abandoned by others. Prahlad, for example, describes the intensity of his terror when his mother left him for the first time at preschool in the following example:

When I realized that Mama had left me, I thought I would never stop crying. Even when I did stop, I soon started again, triggered by the cries of others around me. As terror overcame me, I fell from weeping into quiet despair, into paralysis. When the teacher picked me up, I was already seeing nothing. (Prahlad, 2017, p. 62)

Masking for Social Acceptance. Three of the five authors describe hiding the ways in which they appeared different from others, also referred to as “camouflaging” or “masking” autistic-related traits. O’Toole, in the following excerpt, describes how seeing her differences led her to hide these parts of herself starting at a young age, to appear like those around her:

Your truth is denied, disregarded, and by proxy, so are you. This is what it was like for me as a child, realizing that my own mother had no idea what I was talking about.

Discovering early that being honest meant that I didn’t make sense. That I couldn’t trust what my own eyes saw or ears heard. That no one else talked about colored numbers or girl letters. Four years old, and already I felt strange, and stupid, and even a little bit scared. So I pretended I was like everyone else and said nothing more. (O’Toole, 2018, p. 19)

Misunderstanding Others. Two authors provided insight into their experiences of misunderstanding the intentions and perceptions of others, and the resulting distress. O’Toole (2018), in the following example, reflects on the impact of “trouble with theory of mind” (p. 149), or the ability to understand the mental state and predict the actions of others:

Which is because our fears are born of repeated exposure to the very real threats—either to our bodies, our minds, or both. We ‘mess up’ without realizing it and then have to deal with the fallout—just when we may have thought we’d finally gotten our ‘act’ together. Without a clear understanding of the whys or whens, we negotiate daily social situations that seem random and chaotic, building families, marriages, and incomes upon the relationships we are able to reap in those environments. It’s easy to see why we’d feel as though we need to keep our guard up. We’re walking through a social minefield with blinders on. Trouble with theory of mind, reading tones and interpersonal cues, understanding perspectives, and detecting hidden motivations mean that danger feels random—chaotic—and ever looming. (O’Toole, 2018, p. 149)

She tied this experience directly to the emotions of “fear,” and reactions to “danger,” which speaks to her intense suffering resulting from such misunderstandings.

Being Misunderstood. While misunderstanding the intentions of others was a source of distress for two authors, being misunderstood by those around them was also a source of distress. This emergent theme occurred in three of the five narratives. For example, Williams in her memoir portrays an instance when her actions were misunderstood, leading to a negative emotional reaction by another:

The old man who used to come into the shop I worked in had waved and said hello; and, though I had looked straight at him, I hadn’t seen him, and he thought I’d ignored him.

He came into the shop to buy something later the same day and ignored me. “Hi,” I said, in an effort to reach out. He left without saying a word. I began to panic. My body was operating on ‘automatic pilot’ as I began to lose sense of what was around me. (Williams, 1999, p. 98)

While the intention was not to ignore this acquaintance, Williams’ action was misunderstood by him, leading him to ignore her, and leading Williams to feel panic.

Invalidation of Emotion and Experiences. Two authors identify incidents of invalidation of their emotions and experiences. O’Toole, in one passage, connects her experience of being misunderstood by others with the invalidation of her emotions and perceptions:

What if you speaking up to the “authorities” meant you were told that you must have misinterpreted... every time? What if the authorities themselves ridiculed you? Or stood by and watched in amusement? Or chastised you for being too sensitive or overdramatic? Why couldn’t you just take a joke? Or do this instead so you’ll be liked more and treated better? What if you can’t tease apart your thoughts from countless years of corrections and consequences and condemnations? What if you can’t figure out which are your feelings? How do you know what your gut is saying, then? For that matter, if you’ve spent a lifetime trying to “trust your gut,” only to find, over and over, that your instincts about other people are more often right than wrong... why would you, instead, not be more inclined to do precisely the opposite of what your gut says? I didn’t tolerate awful things because I was needy or insecure. I was needy and insecure because I’d had to tolerate awful things. If you believe you are worthy and strong, you will live up to that

truth. If you believe you are unworthy of love or happiness, you will live up to that truth, too. (O'Toole, 2018, p. 190)

Fear of Intimacy and Vulnerability. This emergent theme is prominent for one memoirist, Williams. It is included in these results to provide insight into her unique experiences. She describes the intensity of her fear of intimacy and the emotional impact in the following example:

I had begun to slap myself and pull out my own hair. I wanted desperately to get out of my own body. To leave it there to be stomped used and abused as its invaders so chose. I was annoyed at this physical body and the way it held me in like the walls of an impenetrable prison. I seemed to me more than useless. I screamed, and my own ears were deafened, but no sound ever came out. I pleaded, but nothing got past the lips of my painted smile and the dead look in my eyes. I had a capacity for closeness, but my intense relentless fear of it made closeness a sort of mocking unreachable dream. This was the price of what may have been termed my autism. It went far deeper than the simplistic blanket termed description of “withdrawn.” (Williams, 1999, p. 137)

Williams identified the conflict between her capacity for closeness, and her intense fear of it. It resulted in such significant distress that she engaged in self-injurious behavior as a method for expressing and regulating her turmoil.

Other Community and Societal Experiences Contributing to Distress

The emergent themes which fall under this superordinate theme were associated based on their shared connection to distress (i.e., fear, anxiety, or discomfort) in the context of community or society, beyond what is considered traumatic or adverse in the superordinate theme interpersonal traumatic experiences and adverse childhood experiences. Other community and

societal experiences contributing to distress were a prominent theme that occurred across the five memoirs and include: feeling different, professionals misunderstanding or misdiagnosing, and masking to navigate societal demands.

Feeling Different. Three of the five memoirists described feeling different or alienated from others, using language that distinctly separates themselves and their experiences from the world and others around them. Tammet, for example, writes:

When I was a child, doctors did not know about Asperger's syndrome (it was not recognized as a unique disorder until 1994) and so for many years I grew up with no understanding of why I felt so different from my peers and apart from the world around me. (Tammet, 2006, p. 12)

Tammet connects feeling different from peers with his sense of being separate from the world around him. In addition, he identifies how having a label for his experience shifted this sense of alienation.

Professionals Misunderstanding or Misdiagnosing. Three of the five memoirists describe the negative impact that professionals who misunderstood or misdiagnosed their experience had on their lives. Kedar, for example, describes how he felt when he witnessed professionals providing assessments of his capabilities that were incorrect:

The consequence of testing me in front of people is that I grew embarrassed and ashamed inside. By analyzing me in front of me, usually wrong, I grew resentful. It was so frustrating I don't like remembering it to tell it now. (Kedar, 2012, p. 57)

Kedar articulates a range of resulting emotions: resentment, embarrassment, and shame. In his case, he was without a way to communicate these emotions or to correct these assessments, until he was provided alternative methods of communication.

Masking to Navigate Societal Demands. In an earlier section, the emergent theme of masking for social acceptance was identified, as authors hid traits that differentiated them from those around them for the purpose of acceptance and fitting in. In addition to the pressure to fit in, a separate emergent theme of masking to navigate societal demands is also present in two of the five memoirs. This included masking to the broader expectations of society, or “the rules,” as Prahlad described:

It was hard following the rules. I was lonelier than I have ever been in my life. I had lots of small breakdowns, meltdowns, and shutdowns. I lived part time in the gray concrete of doctor’s offices and hospitals, therapy clinics and inpatient facilities. Needles, tubes, splints, casts, bandages, catheters, examination tables and beds, pill bottles, thermometers, hospital gowns, and scales. I was sick so much. I had a hard time holding it together, and sometimes, I couldn’t. I was spinning around all of the time. (Prahlad, 2017, p. 204)

Throughout his memoir, Prahlad described periods of attempting to change his behavior and lifestyle to fit societal expectations, to maintain an income and to maintain basic needs. He provided insight into the loneliness and physical health problems such effort led to as well.

Individual Need in Conflict with Circumstance

The superordinate theme of individual need in conflict with circumstance was identified in all five memoirs. It captured the emergent themes related to individual needs, and the resulting distress when those needs were at odds with their circumstance or environment. These emergent themes included intolerance of ambiguity and sensory overwhelm.

Intolerance of Ambiguity. The emergent theme of intolerance of ambiguity was included in four of the five memoirs. Throughout the memoirs in which this theme was found,

uncertainty and the unknown appeared to be a source of great distress for the authors. O'Toole, in the following, summarizes her overall experience of anxiety when faced with unpredictability, or the unknown:

But grab that weed near the base-dig at the roots, and pull—gently. What happens? Yes, another weed may grow elsewhere, but this one is gone. Anxiety is that root. It is the seed from which our topical fixations and “overly sensitive,” routine-driven, black/white, obsessive behaviors arise. We are trying to catch the rain. We are trying to create predictable order in a chaotic, often random world... by asking a million questions, by challenging exceptions to rules, by scripting dialogue we know was funny (once) or dictating play. It's not that we want to be unlikable or difficult or dominate the conversation with topics you don't enjoy. We just want to feel secure, safe and to be able to stop the endless waiting for unwelcome surprises. (O'Toole, 2018, p. 147)

O'Toole connected the intolerance of ambiguity with the ways in which she attempted to create a more predictable, safer, world around her.

Sensory Overwhelm. Four of the five memoirists depicted differences in how they perceived and processed sensory information, which at times led to feeling overwhelmed with sensory input. For example, Tammet wrote:

There were lots of things that I found difficult, like brushing my teeth. The scratchy noise of teeth being brushed was physically painful to me, and when I walked in a room I would have to put my hands over my ears and wait for the noise to stop before I could do anything else. Because of this extreme sensitivity I brushed my teeth only for short periods and then often only with the intervention of my parents. I was very fortunate that I rarely had toothaches, probably in large part because I drank lots of milk and did not eat

much sugary food. The problem continued for several years and led to frequent arguments with my parents, who could not understand why I would not brush my teeth without them having to compel me and often brought the toothbrush and paste into my room, not leaving until I had used them. (Tammet, 2006, pp. 85–86)

In this example, Tammet equated his experience of the sounds made by brushing his teeth to physical pain. This pain, understandably, led Tammet to try to avoid brushing his teeth, resulting in conflict with his parents who did not understand it.

Negative Impact on Sense of Self

Two of the five memoirists included the superordinate theme of negative impact on sense of self, both through internalizing blame and losing touch with their identity. While this did not occur across the narratives, I view it as a superordinate theme as it provides greater insight into the experience of both woman-identified authors.

Diminished Sense of Self. Both Williams and O’Toole identified a diminished sense of self or identity in their narratives. In the following passage, for example, Williams details intentionally embodying other identities to mask certain traits:

I hated calling anyone else by name, including myself. I never told them that I believed my name was Carol and that they were playing characters she met. Fear of betraying the secret was fear of losing the grip on Carol’s world. It was that grip which was my only way out of my inner prison. I had created an ego detached from the self which was still shackled by crippled emotions. It became more than an act. It became my life, and as I had to reject all acknowledgement of an emotional self, I had to reject all acknowledgement of Donna. I eventually lost Donna and became trapped a new way. Carol strove for the unacceptable: social acceptance. In doing so, Carol took the stage.

Willie, my other face to the world and the embodiment of total self-control, sat immobilized in the audience. Donna was still in the cupboard. When I was twenty-two, in search of myself, I again got into that cupboard and closed the door. (Williams, 1999, p. 25)

While there may be some misunderstanding regarding the psychopathological underpinnings of William's use of separate identities with separate names, she appears aware of these identities and later explains that they are the embodiment of her fight and flight responses, not personalities or people that she views as entirely separate from herself. The above passage illustrates her understanding of these identities, and how by adopting them, like in the case of "Carol," she loses connection with who she is, or "Donna."

Self-Blame. Self-blame for the interpersonal traumas she experienced, such as bullying and abuse, was a prominent theme in the writing of O'Toole. While it was not a prominent theme in the other memoirs, it provides deeper insight into O'Toole's unique perspective. For example, she wrote:

My bruises healed decades ago. My heart, too. I hold no bitterness. No anger. Honestly, I'm no longer invested enough to think or care about him one way or another. All of that is long since over. Yet last week, when that man grabbed me and "kissed" (read: assaulted) me, my subconscious mind went into an utter tailspin. Crying, shaking, unable to think straight for two days. I was filled with doubt, questioned my perception of all that had happened, revisited everything I'd said, how I'd sat, and—of course—what I'd worn. (O'Toole, 2018, p. 204)

In this excerpt, O'Toole reflects on her reaction after an assault, and how her early experiences of abuse by a romantic partner impacted her reaction. This passage is also an example of an

emergent theme described earlier, experiencing sexual assault. The emergent theme of self-blame overlapped with other emergent themes under the superordinate theme of interpersonal traumatic experiences and adverse childhood experiences: manipulation by others, experiencing abuse, peer victimization and bullying, and peer rejection and isolation. In addition, self-blame also overlapped with emergent themes under other interpersonal and social experiences contributing to distress, being misunderstood and invalidation of emotion and experience.

Emotion Dysregulation

The superordinate theme of emotion dysregulation was abstracted from emergent themes related to the authors' experience of overwhelming or intense emotion, and the ways in which they reacted to intense emotions. This theme was identified in four of the five memoirs, and encompassed the following emergent themes: emotional overwhelm, frequent anxiety, emotion suppression, self-injurious behavior, and stymieing for emotion regulation and expression.

Emotional Overwhelm. Four of the five memoirists identify themes of emotional overwhelm, naming it directly and describing the intensity of their emotions and their impact, and through identifying a need for emotion regulation skills. Kedar, for example, writes about feeling overpowered by his anxiety:

Anxiety is the source of much of my failure in social situations and in public. It overwhelms me so much I flee or withdraw in my stims or in front of the TV. It is one of the reasons I am so shy— It's not a lack of knowledge or awareness of others. I don't think a person is an object like some experts claim. I just can't relate when my anxiety is overpowering me. So this is one request to all researchers: start looking into anxiety, I think it may be a key to solving the riddle of autism. (Kedar, 2012, p. 60).

Kedar related his overwhelming experience of anxiety to hindering his social interactions, and he wondered about its relationship to his autism.

Frequent Anxiety. In the above example of Kedar’s experience of emotion overwhelm, he described the intensity of his anxiety. Frequent anxiety was also an emergent theme in his memoir, and the memoirs of three other authors. Prahlad for example, states:

But I was feeling too much blue. I was starting to break apart from never being alone.

The weight of everything was starting to crush me. I was feeling almost all the time that I was lost in a strange world. The constant anxiety in my belly came roaring out at night, in my room at Granny’s, I broke things on purpose. Precious things. I tore up some of my favorite books. I tore up *Go Up for Glory* and *On Walden Pond*. I tried to get meals from the blue of Muddy Waters’ guitar. From his voice. From the blue of Joni Mitchell’s album cover. From her high-pitched moaning. I was lost even among the familiar. I had wandered far into the forest, and I hadn’t left behind any crumbs. I ached so badly from the isolation, but I couldn’t think clearly enough to understand why I was aching. Things were moving too fast, and I was being swept along, like in white water, just trying to grab some air when I could. (Prahlad, 2017, p. 110)

In this passage he describes the intensity of his anxiety and reports it to be “constant.” In addition, he details how he manages these emotions through various self-soothing strategies.

Emotion Suppression. A prominent emergent theme included in Williams’ memoir was that of emotion suppression. In one example, Williams wrote:

Living as Carol, completely cut off from my real self and the emotions it embodied, I became terrified of being left alone. I feared becoming possessed by the real me which

seemed to lurk in the shadows like a ghost waiting for Carol to be left alone; waiting for life to slow down and catch up with her. (Williams, 1999, p. 88)

In this passage, she describes suppressing her emotions as a way of concealing her authentic self. For Williams, emotion suppression also intersected with other previously mentioned emergent themes found in her memoir: masking for social acceptance and masking to navigate societal demand.

Self-Injurious Behavior. When faced with emotional overwhelm or dysregulation, three of the five authors described using self-injurious behavior as a means of either expressing or coping with their emotions. Prahlad, for example, describes engaging self-injurious behaviors in moments when he felt overwhelmed with the intensity of his emotions:

I was trying to stitch myself back together at night, where I was coming apart. I was burning candles and losing myself watching the flames. I was turning on my black light and staring at my mushroom poster. I was praying to the universe. I was listening to the blue of Lightnin' Hopkins and Jimi Hendrix, and Roberta Flack. I was cutting myself and bleeding on pages of a girlie magazine I had found beneath knee-deep layers of old newspapers in the old abandoned chicken coop. I looked in the mirror again, and who did I see standing behind me, smiling, but the devil, stubbled and unshaven. (Prahlad, 2017, p. 112)

Emotion Regulation and Stimming. Throughout Kedar's memoir there is a prominent emergent theme of his use of physical self-stimulation, or stimming, for the regulation and expression of his emotions. In one passage he wrote:

Inside I shouted my story, but outside I only flapped in frustration. Then they told me, "hands quiet" or "hands down." Like I mentioned before, each day the experts denied me

hand-flapping but I had no other outlet for my feelings. What else could I do? I couldn't talk, write independently, gesture, or initiate. It was hard to endure this, but I was totally stuck with no way out that I could see. (Kedar, 2012, p. 58)

While other authors did not include stimming for emotion regulation and expression in their memoirs, this theme provides further information adding to the understanding of Kedar's individual experience.

Self-Identifying with Trauma-Related Disorders and Experiences

Each of the five authors used terms related to trauma disorders in their memoirs. The superordinate theme of self-identifying with trauma-related disorders and experiences was created based upon emergent themes in the memoirs in which the author either directly identified with either terms or with symptoms related to the experience of traumatic events. The emergent themes comprising this superordinate theme include complex PTSD, hypervigilance, intergenerational racial trauma, PTSD from treatment, and re-experiencing traumatic events.

Complex PTSD. One memoirist labeled their experience as "complex posttraumatic stress disorder." O'Toole (2018) used the term to describe her experience as an autistic woman and theorizes its relevance to the experience of all "spectrum girls" (p. 119). She writes:

We, spectrum girls, are playing at the game of life without a copy of the rules and, almost universally, the result is complex posttraumatic stress disorder: a normal psychological response to abnormal chronic circumstances. We develop anxiety that feels ridiculous, hypervigilant, tedious, and exhausting to everyone around us but, in all fairness, is entirely informed and relevant and natural, we have not the social armory to bolster our hearts, or to understand our bewilderment. We have not the sophistication or flexible perspective to judge or imagine a world in which our experiences are validated much less

valuable. Therefore, we fully expect to be undercut, undermined, abandoned, ridiculed, and traumatized. And more often than not, we are right. (O'Toole, 2018, p. 119)

In this passage, she connects hypervigilance and exhaustion to “playing at the game of life without a copy of the rules” (O'Toole, 2018, p. 119). Her use of metaphor appears to reference a lack of social understanding as well as feeling misunderstood by those around her.

Hypervigilance. O'Toole referenced being in a state of hypervigilance to the intention of others throughout her memoir in the example above, and it often intersects with the emergent theme of peer victimization and bullying in her memoir. A second author, Prahlad, also depicts experiences of hypervigilance, which is often associated with trauma-sequelae. He writes:

I thought about the girl in the movie Carrie. She was like me. When I saw the movie I cried for two weeks. I didn't talk for seven more days. It was worse when I saw The Elephant Man. I almost had another nervous breakdown. I remember thinking that being black and slow in America was like being a caveman in a land of dinosaurs. Always hunted. Always hyper alert. (Prahlad, 2017, p. 123)

In this excerpt, Prahlad describes the constant vigilance to the dangers he experiences as a Black man with a disability, which suggests the hypervigilance acted as a form of self-protection.

Intergenerational Racial Trauma. Intergenerational racial trauma is another emergent theme in Prahlad's memoir. In the following example, he uses the term “shell shock” to describe the impact of being enslaved upon himself and upon other descendants of enslaved people:

It takes so much longer than anyone wants to admit to get over being a slave, to get over being the grandchildren of people who were in bondage. Because everything still remembers. The earth remembers things. DNA remembers. Objects and things remember. People walked in shell shock. The shell shock we walked in would grow inside us and

deepen, like oak and maple and sweet gum, elm, locust, and crepe myrtle seeds until one day we would be a forest of trees, trapped between time and no time. Aging and having children. And having the grandchildren. And the great-grandchildren. And the great-great-grandchildren. And the cousins. And the aunts. And the uncles. And the nieces. And the nephews. And the shell shock would keep washing over us like waves as we struggled to manage the modern world. It would wash over us like the sea over seashells, while outside the world would move on, imagining we did not exist, pretending we never existed, shoving us as deeply into the corners of its closets as possible. Now and then someone would pick us up, like a seashell, and put us to their ear, and they would hear the waves of ironic laughter that helped us to survive. (Prahlad, 2017, pp. 19–20)

Prahlad describes memories that are held in his DNA, and the objects around him, and the way in which he and others coped using laughter.

PTSD from Treatment. Kedar’s memoir portrays an emergent theme in which he identifies symptoms of PTSD caused by interventions intended to support him. He writes:

I had an interesting experience today. I worked out with two volunteer athletes at an activity that had special needs kids meet with college students. At first they talked to me in simple tones and words, though they were very nice. This horrible memory of patronizing ABA [Applied Behavioral Analysis] words of “good job” triggered turmoil in me. It’s weird. I hear a kindly meant “good job” and I get goosebumps and I feel myself back in my room. At my table, looking at flashcards I can’t answer accurately. It’s an awful thing. I’m obviously still so affected by those memories. If I hear, “no, try again” or “high five” or “good job” I wind up in my room, at my table, trapped and miserable. My mom just told me it’s like a Post-Traumatic Stress Disorder. But, I’m not in my room

anymore, and the table is long gone, and I don't have to look at flashcards, so I need to move on emotionally. (Kedar, 2012, p. 118)

Kedar reflects on how certain phrases led to intrusive re-experiencing of past interventions causing distress, and how these flashbacks indicate PTSD.

Re-Experiencing Traumatic Events. Kedar is also one of three authors whose memoirs include the emergent theme re-experiencing traumatic events through intrusive memories and flashbacks. Williams, for example, describes flashbacks to childhood experiences of physical abuse such as the following:

Then, as my aunty recalled an event when I was three, it triggered something, and my mind replayed it in all its vividness and horror. I was back there. I could see my aunty across the room. I could hear the pleading tone in her voice and sensed danger. I was watching everything around me happened as though in slow motion though moving far too fast for me to be able to respond in time. I looked up at the figure of my mother from the eyes of a three-year-old. I shot silent glances in the direction of the pleading voice from across the room. I looked down at the opened tin of spaghetti in front of me and was aware of the fork in my hand. I had not heard the introduction: the threat of death against my spilling a single drop of food. I never connected the repeated slapping with the event. It was just something which came to me from out of the blue as a series of shocks (Williams, 1999, pp. 117–118)

Environmental Factors Supporting Safety and Comfort

The superordinate theme environmental factors contributing to sense of safety and comfort was found across the five memoirs. The emergent themes included under this superordinate theme describe changes to their environment or context that increased their

experience of safety or comfort. Understandably, many of these emergent themes suggest coping with circumstances in which their individual needs conflict with situational demands. The emergent themes under this superordinate theme include: accommodations and adaptations for sensory overwhelm; rules, routines, and repetition; and time in nature.

Accommodations/Adaptations for Sensory Overwhelm. While four of the memoirists describe pain related to sensory overwhelm, three describe the ways they adapted to overwhelming sensory input. For example, Tammet writes:

Eventually I tried putting cotton into my ears so that I could not hear the noise as I brushed my teeth. I also watched the small television that I had in my room at the same time to take my mind off the fact that I was using the toothbrush; otherwise it would make me gag. Together these small efforts helped me to clean my teeth from day to day.

(Tammet, 2006, pp. 85–86)

Tammet describes the pain caused by hearing sounds associated with brushing his own teeth, and how this caused conflict with his parents. In this excerpt, he explains the accommodations and adaptations he implements to negate this pain, so that he can brush his teeth.

Listening to and Creating Music. Two of the five memoirs included listening to and creating music as forms of expression and anxiety-relief. For example, Williams writes:

Through my music I began more and more to reach and express my true self. My music spoke of the things I loved, of the wind and the rain, of freedom and hope, of happiness in simplicity and of triumph over confusion. However, the closer I came to bringing myself out, the greater became the fears which caused serious conflicts between my inner self and the characters used to communicate with the outside world. (Williams, 1999, p.

115)

Throughout her memoir, she highlights the role that music played in supporting her expressing her emotions and in feeling connected to her authentic self.

Safety in Rules, Routine, and Repetition. Four of the five memoirs include the theme of safety in rules, routine, and repetition. If unpredictability and the unknown lead to distress, as described in an early emergent theme, it stands to reason that repetition and rules which dispel ambiguity lead to an increased sense of safety. For example, O’Toole (2018) writes of how order and organization serve as form of self-protection: “It makes perfect sense that, unrecognized and misunderstood by most everyone—including ourselves—we try to protect ourselves by imposing a façade of order on everything and everyone around us” (p. 221).

Time in Nature. Two authors identify the soothing impact of their time spent in nature. For example, Kedar writes:

I fit in so well. I am so at home in the messy beauty of nature. I relate to it. I see the system is messy, but it works and it is WOW. I see my illness this way. It’s not pretty. It is messy. It has erosion and rivers mud too. But it is part of nature in the same way. I am not a mistake, nor a sorry state of messy neurons. I accept my messy neurological system because it has given me a way of seeing life. I fit in with the path in the woods. (Kedar, 2012, p. 119)

Beyond feeling at home in nature, Kedar also draws parallels between how he views himself and how he views nature.

Social and Community Factors Supporting Resilience

All five memoirs include the superordinate theme social and community factors contributing to resilience and growth. The following emergent themes are connected under this superordinate theme due to their support of the resilience and growth of the memoirists and take

place in social or community contexts: accommodations and adaptations for communication, learning about social intricacies and skills, religious and spiritual beliefs, peer acceptance, supportive and understanding loved ones, supportive and understanding mentors and professionals, and sense of community and network of support.

Accommodations/Adaptations for Communication. Three memoirs include the theme: accommodations or adaptations supporting their communication with others. For example, Kedar writes:

Yesterday with a device I borrowed I talked on the phone. It was so liberating—Not just, “How are you?” but a real conversation. I joked. They laughed. They asked me questions. I answered. Like you do. Only it was my first time. It’s so meaningful to me to have my own voice speaking my thoughts to others. I’m almost thirteen so I’d say it’s about time.

(Kedar, 2012, p. 82)

Kedar describes being nonspeaking in his memoir and how for a long time he was unable to share his thoughts and perspectives with those around him, and the frustration and sadness this led to. However, as the above passage illustrates, it was meaningful for him to utilize accommodations to facilitate his communication so he could be better understood.

Learning about Social Intricacies and Skills. A prominent theme in O’Toole’s memoir is learning about social intricacies and skills. In one passage she writes,

Over the course of my life, as a child and as an adult, in many, deeply intimate ways, I’ve been deceived and abandoned because I never saw problems coming... and because I believed what was in front of me rather than what logic made clear to others. So it’s probably no wonder that I’m now fascinated by stories of long-ago courts where people plotted and manipulated one another to suit their own ends ... or by profilers and forensic

psychology where brilliant minds spar in toe-to-toe dances of tactics and deception. I study out of fascination, yes, and probably, on some level, protection, too. (O'Toole, 2018, p. 120)

O'Toole reflects on the ways in which she learned about perspectives of others and the complexity of interactions, which became as she puts it, a form of "protection," for herself in response to her experiences of abandonment and deception.

Religious and Spiritual Beliefs. Three of the five memoirs include finding meaning and comfort through religious and spiritual beliefs. For example, Kedar writes:

It's a hard struggle. I fight my doubts and my demons every day but I am so sure that hope is like a taste of God's presence. How else would we have this relief if not for God? I think horrible things seem worse without this hope that promises a better tomorrow. It's necessary to see that our suffering leads to calming hope through our love in God.

(Kedar, 2012, p. 106)

This illustrates the importance of Kedar's religious beliefs in providing a sense of hopefulness and in making meaning of his experiences.

Peer Acceptance. Two memoirists depict themes of peer acceptance, and the positive impacts it had on their experiences. This dovetails with the authors' descriptions of their distress in response to peer rejection and bullying described earlier. In the following example from Kedar's (2012) memoir, he describes how the feeling of being accepted by his peers led him to "start on a new road" (p. 52). He writes:

I'm determined to take November's Thanksgiving as a model for trying to relate to people in play. I believe it's a start on a new road. I don't see myself going back to my

old lousy path. I'm done with it. I need to remember that people accepted me, not in a pitying way, but as part of the group. It's a great feeling. (Kedar, 2012, p. 52)

Kedar's narrative includes the impact of peer victimization and isolation, and how these experiences led him to expect this reaction from his peers. However, in the above example, feeling accepted for who he is shifts his expectations and inspires him to engage with others more often.

Supportive and Understanding Loved Ones. Three out of the five memoirs include themes of supportive and understanding loved ones, and descriptions of the ways in which they supported the authors' resilience. Tammet (2006), for example, writes: "Neil has learned not to intervene but to let it pass, which does not normally take very long, and his patience helps a lot. With his support and understanding, such meltdowns have become less frequent over time" (p. 156). In this example Tammet describes how his husband has supported him and helped him to experience fewer "meltdowns."

Supportive and Understanding Mentors and Professionals. Beyond the importance of the support of loved ones, the emergent theme highlighting the importance of supportive and understanding mentors and professionals is also present in three of the five memoirs. Williams, for example, illustrates the role that teachers, adults, and her psychiatrist, played in her personal growth. In one passage she writes:

My supervisor's caring concern did nothing for my thesis, though it did a lot for me. He was the one uninvolved mirror in my life at that time. The me his comments had captured stayed with me as snapshots in a photo album I looked through to remind myself of who, and where, I had been. (Williams, 1999, p. 131)

In this example, she describes the impact her undergraduate thesis supervisor had on her.

Williams attributes his care and his understanding of her as contributing to her growing sense of self.

Sense of Community and Network of Support. Two of the five memoirs include the theme of a sense of community and a network of support, and their contribution to the authors' resilience. In the following example written by O'Toole, she depicts the importance of a network of support for survival:

Our hearts can feel so exposed, so raw that bearing one more sorrow would break us. So, when we don't have healthy activities to busy our perseverating brains or a support network to help us process, survive, or even harness it, many people simply try to turn down the volume. (O'Toole, 2018, p. 125)

Learning Ways to Regulate

The superordinate theme learning ways to cope and regulate is present across all the memoirs. It was created based on emergent themes related to the authors' narratives regarding the many strategies they taught themselves or learned to cope with distress or regulate overwhelming emotions. These emergent themes include: knowledge and information gathering, mental preparation and rehearsal, mental distraction, exercise, comfort objects, meditation and breathing practices, and using sensory input for regulation.

Knowledge and Information-Gathering. Three of the five memoirs include the theme of knowledge and information-gathering as it related to a sense of safety or connection. O'Toole (2018) writes, for example, "Information has always been my life preserver when feelings get too deep. My dad was the same way. Facts. Theories. Give my brain something to grasp hold of, and I will not drown" (p. 3). She also endorses distress and anxiety in uncertain and ambiguous

scenarios, captured by the aforementioned emergent theme intolerance of ambiguity. Knowledge and information-gathering appear to counteract this fear by providing certainty and predictability.

Mental Preparation and Rehearsal. Another emergent theme in two of the five memoirs links mental preparation and rehearsal with increased feelings of safety. For example, Tammet (2006) writes, “I like to prepare myself mentally for an upcoming event, to rehearse the different possibilities or permutations in my mind because of the way I become uncomfortable when something happens suddenly or unexpectedly” (p. 190). For Tammet, this practice of mentally preparing helps with the stress caused by ambiguity and not-knowing.

Mental Distraction. Three of the five memoirs describe mental distraction as a form of coping and regulation in times of distress. Tammet, for example, writes:

When I felt very stressed I counted the powers of 2, like this: 2, 4, 8, 16, 32...2,048, 4,096,8,192 ... 131,072, 262,144... 1,048,576. The numbers formed visual patterns in my head that reassured me. Since I was so different, the boys weren't entirely sure how to tease me and soon tired of it when I did not react as they wanted me to, by crying or running away. The name calling continued, but I learned to ignore it and it did not bother me too much. (Tammet, 2006, pp. 77–78)

In the above example, Tammet uses mathematical problem-solving which he finds comforting when being subjected to peer victimization.

Exercise. Two of the five authors describe exercise as contributing to their wellbeing or feelings of safety. Kedar, for example, explains:

I need to exercise, piano, communicate and write to help me stay focused in reality. If not, I swirl internally in my inner life. So, so, so easy to return to but it's a prison to me so I don't want to return there. (Kedar, 2012, p. 97)

Comfort Objects. Two of the five memoirs include the importance of comfort objects in providing a sense of safety for the authors. Williams, for example, details the importance of her comfort object:

By now I was developing a clear awareness of an ‘I’ and I was becoming aware that I would have to lose my dependence upon the characters as something separate to myself. I was, however, not yet ready to turn to people. I came across a ragged little toy at a market. It was in a pile of broken toys with missing bits. It had a ribbon with blue spots on it and looked like a cross between a sheep, a rabbit and a dog. It was about fifteen to twenty years old and cost twenty pence. I bought it for myself and named him Travel Dog. He was to travel everywhere with me every day, just as the characters had. He was to become my bridge to living things beyond the wall of my own body. (Williams, 1999, p. 168)

In this passage, Williams reflects on depending on a stuffed animal first for comfort, and how this led her to eventually learn trust and depend on other people.

Meditation and Breathing Practices. Three of the five memoirs describe meditation and breathing practices contributing to the memoirists’ abilities to cope. Prahlad, for example, writes:

Meditations helped to center me, to lessen the times when my mind slipped away. They were like medicine. Of all the things I’ve learned, meditation has been one of the most important. Learning to meditate was a turning point. Without it, I don’t know how I would have survived. The university degrees wouldn’t have saved me. They wouldn’t have centered me or given me inner refuge in the storms of life. (Prahlad, 2017, p. 144)

In Prahlad’s memoir, he includes the importance of meditation in grounding himself in the present and building up his ability to navigate future conflict.

Sensory Input for Regulation. The use of sensory input for support as a relaxing or coping method is a prominent theme in four of the five memoirs. The authors provide various examples of sights, physical sensations, and tactile experiences as a way of regulating strong emotions. In one example, Kedar describes his use of physical self-stimulation through hand-flapping:

Hand-flapping is my most embedded stim. I started young. Today I still do it whenever I feel strong emotion. It's like there is a direct route from my emotions neurologically to my hands. No sense to it. I like the feel of it too. It is like a sensory stress release. To hold it in is like forcing me to not vomit; the urge is that strong. I don't think I would try to emotionally hold things in just to stop flapping because I would overflow inside. I know it's stopping me socially. It's a hard choice to make. (Kedar, 2012, p. 43)

In this example, Kedar considers how his physical stimming relieves emotional distress, though recognizes how it may be perceived negatively by those around him.

Individual Processes Contributing to Resilience

The superordinate theme of individual processes supporting resilience and growth is present across all five memoirs. It was abstracted from the emergent themes which provided insight into the internal processes, feelings, and experiences which the memoirists connected to their personal growth and resilience. These emergent themes include identifying personal strengths and areas of growth, self-understanding, acceptance of self and experience, sense of autonomy and control, making meaning of experiences, and using personal experiences to help others.

Identifying Personal Strengths and Growth. In three memoirs, the authors describe the benefits of identifying their personal strengths and ways in which they see themselves as having grown over time. In one example, O'Toole writes:

The neurological hardwiring that makes me blind to social self-sabotage is the same one that tells me that actions speak louder than words. That resilience trumps precision. That bravery isn't something you plan for. That wonder and possibility and wild imagination are truer and more beautiful than anything I know. Quirks, misunderstandings. Part of being the kind of different we are. Keep calm and carry on? No thanks. I'd rather stir it up and change the world. (O'Toole, 2018, pp. 242–243)

In the above example, O'Toole reflects on how her autistic-related differences may contribute to social pitfalls at times, they also inform her values and support her personal strengths.

Self-Understanding. Four of the five memoirs include descriptions of how self-understanding leads to personal growth. Williams, for instance, writes:

I had discovered that my mind, too, was a system. If I understood it, then that was a form of protection. I could learn to explain why I was the way I was. I could work out whether I was in fact mad or stupid and I could explain it as though I was that very symbol of intelligence and sanity I so looked up to: my psychiatrist. (Williams, 1999, p. 108)

In the above passage, Williams describes how understanding her mind served as a form of self-protection, and how she grew this ability through her own self-reflection and study, as well as through her work with her psychiatrist.

Acceptance of Self and Experience. Three of the five memoirs contain depictions of the authors' acceptance of themselves and their experiences as contributors to their resilience.

O'Toole, for example, writes:

This life has not been an easy one: illnesses, loss, separation, abuse, traumas, violence, self-harm ... it's been ugly and terrifying and uncertain. There have been moments I've wished desperately for time to breathe between the waves, but never, ever, ever have I asked, "Why me?" That's not pride speaking. Nor is it some fatalistic statement of pessimism. It's autism, I think. Because, really, in triumph or tragedy, why not me? (O'Toole, 2018, p. 128)

O'Toole describes how her autism has supported her in accepting and navigating hardships she has experienced in her life.

Autonomy and Control. Three of the five memoirists discuss how a sense of autonomy and control contribute to their wellbeing. Tammet's memoir, for example includes the role of autonomy and control in helping him through periods of anxiety:

There was anxiety, of course, about the trip and whether or not the placement would be successful. But there was something else as well: excitement, that I was finally taking charge of my life and my destiny. Such a thought took my breath away. (Tammet, 2006, p. 119)

In the above example, Tammet describes how taking charge, or being in control, of his life leads to feelings of excitement, which ultimately helps him to mitigate feelings of anxiety.

Making Meaning of Experiences. Three authors include the theme making meaning of experiences and depict its relationship to their resilience and wellbeing. O'Toole, for example, ties her negative experiences as a child to her mission in life:

I knew the fresh hell of being a hopeless child. Alone in my room in 1988, I cried myself sick and then made a conscious decision. I would not forget the pain. I would not let myself forget how it felt to live afraid. And in whatever form it took, my life's mission

would be to ferociously champion the right of every heart to be witnessed and loved. That decision remains the singular thread connecting my every venture, value, and story. My perpetual pledge. In every way possible until I close my eyes for the last time, I will, quite literally, love the hell out of this world. (O'Toole, 2018, p. 136)

Using Personal Experiences to Help Others. In O'Toole's example above, of making meaning of her experience, there is also the emergent theme of using personal experiences to help others. This theme can be found in two other memoirs as well. For example, Tammet writes,

There is another way in which I hope that my abilities might help others in the future, by encouraging a wider appreciation of different ways of learning. Visual learning aids can be beneficial to many "neurotypical" learners, as well as those on the autistic spectrum. (Tammet, 2006, p. 222)

Conclusion

The results of this qualitative analysis offer insight into the perspectives of these individuals as they navigate adversity and traumatic experiences, find sources of resilience and growth, and make meaning from their internal experience of autism. The memoirists provided detailed and insightful accounts of the traumatic or stressful live events they faced and reflected on their resiliency and growth in the face of these challenges. In the following chapter, the results of the study are explored and contextualized within the current research regarding the experiences of autistic individuals focusing on both trauma and adversity and resilience and posttraumatic growth.

CHAPTER V: DISCUSSION

In this dissertation, I sought to address gaps in the literature regarding autistic individuals' experiences of trauma and resilience from a transformative framework, by utilizing the pre-existing knowledge available through five memoirs published by autistic authors. I used interpretive phenomenological analysis (IPA) to deeply familiarize myself with the data in these memoirs, and to identify themes relevant to three overarching research questions: (a) What themes in the narration of traumatic and stressful events, and resulting sequelae emerge for the authors? (b) Does the traditional definition of potentially traumatic events (PTEs) as defined by current diagnostic standards and the adverse child experiences (ACEs) studies accurately capture the range of experience for autistic individuals? (c) What themes of resiliency and posttraumatic growth emerge in the authors' narration of their experiences?

Through my qualitative analysis, I identified superordinate themes across the five memoirs relating to resiliency, posttraumatic growth, trauma, and stressful life events. An additional level of conceptualization of these themes lends itself to a sociocultural and interpersonal understanding of trauma and resilience as experienced by autistic individuals (see Appendix B). This can be summarized as a multilayered approach, with each level interacting with the individual, and the other layers. The levels I identify, and expand upon below, are individual identity and internal processes, contextual and environmental factors, interpersonal and relational experiences, and societal and communal factors. In addition, these themes indicate that, in response to my second research question, traditional definitions of traumatic and adverse experiences may not accurately reflect the lived experiences of autistic individuals. Lastly, I discuss the clinical implications of the study, identify areas for further research, and reflect on some limitations to this dissertation.

Individual Identity and Internal Processes

Four themes related to the authors internal individual processes emerged in the results of this dissertation: negative impacts of traumatic exposure on sense of self and individual processes contributing to resilience, as well as emotion dysregulation and learning ways to regulate. The results of previous studies support these findings, while the qualitative nature of my research allows for further depth in understanding these experiences, as described below.

Negative Impacts on Sense of Self

Two memoirs included prominent themes in which the authors described their traumatic and adverse experiences as negatively impacting their sense of self, relating to increased self-blame and uncertainty of who they are. Self-blame, and other inward-directed responses to stress and trauma, are considered internalizing problems (Garnefski et al., 2005). Internalizing problems include disordered mood, anxiety, depression, and withdrawal from others, many of which were described in the memoirs by these two authors.

While both memoirists which included this superordinate theme identified as women, research conducted by McCauley et al. (2019) found that autistic youth, regardless of gender identity, reported higher levels of negative perceptions of their self-worth, and lower self-esteem, when compared to allistic peers. The small sample size of my dissertation, often inherent in qualitative research, may have limited inclusion of narratives regarding impacted sense of self from non-female identified autistic individuals.

An alternative hypothesis considers the intersection of gender identity and autism: stress and adversity may well be differently experienced and expressed in women and girls. There is some empirical data to support this interpretation. For example, Solomon et al. (2012) found that adolescent autistic girls reported higher rates of internalizing psychopathology when compared

to both autistic boys and to allistic girls; these researchers suggest that gender and emotional socialization may have a bigger impact in autism than studies, mostly of males, have previously revealed. Even without the intersection with gender, both the existing literature and the results of this qualitative inquiry point to potentially exacerbated impacts on self-esteem, identity, and self-worth, in autistic individuals in response to stressful life events.

Individual Processes Contributing to Resilience

Growth and Resilience. In the authors' narratives of their own personal growth and resilience, they identified varying individual practices that supported their resilience. Reflection upon their personal growth was a predominant theme across all narratives. Each author described varying ways of pursuing personal growth and resilience. One such process identified was making meaning of adversity, as well as making meaning of their autism and related differences from others. Making meaning of stressful life events, such as through positive reframes and shifts in perspective are related to better mental health outcomes and overall wellbeing (Park, 2010). For example, in her memoir, Jennifer O'Toole details the social misunderstandings and their consequences that she faces as a part of her autism, and throughout her memoir she begins to identify the many strengths such as her compassion, strong values, and ability to dive deep into research, which are also in part related to her autism.

Self-Acceptance. Also inherent in O'Toole's example of making meaning and reframing her perspective, is the way in which this supported her in learning self-compassion and self-acceptance, allowing her to become increasingly resilient in the face of adversity. She, and the other authors, detailed their journeys toward self-understanding and ultimately self-acceptance and compassion, leading toward resilience and growth. These findings are consistent with the qualitative study of Lee et al. (2022). Lee and colleagues (2022) described

similar themes of the importance of self-acceptance supporting the wellbeing and resilience of autistic individuals and concluded that self-acceptance in autistic youth was connected to their personal growth. Similarly, self-compassion, or a kind and understanding approach to one's sense of self and experiences, was significantly correlated with the psychological wellbeing of autistic and allistic research participants (Cai et al., 2022). Notably, Cai et al. (2022) found autistic traits were related to lower levels of self-compassion.

Feelings of Autonomy. Three of the five authors included in this study identified the positive impact of feeling autonomous and in control of their own lives had following their early adversities and traumatic experiences. For the authors, this ranged from learning how to live independently, setting and achieving goals, and using accommodations as needed to support independence. This supports existing research that connects internal locus of control, or an individuals' feeling of control over their lives and to make changes, to greater feelings of empowerment and resiliency in the face of adversity (Benzies & Mychasiuk, 2009). The current literature regarding autonomy, independence, and self-determination, regarding autistic individuals is difficult to summarize, as some are based on behavioral observations of autonomy, while others the felt experiences provided in qualitative and firsthand accounts. However, White et al. (2018) found in their study with autistic young adults, greater self-determination or autonomy was associated with higher ratings of quality of life.

Emotion Regulation

Dysregulation. The memoirists of this dissertation referred to the intensity and overwhelming nature of their emotions at times, including frequently feeling anxious. This parallels existing literature regarding emotion dysregulation introduced in the literature review as a part of both some autistic individuals' experience and exposure to developmental trauma.

Specifically, Samson, Wells, et al. (2015) proposed that the increased likelihood of emotion dysregulation experience by autistic individuals may lead to increased negative emotionality. Further, Kerns et al. (2015) proposed that exposure to traumatic events may exacerbate emotion dysregulation already present for some autistic individuals.

Learning Ways to Cope. While the authors of the memoirs detailed their experiences of emotion dysregulation such as intense anxiety, they also identified the strategies which they learned to cope with or regulate their emotions. These methods included information-gathering, mental distraction, mental preparation and rehearsal, breathing and meditation techniques, using comfort objects, and engaging in physical exercise. The use of voluntary emotion regulation strategies leading to stronger abilities to cope was supported by the findings of Mazefsky et al. (2014). In their study of autistic adolescents' use of voluntary (problem-solving or acceptance) versus non-voluntary (remaining focused on the stressor or shutting down) emotion regulation strategies, Mazefsky et al. (2014) found that the autistic sample reported higher rates of involuntary emotion regulation approaches labeled as maladaptive. They also reported the autistic sample was as likely as the allistic sample to engage in voluntary emotion regulation strategies; notably, the autistic adolescents who reported more use of voluntary emotion regulation strategy also reported lower levels of psychopathology.

Contextual and Environmental Factors

One factor influencing the likelihood of emotional dysregulation identified by the memoirists was the way in which their individual needs, related to their autism, conflicted with the context or environment around them. My results provided rich individualized narratives regarding the intensity and resulting distress such conflicts may lead to. Examples found in my

research included sensory sensitivities or sensory needs that were overwhelmed by the autistic authors' environment, and the authors' need for certainty and predictability in their lives.

Intolerance of Ambiguity

Uncertainty. In the memoirs used in this dissertation, most of the authors cited ambiguity, unexpectedness, and uncertainty as sources of anxiety and distress in a variety of contexts. Some of the memoirists reflected on their distress stemming from the lack of predictability in their social worlds, as well as other parts of their lives. Similarly, other studies have found that in an unpredictable world, individuals often struggle to tolerate ambiguity and uncertainty, harboring negative beliefs regarding situations about which they feel uncertain (Carleton et al., 2012) More difficulty tolerating uncertainty is theorized to correlate with higher levels of anxiety for both allistic and autistic individuals (Jenkinson, et al., 2020). Wigham et al. (2015) expand our understanding of the relationship between anxiety and intolerance of uncertainty for autistic individuals; their study suggests intolerance of uncertainty mediates the relationship between insistence of sameness and the relationship to under-responsiveness or over-responsiveness to sensory input. These data also align with the findings of Corbett et al. (2009) that showed autistic children were measured to have higher levels of stress and cortisol when faced with environmental and daily changes in their routine and activities.

Predictability. If uncertainty and ambiguity illicit distress, it would stand to reason that identifying rules and engaging in routines and repetitive behaviors might be strategies for managing the attendant anxiety, as four of the authors described. Recent studies support this association between anxiety and insistence on sameness, repetitive behaviors, and restricted interests; supporting strategies to regulate emotions is therefore proposed as treatment target for reducing anxiety for autistic individuals (Conner et al., 2020; Rodgers et al., 2012; Wigham et

al., 2015). Taken together with the results of my study, these data provide evidence that autistic individuals struggle with emotion regulation, including significant anxiety following exposure to trauma or adversity; they additionally experience uncertainty as a source of particular stress.

Sensory Processing

Sensory Overwhelm. In addition to difficulties tolerating an ambiguous situation, and world, four of five of the memoirs in my study described how their sensory sensitivities made it harder for them to function in neurotypical settings. Specifically, the authors provided insight into their unique needs and sensitivities regarding sights, sounds, smells, tastes, and touch, and how if a particular sense or senses became overwhelmed, they would feel increasingly overwhelmed and distressed. This theme aligns with the findings of Gillot and Standen (2007), who reported autistic adults had higher levels of stress and anxiety compared to their allistic sample when faced with aversive sensory stimuli. Similarly, research conducted by Pastor-Cerezuela et al. (2020) suggests sensory processing difficulties are related to executive and cognitive dysfunction, such as the ability for autistic individuals to inhibit responses, sustain auditory attention, and to maintain verbal short-term memory. These researchers advocate for the use of interventions which mitigate the effect of sensory overstimulation.

Use of Sensory Regulation. Notably, three of the five memoirists discussed such interventions; they spoke about accommodations and adaptations to mitigate some of their sensory overwhelm, or over-responsiveness. They touch on the empowering effect using accommodations to reach their goals has, as well as how changing and adapting to their environment to better suit their sensory needs reduces their anxiety.

One method used by some of the memoirists to regulate intense emotion and sensory overwhelm was, “stimming” or self-stimulation through stereotyped movements. They, for

example, described how stimming helped them to feel less anxious, to cope with intense emotions, and with sensory under- or over-responsiveness. The theme regarding the utility of stimming to both express and regulate emotions provides new insights into the function of observable behaviors. This aligns with preliminary neurobiological research that proposes stereotyped movements such as these can help autistic individuals improve attention and sensory processing, as it regulates brain rhythm (McCarty & Brumback, 2021).

In addition to using stimming, the memoirists made other changes to their immediate environments to adapt, through the use of music, as well as spending time in nature, to better suit their sensory needs. This is congruent with research which draws a connection between time spent in nature and increased positive emotions, and ability to reflect on life-stressors (Mayer et al., 2009). Specifically, regarding PTSD, Bettmann et al. (2021) found that time spent outdoors decreased PTSD symptomology for war veterans, and that the more time they spent outdoors, the greater the reduction in symptoms. The memoirists in my study suggest the natural world may also hold benefits for autistic individuals who have experienced traumatic events.

As for the psychological benefits of listening to and creating music, multiple memoirists credited listening to and playing music as both anxiety-reduction techniques as well as methods of expressing their emotional experiences. This finding is consistent with the exploration of Redondo Pedregal and Heaton (2021) who found in their preliminary study that the use of music-based interventions may enhance emotion expression, emotion recognition, and emotional awareness for autistic youth with alexithymia. Similarly, in a related study, researchers found that listening to music has been shown to decrease anxiety and stress for autistic youth (De Vries et al., 2015).

Relationships and Interpersonal Experiences

Prominent themes across the narratives of this study included descriptions of the role played by interpersonal relationships in contributing both to the authors' distress and resiliency. Interpersonal and traumatic adverse experiences described in the memoirs included widely accepted potentially traumatic events (PTEs) and adverse childhood experiences (ACEs). In addition, the authors identified adversity in the face of unique experiences related to autism, such as specific phobias and fears, frequently being misunderstood by others, being excluded socially, and the camouflaging of autistic-related differences. On the other hand, perceived support and acceptance by others often played a key role in the memoirists' recovery and resilience.

Interpersonal and Traumatic Experiences

Traditional ACEs and PTEs. Each of the five memoirs of this study included descriptions of adverse childhood experiences occurring in the context of relationships. The traumatic exposures included physical, emotional, and sexual abuse, witnessing the violent treatment of a caregiver, peer isolation and rejection, peer victimization and bullying, manipulation, sexual assault, and discrimination. Congruent with research, the authors included descriptions of sequelae associated with experiencing developmental traumas and adverse childhood experiences, such as emotion dysregulation, altered attributions and distrust of others, and other negative mental health outcomes including PTSD, anxiety, and depression (U.S. DHHS, 2021; van der Kolk, 2005).

The memoirists each identified personal and specific fears related to other people, connecting them to earlier traumatic relational experiences. These included fear of others and crowds (Tammet, 2006; Williams, 1999), fears of being abandoned (Prahlaad, 2017; Williams, 1999), and fears of intimacy and vulnerability (Williams, 1999). These fears overlap with altered attributions and expectations for others including loss of trust and expectations of future

victimization, which have been related to both CPTSD and DTD (Courtois & Ford, 2009; van der Kolk, 2005). In addition to ACEs and interpersonal traumas and their impacts, commonly identified in the literature on trauma in neurotypical adults, the memoirists also acknowledged other relational experiences as sources of distress, which provided insight into their unique perspectives and needs.

Avoidance of Eye Contact. One example of unique experiences held by the authors of my study leading to distress, was Kedar's fear of eye contact. He alone of the five authors wrote about his anxiety when making eye contact with others leading him to avoid it or withstand it when forced to do so, with great distress. His experience has been supported by previous qualitative research which proposes eye contact, and the expectation of maintaining the appropriate amount of eye contact can be particularly stressful for autistic individuals. Trevisan et al. (2017) for example, found in their qualitative study that autistic adults and teenagers described negative emotional and physiological reactions, most commonly fear, anxiety, and panic, as one of many experiences of eye contact. In addition to adverse emotional and physiological reactions, the participants in that study identified feeling invaded or overly intimate when making eye contact, avoiding eye contact due to difficulties listening and looking at a person simultaneously, and difficulties interpreting emotional information provided by looking into another's eyes. While fear and anxiety when holding eye contact was not a shared experience for all of the memoirists in my qualitative research, nor in that of Trevisan et al. it appears to be quite distressing and impactful for the autistic individuals who do experience it.

Camouflaging. "Camouflaging," also referred to as "masking" of autistic or neurodivergent-traits was another theme prevalent in three of the narratives used in this study, and often cited as contributing to distress. The reasons for camouflaging included wanting to

make connections, fit in, and to reduce fear of being othered or victimized for differences. This aligns with the research of Hull et al. (2019) which suggests that greater self-reported camouflaging of autistic-related differences was associated with greater self-reported symptoms of generalized anxiety, social anxiety, and depression. Cage and Troxell-Whitman (2019) also reported that the more contexts in which an individual camouflages neurodivergent-related traits, the higher levels of stress and anxiety the individual reported. Additionally, their qualitative findings suggested that the individuals who engaged in camouflaging autistic-related traits or behaviors did so for multiple reasons including: to get by in work or education, to pursue and maintain relationships, to avoid bullying or retaliation from others, and to manage the impression of others. In both my and the aforementioned findings, autistic individuals identify the stress and toll that camouflaging their differences takes on them both physically and emotionally; however, they persist to adhere to neurotypical expectations for interactions to avoid exclusion or rejection. Mitchell et al. (2019) connected autistic camouflaging to what is known as the “double empathy problem.”

The Double Empathy Problem. Prominent emergent themes in three narratives drawn from this study included distress resulting from both misunderstanding others and being misunderstood by those around them: this is known as the “double empathy problem,” (Milton, 2012). Based on the experiences of the authors in my study, the double empathy problem caused the authors to feel invalidation and dismissal of their emotions and perceptions by neurotypical peers, and adults, in their lives. As their needs may not be fully understood or misperceived by caregivers and other adults, the neurotypical adults’ responses to the memoirists were not empathically attuned, resulting in further distress.

In explanation of this common stressor, Milton (2012) proposed that autistic and neurodivergent individuals experience a lack of empathy or understanding from neurotypical individuals which also impacts their relatedness to others. The “double empathy problem” describes the *mutual* misunderstanding between autistic and allistic individuals, increasing feelings of disconnection and non-acceptance by society. Mitchell et al. (2021) propose that the double empathy problem impacts the social development of both neurodivergent and neurotypical individuals. Their model theorizes that negative perceptions of autistic individuals held by neurotypical individuals leads them to exclude autistic peers. The excluded autistic individual learns to avoid or withdraw from this exclusion or rejection. The interaction between neurotypical and neurodivergent peers decreases in frequency, and neither learn different ways of relating or to understand one another, which leads to future misunderstandings and misperceptions between autistic and allistic peers, and increased likelihood of social isolation for autistic individuals. It stands to reason that if misperceptions and misunderstandings, which result in social exclusion, lead to distress for autistic individuals, then the inverse is also true: social support and acceptance contribute to growth and resiliency.

Social Support and Acceptance

Prominent in the narratives of this study was the role in the authors’ resilience and growth played by relationships characterized by the author feeling understood, supported, and accepted. This is consistent with research identifying social support as a protective factor following exposure to adversity and traumatic experiences (APA, 2013). Additionally, as Orsmond et al. (2004) theorized, autistic individuals perceived as having atypical ways of connecting or seeking relationships were less likely to seek out support. While people vary in their communication styles and desires for intimacy and attachment, an additional factor

impeding several authors in this study from accessing social support was feeling misunderstood by peers, loved ones, professionals, and authority figures in their lives. The impact of these mutual misunderstandings between the autistic authors and others supports the interactional model described by the double empathy problem (Milton, 2012).

Societal and Communal Stressors and Resources

Prevalent in the memoirs used in this study were the ways in which community and society either contributed to the authors' feelings of distress, or to their resiliency. This is reflected in the superordinate themes community and societal experiences contributing to distress and social and community factors contributing to resilience and growth. In the following section, I review neurodivergence as part of intersectionality of identity, the role of community acceptance and awareness regarding neurodiversity and autism, the mental health profession as it intersects with autism through professional training, assessing for trauma and trauma-sequelae, and definitions of traumatic experiences. Then, I review applicable findings regarding neurodiversity and intersectionality, and end with a proposed model for understanding the relationship between autistic and neurodivergent individuals and experiences of trauma and resiliency.

Neurodiversity and Intersectional Identity

Race. Prahlad was the only author to describe his race and ethnicity within his memoir and reflected on his experience as a Black and autistic man faced with both racial discrimination and ableism, or disability-discrimination. Similar to Prahlad's experience, Broder-Fingert et al. (2020) propose that structural racism leads Black, Indigenous, and autistic people of color to receive diagnoses later in life and encounter a higher number of barriers to receiving treatment services. Prahlad was diagnosed as an adult as were most of the other memoirists in this

dissertation—except for Kedar. Perhaps notably, the other memoirists do not identify their race nor ethnicity in their memoirs.

Gender. All the memoirists identify their gender in their writing, though only Prahlad and the two woman-identified memoirists connect their autistic identities to other identities. For example, one of the two woman-identified authors, O’Toole, depicts her experience specifically as an autistic woman, and connects it to her autism being overlooked and misunderstood. Additionally, both O’Toole and Williams were diagnosed in adulthood, which O’Toole connects to her gender, while Williams does not explicitly do so. Research literature has begun to address discrepancies between rates of diagnosis for women and assigned female at birth (AFAB) compared to higher rates of diagnoses for men and assigned male at birth (AMAB) individuals. For example, Hull et al. (2019) suggested that autistic AFAB individuals may be more likely to engage in “camouflaging” or masking, of their autistic-related traits and behaviors than autistic boys. In a related study, Bernardin et al. (2021) reported that both AFAB autistic and allistic adolescents reported higher levels of stress associated with camouflaging their differences when compared to AMAB participants.

Neurodiversity. As described in the review of the literature, neurodiversity refers to diversity of neurodevelopmental traits and types present in human beings (Paletta, 2013). In the face of social justice implications of traditional approaches to diagnosis and treatment of autism, mental health providers may be better able to support neurodivergent clients through exploration and understanding of inequities, discrimination, and bias, as well as privileges, related to their neurodivergence and other identities.

Taking a neurodiversity approach in conceptualizing may include a better understanding of the intersecting identities of autistic individuals. APA (2017) guidelines promote using

intersectionality to incorporate cultural, economic, structural, and social implications of the intersection of the many identities individuals hold, such as race, ethnicity, gender, socioeconomic status, and sexuality.

Some researchers propose that early studies that shaped the diagnostic criteria for autism spectrum disorder were highly homogenous in their samples, focusing mostly on white male participants in middle to upper socioeconomic groups (Durkin et al., 2017; Kreiser & White, 2014; Mandell et al., 2009). In my qualitative inquiry into the intersection of the memoirists' identities, four of the five memoirists were not formally assessed or diagnosed with autism until adulthood, and three of those four held identities that were different than those of majority of the samples in early research studies regarding autism. This may have been related to the memoirists' abilities to camouflage autistic traits, cognitive or academic strengths, access to resources which would have provided a diagnosis, and due to holding non-white or non-male racial and gender identities. Pursuing further research regarding the diagnostic criteria for autism as experienced by a diverse range of individuals could deepen our understanding of neurodivergence, and hopefully improve identification and support for more individuals and families through increasing understanding, acceptance, and access to adequate resources and supports.

Community Acceptance and Awareness of Neurodiversity

Lack of Acceptance and Awareness. The authors of the memoirs used in this study identified the distress felt in response to community and societal experiences, specifically to feeling different, being misdiagnosed and misunderstood, and in masking to fit societal expectations. Other qualitative studies identified similar themes, specifically that lack of understanding and acceptance in society was detrimental for autistic youth and their families (Lee et al., 2022). Additionally, chronic ostracism, or chronic social exclusion and rejection,

have been linked to feelings of helplessness and depression. Even brief episodes of ostracism can result in negative emotions and threaten one's sense of safety (Williams, 2007). Similar to the stress of exclusion described by the memoirists in my study, Kerns et al. (2022) conducted a qualitative exploration of childhood trauma in autistic adults and found social marginalization to be a potential source of trauma for their participants.

Acceptance and Community. The five memoirists each identified the importance of the acceptance and understanding of peers, mentors and professionals, through shared religious, and through a general sense of community and network of support. This coincides with research which found social inclusion and inclusive educational environments to promote wellbeing for autistic individuals (Seltzer et al., 2003; Taylor et al., 2012). In addition, Biggs and Carter (2016) found in their research that higher reported religious faith by the parents and caregivers of autistic adolescents and young adults correlated with higher reported well-being, defined as social support, engagement with peers, levels of autonomy, and parent relations. These findings dovetail with the accounts of my memoirists, many of whom described religious or spiritual faith as factors in their growth and resilience.

Professional Awareness and Training

The memoirists included in this dissertation also provided insight into how their resilience and growth was supported by understanding and accepting professionals and adults in their lives: teachers, professors, psychiatrists, and psychotherapists. In addition, they provided insight into their experiences with mental health and educational professionals that misunderstood them.

The negative impact of mental health professionals misdiagnosing or misunderstanding memoirists of this dissertation coincides with previous qualitative findings. Au-Yeung et al.

(2019) found their autistic and possibly autistic participants perceived their mental health diagnoses as both misdiagnosed and misunderstood by mental health professionals. Specifically, the participants of this study believed their autistic traits were misconstrued as mental health disorders or that their mental health concerns were a result of their autistic identity. Themes identified by participants included barriers to mental health treatment such as professionals' lack of awareness or training regarding autism, treatment which was not suited to their needs, and a breakdown in communication between healthcare professionals and autistic adults. Similarly, findings by Lipinski et al. (2022) suggest that autistic individuals face multiple barriers in seeking mental health services, despite the frequency of co-occurring mental health conditions, due to many psychotherapists' lack of training and education regarding the mental health comorbidities common for autistic individuals. For example, regarding misdiagnosis of autism spectrum, Fusar-Poli et al. (2022) found varying rates of missed diagnoses, or misdiagnoses, of adults due to overlap in symptoms as well as comorbid psychopathology. In their sample, they found that prior to being assessed for autism, the autistic individuals were diagnosed with psychotic disorders (16.1%), personality disorders (14.9%), depressive disorders (13.7%), obsessive-compulsive disorder (7.5%), anxiety disorders (7.5%), and attention-deficit (6.8%) and conduct disorders (7.5%). My study, in which most of the memoirists got diagnosed in adulthood, supports these data. There is an urgent need for further training and education of mental health professionals regarding the diverse presentations of autism and its overlap with mental health diagnoses.

Trauma- and Stressor-Related Disorders

Although, no memoirist identified a formal assessment or diagnosis of a trauma- or stress-related disorder by a mental health professional, they all described symptoms consistent

with traumatic exposure including, for example, hypervigilance and re-experiencing (APA, 2013). As cited in the literature review, current research is limited and reports various prevalence rates of PTSD in the autistic research participants (Hoover, 2015; Kerns et al., 2015; van Steensel et al., 2011). Three of the memoirists reported upwards of four ACEs, and two reported at least two. However, current methods of assessing and measuring traumatic events and sequelae may not be sufficient to provide accurate assessment of autistic individuals, due to differences in communication, professionals misunderstanding, and lack of representation of the range of potentially traumatic or adverse experiences in assessment and research on autistic and neurodivergent individuals and their subjective experiences.

It is important to underscore the subjective nature of trauma, as what is experienced as traumatic for some individuals will not have a lasting emotional impact on others. For example, one memoirist, Kedar, detailed what he referred to as PTSD following Applied Behavioral Analysis (ABA), a recommended childhood intervention intended to increase communication and social skills, and decrease behaviors that may be viewed as disruptive, and even harmful, to the individual and those around them using a rewards-based model.

There is currently little to no peer-reviewed research that aligns with Kedar's experience of ABA which remains a highly evidentiary-supported approach for early intervention. However, various autistic self-advocates and allies have published their personal accounts critical of ABA-interventions noting that the methods used to promote their conformity to neurotypical standards for behavior was experienced as traumatic and distressing (Kupferstein, 2018; Lynch, 2019; Ram, 2020). Leaf et al. (2021) recommends, based upon their investigation of these experiences, that practitioners and patients of ABA-based interventions consider the nuance of specific interventions in identifying potential strengths and harm in this form of intervention,

with the goal of improving intervention and the wellbeing of autistic individuals. Thus, the field of autism research is at a crossroads marked by sometimes disparate goals between researchers and neurodivergent self-advocates and allies, calling for examination of how professionals define and examine problems faced by individuals with neurodivergent, and other historically underrepresented and marginalized identities.

Expanding Understanding of Traumatic Experiences. The memoirs used in this dissertation highlighted potentially traumatic and adverse experiences beyond what has been identified to date by mental health professionals working on diagnostic changes and conducting research (APA, 2013; U.S. DHHS, 2021). For example, several memoirists wrote passionately about their intolerance of ambiguity and acute distress in the face of unknown, sudden changes, and unpredictability in a variety of contexts. In addition, they clearly delineated sensory processing difficulties leading to lasting emotional distress and physical pain. While previous research has looked at perceived and measured levels of stress, these qualitative findings provide additional information regarding how these experiences affected the memoirists subjectively, and over time.

My findings are consistent with previous research which found autistic individuals experienced higher levels of stress and cortisol when faced with environmental changes and changes to their routine and took longer to calm down than their neurotypical peers (Corbett et al., 2009; Gillon & Standen, 2007). Additionally, Gillon and Standon (2007) found that autistic adults reported higher levels of stress and anxiety when faced with aversive sensory stimuli. It is evident that common definitions of what constitutes a traumatic event fall short of capturing the lived experience of neurodivergent individuals. Therefore, expanding upon the research that accounts for the individual and subjective experiences of traumatic experiences, especially for

neurodivergent individuals, will provide further insight for clinical interventions and other needs to best support the resiliency and equity of neurodivergent individuals.

The Double Empathy Problem within a Sociocultural Framework

The double empathy problem introduced earlier in this discussion broadens a symptom-focused and individual view of autism. In this interactional model, we also consider the role of the perceptions and behaviors of neurotypical individuals, and their impact on social interactions with neurodivergent individuals (Milton, 2012).

The double empathy problem has developmental implications for neurodivergent and neurotypical individuals, both engaging in a cycle of misperceptions and behavior that leads to further separation and less understanding of neurodiversity in social connections (Mitchell et al., 2021). In addition to the interactional and interpersonal level, through the lens of intersectionality, these misunderstandings and misperceptions are sustained within a larger sociocultural context that has prioritized traditionally neurotypical-traits and behaviors and marginalized those with neurodivergent-behaviors and traits (see Appendix C). Thus, neurotypical individuals enter exchanges with neurodivergent individuals with bias and assumptions regarding perceived deviations from what is considered the norm. Societal level shifts, such as those proposed by proponents of neurodiversity and intersectionality may change the narrative regarding how we think about individual difference and neurodivergence, encouraging greater awareness and acceptance at community and societal levels.

Taken with the current literature, the results of my study support the double empathy model, as well as inclusion of a sociocultural model for the conceptualization of trauma and resilience experienced by autistic individuals, which considers an individual's identities, needs, and goals, the contexts and environments surrounding them, their relationships, and the culture

and society that they are in. Each level, the individual, contextual and environmental, interpersonal, and sociocultural interact with each other in dynamic and complex ways, impacting the developmental and psychological experiences of neurodivergent individuals regarding, adversity, trauma, resilience, and growth. Based on this proposed model for understanding trauma and resilience through a neurodiverse lens, in the following section I will review clinical implications at each level, as well as areas for future research.

Clinical Implications and Future Directions

Individuals' experiences of neurodivergence, including autism, are highly heterogeneous. The following clinical implications are provided based on the themes present for the five memoirists in my dissertation and supporting literature, and therefore may be assessed as to whether they are potentially applicable in individual cases. Based on the sociocultural model proposed above, the following implications are divided into individual and interpersonal interventions, and community-level interventions and advocacy. In addition, areas for future research are included at each level.

Individual and Interpersonal Interventions

Throughout the memoirs of this study, narratives included specific ideas of what each memoirist found supported their resilience and growth. For a couple of memoirists, this included individual psychotherapy with a psychotherapist that they perceived as understanding them, being open and supporting insight while guiding them through trauma-informed interventions. Existing research has investigated the efficacy of various psychotherapies as they support autistic individuals, tailoring adjustments to protocols for individuals.

For example, some researchers propose adaptations of trauma-focused cognitive behavioral therapy (TF-CBT) to use alternative modes of communication, using visual aids and

schedules, increased time and repetition, incorporation of interests, and teaching of socially appropriate behaviors (Peterson et al., 2019). Similarly, researchers have investigated adapted Dialectical and Behavioral Therapy (DBT) approaches for emotion regulation concerns, and Acceptance and Commitment Therapy (ACT) for intolerance of uncertainty (Garcia et al., 2022; Ritschel et al., 2022), both of which I detail further in the sections below. Potential areas to for further assessment regarding traumatic or adverse impacts to inform interventions, based on the accounts of the memoirists, includes psychoeducation for the individual and important others, the role and impact of camouflaging autistic-related traits, emotion regulation including high anxiety in the face of uncertainty, self-compassion and self-esteem, and the role of heightened sensory processing.

Psychoeducation and Advocacy. Based on the themes identified in my dissertation, lack of understanding and acceptance between memoirists and their neurotypical family members, peers, and others was often a source of distress leading to negative emotions and lower self-esteem. This is captured as well by Milton's proposed double empathy model, which proposes that empathic failure on the part of neurotypical individuals contributes to difficulties forming connections between neurotypical and neurodivergent. If growing and fostering close relationships is a goal for autistic clients when presenting for psychotherapy, supporting them in articulating their desires for connections and their ways of seeking these connections may be essential. This may include psychoeducation regarding the double empathy problem and neurodiversity, and how that can impact relationships. In addition, psychoeducation regarding neurodiversity for professionals, partners, families, friends, and those close to the neurodivergent client, could reduce the instances of misunderstandings and relational traumas, and promote open communication regarding perceptions and misperceptions.

In addition to providing psychoeducation, clinicians could also play a key role in advocating for needed support and accommodations for autistic clients. Through psychological assessment and clinical work, clinicians can work to support autistic clients in identifying areas of need and recommending professional resources to meet those needs. From educational settings, healthcare, workplaces, and beyond, a clinician can apply their professional knowledge of their client's mental health needs to support them in pursuing empowerment, equity, and other personal goals, through advocating for, and connecting clients to, accommodations and supports.

Camouflaging. Fear of rejection, ostracism, and harm were often at the root of the autistic memoirists' efforts to mask or camouflage their differences from neurotypical others. Advocating for people and communities to increase their tolerance, and acceptance, of autistic and neurodivergent experiences could support the resiliency, mental health, and wellbeing of neurodivergent individuals. Through this increase in acceptance and tolerance, ideally autistic individuals would be less likely to face discrimination, victimization, negative assumptions, and misunderstandings based on their neurodivergence, reducing their exposure to potentially traumatic interpersonal experiences. Additionally, this would allow both neurotypical individuals and communities to grow through embracing new ideas, concepts, and so on, beyond the limits of narrowly defined "neurotypical" ways of being. Clinicians can promote this in their own self-reflection of biases based on neurotypical assumptions, as well as encourage trainees and other professionals to do the same. They can also work with individuals and groups to provide psychoeducation and encourage tolerance and acceptance in various workplaces, communities, and professional fields.

At the individual level, to support neurodivergent individuals in navigating spaces that are not tolerant, accepting, or safe, clinicians may provide space to process and identify

relationships in which they employ camouflaging. They may want to consider their current relationships and identify those in their life who are safe to engage with in authentic and meaningful ways. While this may include helping individuals to reflect on their current relationships, it could also include pursuing support groups or group therapy particularly for autistic and/or neurodivergent people or finding supportive online and in-person communities.

Emotion Regulation. The results of this dissertation—and other supporting research—highlights the potential for collaborating with autistic individuals who have experienced traumatic events to explore their use of emotion regulation strategies, investigate the efficacy of these strategies, build upon those that are effective, and identify new adaptive emotion regulation strategies. Both early childhood traumatic experiences and autism are linked to future problems with emotion dysregulation; thus, identifying effective means for supporting emotion dysregulation for autistic individuals who have experienced traumatic events may be central to their healing. One evidence-based strategy is Dialectical Behavioral Therapy skills training (DBT-ST) group therapy specifically designed for autistic adults experiencing emotional and behavioral dysregulation. Ritschel et al. (2022) found it to be a good fit for their preliminary study participants based on clinical impressions, retention and attendance rates, and strong satisfaction ratings by the participants. They also propose various adaptations to better suit the learning styles and needs of their participants, such as use of visual and tactile activities for abstract concepts, incorporating participants' special interests, and systematic structures for groups providing written schedules to reduce uncertainty about what happens next.

In addition, the memoirists in this dissertation all found evidence-supported methods to tolerate and regulate overwhelming emotions on their own including: mental distraction, meditation and breathing practices, physical exercise, using sensory input through other sources

of physical stimulation, and using comforting objects (Mazefsky et al., 2014). Effective interventions may help autistic clients to identify and build upon their already established methods of coping, examine the efficacy of current methods, and experiment with new ones.

Anxiety Management and Distress Tolerance. A common theme related to the memoirists' experiences of emotional dysregulation included high levels and frequent experiences of anxiety and distress. Difficulties with uncertainty and ambiguity often appeared to be the internal process related to the observable behaviors such as need for routine, repetition, and special interests. In fact, a couple of memoirists directly call on researchers and professionals to explore anxiety and its intersection with autism. Intervening with autistic individuals presenting with concerns regarding anxiety may benefit from interventions that explore the ways in which they have learned to cope with anxiety thus far, assessing their short- and long-term effectiveness, and collaborating to find ways to empower autistic individuals to navigate uncertainty, as well as help advocate for needed routine and predictability.

Self-Compassion. In addition to support with emotion and anxiety regulation, findings of this study and applicable research findings point to the importance of supporting self-understanding and self-compassion for autistic individuals who have experienced traumatic or adverse life events. Increasing self-understanding may include reviewing with autistic individuals the neurodiversity paradigm and supporting them in naming and understanding their various strengths and areas for growth. In addition, this may also include identifying the messages or standards that individuals have internalized based on cultural and neurotypical expectations, and the emotional impacts of these messages. Thus, through greater self-knowledge and understanding, one can be supported in taking a compassionate and kind approach to themselves. The existing literature proposes ACT-based interventions when working with

autistic individuals, specifically interventions focused on increasing self-compassion, though the efficacy of these interventions, specifically with autistic individuals exposed to trauma and adversity, warrants further investigation (Garcia et al., 2022).

Sensory Processing. Sensory over-responsiveness, or sensory overwhelm as some of the memoirists of my study refer to it, has been linked to increased anxiety and negative impacts on executive and cognitive function. Thus, clinicians should consider working with professionals trained in assessing and addressing sensory-based needs, such as occupational therapists. In addition, in collaboration with such professionals, clinicians may include in their conceptualizations of autistic patients how their experiences of trauma may intersect with sensory processing. If sensory processing is identified as an area of need, therapists do well to collaborate with occupational therapists and other experts, and of course, the autistic individuals, to support strategies and adaptations to manage sensory processing difficulties.

In addition to feeling overwhelmed by sensory input, the memoirists of this dissertation also described how certain sensory-seeking behavior, referred to as stimming, helped them to cope with difficult emotions, focus, and remain present—an observation that has been supported by preliminary neurobiological research (McCarty & Brumback, 2021). Therefore, for many autistic individuals, interventions that extinguish these behaviors, without providing effective alternatives for supporting emotion regulation and sensory needs, may prove more harmful than beneficial.

Additionally, clinicians meeting with clients in person could collaborate with occupational therapists, their clients, and their clients' treatment teams to consider how sensory needs may be supported or hindered in the therapeutic or assessment setting. Therapists may need to make environmental adjustments: changing lighting and seating arrangements, avoiding

strong scents, providing tactile methods of self-regulation, such as fidget-friendly objects, and being open to incorporating nature or music into their practices when feasible. Further, supporting autistic clients in identifying and understanding their sensory needs, and use of coping mechanisms, including their use of stimming and need for accommodations or supportive technology, may promote their personal growth and autonomy.

Individual and Interpersonal Implications for Future Research. All in all, adaptations for evidence-based and trauma-focused approaches specifically for autistic individuals are in the beginning stages of empirical investigation, though the narratives in this dissertation seem to align with their proposed mechanisms of change (Garcia et al., 2022; Peterson et al., 2019; Ritschel et al., 2022). Further qualitative accounts, and quantitative inquiries, into the experience of autistic individuals in psychotherapy and therapeutic outcomes is certainly warranted. This may illuminate further what autistic and neurodivergent clients are asking for and needing in psychotherapy, as well as highlight which adaptations are effective and with whom.

Additionally, future research might explore more effective methods of assessing co-occurring disorders, including trauma and other mental disorders for neurodivergent and autistic individuals. As identified in several of the memoirs used in this research, when memoirists sought help for their experiences, their unidentified autism led to misunderstanding and misdiagnoses. It is likely that autistic and traumatized individuals are underserved due to lack of training or awareness, or due to failures to appropriately adapt methods for assessing and screening for psychopathology.

Community-Level Intervention and Advocacy

The results of this dissertation also indicate the importance of society and

community-levels of intervention to support the inclusion and resiliency of neurodivergent individuals. As psychologists and mental health professionals our role includes the pursuit of social justice; we do well to be part of the neurodiversity movement advocating for equity and inclusion. From this approach, there are multiple systems-level interventions that could promote neurodiversity and the wellbeing of autistic individuals both within the field of mental health, and beyond. Clinical implications include further push for professional specialization as well as general training for mental health professionals regarding autism and neurodivergence, further research and adaptations of assessment practices, adoption of the reframed optimal outcome model, and advocacy at the local and national level. Each of these implications are detailed below, as well as the areas for future research that they bring up.

Professional Specialization and Training. Increasing the number of mental health professionals who are trained in neurodivergence, autism, and how it intersects with psychopathology would allow overall for more availability and confidence in working with neurodivergent clients. This would require potential changes in training programs to include information regarding neurodiversity, availability for supervised experiences, and professional development training—all of which require time and resources. Thus, advocating for the allotment of resources would be central to supporting such initiatives.

Additionally, growing the number of specialized providers and enhancing knowledge to pass along in training and educational-settings will require further research into neurodivergent experiences related to trauma and trauma-related sequelae. Specifically, incorporating more knowledge held by autistic individuals regarding their needs and wants, and focusing on the areas of needs identified by autistic self-advocates and allies, could provide even greater insight

into how, as psychologists and mental health professionals, we can improve our skill set to become more effective and accessible in our work.

Accessibility. While one potential barrier to receiving adequate treatment for autistic and neurodivergent individuals may be the limited number of professionals trained in the areas of concern they are looking for, other environmental barriers could also be reduced to ease access of needed services. One such way to improve accessibility and offer welcome to mental health services may include adapting offices to make them more hospitable to sensory overstimulation—keeping a neutral smell and avoiding scented products in therapeutic spaces, providing fidget-devices or objects to be used for tactile experiences, and considering potential noises, distractions, and lighting as they might be experienced by a neurodivergent client.

Assessment. We do not have standardized measures which assess for a broader range of trauma and traumatic stress in neurodivergent individuals. Such protocols would be more inclusive of events that are traumatic for neurodivergent children and adults. Adaptations for diverse methods of communication would also offer services to autistic individuals who are nonverbal or have idiosyncratic strategies. For example, one recently proposed measure, the Interactive Trauma Scale, uses touch screen, graphics, and an interactive assessment, to assess self-report of traumatic experiences and sequelae, including peer victimization, in autistic individuals responsive to written or spoken English (Hoover & Romero, 2019). The preliminary study of this measure found it may be an accessible and effective assessment tool.

Optimal Outcome. To account for the heterogeneity and complexity of individual experiences, in autism and neurodivergence, assessment, intervention, and the provision of services should shift toward the optimal outcome paradigm (Georgiades & Kasari 2018). This collaborative approach is person-centered and removes neurotypical assumptions of what

“optimal” looks like, allowing individuals and families to identify their goals and measure their progress based on a case-by-case basis.

Advocacy. Whether in schools, universities, workplaces, or community settings, clinicians can engage in advocacy activities, pushing for systemic changes to support the mental wellbeing of autistic and neurodivergent individuals. For example, university research on autism could be conducted collaboratively and include autistic participants and self-advocates. Activities that promote general awareness and understanding of neurodiversity may also help to reduce negative bias and assumptions regarding neurodivergence. Through training and community education, we can help involved individuals to reflect on their assumptions and biases regarding neurodiversity and autism, considering how to modify or change inequitable systems that prioritize neurotypical approaches.

Community-Level Implications for Future Research. Further research regarding effective assessment of trauma and trauma-related sequelae for autistic individuals is warranted. In addition, research regarding narrative and qualitative experiences of autistic individuals will provide greater depth of knowledge into areas in need of further research, intervention, and advocacy. To support the resiliency and growth of autistic and neurodivergent individuals, we as professionals and as a society should start by listening and uplifting the voices that are already advocating for change, equity, and equality. Once such way, is through the widespread adoption of the optimal outcome model.

Limitations

This dissertation used published memoirs, and therefore may represent a homogenous sample of those with aptitude, access to resources, and determination to write and publish a memoir. Additionally, this study is built entirely on the experiences of these individuals who

have developed a coherent life narrative and have chosen to share their life stories publicly, perhaps distinguishing their voices further. In any event, as a qualitative study, the results are not generalizable to a wider swath of autistic individuals.

A second limitation resulted from the way in which the data were gathered. This study relied on authors who chose to publish their memoirs and not a sample of autistic individuals recruited to discuss their traumatic exposure. Thus, I could not capture a structured set of responses to specific questions about trauma, adversity, resiliency, and growth as they intersect with neurodivergence. While there were differences in themes among memoirs, I have no method to examine responses more closely nor inquire further about discrepancies within and between accounts.

While I worked to reflect on and identify my personal biases throughout this dissertation, my own subjectivity remains a part of the research process, inherent to IPA, as I determined what was worth noting and identified the emergent and superordinate themes. Despite these limitations, the results offer insights into the unique perspectives of the memoirists and their experiences related to autism, trauma, and resilience. Some findings were consistent with the existing literature and offered a richer understanding of the impact of traumatic exposure on development and growth for autistic adults.

Conclusion

In this study, I sought to better understand the firsthand perspectives of five autistic memoirists as they detailed their lives, both the traumas and adversities they faced as well as their growth and resilience through it all. Through qualitative analysis, I identified themes in their memoirs relating to traumas and supports at the individual, interpersonal, and community levels. Some themes were unique to individual memoirists, while other themes were shared

across many or all five. This analytic strategy provided a rich narrative of the complexity of trauma and resilience intersecting with neurodivergent identities.

Through this process, I found my own perspective of what is considered “typical”—or not—shifting with each memoir. I believe my own ability to empathize and remain curious about a wider range of experiences grew from reading each differing perspective. As Jennifer O’Toole (2018) wrote, she learned “to notice how much certainty I attributed to my perspectives of other people’s perspectives and motivations... even though, I started to realize, I was wrong about them as often as they were wrong about me” (p. 200). I hope to continue to grow and build upon this mindset, throughout my future professional, and personal, endeavors. Beyond its personal impact on me as the researcher, it has broader implications as well. This study highlights the need for further research into the heterogeneity of the autistic psychological experience. It suggests a need for further firsthand accounts to connect research and researchers with the knowledge already held by many individuals regarding themselves.

References

- American Psychiatric Association. (1952). *Diagnostic and statistical manual: Mental disorders* (1st ed.). American Psychiatric Publishing, Inc.
- American Psychiatric Association. (1980). *Diagnostic and Statistical Manual* (3rd ed.). APA Press.
- American Psychiatric Association. (1987). *Diagnostic and statistical manual of mental disorders* (3rd ed., rev.). American Psychiatric Publishing, Inc.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). American Psychiatric Publishing, Inc.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Publishing, Inc.
<https://doi.org/10.1176/appi.books.9780890425596>
- American Psychological Association. (2021). *Inclusive language guidelines*.
<https://www.apa.org/about/apa/equity-diversity-inclusion/language-guidelines.pdf>
- American Psychological Association. (2017). Multicultural guidelines: An ecological approach to context, identity, and intersectionality, 2017.
<http://www.apa.org/about/policy/multicultural-guidelines.pdf>
- American Psychological Association. (2020). *Publication manual of the American Psychological Association: The official guide to APA style* (7th ed.). American Psychological Association.
- Asperger, H. (1991). 'Autistic psychopathy' in childhood (U. Frith, Trans.). In U. Frith (Ed.), *Autism and Asperger Syndrome* (pp. 37–92). Cambridge University Press. (Original work published in 1944) <https://doi.org/10.1017/CBO9780511526770.002>
- Au-Yeung, S. K., Bradley, L., Robertson, A. E., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults. *Autism: The International Journal of Research and Practice*, 23(6), 1508–1518. <https://doi.org/10.1177/1362361318818167>
- Barahona-Corrêa, J. B., & Filipe, C. N. (2016). A concise history of Asperger syndrome: The short reign of a troublesome diagnosis. *Frontiers in Psychology*, 6, 2024.
<https://doi.org/10.3389/fpsyg.2015.02024>
- Baxter, A. J., Brugha, T. S., Erskine, H. E., Scheurer, R. W., Vos, T., & Scott, J. G. (2015). The epidemiology and global burden of autism spectrum disorders. *Psychological Medicine*, 45(3), 601–613. <https://doi.org/10.1017/S003329171400172X>

- Benzies, K., & Mychasiuk, R. (2009). Fostering family resiliency: A review of the key protective factors. *Child & Family Social Work, 14*(1), 103–114. <https://doi.org/10.1111/j.1365-2206.2008.00586.x>
- Berg, K. L., Shiu, C. S., Acharya, K., Stolbach, B. C., & Msall, M. E. (2016). Disparities in adversity among children with autism spectrum disorder: A population-based study. *Developmental Medicine and Child Neurology, 58*(11), 1124–1131. <https://doi.org/10.1111/dmcn.13161>
- Bernardin, C. J., Lewis, T., Bell, D., & Kanne, S. (2021). Associations between social camouflaging and internalizing symptoms in autistic and non-autistic adolescents. *Autism: The International Journal of Research and Practice, 25*(6), 1580–1591. <https://doi.org/10.1177/1362361321997284>
- Bettmann, J. E., Prince, K. C., Ganesh, K., Rugo, K. F., Bryan, A. B. O., Bryan, C. J., Rozek, D. C., & Leifker, F. R. (2021). The effect of time outdoors on veterans receiving treatment for PTSD. *Journal of Clinical Psychology, 77*(9), 2041–2056. <https://doi.org/10.1002/jclp.23139>
- Biggs, E. E., & Carter, E. W. (2016). Quality of life for transition-age youth with autism or intellectual disability. *Journal of Autism and Developmental Disorders, 46*(1), 190–204. <https://doi.org/10.1007/s10803-015-2563-x>
- Bleuler, E. (1934). *Textbook of psychiatry* (A. Brill, Trans.). The Macmillan Company. (Original work published 1924)
- Broder-Fingert, S., Mateo, C. M., & Zuckerman, K. E. (2020). Structural racism and autism. *Pediatrics, 146*(3). <https://doi.org/10.1542/peds.2020-015420>
- Brown, L. (2011). Identity first language. Autistic Self Advocacy Network (ASAN). <https://autisticadvocacy.org/about-asan/identity-first-language/>
- Cage, E., & Troxell-Whitman, Z. (2019). Understanding the reasons, contexts and costs of camouflaging for autistic adults. *Journal of Autism and Developmental Disorders, 49*(5), 1899–1911. <https://doi.org/10.1007/s10803-018-03878-x>
- Cai, R. Y., Gibbs, V., Love, A., Robinson, A., Fung, L., & Brown, L. (2022). “Self-compassion changed my life”: The self-compassion experiences of autistic and non-autistic adults and its relationship with mental health and psychological wellbeing. *Journal of Autism and Developmental Disorders, 53*(3), 1066–1081. <https://doi.org/10.1007/s10803-022-05668-y>
- Calhoun, L. G., & Tedeschi, R. G. (2006). The foundations of posttraumatic growth: An expanded framework. In L. G. Calhoun & R. G. Tedeschi (Eds.), *Handbook of posttraumatic growth* (pp. 3–23). Lawrence Erlbaum Associates.

- Cappadocia, M. C., Weiss, J. A., & Pepler, D. (2012). Bullying experiences among children and youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42(2), 266–277. <https://doi.org/10.1007/s10803-011-1241-x>
- Carleton, R. N., Mulvogue, M. K., Thibodeau, M. A., McCabe, R. E., Antony, M. M., & Asmundson, G. J. G. (2012). Increasingly certain about uncertainty: Intolerance of uncertainty across anxiety and depression. *Journal of Anxiety Disorders*, 26(3), 468–479. <https://doi.org/10.1016/j.janxdis.2012.01.011>
- Conner, C. M., White, S. W., Scahill, L., & Mazefsky, C. A. (2020). The role of emotion regulation and core autism symptoms in the experience of anxiety in autism. *Autism: The International Journal of Research and Practice*, 24(4), 931–940. <https://doi.org/10.1177/1362361320904217>
- Conroy, K., Sandel, M., & Zuckerman, B. (2010). Poverty grown up: How childhood socioeconomic status impacts adult health. *Journal of Developmental & Behavioral Pediatrics*, 31(2), 154–160. <https://doi.org/10.1097/DBP.0b013e3181c21a1b>
- Cooper, K., Smith, L. G. E., & Russell, A. J. (2018). Gender identity in autism: Sex differences in social affiliation with gender groups. *Journal of Autism and Developmental Disorders*, 48(12), 3995–4006. <https://doi.org/10.1007/s10803-018-3590-1>
- Corbett, B. A., Schupp, C. W., Levine, S., & Mendoza, S. (2009). Comparing cortisol, stress, and sensory sensitivity in children with autism. *Autism Research*, 2(1), 39–49. <https://doi.org/10.1002/aur.64>
- Courtois, C. A., & Ford, J. D. (2009). *Treating complex traumatic stress disorders: An evidence-based guide*. Guilford Press.
- Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry & research design*. SAGE Publications, Inc.
- Cronholm, P. F., Forke, C. M., Wade, R., Bair-Merritt, M. H., Davis, M., Harkins-Schwarz, M., Pachter, L. M., & Fein, J. A. (2015). Adverse childhood experiences: Expanding the concept of adversity. *American Journal of Preventive Medicine*, 49(3), 354–361. <https://doi.org/10.1016/j.amepre.2015.02.001>
- de Bruin, E. I., Ferdinand, R. F., Meester, S., de Nijs, P. F., & Verheij, F. (2007). High rates of psychiatric co-morbidity in PDD-NOS. *Journal of Autism and Developmental Disorders*, 37, 877–886. <https://doi.org/10.1007/s10803-006-0215-x>
- De Vries, D., Beck, T., Bethany, S., Winslow, K., & Meines, K. (2015). Music as a therapeutic intervention with autism: A systematic review of the literature. *Therapeutic Recreation Journal*, 49(3), 220–237. <https://doi.org/10.1007/s10803-006-0215-x>

- Delobel-Ayoub, M., Ehlinger, V., Klapouszczak, D., Maffre, T., Raynaud, J.-P., Delpierre, C., & Arnaud, C. (2015). Socioeconomic disparities and prevalence of autism spectrum disorders and intellectual disability. *Plos One*, *10*(10), 1–13. <https://doi.org/10.1371/journal.pone.0141964>
- Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators, & Centers for Disease Control and Prevention (CDC). (2014). Prevalence of autism spectrum disorder among children aged 8 years- autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report. Surveillance Summaries* (Washington, D.C.: 2002), *63*(2), 1–21.
- Dewinter, J., Van Parys, H., Vermeiren, R., & Van Nieuwenhuizen, C. (2017). Adolescent boys with an autism spectrum disorder and their experience of sexuality: An interpretative phenomenological analysis. *Autism*, *21*(1), 75–82. <https://doi.org/10.1177/1362361315627134>
- Dickerson, A. S., Rahbar, M. H., Pearson, D. A., Kirby, R. S., Bakian, A. V., Bilder, D. A., Harrington, R. A., Pettygrove, P., Zahorondny, W. M., Moye, L. A., III, Durkin, M., & Slay Wingate, M. (2017). Autism spectrum disorder reporting in lower socioeconomic neighborhoods. *Autism: The International Journal of Research and Practice*, *21*(4), 470–480. <https://doi.org/10.1177/1362361316650091>
- Dong, M., Anda, R. F., Felitti, V. J., Dube, S. R., Williamson, D. F., Thompson, T. J., Loo, C. M., & Giles, W. H. (2004). The interrelatedness of multiple forms of childhood abuse, neglect, and household dysfunction. *Childhood Abuse & Neglect*, *28*(7), 771–784. <https://doi.org/10.1016/j.chiabu.2004.01.008>
- Dube, S. R., Anda, R. F., Felitti, V. J., Chapman, D. P., Williamson, D. F., & Giles, W. H. (2001). Childhood abuse, household dysfunction, and the risk of attempted suicide throughout the life span: Findings from the adverse childhood experiences study. *The Journal of the American Medical Association*, *286*(24), 3089–3096. <https://doi.org/10.1001/jama.286.24.3089>
- Duchin, A., & Wiseman, H. (2019). Memoirs of child survivors of the Holocaust: Processing and healing of trauma through writing. *Qualitative Psychology*, *6*(3), 280–296. <https://doi.org/10.1037/qup0000128>
- Dunn, D.S., & Andrews, E. E. (2015). Person-first and identity-first language: Developing psychologists' cultural competence using disability language. *The American Psychologist*, *70*(3), 255–264. <https://doi.org/10.1037/a0038636>
- Durkin, M. S., Maenner, M. J., Baio, J., Christensen, D., Daniels, J., Fitzgerald, R., Imm, P., Lee, L., Schieve, L. A., Van Naarden Braun, K., Wingate, M. S., & Yeargin-Allsopp, M. (2017). Autism spectrum disorder among US children (2002–2010): Socioeconomic, racial, and ethnic disparities. *American Journal of Public Health*, *107*(11), 1818–1826. <https://doi.org/10.2105/AJPH.2017.304032>

- Dyches, T. T., Wilder, L. K., Sudweeks, R. R., Obiakor, F. E., & Algozzine, B. (2004). Multicultural issues in autism. *Journal of Autism and Developmental Disorders*, *34*(2), 211–222. <https://doi.org/10.1023/B:JADD.0000022611.80478.73>
- Felitti, V. J., Anda, R. F., Nordenberg, D., Williamson, D. F., Spitz, A. M., Edwards, V., Koss, M. P., & Marks, J. S. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. *American Journal of Preventive Medicine*, *14*(4), 245–258. [https://doi.org/10.1016/S0749-3797\(98\)00017-8](https://doi.org/10.1016/S0749-3797(98)00017-8)
- Fenton, A., & Krahn, T. (2007). Autism, neurodiversity, and equality beyond the “normal.” *Journal of Ethics and Mental Health*, *2*(2), 1–6.
- Finklehor, D., Shattuck, A., Turner, H., & Hamby, S. (2015). A revised inventory of Adverse Childhood Experiences. *Childhood Abuse & Neglect*, *48*, 13–21. <https://doi.org/10.1016/j.chiabu.2015.07.011>
- Fusar-Poli, L., Brondino, N., Politi, P., & Aguglia, E. (2022). Missed diagnoses and misdiagnoses of adults with autism spectrum disorder. *European Archives of Psychiatry and Clinical Neuroscience*, *272*(2), 187–198. <https://doi.org/10.1007/s00406-020-01189-w>
- Garcia, Y., Keller-Collins, A., Andrews, M., Kurumiya, Y., Imlay, K., Umphrey, B., & Foster, E. (2022). Systematic review of acceptance and commitment therapy in individuals with neurodevelopmental disorders, caregivers, and staff. *Behavior Modification*, *46*(5), 1236–1274. <https://doi.org/10.1177/01454455211027301>
- Garnefski, N., Kraaij, V., & van Etten, M. (2005). Specificity of relations between adolescents' cognitive emotion regulation strategies and internalizing and externalizing psychopathology. *Journal of Adolescence*, *28*(5), 619–631. <https://doi.org/10.1016/j.adolescence.2004.12.009>
- Gengoux, G. (2013). Infantile autism. In F. R. Volkmar (Ed.), *Encyclopedia of autism spectrum disorders*. Springer. https://doi.org/10.1007/978-1-4419-1698-3_100717
- Georgiades, S., & Kasari, C. (2018). Reframing optimal outcomes in autism. *JAMA Pediatrics*, *172*(8), 716–717. <https://doi.org/10.1001/jamapediatrics.2018.1016>
- Gernsbacher, M. A. (2017). Editorial perspective: The use of person-first language in scholarly writing may accentuate stigma. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, *58*(7), 859–861. <https://doi.org/10.1111/jcpp.12706>
- Gillott, A., & Standen, P. (2007). Levels of anxiety and sources of stress in adults with autism. *Journal of Intellectual Disabilities*, *11*(4), 359–370. <https://doi.org/10.1177/1744629507083585>

- Giourou, E., Skokou, M., Andrew, S. P., Alexopoulou, K., Gourzis, P., & Jelastopulu, E. (2018). Complex posttraumatic stress disorder: The need to consolidate a distinct clinical syndrome or to reevaluate features of psychiatric disorders following interpersonal trauma? *World Journal of Psychiatry*, 8(1), 12–19. <https://doi.org/10.5498/wjp.v8.i1.12>
- Greydanus, D. E., & Toledo-Pereyra, L. H. (2012). Historical perspectives on autism: Its past record of discovery and its present state of solipsism, skepticism, and sorrowful suspicion. *The Pediatric Clinics of North America*, 59(1), 1–11. <https://doi.org/10.1016/j.pcl.2011.10.004>
- Gross, J. J. (1998). The emerging field of emotion regulation: An integrative review. *Review of General Psychology*, 2(3), 271–299. <https://doi.org/10.1037/1089-2680.2.3.271>
- Habermas, T., & Bluck, S. (2000). Getting a life: The emergence of the life story in adolescence. *Psychological Bulletin*, 126(5), 748–769. <https://doi.org/10.1037/0033-2909.126.5.748>
- Harding, S., Power, M., & Quayle, E. (2014). *Interpretative phenomenological analysis of the experiences of autism and perceptions of parenting in parents with a child with autism* [Doctoral Dissertation, University of Edinburgh]. ETDs: Edinburgh Research Archives. <http://hdl.handle.net/1842/9880>
- Hartley, S. L., Barker, E. T., Seltzer, M. M., Floyd, F., Greenberg, J., Orsmond, G., & Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, 24(4), 449–457. <https://doi.org/10.1037/a0019847>
- Henwood, K. L., & Pidgeon, N. F. (1992). Qualitative research and psychological theorizing. *British Journal of Psychology*, 83(1), 97–111. <https://doi.org/10.1111/j.2044-8295.1992.tb02426.x>
- Herman, J. L. (1992). Complex PTSD: A syndrome in survivors of prolonged and repeated trauma. *Journal of Traumatic Stress*, 5(3), 377–391. <https://doi.org/10.1002/jts.2490050305>
- Hill, E. L. (2004). Executive dysfunction in autism. *Trends in Cognitive Sciences*, 8, 26–32. <https://doi.org/10.1016/j.tics.2003.11.003>
- Hoover, D. W. (2015). The effects of psychological trauma on children with autism spectrum disorders: A research review. *Review Journal of Autism and Developmental Disorders*, 2, 287–299. <https://doi.org/10.1007/s40489-015-0052-y>
- Hoover, D. W., & Romero, E. M. G. (2019). The interactive trauma scale: A web-based measure for children with autism. *Journal of Autism and Developmental Disorders*, 49(4), 1686–1692. <https://doi.org/10.1007/s10803-018-03864-3>
- Hudson, W. (2019). Asperger's syndrome, autism, and camouflaging: Reduced empathy revisited. *Interactions*, 26(2), 55–59. <https://doi.org/10.1145/3305356>

- Hughes, C., Russell, J., & Robbins, T. (1994). Evidence for executive dysfunction in autism. *Neuropsychologia*, *32*(4), 477–492. [https://doi.org/10.1016/0028-3932\(94\)90092-2](https://doi.org/10.1016/0028-3932(94)90092-2)
- Hull, L., Petrides, K. V., Mandy, W., Lai, M.-C., Baron-Cohen, S., Allison, C., & Smith, P. (2019). Gender differences in self-reported camouflaging in autistic and non-autistic adults. *Autism*, *24*(2), 352–363. <https://doi.org/10.1177/1362361319864804>
- Huws, J. C., & Jones, R. S. P. (2008). Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism. *Journal of Intellectual & Developmental Disability*, *33*(2), 99–107. <https://doi.org/10.1080/13668250802010394>
- Jenkinson, R., Milne, E., & Thompson, A. (2020). The relationship between intolerance of uncertainty and anxiety in autism: A systematic literature review and meta-analysis. *Autism*, *24*(8), 1933–1944. <https://doi.org/10.1177/1362361320932437>
- Jones, S. (2020, May 19). How the loss of Asperger Syndrome has lasting repercussions. *Spectrum News*. <https://www.spectrumnews.org/opinion/viewpoint/how-the-loss-of-asperger-syndrome-has-lasting-repercussions/>
- Josselson, R. (2008). *Reflections of a narrative researcher*. In J. A. Belzen & A. Geels (Eds.), *Autobiography and the psychological study of religious lives* (pp. 369–375). *International Series in the Psychology of Religion*. https://doi.org/10.1163/9789042029125_015
- Jowett, S., Karatzias, T., Shevlin, M., & Albert, I. (2020). Differentiating symptoms profiles of ICD-11 PTSD, Complex PTSD, and Borderline Personality Disorder: A latent class analysis in a multiply traumatized sample. *Personality Disorders: Theory, Research, and Treatment*, *11*(1), 36–45. <https://doi.org/10.1037/per0000346>
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, *2*, 217–250.
- Kapp, L., & Brown, O. (2011). Resilience in families adapting to autism spectrum disorder. *Journal of Psychology in Africa*, *21*(3), 459–463. <https://doi.org/10.1080/14330237.2011.10820482>
- Kedar, I. (2012). *Ido in Autismland: Climbing out of Autism's silent prison*. (n.p.)
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, *20*(4), 442–462. <https://doi.org/10.1177/1362361315588200>
- Kerns, C. M., Lankenau, S., Shattuck, P. T., Robins, D. L., Newschaffer, C. J., & Berkowitz, S. J. (2022). Exploring potential sources of childhood trauma: A qualitative study with autistic adults and caregivers. *Autism*, *26*(8), 1987–1998. <https://doi.org/10.1177/13623613211070637>

- Kerns, C. M., Newschaffer, C. J., & Berkowitz, S. J. (2015). Traumatic childhood events and autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 45(11), 3475–3486. <https://doi.org/10.1007/s10803-015-2392-y>
- Kerns, C. M., Newschaffer, C. J., Berkowitz, S. J., & Lee, B. K. (2017). Brief report: Examining the association of autism and adverse childhood experiences in the National Survey of Children's Health: The important role of income and cooccurring mental health conditions. *Journal of Autism and Developmental Disorders*, 47, 2275–2281. <https://doi.org/10.1007/s10803-017-3111-7>
- Klin, A., Pauls, D., Schultz, R., & Volkmar, F. (2005). Three diagnostic approaches to Asperger syndrome: Implications for research. *Journal of Autism and Developmental Disorders*, 35(2), 221–234. <https://doi.org/10.1007/s10803-004-2001-y>
- Kreiser, N. L., & White, S. W. (2014). ASD in females: Are we overstating the gender difference in diagnosis? *Clinical Child and Family Psychology Review*, 17(1), 67–84. <https://doi.org/10.1007/s10567-013-0148-9>
- Kupferstein, H. (2018). Evidence of increased PTSD symptoms in autistics exposed to applied behavioral analysis. *Advances in Autism*, 4(1), 19–29. <https://doi.org/10.1108/AIA-08-2017-0016>
- Lai, M. C., & Szatmari, P. (2019). Resilience in autism: Research and practice prospects. *Autism: The International Journal of Research and Practice*, 23(3), 539–541. <https://doi.org/10.1177/1362361319842964>
- Lai, M. C., Lombardo, M. V., Pasco, G., Ruigrok, A. N., Wheelwright, S. J., Sadek, S. A., Chakrabarti, B., MRC AIMS Consortium, & Baron-Cohen, S. (2011). A behavioral comparison of male and female adults with high functioning Autism Spectrum conditions. *Plos One*, 6(6), 20835. <https://doi.org/10.1371/journal.pone.0020835>
- Leaf, J. B., Cihon, J. H., Leaf, R., McEachin, J., Liu, N., Russell, N., Unumb, L., Shapiro, S., & Khosrowshahi, D. (2021). Concerns about aba-based intervention: An evaluation and recommendations. *Journal of Autism and Developmental Disorders*, 52(6), 2838–2853. <https://doi.org/10.1007/s10803-021-05137-y>
- Lee, G. K., Curtiss, S. L., Kuo, H. J., Chun, J., Lee, H., & Nimako, D. D. (2022). The role of acceptance in the transition to adulthood: A multi-informant comparison of practitioners, families, and youth with autism. *Journal of Autism and Developmental Disorders*, 52(4), 1444–1457. <https://doi.org/10.1007/s10803-021-05037-1>
- Lipinski, S., Boegl, K., Blanke, E. S., Suenkel, U., & Dziobek, I. (2022). A blind spot in mental healthcare? Psychotherapists lack education and expertise for the support of adults on the autism spectrum. *Autism: The International Journal of Research and Practice*, 26(6), 1509–1521. <https://doi.org/10.1177/13623613211057973>

- Lynch, C. L. (2019, March 28). Invisible abuse: ABA and the things only autistic people can see. <https://neuroclastic.com/2019/03/28/invisible-abuse-aba-and-the-things-only-autistic-people-can-see/>
- MacLeod, A. (2019). Interpretative phenomenological analysis (IPA) as a tool for participatory research within critical autism studies: A systematic review. *Research in Autism Spectrum Disorders*, 64, 49–62. <https://doi.org/10.1016/j.rasd.2019.04.005>
- Maenner, M. J., Shaw, K. A., Baio, J., Washington, A., Patrick, M., DiRienzo, M., Christensen, D. L., Wiggins, L. D., Pettygrove, S., Andrews, J. G., Lopez, M., Hudson, A., Baroud, T., Schwenk, Y., White, T., Robinson Rosenberg, C., Lee, L., Harrington, R. A., Huston, M... Dietz, P. M. (2020). Prevalence of Autism Spectrum Disorder among children aged 8 years-Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2016. *Surveillance Summaries*, 69(4), 1–12. <https://doi.org/10.15585/mmwr.ss6904a1>
- Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuseppi, C., Durkin, M. S., Giarelli, E., Morrier, M. J., Nicholas, J. S., Pinto-Martin, J. A., Shattuck, P. T., Thomas, K. C., Yeargin-Allsopp, M., & Kirby, R. S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, 99(3), 493–498. <https://doi.org/10.2105/AJPH.2007.131243>
- Masataka, N. (2017). Implications of the idea of neurodiversity for understanding the origins of developmental disorders. *Physics of Life Reviews*, 20, 85–108. <https://doi.org/10.1016/j.plrev.2016.11.002>
- Mayer, F. S., Frants, C. M. P., Bruehlman-Senecal, E., & Dolliver, K. (2009). Why is nature beneficial? The role of connectedness to nature. *Environment and Behavior*, 41(5), 607–643. <https://doi.org/10.1177/0013916508319745>
- Mazefsky, C. A., Borue, X., Day, T. N., & Minshew, N. J. (2014). Emotion regulation patterns in adolescents with high-functioning autism spectrum disorder: Comparison to typically developing adolescents and association with psychiatric symptoms. *Autism Research*, 7(3), 344–354. <https://doi.org/10.1002/aur.1366>
- McCauley, J. B., Harris, M. A., Zajic, M. C., Swain-Lerro, L. E., Oswald, T., McIntyre, N., Trzesniewski, K., Mundy, P., & Solomon, M. (2019). Self-esteem, internalizing symptoms, and theory of mind in youth with autism spectrum disorder. *Journal of Clinical Child and Adolescent Psychology*, 48(3), 400–411. <https://doi.org/10.1080/15374416.2017.1381912>
- McCrimmon, A. W., Matchullis, R. L., & Altomare, A. A. (2016). Resilience and emotional intelligence in children with high-functioning autism spectrum disorder. *Developmental Neurorehabilitation*, 19(3), 154–161. <https://doi.org/10.3109/17518423.2014.927017>
- McCarty, M. J., & Brumback, A. C. (2021). Rethinking stereotypes in autism. *Seminars in Pediatric Neurology*, 38, 100897. <https://doi.org/10.1016/j.spen.2021.100897>

- Mehtar, M., & Mukaddes, N. M. (2011). Posttraumatic stress disorder in individuals with diagnosis of autistic spectrum disorders. *Research in Autism Spectrum Disorders*, 5(1), 539–546. <https://doi.org/10.1016/j.rasd.2010.06.020>
- Mertens, D. M. (2009). *Transformative research and evaluation*. Guilford Press.
- Milton, D. E. M. (2012). On the ontological status of autism: The “double empathy problem.” *Disability & Society*, 27(6), 883–887. <https://doi.org/10.1080/09687599.2012.710008>
- Mitchell, P., Sheppard, E., & Cassidy, S. (2021). Autism and the double empathy problem: Implications for development and mental health. *The British Journal of Developmental Psychology*, 39(1), 1–18. <https://doi.org/10.1111/bjdp.12350>
- National Research Council (U.S.). Committee on Educational Interventions for Children with Autism. (2001). *Educating children with autism*. National Academy Press.
- Neubacher, K. (2015). *The experience of sibling death in childhood: A qualitative analysis of memoirs*. [Doctoral dissertation, Antioch University New England]. Student & Alumni Scholarship, including Dissertations & Theses (ETDs). <http://aura.antioch.edu/etds/255>
- Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders*, 34(3), 245–256. <https://doi.org/10.1023/B:JADD.0000029547.96610.df>
- Ortega, F. (2009). The cerebral subject and the challenge of neurodiversity. *BioSocieties*, 4, 425–445. <https://doi.org/10.1017/S1745855209990287>
- O’Toole, J. C. (2018). *Autism in heels: The untold story of a female life on the spectrum*. Skyhorse Publishing, Inc.
- Paletta, D. (2013). Equality, capability, and neurodiversity. In C. D. Herrera & A. Perry (Eds.), *Ethics and neurodiversity* (pp. 39–51). Cambridge Scholars Publishing.
- Park, C. L. (2010). Making sense of the meaning literature: An integrative review of meaning making and its effects on adjustment to stressful life events. *Psychological Bulletin*, 136(2), 257–301. <https://doi.org/10.1037/a0018301>
- Pastor-Cerezuela, G., Fernández-Andrés, M.-I., Sanz-Cervera, P., & Marín-Suelves, D. (2020). The impact of sensory processing on executive and cognitive functions in children with autism spectrum disorder in the school context. *Research in Developmental Disabilities*, 96, 103540. <https://doi.org/10.1016/j.ridd.2019.103540>
- Peterson, J. L., Earl, R. K., Fox, E. A., Ma, R., Haidar, G., Pepper, M., Berliner, L., Wallace, A. S., & Bernier, R. A. (2019). Trauma and autism spectrum disorder: Review, proposed treatment adaptations and future directions. *Journal of Child & Adolescent Trauma*, 12(4), 529–547. <https://doi.org/10.1007/s40653-019-00253-5>

- Phelps, K. W., McCammon, S. L., Wuensch, K. L., & Golden, J. A. (2009). Enrichment, stress, and growth from parenting an individual with an autism spectrum disorder. *Journal of Intellectual & Developmental Disability, 34*(2), 133–141. <https://doi.org/10.1080/13668250902845236>
- Power, T., Jackson, D., Weaver, R., Wilkes, L., & Carter, B. (2012). Autobiography as genre for qualitative data: A reservoir of experience for nursing research. *Collegian, 19*(1), 39–43. <https://doi.org/10.1016/j.colegn.2011.09.001>
- Prahlad, A. (2017). *The secret life of a Black Aspie*. University of Alaska Press.
- Rai, D., Lewis, G., Lundberg, M., Araya, R., Svensson, A., Dalman, C., Carpenter, P., & Magnusson, C. (2012). Parental socioeconomic status and risk of offspring autism spectrum disorders in a Swedish population-based study. *Journal of the American Academy of Child & Adolescent Psychiatry, 51*(5), 467–476. <https://doi.org/10.1016/j.jaac.2012.02.012>
- Ram, J. (2020, June 2). I am a disillusioned BCBA: Autistics are right about ABA. <https://neuroclastic.com/2020/06/02/i-am-a-disillusioned-bcba-autistics-are-right-about-aba/>
- Redondo Pedregal, C., & Heaton, P. (2021). Autism, music and alexithymia: A musical intervention to enhance emotion recognition in adolescents with ASD. *Research in Developmental Disabilities, 116*. <https://doi.org/10.1016/j.ridd.2021.104040>
- Rigles, B. (2017). The relationship between adverse childhood events, resiliency and health among children with autism. *Journal of Autism and Developmental Disorders, 47*(1), 187–202. <https://doi.org/10.1007/s10803-016-2905-3>
- Ritschel, L. A., Guy, L., & Maddox, B. B. (2022). A pilot study of dialectical behaviour therapy skills training for autistic adults. *Behavioural and Cognitive Psychotherapy, 50*(2), 187–202. <https://doi.org/10.1017/S1352465821000370>
- Rodgers, J., Glod, M., Connolly, B., & McConachie, H. (2012). The relationship between anxiety and repetitive behaviours in autism spectrum disorder. *Journal of Autism and Developmental Disorders, 42*(11), 2404–2409. <https://doi.org/10.1007/s10803-012-1531-y>
- Runswick-Cole, K. (2014). ‘Us’ and ‘them’: The limits and possibilities of a ‘politics of neurodiversity’ in neoliberal times. *Disability & Society, 29*(7), 1117–1129. <https://doi.org/10.1080/09687599.2014.910107>
- Rutter, M. (2006). Implications of resilience concepts for scientific understanding. *Resilience in Children, 1094*(1), 1–12. <https://doi.org/10.1196/annals.1376.002>

- Samson, A. C., Hardan, A. Y., Lee, I. A., Phillips, J. M., & Gross, J. J. (2015). Maladaptive behavior in autism spectrum disorder: The role of emotion experience and emotion regulation. *Journal of Autism and Developmental Disorders*, *45*(11), 3424–3432. <https://doi.org/10.1007/s10803-015-2388-7>
- Samson, A. C., Wells, W. M. Phillips, J. M., Hardan, A. Y., & Gross, J. J. (2015). Emotion regulation in autism spectrum disorder: Evidence from parent interviews and children's daily diaries. *The Journal of Child Psychology and Psychiatry*, *56*(8), 903–913. <https://doi.org/10.1111/jcpp.12370>
- Sanua, V. D. (1987). Infantile autism and parental socioeconomic status: A case of bimodal distribution. *Child Psychiatry and Human Development*, *17*(3), 189–198. <https://doi.org/10.1007/BF00706229>
- Seltzer, M. M., Krauss, M. W., Shattuck, P. T., Orsmond, G., Swe, A., & Lord, C. (2003). The symptoms of autism spectrum disorders in adolescence and adulthood. *Journal of Autism and Developmental Disorders*, *33*, 565–581. <https://doi.org/10.1023/B:JADD.0000005995.02453.0b>
- Sinclair, J. (1999). Why I dislike 'person-first' language. Internet Archive. web.archive.org/20090210190652/web/http://web.syr.edu/~jisincla/person_first.htm
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretive phenomenological analysis: Theory, method, and research*. SAGE Publications, Inc.
- Smith, S., & Watson, J. (2013). *Reading autobiography: A guide for interpreting life narratives* (2nd ed., 3rd print). University of Minnesota Press.
- Smith-Sullivan, K. (2008). Diaries and journals. In L. M. Given (Ed.), *The SAGE encyclopedia of qualitative research methods* (pp. 214–215). SAGE Publications, Inc. <https://doi.org/10.4135/9781412963909>
- Solomon, M., Miller, M., Taylor, S. L., Hinshaw, S. P., & Carter, C. S. (2012). Autism symptoms and internalizing psychopathology in girls and boys with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *42*(1), 48–59. <https://doi.org/10.1007/s10803-011-1215-z>
- Sopaul, T. (2019). An interpretative phenomenological analysis of families affected by Autism in Dubai. *Dubai Medical Journal*, *2*(3), 82-89. <https://doi.org/10.1159/000501770>
- Storch, E. A., Sulkowski, M. L., Nadeau, J., Lewin, A. B., Arnold, E. B., Mutch, P. J., Jones, A. M., & Murphy, T. K. (2013). The phenomenology and clinical correlates of suicidal thoughts and behaviors in youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *43*(10), 2450–2459. <https://doi.org/10.1007/s10803-013-1795-x>

- Sullivan, P. M., & Knutson, J. F. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse & Neglect*, *24*(10), 1257–1273. [https://doi.org/10.1016/S0145-2134\(00\)00190-3](https://doi.org/10.1016/S0145-2134(00)00190-3)
- Swaab, L., McCormack, L., & Campbell, L. E. (2017). Distress and psychological growth in parenting an adult child with autism spectrum disorder and aggression. *Advances in Neurodevelopmental Disorders: Multidisciplinary Research and Practice Across the Lifespan*, *1*(4), 260–270. <https://doi.org/10.1007/s41252-017-0033-5>
- Szatmari, P. (2018). Risk and resilience in autism spectrum disorder: A missed translational opportunity? *Developmental Medicine and Child Neurology*, *60*(3), 225–229. <https://doi.org/10.1111/dmcn.13588>
- Tammet, D. (2006). *Born on a blue day: Inside the extraordinary mind of an Autistic savant: A memoir*. Free Press.
- Taylor, J. L., McPheeters, M. L., Sathe, N. A., Dove, D., Veenstra-Vanderweele, & Warren, Z. (2012). A systematic review of vocational interventions for young adults with autism spectrum disorders. *Pediatrics*, *130*(3), 531–528. <https://doi.org/10.1542/peds.2012-0682>
- Trevisan, D. A., Roberts, N., Lin, C., & Birmingham, E. (2017). How do adults and teens with self-declared autism spectrum disorder experience eye contact? A qualitative analysis of first-hand accounts. *Plos One*, *12*(11), 0188446. <https://doi.org/10.1371/journal.pone.0188446>
- Ungar, M. (2015). Practitioner review: Diagnosing childhood resilience—A systemic approach to the diagnosis of adaptation in adverse social and physical ecologies. *Journal of Child Psychology and Psychiatry*, *56*(1), 4–17. <https://doi.org/10.1111/jcpp.12306>
- United States. (1978). The Belmont Report: Ethical principles and guidelines for the protection of human subjects of research. Bethesda, MD.: The Commission. <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>
- U.S. Department of Health and Human Services. (2021, January 5). *Violence prevention: Adverse Childhood Experiences*. Center for Disease Control and Prevention. <https://www.cdc.gov/violenceprevention/aces/>
- van der Kolk, B. A. (2005). Developmental trauma disorder: Toward a rational diagnosis for children with complex trauma histories. *Psychiatric Annals*, *35*(5), 401–408. <https://doi.org/10.3928/00485713-20050501-06>
- van Steensel, F. J., Bögels, S. M., & Perrin, S. (2011). Anxiety disorders in children and adolescents with autistic spectrum disorders: A meta-analysis. *Clinical Child and Family Psychology Review*, *14*, 302–317. <https://doi.org/10.1007/s10567-011-0097-0>
- Vivanti, G. (2020). Ask the editor: What is the most appropriate way to talk about individuals with a diagnosis of autism? *Journal of Autism and Developmental Disorders*, *50*(2), 691–693. <https://doi.org/10.1007/s10803-019-04280-x>

- Volkmar, F. R., Cicchetti, D. V., Bregman, J., & Cohen, D. J. (1992). Three diagnostic systems for autism: DSM-III, DSM-III-r, and ICD-10. *Journal of Autism and Developmental Disorders*, 22(4), 483–492. <https://doi.org/10.1007/BF01046323>
- Walker, N. (2014, September 27). Neurodiversity: Some basic terms & definitions. Neurocosmopolitanism. <https://neurocosmopolitanism.com/neurodiversity-some-basic-terms-definitions/>
- Waters, D. (n.d.). The AWAKE Project. <https://www.theawakeproject.org/>
- Wayment, H. A., Al-Kire, R., & Brookshire, K. (2019). Challenged and changed: Quiet ego and posttraumatic growth in mothers raising children with autism spectrum disorder. *Autism: The International Journal of Research and Practice*, 23(3), 607–618. <https://doi.org/10.1177/1362361318763971>
- Welch, C., Polatajko, H., Rigby, P., & Fitch, M. (2019). Autism inside out: Lessons from the memoirs of three minimally verbal youths. *Disability and Rehabilitation*, 41(19), 2308–2316. <https://doi.org/10.1080/09638288.2018.1465133>
- White, K., Flanagan, T. D., & Nadig, A. (2018). Examining the relationship between self-determination and quality of life in young adults with autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, 30(6), 735–754. <https://doi.org/10.1007/s10882-018-9616-y>
- Wigham, S., Rodgers, J., South, M., McConachie, H., & Freeston, M. (2015). The interplay between sensory processing abnormalities, intolerance of uncertainty, anxiety and restricted and repetitive behaviours in autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 45(4), 943–952. <https://doi.org/10.1007/s10803-014-2248-x>
- Williams, D. (1999). *Nobody Nowhere: The extraordinary autobiography of an Autistic*. Times Books.
- Williams, K. D. (2007). Ostracism. *Annual Review of Psychology*, 58(1), 425–452. <https://doi.org/10.1146/annurev.psych.58.110405.085641>
- Wing, L. (1981). Asperger syndrome: A clinical account. *Psychological Medicine*, 11(1), 115–129. <https://doi.org/10.1017/S0033291700053332>
- Wolitzky-Taylor, K., Sewart, A., Vrshek-Schallhorn, S., Zinbarg, R., Mineka, S., Hammen, C., Bobova, L., Adam, E., & Craske, M. G. (2017). The effects of childhood and adolescent adversity on substance use disorders and poor health in early adulthood. *Journal of Youth and Adolescence: A Multidisciplinary Research Publication*, 46(1), 15–27. <https://doi.org/10.1007/s10964-016-0566-3>
- World Health Organization. (2020). *International statistical classification of diseases and related health problems* (11th ed.). <https://icd.who.int/>

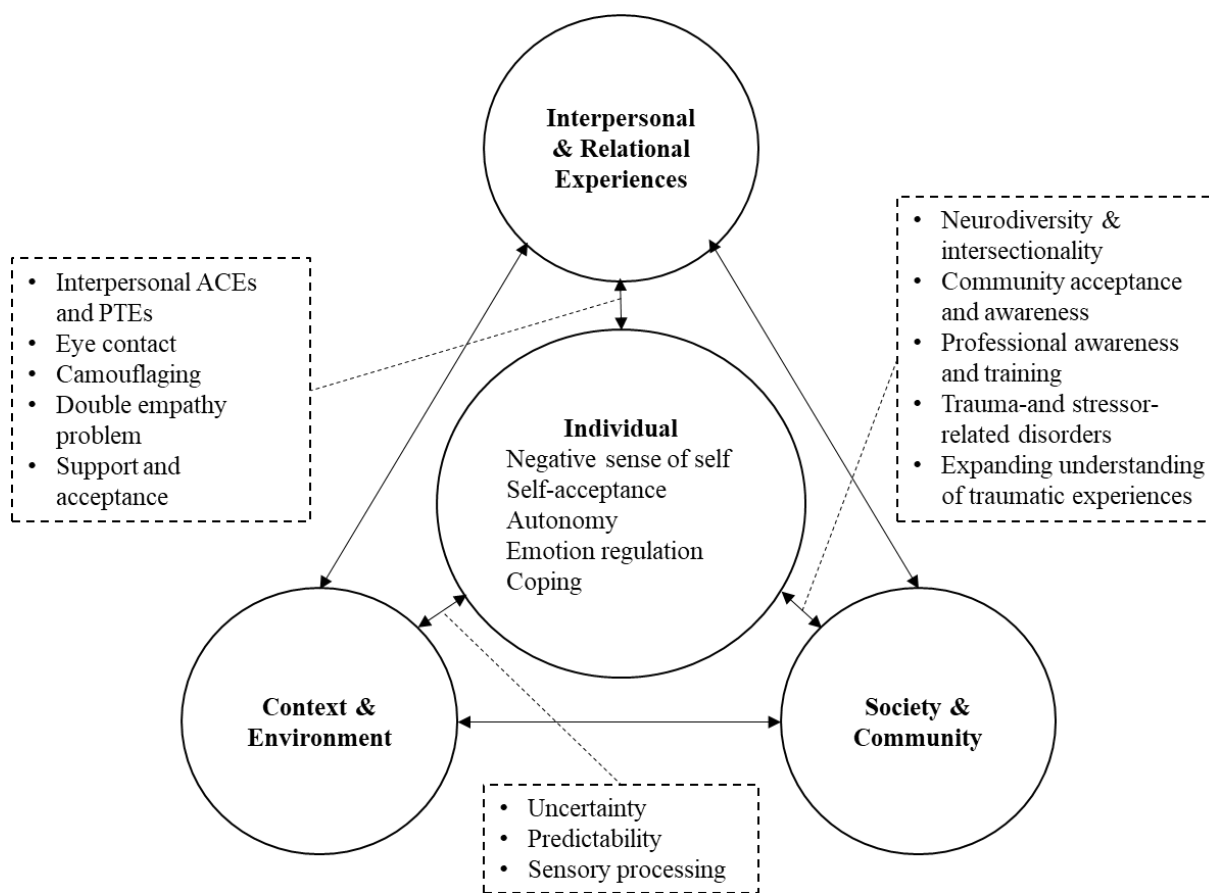
Zaidman-Zait, A., & Curle, D. (2018). Complexity: An interpretative phenomenological analysis of the experiences of mothers of deaf children with cochlear implants and autism. *Journal of Health Psychology, 23*(9), 1173–1184. <https://doi.org/10.1177/1359105316646171>

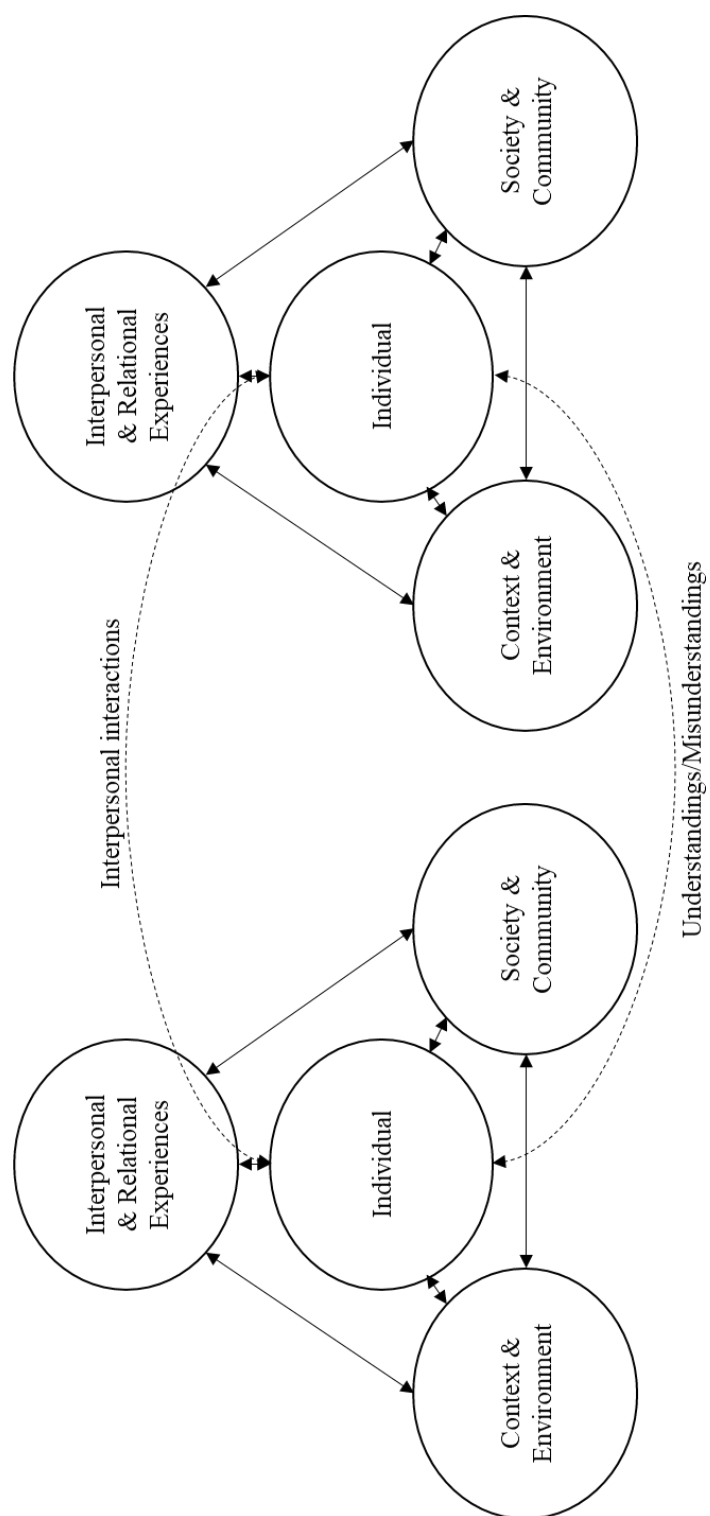
APPENDIX A: LIST OF MEMOIRS USED AS DATA

1. Kedar, I. (2012). *Ido in Autismland: Climbing out of Autism's silent prison*. (n.p.)
2. O'Toole, J. C. (2018). *Autism in heels: The untold story of a female life on the spectrum*. Skyhorse Publishing, Inc.
3. Prahlad, A. (2017). *The secret life of a Black Aspie*. University of Alaska Press.
4. Tammet, D. (2006). *Born on a blue day: Inside the extraordinary mind of an Autistic savant: A memoir*. Free Press.
5. Williams, D. (1999). *Nobody nowhere: The extraordinary autobiography of an Autistic*. Times Books.

APPENDIX B: SOCIOCULTURAL FRAMEWORK OF TRAUMA AND RESILIENCE

FACTORS FOR AUTISTIC INDIVIDUALS



APPENDIX C: SOCIOCULTURAL DOUBLE EMPATHY MODEL

APPENDIX D: EXAMPLE OF EXPLORATORY COMMENTS AND EMERGENT

THEMES: IDO KEDAR

Page	Narrative Passage	Exploratory Comments	Emergent Theme
42	They [stims] work to let me release emotions sometimes. Other times they take over my emotions, like a frenzy I get on and can't stop well. I treat stims like a welcomed friend because they are really with the time. I am so needy to escape reality and stims take me to another world. I feel forces like waves of sensory energy. I am bombarded with silver lights and streams of color. It's beautiful to watch. They mesmerize me, but sometimes they scare me. Too many frenzied colors in my imagination terrify me. I am lost in the sensory world that is a relief and a poisonous prison.	The author describes the emotional release, and sometimes overwhelm, by his stims, as well as sensory experiences	Emotion regulation through stimming; sensory overwhelm
43.1	Hand-flapping is my most embedded stim. I started young. Today I still do it whenever I feel strong emotion. It's like there is a direct route from my emotions neurologically to my hands. No sense wit. I like the feel of it too. It is like a sensory stress release. To hold it in is like forcing me to not vomit; the urge is that strong. I don't think I would try to emotionally hold things in just to stop flapping because I would overflow inside. I know it's stopping me socially. It's a hard choice to make.	Physical stimming is a way the author expresses his emotion and considers the perception of others for his stimming.	Emotion regulation through stimming
43.2	Mostly it's the reaction of others to my flapping that is hard to deal with. It's painful to see people react like I'm so strange to them. I'd if I had another way to release my tension. I hope that writing my feelings to others will let me free myself from flapping's hold response to strong feelings. It's not so pleasant to have everyone perceive my emotions even if I'd like to keep my thoughts to myself.	Reflects on feeling judged by others for his stimming	Peer rejection and isolation
44	I can't stop my senses. No one can. But mine overwhelm me. I hear my dog bark like a gunshot. My ears ring and I lose focus on my task. Tiny sounds are like soft buzzes I hear long after they have stopped. My hearing has	The author identifies the pros and cons to his sensory sensitivities-- and	Sensory overwhelm

Page	Narrative Passage	Exploratory Comments	Emergent Theme
	advantages too. Boring lectures roar into street so I tune them out. I can overhear interesting stories because through walls in other rooms. Whispering is no defense. I have supersonic ears to eavesdrop.	describes feeling overwhelmed by them.	
47	The hardest part of autism is the communication challenge. I feel depressed often by my inability to speak. I talk in my mind, but my mind doesn't talk to my mouth. It's frustrating even though I can communicate by pointing now. Before I could, it was like solitary confinement. It was terrible having experts talk to each other about me, and to hear them be wrong in their observations and interpretations, but to not be capable of telling them.	"Communication challenge"= hardest part, leads to feeling depression, frustration, etc. for this author	Communication challenges
49	Eye contact is hard because the light reflecting off the eyes is not calming. It's hard to explain because I'm not aware that I don't look at people until someone tells me to look at them. It's a strange habit I can listen better if I don't look at the person. I can look, but it's not pleasant. In ABA I had to look in people's eyes with a timer. It was so torturous I did it, but with terrible anxiety. I can't explain why. It just is that way.	Describing forced eye contact as tortuous, and leading to terrible anxiety	Discomfort with eye contact
50	Then, we found Soma. She saved my life. She talked to me like I was smart. She taught me how to communicate in steps. She is an angel, I think. I am eternally grateful to her for her help.	The gratitude for Soma seems two-pronged, first for her acknowledging that he is smart (insinuating that his intelligence has rarely been acknowledged previously), and that she taught the other how to communicate with others	Supportive and/or understanding mentors
52.1	Often I anticipate rejection, but it never came. I'd love to have more nights like this. It was so heartwarming: I got a taste of how much better my life can be if I stop destructive self-pity and engage with respectful people. I'm a good person to know. I should be proud of myself, not bitter.	The author reflects on how he enjoyed others' company, and felt they enjoyed his as well. It's almost as if this supported him in his positive narrative of	Peer Acceptance

Page	Narrative Passage	Exploratory Comments	Emergent Theme
52.2	<p>I shouldn't isolate myself, I'm sad to think how much time I've wasted in self-pity, but I see it's a decision.</p> <p>I'm determined to take November's Thanksgiving as a model for trying to relate to people in play. I believe it's a start on a new road. I don't see myself going back to my old lousy path. I'm done with it. I need to remember that people accepted me, not in a pitying way, but as part of the group. It's a great feeling.</p>	<p>himself, "I'm a good person to know."</p> <p>Acceptance into the group led to positive feelings; again, making me think of how he often did not feel accepted in other parts of his memoir, to highlight the importance of this night.</p>	Peer Acceptance
57.1	<p>The consequence of testing me in front of people is that I grew embarrassed and ashamed inside. By analyzing me in front of me, usually wrong, I grew resentful. It was so frustrating I don't like remembering it to tell it now.</p>	<p>The author describes his experience of being misunderstood by professionals that assessed him, and the frustration with their incorrect assessment</p>	Professionals misunderstanding/misdiagnosing
57.2	<p>Even if I thought about interesting ideas, since I couldn't share them it was pointless. Once I had communication my world opened. If I had interesting thoughts I could tell my mom, or my aide, or Soma, or my tutor, or my mom could tell people what I wrote. This made me hopeful and interested in learning more.</p>	<p>He highlights his despair at lack of communication through use of "pointless," and how having this ability create hope and curiosity</p>	Accommodations/adaptations for communication
58.1	<p>Inside I shouted my story, but outside I only flapped in frustration. Then they told me, "hands quiet" or "hands down." Like I mentioned before, each day the experts denied me hand-flapping but I had no other outlet for my feelings. What else could I do? I couldn't talk, write independently, gesture, or initiate. It was hard to endure this, but I was totally stuck with no way out that I could see.</p>	<p>Ido identifies the internal and external discrepancies, and how he manages this frustration</p>	communication challenges; emotion regulation through stimming
58.2	<p>This is why communication is so essential. No one should be unable to stand up for themselves. During these years I felt so trapped. Many times I felt like killing my dumb self and being free of this hell. I never would and I've overcome this feeling now. I'm intent on living. I appreciate that I have a</p>	<p>The feeling of being trapped for so long understandably led to feelings of hopelessness and suicidal ideation; having communication</p>	Accommodations/adaptations for communication

Page	Narrative Passage	Exploratory Comments	Emergent Theme
59.1	<p>wonderful family, a good home, friends, and three dogs too. I get lots of love and support. I believe it will get better. I'm not without hope now, but I once was.</p> <p>It's obvious to anyone who spends time with an autistic kid that we are always anxious. Some even hurt themselves. In one case I see a boy hit his head and bite hand. In another, I know a boy who yells, "I've got to get out of here!" often. I see kids flee and flap and cry and scream. They have no good outlet for strong tension so anxiety is a symptom of autism, I'm sure.</p>	<p>helped him to overcome these feelings</p> <p>The author reflects on his intense anxiety and what he sees in others as representing similar anxieties and their outlets.</p>	<p>Frequent anxiety or hypervigilance</p>
59.2	<p>I'm anxious with kids especially because they often are staring at me or impatient. Their high energy also stresses me out. I feel my body tense up instantly when kids who are yelling in play enter a room. Then I only want to flap or pace to calm down. I think the doctor may be on to something. I realize I am anxious twenty-four hours a day. Sometimes I can manage it and sometimes it overtakes me. The problem is that my anxiety can be like a form of paralysis. I can't speak or move to my thoughts so it interferes with my life terribly. Then people misunderstand my behavior.</p>	<p>This reminds me of another author's description of being in a state of "perpetual anxiety."</p>	<p>Frequent anxiety or hypervigilance</p>
60.1	<p>Anxiety is the source of much of my failure in social situations and in public. It overwhelms me so much I flee or withdraw in my stims or in front of the TV. It is one of the reasons I am so shy- It's not a lack of knowledge or awareness of others. I don't think a person is an object like some experts claim. I just can't relate when my anxiety is overpowering me. So this is one request to all researchers: start looking into anxiety I think it may be a key to solving the riddle of autism.</p>	<p>The author reflects on feeling overwhelmed and overpowered by his anxiety, and requests researchers further explore this link.</p>	<p>Emotional overwhelm/dysregulation</p>
60.2	<p>Some treatments increase anxiety, especially hand-anxiety in my case. To this day if I behave badly I wait for the "neutral no." I imagine if the behaviorists all heard "neutral no's" all day I did something wrong it would make them edgy and tense and they would</p>	<p>"Some treatments make anxiety worse," in this case the author is identifying the behavioral interventions as</p>	<p>Anxiety/ trauma from treatment</p>

Page	Narrative Passage	Exploratory Comments	Emergent Theme
	start to flub in their nervousness, especially if it started when they were two years old. So I am realizing that some treatments make anxiety worse.	sources for his nervousness and anxiety	
62	I'm still very autistic. I stimulate and am impulsive and am not very verbal. I am anxious and shy too but I am a free soul because I can communicate my thoughts to the world. I wish this for all autistic people.	Again, the freeing nature of communication versus feeling trapped or stuck internally.	Accommodations/adaptations for communication
82	Yesterday with a device I borrowed I talked on the phone. It was so liberating- Not just, "How are you?" but a real conversation. I joked* They laughed. They asked me questions. I answered. Like you do. Only it was my first time. It's so meaningful to me to have my own voice speaking my thoughts to others. I'm almost thirteen so I'd say it's about time.	Able to speak his mind, let himself be known to others	Accommodations/adaptations for communication
93	How easy to be on the sofa and watch TV in self-pity. How hard to say, "I won't be defeated by my challenges." Why not me? I can work on my body too. I can run, or swim, or skateboard if I try, but need to practice more than average. Oscar Pistorius said, "You're not disabled by the disabilities you have you are able by the abilities you have." Yes! By focusing on my abilities I can grow them. By focusing on my disabilities I am stuck.	"Why not me" was in another memoir, again as a phrase used to motivate the authors toward their goals or through difficult experiences	Sense of autonomy and control
94.1	You intuitively know what sound is important. This is lucky because: I can't. The air conditioner, the dog bark, the conversation, the fridge hum are all equal in my mind. When I was little it was too much information. It overwhelmed so much I would tune out and stim.	Auditory overwhelm leads to dissociation and stimming	Sensory overwhelm
94.2	Visually too I get overwhelmed. It's as if I see everything foreground and nothing in the background. Sometimes I see in a tunnel and I miss the sides. Other times I see the sides and miss the big picture because I'm lost in details.	Visual overwhelm	Sensory overwhelm
95	I used to have a phobia of small showers. My senses got overwhelmed in them, like an intense claustrophobia. My mom and dad	Sensory overwhelm = feeling like a panic attack	Sensory overwhelm

Page	Narrative Passage	Exploratory Comments	Emergent Theme
97.2	<p>made me learn deal with it, and now I'm fine. I was also afraid of horses, and theaters in the dark, and the rides at amusement parks. I wanted to ride them but I felt so panicked I couldn't get on. It's a lot like a panic attack I think. It's improving now that I feel more in charge of my life but there's still a lot of things I can't get myself to do.</p>	<p>Again, importance of building autonomy and self-awareness (similar to the growth journey of previous authors)</p>	<p>Self-understanding</p>
104	<p>It's my job to fight my self-pity by remembering that it isn't all bad. In fact, as much as I hate to admit it, autism has given me a lot of good things too. In the silence I lived in I learned to think deeply about things. I learned to observe and to understand people and their emotions, and I see that my illness is not the end. It is only a challenge that I now know I can deal with. The secret to happiness must be stopping self-pity.</p>	<p>Reframing his experience and shifting his relationship with Autism experience.</p>	<p>Identifying personal strengths and growth</p>
106	<p>It's a hard struggle. I fight my doubts and my demons every day but I am so sure that hope is like a taste of God's presence. How else would we have this relief if not for God? I think horrible things seem worse without this hope that promises a better tomorrow. It's necessary to see that our suffering leads to calming hope through our love in God.</p>	<p>His religious beliefs appear to bring him great comfort and sense of meaning.</p>	<p>Comfort in religion and spiritual beliefs</p>
107	<p>My emotions are like a force that takes over my entire self, It may be good feelings or bad. I get happy. Then I get so happy I roller coaster to goofy and I laugh or stim uncontrollably. This can feel sort of scary. It is taking over so quickly. I try to resist. It is like stopping a rolling boulder. It's more powerful than I am, so I roll with it. I can't stop it on my own. I need someone to calm me in some way. I need to walk or leave to have a return to my control. I am relieved if I</p>	<p>He describes some fear in feeling overwhelmed with emotions, and how it helps to have other's support him.</p>	<p>Emotional overwhelm/dysregulation</p>

Page	Narrative Passage	Exploratory Comments	Emergent Theme
109	<p>return to control. It's overwhelming to be on an emotional roller coaster. I get so sad to be so stuck in my body at these moments. It is tempting to give up then.</p> <p>I love being in nature. Noisy environments drive me mad inside. It's sort of terrible because I overload in my sensory system too easily. I can tolerate a baseball game with headphones on or eat in a restaurant. Not easy for me to cope with the din, but I do.</p>	Difficulty being in sensory-overwhelming environments, using headphones to adapt	Accommodations/adaptations for sensory overwhelm; benefit of nature
111	<p>I may never lose this illness but I'm getting closer to accepting it as part of me. I will continue to work on it because I need to be happy. If I accept that I can exercise, practice the piano, and write and this helps me improve my mood and skills, then it is a lot. I don't need a miracle cure to live well, but I must persevere in trying, like my cousin did.</p>	Self-acceptance, acceptance of situation leading to motivation to persevere	Acceptance of self
117	<p>Thanks to my really good luck of meeting Soma, having a satisfactory mind, the most amazing parents who insisted I be a self-sufficient human-being, or as much as I could be, I am in mainstream classes getting an education, writing a book, having friends, getting in shape, giving speeches to audiences, going to sleep away camp for a week, doing chores like making my own bed and folding my laundry (even if I still need help). I see light where once saw darkness.</p>	Reflecting on what has assisted him in feeling hopeful and achieving goals (Soma=teaching him to communicate, intelligence, support system, self-sufficiency).	Accommodations/adaptations for communication peer acceptance; Sense of autonomy and control
118	<p>I had an interesting experience today. I worked out with two volunteer athletes at an activity that had special needs kids meet with college students. At first they talked to me in simple tones and words, though they were very nice. This horrible memory of patronizing ABA words of "good job" triggered turmoil in me. It's weird. I hear a kindly meant good job" and I get goosebumps and I feel myself back in my room. At my table, looking at flashcards I can't answer accurately. It's an awful thing. I'm obviously still so affected by those memories. If I hear, "no, try again" or "high five" or "good job" I wind up in my room, at my table, trapped and miserable. My mom</p>	The author reflects on how certain words triggered memories from ABA work, which led to internal turmoil (trapped, miserable) and compares it to PTSD	Anxiety/ trauma from treatment

Page	Narrative Passage	Exploratory Comments	Emergent Theme
119	<p>just told me it's like Post Traumatic Stress Disorder. But, I'm not in my room anymore, and the table is long gone, and I don't have to look at flashcards, so I need to move on emotionally.</p> <p>I fit in so well. I am so at home in the messy beauty of nature. I relate to it. I see the system is messy, but it works and it is WOW. I see my illness this way. It's not pretty. It is messy. It has erosion and rivers mud too. But it is part of nature in the same way. I am not a mistake, nor a sorry state of messy neurons. I accept my messy neurological system because it has given me a way of seeing life. I fit in with the path in the woods.</p>	<p>Comparing his own balanced view of himself to that of nature-- that there is beauty in both nature and his experience</p>	<p>Nature for emotional regulation and safety</p>
120	<p>The triggers can be silly to others. Inside, they are serious. I get nervous. It overflows. I get stressed. It overflows. It overflows. Oh man, do I hate that. I behave the way people expect autistic people to act when I overflow, so they assume I'm not smart or something. Then I stop trying. I think this is common for autistic people and it probably explains the tantrums some kids have. They tantrum from fear, anxiety or stress, but oh how quickly it becomes anger if people try to stop it with "hands down" or "no" or "all done" to a teenager. The train is stopped by rules and understanding.</p>	<p>"I get nervous. It overflows." He reflects on how "tantrums" may be from fear, anxiety, or stress.</p>	<p>Emotional overwhelm/dysregulation</p>
125.1	<p>I got to line three and couldn't take the stress of the class staring at me. I felt SO weird, so stuck, SO disrespected by this teacher. It was overflow. I did what I hate time after time in overflow, which is really rare, but it happens. I can't control myself. I'm ashamed to say that I pulled aide's hair in front of the entire class of about forty or so kids. Ched and remorseful. On the other hand, if my teacher had been sensitive to my disability none of this would have happened. I learned an important lesson to say no if I can't do something, so maybe something happened in spite of my miserable performance that will help me in life.</p>	<p>Overwhelmed with social anxiety in this moment</p>	<p>Emotional overwhelm/dysregulation</p>

Page	Narrative Passage	Exploratory Comments	Emergent Theme
125.2 again	So very nervous inside all the time. That's what Temple Grandin says. That's the way it is for the majority of autistic people. Really, I overflow hoping I can control the stress I feel. The stress is so vicious inside. Even with communication and better skills I still suffer from it sometimes. You see it in so many autistic people. They bolt or dash out. They stim because it soothes them. I see kids who bite and hit themselves who scream and have meltdowns, not to get anything, but to have an outlet. These are the reasons why: severe nervousness, stress, internal overflow. You can imagine how rough this is for people who can't communicate their ideas and feelings. They get told, "hands down" or "no" or people think they are not really aware of their emotions. Well, it is a bit different. It is sort of like a car rolling down a hill. It gains acceleration as it rolls. Think of that in an emotional sense.	The author identifies with Temple Grandin's description of feeling "so very nervous inside all the time." Also, he again labels emotional overflow as a distressing, and stimming as a way of self-soothing	Emotion regulation through stimming Emotional overwhelm/dysregulation; Frequent anxiety/hypervigilance
126	What can you do to help? Quick removal from the stressful situation. If you need to come back, OK. The interruption is helpful in breaking the momentum. Also, it helps to get some caring.	The author gives explicit ways others can help autistic individuals through stressful situations	Accommodations/adaptations for sensory overwhelm
132	In my silent years I was dialoging internally all the time with God because He was filling my lonely days with hope.	Again, the author reflects on his religious relationship, and how it brought him hope	Making meaning of personal suffering
146	My struggle is to get an education and to make a difference in the world for the good, and my goal stays the same no matter how tough the fight. I look forward to the next phase in my education in a friendlier school.	"Make a difference in the world for the good." The author is clearly articulating a life goal, shaped by his personal experiences	Making meaning of personal suffering

APPENDIX E: AUTHORS' EXAMPLES OF EMERGENT THEMES

Emergent Themes	Author	Example	Page #
<i>Interpersonal Traumatic and Adverse Childhood Experiences</i>			
Experiencing abuse	O'Toole	Banging on my door. Maybe four or five voices outside. "Open up right now!" someone yelled. I got to my knees, plucked a small shard of broken ceramic from the carpet, and crawled out to the light. A mob of girls engulfed me, but I couldn't find words in the sounds. All I could do was repeat, "He hit me... he hit me." In my mind, not until that last strike had I been abused. Fingerprints were blooming on my arms. Soon they would become matching handprints. Masticated rose petals fell off with my tears. The poor flower. I felt so sorry for the poor, beautiful flower. And Minnie, sweet Minnie, sweet Minnie, was destroyed. What a particularly awful obscenity that something so innocent, so happy-- was now so tainted. Diminished. Right in the palm of my hand, kindness had turned jagged. Gentleness had snapped into sharp angles. Tenderness had shattered into fury. I squeezed the glass in my palm. Piercing the flesh. Drawing blood. I wanted the pain. Welcomed its vivid colors. In the absence of passion, this bright feeling was the only clarity. The only way to be sure I was real.	P 197
	Williams	<i>Example provided in results section</i>	P 41
Experiencing sexual assault	Prahlad	<i>Example provided in results section</i>	P 157
	O'Toole	My bruises healed decades ago. My heart, too. I hold no bitterness. No anger. Honestly, I'm no longer invested enough to think or care about him one way or another. All of that is long since over. Yet last week, when that man grabbed me and "kissed" (read: assaulted) me, my subconscious mind went into an utter tailspin. Crying, shaking, unable to think straight for two days. I was filled with	P 204

Emergent Themes	Author	Example	Page #
		doubt, questioned my perception of all that had happened, revisited everything I'd said, how I'd sat, and-- of course--what I'd worn.	
Manipulation by others	O'Toole	<i>Example provided in results section</i>	P 186
Peer victimization and bullying	O'Toole	Two hours before our big performance, I finally got my turn in our hotel room shower. I'd just stepped in when a burst of cold air rushed through the suddenly open door. The lights went out. Confused, I grabbed at the slick shower curtain and opened my mouth to scream when I heard laughter-- and a bucket full of ice came raining down over my naked body. Stunned, I stood shaking in the dark and began to cry. I just wanted my mom. Maybe it was a joke, she said after the performance. Just playing around. But I knew it wasn't. I'd danced since I was two. Had been invited to come to the school for the performing arts. It was my passion. My soul. Now, I couldn't stop shaking. I'd made them hate me, too. I'd just been me. I'd been naked. And that day, dance became another place to scare me. To hurt me. That last day. The day I decided to never go back again.	P 141
	Tammet	<i>Example provided in results section</i>	P 52
Peer rejection and isolation	O'Toole	Imagine the confusion of being small and innocently describing the world you know, only to watch as heads shake, brows raise, and eyes roll. Adults dismiss you. Kids inch away. Imagine the loneliness of not being understood. The hurt of being disregarded. Imagine what seeds of lifetime self-doubt are planted--what permanent paradigms are being created: maybe, somehow, you really are imagining it all... or worse, maybe you are crazy.	P 19
	Tammet	The keen sense of isolation was something I felt very deeply and was very painful for me. As a way of compensating for the lack	P 78

Emergent Themes	Author	Example	Page #
		of friends, I created my own to accompany me on my walks around the trees in the playground.	
	Prahlad	I was lost even among the familiar. I had wandered far into the forest, and I hadn't left behind any crumbs. I ached so badly from the isolation, but I couldn't think clearly enough to understand why I was aching. Things were moving too fast, and I was being swept along, like in white water, just trying to grab some air when I could.	P 110
	Kedar	<i>Example provided in results section</i>	P 43
Interpersonal racism	Prahlad	<i>Example provided in results section</i>	P 113
Witnessing abuse in the home	Williams	<i>Example provided in results section</i>	P 38
<i>Other Interpersonal and Social Experiences Contributing to Distress</i>			
Anxiety with eye contact	Kedar	<i>Example provided in results section</i>	P 49
Fear of others and crowds	Tammet	<i>Example provided in results section</i>	P 68
	Williams	The more I became aware of the world around me, the more I became afraid. Other people were my enemies, and reaching out to me was their weapon, with only a few exceptions-my grandparents, my father and my Aunty Linda.	P 13
Fear of being alone or abandoned	Williams	Living as Carol, completely cut off from my real self and the emotions it embodied, I became terrified of being left alone. I feared becoming possessed by the real me which seemed to lurk in the shadows like a ghost waiting for Carol to be left alone; waiting for life to slow down and catch up with her.	P 88
	Prahlad	<i>Example provided in results section</i>	P 62
	O'Toole	The only choice I had was to work harder. To do better. Every compliment I received made them beam. Every perfect report card brought praise. I had the überpolite manners of a "little lady." Enchanted teachers. Made the cut for traveling sports teams. Was the youngest ever invited to	P 135

Emergent Themes	Author	Example	Page #
Masking for social acceptance	Williams	<p>elite music programs. Of course my parents enjoyed their child's successes. Of course they encouraged me to pursue natural talents. Of course I enjoyed doing well. But success itself wasn't ever the reward. What I worked for every single day was the guarantee that, though friendships were unpredictable and I always ended up the outsider, my parents would like me. Because if they did, I'd never really be all alone.</p>	P 25
	O'Toole	<p><i>Example provided in results section</i></p>	P 19
	Prahlad	<p>I would enter classrooms and light would split my head. I would sit behind desks and be invisible as the wind. Nothing soft. Nothing soft. The talking around me would never seem to stop. There were so many different voices. So many different tones. So many different pitches, cadences, and anxious sounds like foot tapping, and shuffling, and one hand pinching the skin of the other hand, or hands tugging on elastic socks or waistbands all at once. It would make me dizzy. I would be drowning in the scents. Grease and burnt toast. Scrambled eggs and beans. The mix of soap and water, urine and foot funk, shower mold, sweat and underarms. Powder and cologne. Deodorant and perfumes. Peppermint and lotions. Listerine. I had to hold onto myself to keep from vomiting. I would</p>	P 169

Emergent Themes	Author	Example	Page #
		<p>have to put my hand on the back of my head to keep my head from exploding. I would have to hold tightly to the corner of the desk and the chairs and look straight ahead to keep from having a seizure. I would be holding it together so people would think I was normal. So they would think I was one of them.</p>	
Misunderstanding others	Tammet	<p>I had no idea that my behavior could be irritating and intrusive and felt hurt when a brother or sister became angry with me for what I considered to be no reason.</p>	P 85
	O'Toole	<p><i>Example provided in results section</i></p>	P 149
Being misunderstood	Tammet	<p>This happened once during a science lesson where Mr. Thraves had helped one of the pupils to prepare an experiment involving a ball of play dough suspended on a piece of string. I was fascinated by this unusual sight and—unaware at it was part of an ongoing experiment—walked over to it and started to touch and pull the dough with my fingers. At this point my teacher became annoyed that I had interfered for no reason (at least as he understood it) and told me off, but I had no idea why he was angry with me and became very confused and upset. I ran from the class, slamming the door behind me with such force that the glass window shattered into pieces.</p>	P 68
	O'Toole	<p>Multiple times every single day, we are misunderstood. We misunderstand others just as often. Every conversation, every gesture, every moment has to be edited and defended. Explained and examined. As children, we discover that, to be treated with any kindness, we must exist in a constant state of hypervigilance. Life is a perpetual feeling of fight or flight. So when self-doubt, criticism, and guilt enter intimate relationships, the walking-on-eggshells dynamic is painfully familiar. In fact, it's what we've come to expect.</p>	P 185

Emergent Themes	Author	Example	Page #
	Williams	<i>Example provided in results section</i>	P 98
Invalidation of emotion and experiences	Tammet	Mr. Thraves, worried that the ladybirds might escape from the tub and fly all over his classroom, had told one of the other children to take it outside and release all the ladybirds. When I realized what had happened, my head felt like it was going to explode. I burst into tears and ran from the class all the way home. I was absolutely distraught and didn't say a word to the teacher for weeks afterwards and became agitated if he even called my name.	P 66
	O'Toole	<i>Example provided in results section</i>	P 190
Fear of intimacy and vulnerability	Williams	<i>Example provided in results section</i>	P 137
<i>Other Community and Societal Experiences Contributing to Distress</i>			
Feeling different	Tammet	<i>Example provided in results section</i>	P 12
	Williams	I rejected much interactive contact because its generally socially invasive and intellect-jolting nature robbed me of the security I found in my ability to lose myself through color, sound, pattern and rhythm. This world of sensing in pattern, theme and feel was a stilling sanctuary compared to the emotion-jolting threat of intimacy and closeness. For those who would talk of alienation, I was, as far as I can make out, born alienated from the world and later alienated from myself in responding to 'the world'.	P 180
	Prahlad	The feeling that I was from another planet gave life meaning. There was a reason for my suffering. There was a reason why I never really fit in. For why I so seldom had any feelings for many of the things people usually have feelings about. There was a reason why I couldn't remember things. Why everything around me seemed to be a noisy blur, moving too fast to catch hold of.	P 3

Emergent Themes	Author	Example	Page #
Professionals misunderstanding or misdiagnosing	Williams	It seemed to me that she had interpreted my predicament as schizophrenia. Naturally I was insulted. Had tried so hard to believe, yet feared, that I was mad. Mary had unknowingly confirmed it.	P 97
	O'Toole	Had the staff been able to help me discover that I was not a catastrophic burden or some intrinsically defective fake ... had anyone named the autism they were all witness to, they might have saved me-- and my family-- ten more years of disordered thinking, of self-sabotage, of chaos, danger, and pain. Had they paid closer attention to the social dynamics on the ward, they might even have noticed that I was crying into my pillow not because I was sick, but mostly because I was being teased by a group of inpatient teenagers, too embarrassed to tell the therapist, and too scared to keep it together without my coping mechanism.	P 229
	Kedar	<i>Example provided in results section</i>	P 57
Masking to navigate societal demands	Williams	When I locked myself in, I locked other people out. In my own family I felt I still had reasonable control over this. At the same time, it was the very threat of having my circumstances changed (no matter how bad they may have seemed) that made me try so hard to convince people that I was capable of their precious 'normality'. It was this that, so strongly against my own will, caused me to fight so hard for so little reward at the joyless achievements of remaining aware and responsive. It was this fear of having 'my own world' taken away from me that resulted in behaviour which forced me to deny 'my own world' in place of a more presentable, well-mannered, sociable, though emotionless, shell. They never got to lay a hand on the real me, but more and more, to their elation, I began to stop visiting myself.	P 74
	Prahlad	<i>Example provided in results section</i>	P 204

Emergent Themes	Author	Example	Page #
<i>Individual Need in Conflict with Circumstance</i>			
Intolerance of ambiguity	Tammet	I had rehearsed what I wanted to say many times over in my head, but entering the room I still felt a pang of sickness because I had no idea what their reaction would be and I do not like situations where anything could happen, because they make me feel dizzy and nauseous.	P 144
	Williams	For me, life was a movie-theatre and my only means of walking out was to close out anything else that was going to reach out and affect me, particularly touch or affection. Just like in a 3D cinema the things on the screen begin to invade your world. That which was only a picture comes to life. This was the frightening reality of moving within 'the world'; and, in comparison, mine held a lot more comfort. 'My world' may have been lonely but it was predictable and came with guarantees.	P 67
	O'Toole	<i>Example provided in results section</i>	P 147
	Prahlad	Try as I may, I couldn't keep up. The wheel would go around and around, but each time the places would be different, would have changed. Fall semester. Thanksgiving break. Christmas break. Spring semester. Spring break. Summer session. Summer break. Each time, they would have completely new faces. New colors, new dates, new courses, new classrooms, new times, new names, new scents, new tones, new moods, new paces, new windows, new weather out the windows, new desks, new tables, new chairs, new I, and new me. New me. I collapsed after every change. I lay awake worried, before each new season. I fell off the cliff each time a routine was chopped off like a limb, and floated for days in nothingness; like a maple tree's helicopter picked up again and again by heavy wind.	P 210
Sensory overwhelm	Tammet	<i>Example provided in results section</i>	P 85

Emergent Themes	Author	Example	Page #
	O'Toole	And though particular sensory issues change from day to day, person to person, even hour to hour, this remains consistent: what we are experiencing is entirely real, entirely overwhelming, and, when we are “dysregulated” (our brains are screaming for either more or less input-or more of one kind but less of another) and entirely awful. When we feel either under stimulated or overstimulated, we physically cannot reason, listen, or think about anything else. We can't just ignore it. We can't learn. We can't be spontaneous or fun. We can't rationalize well. And we can't hear others' needs, let alone be certain we understand our own. It's like trying to see your own reflection in a pot of boiling water. Nothing is clear.	P 69
	Kedar	I can't stop my senses. No one can. But mine overwhelm me. I hear my dog bark like a gunshot. My ears ring and I lose focus on my task. Tiny sounds are like soft buzzes I hear long after they have stopped. My hearing has advantages too. Boring lectures roar into street sounds so I tune them out. I can overhear interesting stories because I hear through walls in other rooms. Whispering is no defense. I have supersonic ears to eavesdrop.	P 44
	Prahlad	If you put your hand on a hot stove, your brain would send a signal to your hand to make it jerk back off of the stove. If I walk into a room that's too bright, my brain would send the same message to my whole body. My descriptions are of what I really experience, not what I imagine. If I say my skin is on fire, I really mean it.	P 11
<i>Negative Impacts on Sense of Self</i>			
Diminished sense of self	Williams	<i>Example provided in results section</i>	P 25
	O'Toole	Even in an absence of major incidents, the residue of “little t traumas” accumulates: bullying, educational and professional uncertainty, emotional manipulation,	P 55

Emergent Themes	Author	Example	Page #
		discrepancies between what we perceive or express and what others see or express, and gaslighting (being convinced that mistreatment is the invention of one's own mind) make it difficult to imagine-much less establish-healthy interpersonal boundaries or a sense of where "I begin and you end." If others' reactions are our main source of determining who and how we are, and if, as Dr. Salters-Pedneault asserts, those reactions have been unpredictable and/or scary, we are literally without a framework within which to develop a strong sense of identity.	
Self-blame	O'Toole	<i>Example provided in results section</i>	P 186
<i>Emotion Dysregulation</i>			
Emotional overwhelm	Williams	I had always experienced being touched emotionally as the threat of death. The tremors associated with this were equivalent to having been in a near-death situation where the only thing your mind is saying is 'Get me out of here; I'm going to die.'	P 151
	O'Toole	A lethal coping mechanism that, for an autistic person, would have to be replaced by something equally repetitive and sensory-based but that had built-in limits, was bolstered by social and life skills training, and supported me with my own emotional regulation.	P 230
	Kedar	<i>Example provided in results section</i>	P 60
	Prahlad	Sometimes someone stepped on a leaf and I burst into tears. Or someone moved a marble I had set on a ledge to keep the world balanced, to keep my heart from sinking. Finding it gone, would feel like I was plummeting down an abandoned well. I would spend days at the bottom, cold and wet and sucking my thumb. I would spend weeks after that climbing out.	P 48
Frequent anxiety	Williams	I had become agoraphobic. I tried to walk to the local shops. I would shake, feeling my knees give out from under me. I was	P 90

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		again a frightened caged animal, running from and flinching at any efforts to come near me, though clutching at Chris as the only adult who could protect me from the invasion of the outside world. I became unable to work, running out on jobs without explanation. I began to tremble and feel like I was going to faint. In panic I would look around my once familiar surroundings, unable to make sense of them or why I had forced myself to be there.	
	O'Toole	But grab that weed near the base-- dig at the roots, and pull—gently. What happens? Yes, another weed may grow elsewhere, but this one is gone. Anxiety is that root. It is the seed from which our topical fixations and “overly sensitive,” routine-driven, black/white, obsessive behaviors arise.	P 147
	Kedar	It’s obvious to anyone who spends time with an autistic kid that we are always anxious. Some even hurt themselves. In one case I see a boy hit his head and bite his? hand. In another, I know a boy who yells, “I’ve got to get out of here!” often. I see kids flee and flap and cry and scream. They have no good outlet for strong tension so anxiety is a symptom of autism, I’m sure.	P 59
	Prahlad	<i>Example provided in results section</i>	P 110
Emotion suppression	Williams	<i>Example provided in results section</i>	P 88
Self-injurious behavior	Williams	I was losing my ability to feel. My own world may have been a void, but losing my ability to keep grip on it left me unmercifully in some sort of limbo without any feeling or comfort whatsoever. I, like so many other ‘disturbed’ people, began to hurt myself in order to feel something. It seemed that other people’s ‘normality’ was the road to my insanity. My ability to close them out kept me sane.	P 56

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	O'Toole	Cutting. Starving. Compulsive exercising. Drinking. Drugs. Hair pulling. Skin picking. These are not attention-grabbing strategies, or else why would we, who employ them, work so very hard to keep our behaviors secret? They are evidence of poor coping skills. Of terrible anxiety. Of invalidation and loneliness-and shame. Manifestations of anxiety and cognitive rigidity to the point of epidemic levels. Why? It's all about relief. About trying to escape from your own feelings and experiences of the world that those of us on the spectrum are constantly told are wrong. And for a while, it may feel like it works. Being left out is what many of us have come to expect-what we should expect without spectrum-tailored anxiety management, sensory controls, goal planning, and social skills work. We aren't just hungry to be wanted. We're starving. And bleeding. And dying. And though we'd never say as much out loud, it's not a far stretch to say that broken hearts will do anything-- believe anything-- to be loved.	P 228
	Prahlad	<i>Example provided in results section</i>	P 112
Emotion regulation and stimming	Kedar	<i>Example provided in results section</i>	P 58
<i>Self-Identifying with Trauma-Related Disorders and Sequelae</i>			
Complex PTSD	O'Toole	<i>Example provided in results section</i>	P 119
Hypervigilance	O'Toole	Many who are subject to regular bullying or abuse, like I was, may not have any way out of what they perceive as a trapped situation. Day-to-day life is filled with tiny terrors embedded within larger cracks in the psychological war zone of our minds-a release of prickly "shock" hormones that says either "Run!" "Destroy." It's wearing, depressing, and worst of all, we can't escape it easily because for us, hypervigilance may seem like our only form of self-protection because, so often, reporting incidents tags us as	P 148

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	Prahlad	troublemakers and tattletales and gives the bullies more material to work with. <i>Example provided in results section</i>	P 123
Intergenerational racial trauma	Prahlad	<i>Example provided in results section</i>	P 19
PTSD from treatment	Kedar	<i>Example provided in results section</i>	P 118
Re-experiencing Traumatic Events	Williams Prahlad	<i>Example provided in results section</i> Out the window, I watched a large tree branch sagging more and more under the weight of snow. And then it finally cracked, split and crashed half way across the street. The creaking, cracking and splitting and thumping down were filled with cries of pain, and I was back in downtown San Francisco, a few months earlier, in the middle of the big earthquake. There was a long, low moaning and then things started to sway when they were supposed to be steady. The buildings shifted their angles and the windows and doors could not stand it. They tried to stay square and rectangular, like soldiers who have been ordered to stay at attention, but they couldn't hold. Glass popped from windows and people came running out of builds and put their arms out to balance themselves, and held their arms up to keep from getting cut. Pipes screamed as they were ripped from their sockets, and water spurted out of them like lost dreams. Electric current fled from wires and conduits and danced in the air, going "na na na na na." Traffic lights went out, but everyone saw green anyway, and raced through intersections like lemmings toward cliffs. Tires screeched and metal crashed against other metal. Sirens screamed into reddened air thick with the tastes of smoke, of something burning, of fear and tears and blood. Heels scurried and concrete and plaster buckled, and white powder and debris drifted down around us like snow. I walked in a daze,	P 117 P 199

Emergent Themes	Author	Example	Page #
		listening to the broadcast on radios that people who had run shrieking from buildings were listening to as they stood, shaken. Along the streets. Standing at the window, I still had that feeling of not being able to trust the ground beneath my feet. Everything teetered. The illusion of stability was gone, and there was nothing to replace it.	
<i>Environmental Factors Supporting Safety and Comfort</i>			
Accommodations/adaptations for sensory overwhelm	Tammet	<i>Example provided in results section</i>	P 85
	Kedar	I love being in nature. Noisy environments drive me mad inside. It's sort of terrible because I overload in my sensory system too easily. I can tolerate a baseball game with headphones on or eat in a restaurant. Not easy for me to cope with the din, but I do.	P 109
	Prahlad	It helps when Karen pats me on the arm. It also helps if we go to mostly the same restaurants. Ones where the owners know me. The waiters are familiar. They are generous, patient. The chefs put special memories in the food. Special warmth that stays, like smooth stones heated all day by the hot sun.	P 219
Listening to and creating music	Tammet	"I have always loved music, because of its ability to help relieve any anxiety I might be feeling and to make me feel calm and peaceful inside.	P 67
	Williams	<i>Example provided in results section</i>	P 115
Safety in rules, routine, and repetition	Tammet	"When playing by myself chess was soothing, with its fixed and consistent rules and repeated patterns of pieces and positions"	P 107
	O'Toole	<i>Example provided in results section</i>	P 221
	Williams	"The constant change of most things never seemed to give me any chance to prepare myself for them. Because of this I found pleasure and comfort in doing the same things over and over again,"	P 45

Emergent Themes	Author	Example	Page #
	Prahlad	“From the earliest age, I lived by ritual, and as I got older the rituals magnified. They held the world together, even though the world was still in a fog. They minimized the pain”	P 49
Time in nature	Williams	The mountain stream trickled over a steep path of multicoloured pebbles which nature had made. There were trees everywhere, and each seemed to have its own personality. The mountain stream ran down into a creek which ran directly past the back of this house. I’d cross the creek and throw pebbles on to the opposite bank, creating an island, then go and sit upon it, safe, untouchable and alone.	P 119
	Kedar	<i>Example provided in results section</i>	P 119
<i>Social and Community Factors Supporting to Resilience</i>			
Accommodations/adaptations for communication	Tammet	There is something exciting and reassuring for individuals on the autistic spectrum about communicating with other people over the internet. For one thing, talking in chat rooms or by email does not require you to know how to initiate a conversation or when to smile or the numerous intricacies of body language, as in other social situations. There is no eye contact and it is possible to understand the other person’s every word because everything is written down. The use-of, “emojicons,” such as 🟡 and 😊, in chat room conversations also makes it easier to know how the other person is feeling, because he or she tells you in a simple, visual method.	P 142
	O’Toole	“In fact, special interests do present us with the power to articulate an emotional vocabulary we often lack—à la expressing anguish by saying, ‘It was like Snape seeing himself with Lily in the Mirror of Erised,’”	P 154
	Kedar	<i>Example provided in results section</i>	P 82
Learning about social intricacies and skills	O’Toole	<i>Example provided in results section</i>	P 120

Emergent Themes	Author	Example	Page #
Religious and spiritual beliefs	Kedar	<i>Example provided in results section</i>	P 106
	Tammet	My autism can sometimes make it difficult for me to understand how other people might think or feel in any given situation. For this reason, my moral values are based more on ideas that are logical, make sense to me and that I have thought through carefully, than on the ability to “walk in another person’s shoes.” I know to treat each person I meet with kindness and respect, because I believe that each person is unique and created in God’s image.	P 225
	Prahlad	“I was happy to be rejoining so many familiar souls. I was happy to know I was sharing my journey. I was happy to have positive routines to help guide me,”	P 144
Peer acceptance	O'Toole	Unlike most kids, who were assigned to “talking groups” with our main teachers (in my case, that would’ve put me right back in the “Ding, dong, the witch is dead” crew), I somehow managed to get “assigned” to the music teacher (whom I loved). Mrs. Silbert just seemed to sense that I needed some serious lifelines thrown my way. So, without any official fanfare, she simply casually extended “AA” into the following period, lunch. Besides myself, three other students- a new girl I enjoyed, a Star Trek-loving shy guy, and a popular football player—stayed, too. Though there were times in years to come that we each disappointed one another, we became more than just good friends—we became family, giving phone tips on what to do (or not to do) in social situations, broadening social circles. Heck, I even took one of the guys for a makeover, and we two girls taught him to dance. Families vacationed together, and years later, we were attending (or actually being part of) one another’s weddings. Even Mrs. Silbert, the teacher who created our “Breakfast Club” of sorts, was tearing up	P 145

Emergent Themes	Author	Example	Page #
		the dance floor at mine. She changed my life, plain and simple.	
	Kedar	<i>Example provided in results section</i>	P 52
Supportive and understanding loved ones	Tammet	<i>Example provided in results section</i>	P 156
	O'Toole	We need understanding, respect, patience. Like I did years ago, we need allies-- stuffed or otherwise-- to cling to until we can steady ourselves... until we can see, peeking through the fear, the safety and calm of an unsullied tomorrow.	P 147
	Prahlad	Me and Karen also work on other things. We monitor my social energy like a diabetic monitoring blood sugar. We talk about little things before they can happen. Like when we are going out. I used to have tearful meltdowns in the restaurant if the food wasn't just right on the plate. Or if there wasn't enough sauce. Or if the sauce touched the rice. Or if the colors of the food weren't arranged correctly. Or if the heat inside the food wasn't at just the right temperature. It was like the world was ending. I felt so hurt. I felt like I had been watching the sunset and someone had suddenly yanked the plank from under my feet and I had fallen into cold water and was drowning. I've learned to contain myself when things are not perfect. At least somethings, most of the time. It helps when Karen pats me on the arm.	P 219
Supportive and understanding mentors and professionals	Williams	<i>Example provided in results section</i>	P 131
	O'Toole	Unlike most kids, who were assigned to "talking groups" with our main teachers (in my case, that would've put me right back in the "Ding, dong, the witch is dead" crew), I somehow managed to get "assigned" to the music teacher (whom I loved). Mrs. Silbert just seemed to sense that I needed some serious lifelines thrown my way. So, without any official fanfare, she simply casually extended "AA" into the following period, lunch. Besides myself, three other students- a new girl I	P 145

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	Kedar	<p>enjoyed, a Star Trek-loving shy guy, and a popular football player—stayed, too. Though there were times in years to come that we each disappointed one another, we became more than just good friends—we became family, giving phone tips on what to do (or not to do) in social situations, broadening social circles. Heck, I even took one of the guys for a makeover, and we two girls taught him to dance. Families vacationed together, and years later, we were attending (or actually being part of) one another’s weddings. Even Mrs. Silbert, the teacher who created our “Breakfast Club” of sorts, was tearing up the dance floor at mine. She changed my life, plain and simple.</p> <p>“Then, we found Soma [inventor of Rapid Prompting Method]. She saved my life. She talked to me like I was smart. She taught me how to communicate in steps. She is an angel, I think. I am eternally grateful to her for her help,”</p>	P 50
Sense of community and network of support	O'Toole	<i>Example provided in results section</i>	P 125
	Prahlad	<p>Someone had taken the time to give names to the millions of animals and plants. To the planets and stars. To the clouds. Someone had mapped out how the sky fit together into constellations. The parts of the body, inside and out. The bodies of land and water. Mountains. The shapes of things. The metals and stones and gems. The seasons. Someone had split the world in half and named the hemispheres. Angles. And the names were all so beautiful. So mysterious. Orion. The Himalayas. The Amazon. The Red Sea. Circles. Trapezoids. Stamen. Amoeba. Retina. It made the world less overwhelming, safer. It told me that there were people like me, who had spent most of their time paying close attention to the</p>	P 67

Emergent Themes	Author	Example	Page #
		nature of the world, thinking about and organizing things.	
<i>Learning Ways to Regulate</i>			
Knowledge and information-gathering	Williams	“University had been my only consistency throughout the chaos. It gave structure to my life whilst allowing me the distance of relating via books and theories”	P 129
	O'Toole	<i>Example provided in results section</i>	P 3
	Prahlad	Someone had taken the time to give names to the millions of animals and plants[...] It made the world less overwhelming, safer. It told me that there were people like me, who had spent most of their time paying close attention to the nature of the world, thinking about and organizing things.	P 67
Mental preparation and rehearsal	Tammet	<i>Example provided in results section</i>	P 190
	Prahlad	We talk about things before they can happen. Like when we're going out. I used to have tearful meltdowns in restaurants if the food wasn't just right on the plate. Or if there wasn't enough sauce. Or if the sauce touched the rice. Or if the colors of the food weren't arranged correctly. Or if the heat inside the food wasn't at just the right temperature. It was like the world was ending. I felt so hurt. I felt like I had been watching the sunset and someone had suddenly yanked the plank from under my feet and I had fallen into cold water and was drowning.	P 219
Mental distraction	Tammet	<i>Example provided in results section</i>	P 77
	Williams	I taught Tom about singing a tune over and over in his head, if what he was hearing hurt. I taught him about looking straight through people, even if you had to look into their eyes to convince them you were listening. I taught him about jumping up and down as he recited things in order to learn them and I taught him about losing himself in the spots. We began with a dot on the wall and worked our way up.	P 43

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	O'Toole	Our hearts can feel so exposed, so raw that bearing one more sorrow would break us. So, when we don't have healthy activities to busy our perseverating brains or a support network to help us process, survive, or even harness it, many people simply try to turn down the volume.	P 125
Exercise	Kedar	<i>Example provided in results section</i>	P 97
Comfort objects	Tammet	Inside my room I sorted the books into piles on the floor until they surrounded me on all sides. It was hard for my parents to come into the room for fear of knocking one of the piles on top of me. If they tried to remove any of the books, I would burst into tears and have a tantrum. The pages of my books all had numbers on them and I felt happy surrounded by them, as though wrapped in a numerical comfort blanket.	P 24
	Williams	<i>Example provided in results section</i>	P 168
Meditation and breathing practices	Williams	People think of reality as some sort of guarantee they can rely on. Yet from the earliest age I can remember I found my only dependable security in letting go all awareness of the things usually considered real. In doing this, I was able to lose all sense of self. Yet this is a strategy said to be the highest stage of meditation, indulged in to achieve inner peace and tranquility. Why should it not be interpreted as such for autistic people?	P 180
	O'Toole	So, let me offer my part ... the kind of calm we need when we reach the edge, and what we sense and think are too big for one person: Breathe slowly. Smell the roses (inhale, through your nose), blow out the candles (exhale completely out of your mouth). Again, Breathe. You're going to be okay. You've felt this before-these feelings you have right now. Uncomfortable. Anxious. Embarrassed. Afraid. You've felt them, and you have survived. Breathe, and know you will	P 72

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		<p>survive this, too, wiser and stronger. The feelings can't break you. They can hurt. They can sting. They can waylay your plans. But if you'll sit with the feelings--notice them, stay with them without trying to run-if you do sit with them and really feel them--you'll discover they have a bottom. They have an end. They aren't all-consuming. You won't drown in them. They will become shallower... eventually, shallow enough that you will begin to walk again. Keep breathing. Keep moving. Soon, you'll emerge from the hurt. You'll be able to turn around and see the far shore where you started. You'll know that you made it through and that you are powerful and resilient enough to float above anything. Right now, that sounds impossible. It feels unbearable. I know. So for now, just breathe. There is a bottom and an end. You will get there. One breath at a time. This moment will pass. It will be over. And you won't be.</p>	
	Prahlad	<i>Example provided in results section</i>	P 144
Sensory input for regulation	Tammet	“ I cook regularly, because it is a tactile experience that helps me to relax,”	P 218
	Kedar	<i>Example provided in results section</i>	P 43
	Prahlad	“The jars of jam sang and talked to me. They mesmerized me with the colors of their light. I spent hours with the pantry door closed, listening to them, watching them, being soothed”	P 25
	Williams	My mother had recently rented a piano, and I loved the sound of anything that tinkled. I would string safety-pins together and, when I wasn't chewing on them, would tinkle them in my ear. Similarly, I loved the sound of metal striking metal, and my two most favorite objects were a piece of cut crystal and a tuning fork which I carried with me for years. When all else, failed, music could always make me feel.	P 70

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<i>Individual Processes Contributing to Resilience</i>			
Identifying personal strengths and growth	Tammet	Not being the same as everyone else had been a positive advantage to me in Kaunas, and an opportunity to help others. I also now had a database of widely varied experiences that I could reference in all manner of future situations. It gave me a greater confidence in my ability to cope with whatever life might bring to me. The future wasn't anything for me to be afraid of anymore.	P 142
	O'Toole	<i>Example provided in results section</i>	P 242
	Kedar	It's my job to fight my self-pity by remembering that it isn't all bad. In fact, as much as I hate to admit it, autism has given me a lot of good things too. In the silence I lived in I learned to think deeply about things. I learned to observe and to understand people and their emotions, and I see that my illness is not the end. It is only a challenge that I now know I can deal with. The secret to happiness must be stopping self-pity.	P 104
Self-understanding	Williams	<i>Example provided in results section</i>	P 108
	O'Toole	For the very first time in my life, I began working with a therapist. In our sometimes twice-weekly sessions, she walked me through several more months of horror... and along our journey—which ended up lasting a full year—I began to unpack the disempowering absolutes that haunted my thinking and poisoned my self-image. She taught me to consider alternate possibilities in moments when I saw despair and to notice how much certainty I attributed to my perceptions of other people's perspectives and motivations. . . even though, I started to realize, I was wrong about them as often as they were wrong about me. She encouraged me to look backward in time, and she let me know when stories I shared were, in fact, accounts and dismissals of a seemingly	P 200

Emergent Themes	Author	Example	Page #
	Kedar	<p>endless parade of abuse. And most important, she taught me to observe, examine, and question disparaging opinions about me that, for a lifetime, I had accepted unconditionally as fact. Because of that relationship, I continued a journey of self-awareness that sustained me through the hell to come and continues here, with you, today.</p>	P 97
	Prahlad	<p>In truth, it organizes me to write about and analyze my illness. I stopped writing recently because I thought my book was done and in no time I was going back to old behaviors I had not done in months. It's good to know I need to write about my feelings to have more self autonomy and self awareness. It's like a talking treatment.</p>	P 127
Acceptance of self and experience	Williams	<p>Willie would be supportive until I accepted those skills as my own and applied them to myself. Carol would talk where necessary to keep down a job until I felt I could accept those skills as my own. I knew I would one day find friends in 'the world' to replace my attachment and dependence upon the characters as they</p>	P 170

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		faded away. Until then, I had Travel Dog. As Travel Dog became less of a protector and more of a comforting companion, I myself took on the dual roles of taking responsibility and being a friend. The war against 'the world' was over. Nobody had won. There was a truce.	
	Kedar	I may never lose this illness but I'm getting closer to accepting it as part of me. I will continue to work on it because I need to be happy. If I accept that I can exercise, practice the piano, and write and this helps me improve my mood and skills, then it is a lot. I don't need a miracle cure to live well, but I must persevere in trying, like my cousin did.	P 111
	O'Toole	<i>Example provided in results section</i>	P 128
Autonomy and control	Tammet	<i>Example provided in results section</i>	P 119
	Williams	"I developed a language of my own. Everything I did, from holding two fingers together to scrunching up my toes, had a meaning, usually to do with reassuring myself that I was in control, and no-one could reach me.	P 33
	Kedar	Thanks to my really good luck of meeting Soma, having a satisfactory mind, the most amazing parents who insisted I be a self-sufficient human-being, or as much as I could be, I am in mainstream classes getting an education, writing a book, having friends, getting in shape, giving speeches to audiences, going to sleep away camp for a week, doing chores like making my own bed and folding my laundry (even if I still need help). I see light where I once saw darkness.	P 117
Making meaning of experiences	O'Toole	<i>Example provided in results section</i>	P 136
	Kedar	My struggle is to get an education and to make a difference in the world for the good, and my goal stays the same no matter how tough the fight. I look forward to the next phase in my education in a friendlier school.	P 146

Emergent Themes	Author	Example	Page #
	Prahlad	The feeling that I was from another planet gave life meaning. There was a reason for my suffering. There was a reason why I never really fit in. For why I so seldom had any feelings for many of the things people usually have feelings about. There was a reason why I couldn't remember things. Why everything around me seemed to be a noisy blur, moving too fast to catch hold of.	P 3
Using personal experiences to help others	Tammet	<i>Example provided in results section</i>	P 222
	Williams	She said that, although she had never been close to me, she had been inspired by me and had learned a lot about life by the courage and endurance she had seen me display. She felt guilty for having had a privileged life and wrote that she had decided to become a nurse. Tears came to my eyes as I read this, alone in my empty flat at Christmas. It was the first time I realized that I had inspired anybody, yet I had done so not through courage but through the dual motivation of hope and fear.	P 111