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Authentic Perspectives on Autistic Resilience: Implications for Schools and Society

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AUTHENTIC PERSPECTIVES ON AUTISTIC RESILIENCE: IMPLICATIONS FOR SCHOOLS AND SOCIETY

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APPROVAL OF DISSERTATION

We, the faculty supervising the work of **Andrew Nelson**, affirm that the dissertation, *Authentic Perspectives on Autistic Resilience: Implications for Schools and Society*, meets the high academic standards for original scholarship and creative work established by the EdD Program in **Leadership Studies** and the College of Education and Professional Development. This work also conforms to the editorial standards of our discipline and the Graduate College of Marshall University. With our signatures, we approve the manuscript for publication.

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DEDICATION

I dedicate this dissertation to my friend and mentor Dr. Valerie Paradiz. Val, without your guidance, creativity, and kindness I would still be in the dark; thank you for all you have taught me and for bringing me into the light.

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ABSTRACT

This study explored resilience factors as identified by autistic adults with authentic lived experience. Historically, Autism Spectrum Disorder (ASD) has been diagnosed using deficit models and criteria designed by outsiders with little input from the autism community. While risk of adversity is often high for those with ASD, scant research exists looking at the strengths, adaptive skills, and environmental factors contributing to the resilience of people with ASD. Autistic adults were interviewed (N = 10) to assess which internal and external risks and protections participants deemed important to their resilience. Responses were coded, analyzed, and compared to existing resilience data from the literature. Results indicated a high overlap (87.5%) of risk and protection factors between existing literature and interview results. However, many novel risks and protections were shared by participants, and autistics likely need unique and individualized systems of support to nurture their development of resilience. Implications for the field of resilience research are presented, and new methods to assess the capacity of systems to foster autistic resilience are discussed.

CHAPTER 1: INTRODUCTION

Background

Autism Spectrum Disorder (ASD) is a neurological difference affecting one's communication, socialization, sensory regulation, and repertoire of activities and interests. Awareness and acceptance of ASD has grown as narratives appear more frequently in media, entertainment, and mainstream culture. Autistics are also using social media and public speaking opportunities to talk about their experiences and viewpoints. While widespread research about a variety of ASD factors and topics has been conducted, few studies ask autistic participants to share their knowledge and experience directly with researchers. Resilience research focused on child development, trauma, and at-risk populations is gaining momentum. To date, no in-depth studies have been completed focusing on resilience and ASD. The handful of studies in existence look at resilience and ASD from a philosophical point of view and do not seek the input of autistics to determine specific, authentic resilience factors. The connection between ASD and risk of adversity is clear, and the opportunity to discuss and develop positive aspects of ASD in the context of resilience has never been better.

Resilience Definitions and Theory

Humans have likely identified with some notion of grit, tenacity, and toughness in the face of life challenges since time immemorial. Simple definitions of that tenacity or grit from popular culture might follow McCubbin's (2001) distilled description of resilience: overcoming adversity and adapting to one's environment. Resilience is open to subjective interpretation. In past research, this subjectivity has been problematic (McCubbin, 2001), and investigation must begin with clearly established definitions and terms.

Masten (2001) framed resilience using terms similar to those of the early ecologists when she noted how "individuals as complex living systems interact effectively and ineffectively over time with the systems in which they are embedded" (p. 235). Luthar (2003) said resilience was the "manifestation of positive adaptation despite significant life adversity" (p. xxix), a definition that closely echoes Masten and Obradović (2006) who defined resilience as the "positive patterns of adaptation in the context of adversity" (p. 14). This final definition was the one assumed moving forward in this study. While establishing a working definition is essential to proceeding with clarity, seeing resilience as continuous and not dichotomous (Condly, 2006) is crucial to combatting the formation of static or oversimplified views.

The formal study of resilience as a phenomenon of behavior and adaptation first appeared in physical and biological science literature, and a variety of resilience theories and applications emerged shortly after concepts were introduced in ecology studies. Social workers providing support to those affected by natural disasters, wartime conditions, poverty, and community violence assessed trauma and adversity through resilience frameworks (Greene, Galambos, & Lee, 2003). Community developers, organizational leaders, and even corporate consultants use resilience models in their practices (Yates, Tyrell, & Masten, 2015). Resilience theory is also found in education domains; researchers recognize the role a positive and supportive environment has on school connectedness and engagement in learning (Cahill, Beadle, Farrelly, Forster, & Smith, 2014). In fact, specific research on student resilience in education has considered the power of internal characteristics like IQ (Condly, 2006; Garmezy, Masten, & Tellegen, 1984; McCrimmon & Montgomery, 2014) and mastery motivation (Garmezy et al., 1984; Kantor, Lipsitt, Woodard, & Groden, 2011; Masten, 2001; Southwick, Bonanno, Masten,

Panter-Brick, & Yehuda, 2014) along with many other internal and external student resilience factors. These factors are described in detail in subsequent sections of this study.

The child development field also has a storied presence in resilience theory and practice. In 1961, the University of Minnesota launched the child development and competence movement following the arrival of Norman Garmezy. Garmezy, an expert in serious mental disorders, founded Project Competence to examine adversity, competence, and eventually resilience in children at risk (Masten & Powell, 2003). Masten and Obradović (2006), for instance, categorized competence and resilience research as having four waves: a) developing lists of protective factors; b) discovering systems that account for protective factors; c) prevention, intervention, and policy development; and d) the study of resilience across species and disciplines. Garmezy and others shepherded the third wave of prevention and intervention policy and inspired a new generation of researchers interested in understanding and helping children at risk (Masten & Powell, 2003). Project Competence continues at the Institute for Community Inclusion at the University of Minnesota, and several of Garmezy's protégés carry on resilience research today.

Many other child development researchers and institutions took an interest in resilience as well. Luthar (2003) collected the views of such child development experts into one volume that focused on three major factors of child resilience: familial adversity, exosystemic variables, and genetics and neurology. At present, resilience research and practice is gaining momentum in education. One specific aspect of educational research is the study of the resilience of students with disabilities. This study takes many of its cues from the child development theoretical framework and focuses on the resilience of people with ASD and the education and societal systems supporting them.

Risk and Protective Factors

The two elements of risk and protective factors are consistent across virtually all domains of human resilience theory. Greene, Galambos, and Lee (2003) illuminated "the ability to overcome adversity, and be successful in spite of exposure to high risk" (p. 77) in their definition of resilience. Luthar, Sawyer, and Brown (2006) claimed resilience research hinges on the study of vulnerability and protective factors, also referred to as risk modifiers. Kantor et al. (2011) provided a clean description of both saying protective factors are those skills, capabilities, resources, and experiences that support resilience, while risks are factors that challenge one's adaptation system and resilience. Risks and protective factors are internal and external in nature; one carries their own set of internal risks and adaptive systems and simultaneously lives in external environments rich in risk and protective factors. The interaction of these diverse factors makes up the fluid continuum of one's resilience.

In order to prepare for this study, it was essential to complete a broad assessment of the literature to identify common internal and external risks and protective factors. Following is a general summary of the findings from the review of relevant research on those factors.

Internal protection factors tend to aggregate around five themes: 1) cognitive ability (Cahill et al., 2014; Condly 2006; Garmezy et al., 1984; Luthar, 2003; Masten, 2001; Masten & Powell, 2003); 2) social competence (Cahill et al., 2014; Condly, 2006; Masten & Powell 2003), 3) internal drive (Condly, 2006; Garmezy et al., 1984; Masten, 2001); 4) emotional processing (Greene et al., 2003; Masten, 2001), and 5) self-awareness (Cahill et al., 2014; Condly, 2006; Greene et al., 2003; Masten, 2001; Masten & Powell 2003).

External protection factors identified in the literature center on four themes: 1) parent and familial involvement (Condly, 2006; Masten, 2001; Masten & Powell, 2003); 2) robust social

networks full of competent and caring adults and good role models (Greene et al., 2003; Masten, 2001; Masten & Powell, 2003); 3) schools with high standards and values (Masten & Powell, 2003) and well-trained and well-compensated teachers (Cahill et al., 2014; Greene et al., 2003); and 4) opportunities to rest, explore, and dream with external affirmation of worth and capability (Condly, 2006; Greene et al., 2003).

Internal risk factors challenges with cognition and intelligence, adverse birth factors, and the absence of coping skills like problem solving and behavior regulation are common in the literature (Garmezy et al., 1984). External risk factors tend to land in four categories: 1) parental abuse, divorce, and parental illness (Luthar, 2003); 2) school challenges with lacking resources and under qualified staff (Condly, 2006); 3) low socio-economic status and neighborhood factors (Condly, 2006; Luthar, 2003); and 4) racism and discrimination (Luthar, 2003).

Resilience and Positive Psychology

A key aspect of resilience theory is its close connection to positive psychology. Martin Seligman is generally considered the founder of a movement in psychology that promoted the study of positive emotions, positive character traits, and enabling institutions (Seligman, Steen, Park, & Peterson, 2005). This strengths-based model grew out of the humanistic psychology theories of experts such as Maslow and Rogers and followed a similar trajectory away from deficits models. Cahill et al. (2014) discussed how resilience models shift to "strengths-based approaches that aim to take advantage of existing strengths, positive qualities, and the intentional promotion of wellbeing and resilience" (p. 16). This shift breaks away from medical models focused on eliminating disease or distress as resilience models aim to promote health and well-being (Yates et al., 2015).

People with disabilities, particularly autistic individuals, have faced decades, if not a century or more, of diagnosis and characterization using deficit and disease models (Myers, 2019). Positive psychology and resilience approaches are a breath of fresh air to both the autistic community and those seeking to promote strength and competence in vulnerable individuals and groups (Greene et al., 2003; Yates et al., 2015).

Autism Spectrum Disorder (ASD) and Adversity

Masten and Powell (2003) said "resilience is an inference about a person's life that requires two fundamental judgments: (1) that a person is "doing okay" and (2) that there is now or has been significant risk or adversity to overcome" (p. 4). In order to move forward with a resilience approach to ASD, a context of adversity must first be established (Masten & Obradović, 2006). This proof of adversity is a necessary look at risk factors and is by no means a dismissal of the strengths and competencies a diagnosis of ASD can bring.

Suicidal ideation and behavior occurs at higher rates for people with ASD (Hedley, Uljarević, Bury, & Dissanayake, 2019). In an online survey of 76 adults with ASD, 25% of respondents were in the clinical range for depression, and 20% reported recent suicidal ideation (Hedley, Uljarević, Wilmot, Richdale, & Dissanayake, 2017).

Autistic individuals experience higher rates of premature mortality than the general population (Hedley et al. 2019). Hirvikoski, Mittendorfer-Rutz, Boman, Larsson, Lichtenstein, and Bölte (2016) examined all-cause and cause-specific mortality of a sample of 27,122 people with ASD against a control population of 2,672,185 Swedish citizens using the National Patient Register and the Cause of Death Register. Individuals with ASD had a 2.56-fold increased odds of mortality compared with matched general population controls. Mortality was significantly elevated in both genders of ASD samples relative to the general population.

Maltreatment, or harm caused by brutality, abuse, or neglect (Fisher, Epstein, Urbano, Vehorn, Cull, & Warren, 2018) has been examined in children with versus those without ASD. Children with ASD are referred for investigation of maltreatment at higher rates than children without ASD, and those ASD cases are less likely to be screened for further action. Girls with ASD are especially vulnerable to maltreatment (Fisher et al., 2018). Researchers are calling for an increased focus on the risk factors contributing to the maltreatment of children with ASD.

Roux, Shattuck, Rast, Rava, and Anderson (2015) achieved groundbreaking research with their National Autism Indicators Report on youth with autism transitioning to adulthood. Several adversity signposts for adolescents age 15 to 17 with ASD were generated, including autistic youth being victims of bullying during high school and lacking a transition plan by the federally required age. Only about half of young adults with ASD worked for pay outside the home, and even less attended postsecondary education. In addition to their diagnosis of ASD, over half of the surveyed youth had at least two health or mental health conditions. Independent living rates were well-below average and many young adults with ASD experienced social isolation.

A comparison of risk factors identified by resilience researchers (Condly, 2006; Garmezy et al., 1984; Luthar, 2003) and those distilled from the autism literature supports the notion that autistic individuals are likely to experience significant adversity. Risk factors tend to aggregate and pile up in the lives of individuals, families, communities (Yates et al., 2015), and persons with ASD are no exception.

Statement of the Problem

People with autism are at risk for adversity. Research indicates suicide, early mortality, targeted bullying, underemployment, low rates of post-secondary education, social isolation, and safety concerns make up the core risks associated with a diagnosis of ASD. The study of

resilience, especially in the field of child development, has focused on both risk and protective factors as they relate to adversity; resilience approaches work to reduce risk and vulnerability through a focus on the strengths and assets of at-risk individuals. Research and practice in the area of resilience and ASD, however, are virtually non-existent.

To date, approaches to ASD support typically focus on deficits and remediating the perceived challenges accompanying an ASD diagnosis. Furthermore, those without a diagnosis often define what life is like for those with ASD. Social media accounts and personal online blogs of autistics are calling for others to recognize their strengths and assets and for inclusion in the research projects and programs designed to help them (Holmans, 2019; Nicolaidis, 2018). The high risk of adversity, lack of data on resilience and ASD, and missing representation of authentic autistic experience create a need to answer central questions related to ASD and resilience.

Purpose

The high risk of adversity, lack of data on resilience and autism spectrum disorder (ASD), and missing representation of authentic autistic experience in ASD research created a need to answer central questions related to ASD and resilience. This study investigated what resilience factors autistics identify based on their lived experiences and how those factors can contribute to the design of stronger systems of support.

Research Questions

1. What internal and external factors do autistic adults perceive as protections against adversity?
2. What internal and external factors do autistic adults perceive as contributors to risk of adversity?
3. How do these factors match with, or diverge from, broadly accepted resilience factors from existing literature?

4. How can resilience factors unique to the autistic experience inform systems design and implementation?

Significance

Resilience has been studied in a wide variety of at-risk populations, but has not received sufficient research attention in the ASD domain. Results from this study may contribute much-needed data and information to the scant resilience research in the field and to ASD knowledge. Gathering resilience perspectives directly from autistic individuals models the community-based participatory research approaches many with ASD endorse. The outcome of this investigation could be a rich study that appeals to both researchers and the autistic community.

ASD support practices are often slow to develop; many outmoded techniques are still applied across a variety of settings despite significant advances in theory and culture. Data from this study may guide the design and delivery of innovative supports for individuals with ASD in those key settings. This study may reveal that adversity risks and protections for autistics are quite different from those pulled from the general resilience literature. If this is the case, discoveries could be leveraged to foster resilience-building approaches in the homes, classrooms, institutions, workplaces, and communities where individuals with ASD live and grow. This study may also reveal that autistic beliefs about risk, protection, and adversity closely mirror those found in the broader resilience literature. Professionals employing resilience-based strategies to help at-risk populations could proceed with confidence knowing universally designed strategies have a high probability of supporting individuals with ASD as well.

Supporting students with ASD presents many challenges; typical approaches to teaching and school culture tend to fall short as education professionals struggle to find meaningful strategies to meet the needs of autistic students. A student's deficits determine eligibility for

special education services; the frequent result is programming focused only on those shortcomings. Resilience approaches rooted in positive psychology harness a student's strengths and unique abilities to achieve positive outcomes. This study and its revelations may be used to help shift school systems and individual educators away from deficits-only approaches to ones anchored in resilience theory and practice. Detailed resilience and ASD educational checklists or curricula could also be developed if the data and results from this study provide sufficient specificity and clarity.

The introduction of resilience-building strategies has the potential to reduce adversity for people with ASD. If this study solves some of the problems posed, the autistic community may one day experience fewer threats to mental and physical health. The occurrence and effects of bullying and maltreatment may reduce, and individuals with ASD may become less socially isolated. Post-secondary education access, employment opportunities, and successful independent living may increase. This study's conclusions may help those with ASD live longer, fuller lives.

Definitions of Terms

Autism Spectrum Disorder. Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disorder diagnosed through the observation of clinically significant impairments in social communication and social interaction, and rigid, repetitive patterns of behavior. (American Psychiatric Association's (APA) *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (*DSM-5*), 2013). To meet diagnostic criteria, characteristics of the disorder must be present in early childhood. ASD is diagnosed according to one of three tiers that range in level of severity from: level 1 'requiring support,' level 2 'requiring substantial support,' to level 3 'requiring very substantial support' (APA, 2013).

Resilience. Refers to the way in which individuals interact effectively and ineffectively with the systems in which they are embedded (Masten, 2001), and is defined more specifically as "positive patterns of adaptation in the context of adversity" (Masten and Obradović, 2006, p. 14).

Adaptation. Denotes adjustment or change in individuals or systems in response to stressors or challenging situations in order to achieve stability by disrupting existing patterns of functioning (McCubbin, McCubbin, Thompson, & Thompson, 1998).

Adversity. An individual's experience of disadvantage, risk, threat, environmental hazard, or other negative variables (Masten, 2001).

Protective and Risk Factors. Protective factors are those skills, capabilities, resources, and experiences that support resilience, while risks are factors that challenge one's adaptation system and resilience (Kantor et al., 2011).

Internal and External. Refers to the distinction between risk and protective factors that are internal or external in nature based on the notion that one carries their own set of internal risks and adaptive systems and simultaneously lives in external environments rich in risk and protective factors (Masten, 2001).

Positive Psychology. A movement in psychology that promoted the study of positive emotions, positive character traits, and enabling institutions. This strengths-based model grew out of the humanistic psychology theories of experts such as Maslow and Rogers and attempts to move away from deficits models (Seligman, Steen, Park, & Peterson, 2005).

Emic. Relating to information provided by participants in their own words; the capture of language, actions, expressions, terms, or explanations communicated by participants (McMillan, 2015).

Limitations and Delimitations

Several limitations are inherent in this study. Participants must have certain communication and language skills to complete the semi-structured interview. As a result, limitations with external validity may arise, as the responses provided by the sample may not fully represent those with certain learning and communication differences in the ASD population. The relatively small sample size of 10 participants, though rich enough to achieve saturation, is another limitation. Additionally, the geographic boundary used to focus recruitment may have introduced certain biases based on region-specific variables. Generalization is not an aim of this qualitative study, but transferability of the findings may be possible if proper descriptions, participant selection, and data collection are used. Causal relationships will not be an objective in this study.

Limitations with this study's measures and methods are also possible. For example, participants' ability or willingness to describe their experiences through the interview may vary, resulting in challenges with validity and reliability. The conceivable limitations of subjectivity of coding and researcher bias common in qualitative studies also deserve attention.

A handful of delimitations were used to draw boundaries around this study. Guideposts from resilience research established a theoretical foundation, and research questions were used to develop new lines of resilience research from an ASD population previously underserved by resilience approaches. A sample of 10 autistic adults were selected and interviewed to frame the target population of resilient adults with ASD.

Methods

Resources for measuring and predicting resilience are emerging in the field (A. Masten, personal communication, August 2, 2019). Morris, Hays-Grudo, Treat, Williamson, Roblyer, and

Staton (2014) developed the Protective and Compensatory Experiences (PACES) Questionnaire that uses a simple 10-question format to assess resilience. The Benevolent Childhood Experiences (BCEs) scale is another 10-question instrument designed to assess positive early life experiences in adults with histories of childhood maltreatment and other adversities (Narayan, Rivera, Bernstein, Harris, & Lieberman, 2018). Finally, The Child and Youth Resilience Measure (CYRM-R) and the Adult Resilience Measure (ARM-R) are internationally recognized tools with short form 12-question and long form 28-question versions (Jefferies, McGarrigle, & Ungar, 2019).

The purpose of this study was to determine how people with ASD experience resilience and if those factors depart from common resilience factors found in the literature. Rather than having autistic individuals answer 10 items on a questionnaire designed for at risk children or adults, this study aimed to capture emic data from the lived experiences of resilient autistics and analyze responses in the context of resilience. Therefore, a phenomenological qualitative approach was used. Semi-structured interviews were conducted with 10 participants from five contiguous states in the Appalachian region of the United States. Interviews were recorded, transcribed, and then coded using the ATLAS.ti Qualitative Data Analysis software. Once all interviews were coded and clustered, the data analysis function of the ATLAS.ti software was used to generate statistics showing the frequency of specific codes for the internal and external risk and protection categories. Results from this process were then used to answer research questions one through three of this study.

CHAPTER 2: REVIEW OF LITERATURE

The purpose of this study was to situate an exploration of autistic resilience within the broader body of resilience research and determine whether and how autistic perspectives on resilience can help build stronger systems of support. To build a framework for exploration, this literature review followed a progression through foundational resilience definitions and theory, examples of adversity risks and protections, common Autism Spectrum Disorder (ASD) adversity factors, and the existing literature on autistic resilience. Additionally, the importance of resilience approaches to ASD, including positive psychology, and the need for authentic input from the ASD community were reviewed.

Resilience Definitions and Theory

Human resilience research emerged from work began in the natural and biological sciences. Studies on ecological resilience and stability examined resistance, persistence, and equilibrium states in nature and introduced terms that would later underpin the work of child psychologists and social scientists (Harrison, 1979; Holling, 1973). For example, Holling's (1973) idea that "resilience determines the persistence of relationships within a system and is a measure of the ability of these systems to absorb changes of state variables, driving variables, and parameters, and still persist" (p. 17) was co-opted virtually word for word by some child development experts.

History

Masten (2018) developed a broad synthesis of the history of human resilience research. The work of Charles Darwin and other biologists, she noted, provided conceptual elements such as adaptation that were later co-opted into resilience theory. For example, researchers in the early twentieth century became interested in the effects of trauma and stress following calamities like

the Great Depression and World War II. They began to see human responses to such calamities through a lens of vulnerability and adaptation. Much of this early exploration centered on the abilities of families to withstand trauma and stress. In approximately 1970, the study of human resilience solidified, and research began to move from family to individual-focused models of resilience (Masten, 2018). Social workers, psychologists, educators, social scientists, community developers, and consultants applied resilience frameworks to better understand human responses to adverse situations like natural disasters, wartime conditions, poverty, and community violence (Greene, Galambos, & Lee, 2003; Yates et al., 2015). While resilience research was often occurring under the same roof at places like the University of Minnesota's Project Competence (Masten & Powell, 2003), theoretical silos developed, and a lack of continuity led to the need to harmonize definitions (Masten, 2018).

Essential Definitions

Early resilience researchers were often in separate camps in terms of how resilience was defined. Some saw resilience as a heritable trait while others characterized resilience as an inferred capacity based on one's success in academic, social, and work environments (Masten, 2018). This division limited the meta-analysis and aggregation of approaches until the modern era of systems theories of resilience took hold. Systems theory sees resilience as an interconnected web of factors interplaying in various timings and cascades as individuals, families, and systems work through adversity. Masten (2018) incorporated this new wave into her scalable definition of resilience as "the capacity of a system to adapt successfully to significant challenges that threaten the function, viability, or development of the system" (p. 16). This study recognized the importance of systems theory as individuals with ASD exist in

dynamic realities but operated using the simplified definition of "positive patterns of adaptation in the context of adversity" (Masten & Obradović, 2006, p. 14).

Adversity, Risks, and Protections

This study assumed Masten's (2001) definition of adversity as an individual's experience of disadvantage, risk, threat, environmental hazard, or other negative variables. Wright, Masten, and Narayan (2013) provided a more detailed description of adversity as "disturbances to the function or viability of a system; experiences that threaten adaptation or development" (p. 17). Essentially, resilience research is guided by an understanding of the threats and risks to a person and the protective factors that limit their exposure to adversity.

Over the course of several decades, researchers discovered that protection and risk variables follow surprisingly predictable patterns across many communities (Masten, 2001; Masten, 2018; Wright et al., 2013), and a few key "shortlists" of these variables have been created. Masten (2018), for example, created a 10-item list of resilience factors:

- nurturing, sensitive caregiving;
- attachment relationships, emotional security, belonging;
- skilled parent management and discipline tailored to child;
- agency, motivation to adapt;
- problem solving, planning, executive function skills;
- self-regulation, emotion regulation;
- hope, faith, optimism;
- meaning making, belief life has meaning;
- positive views of the self or identity;
- routines and rituals (p. 19).

Formal measures of resilience have adopted similar condensed lists. The Protective and Compensatory Experiences (PACES) Questionnaire (Morris et al. 2014) uses a simple 10-question format to assess resilience. The Benevolent Childhood Experiences (BCEs) scale is a 10-question instrument designed to assess positive early life experiences in adults with histories of childhood maltreatment and other adversities (Narayan et al., 2018). The Child and Youth

Resilience Measure (CYRM-R) and the Adult Resilience Measure (ARM-R) are metrics with short form 12-question and long form 28-question versions (Jefferies et al., 2019).

For the purpose of clarity, Masten's (2018) 10-item list and results from an expansive review of the literature for protection and risk factors (see Chapter 1) were combined to create Table 1 to root this study's data analysis in manageable, well-established resilience criteria.

Protective Internal	**Risks Internal**
- Agency, motivation to adapt, internal drive - Problem solving, planning, executive functioning skills - Self-regulation, emotional regulation - Social competence - Hope, faith, optimism - Meaning making, belief life has meaning - Positive views of self or identity - Routines and rituals	- Cognitive challenges - Adverse birth factors - Absence of problem solving and behavior regulation skills
Protective External	**Risks External**
- Nurturing, sensitive caregiving - Attachment relationships, emotional security, belonging - Skilled parent management and discipline tailored to child - Schools with high standards and values - Well trained and compensated teachers - Opportunities to rest, explore, dream, with external affirmation of worth and capability	- Parent abuse, divorce, illness - Schools lacking resources and qualified staff - Low socio-economic status (SES) - Dangerous neighborhoods - Racism and discrimination

Table 1. Resilience Risk and Protective Factors from the Literature.

Note. Major sources for the listed factors include the following: Cahill et al., 2014; Condly 2006; Garmezy et al., 1984; Greene et al., 2003; Luthar, 2003; Masten, 2001; Masten, 2018; Masten & Powell, 2003.

Common Autism Spectrum Disorder (ASD) Adversity Factors

Autistics are at a high risk of adversity. Some of the risk is likely due to the interaction between core characteristics of the disorder itself and societal and cultural norms. For example, we know that many people with ASD struggle to adapt, problem solve, plan and sequence

events, engage executive function skills, self-regulate, and socialize. A review of the literature on resilience shows those aforementioned factors as essential to resilience (see Table 1). As a result, autistics by definition are at an increased risk of adversity, and that threat exposure can have deep and concerning consequences.

Suicidality

Segers and Rawana (2014) completed a systematic review of 10 studies of ASD and suicidality. Suicidality was defined as ideation, self-harm, attempts, and completed suicide. Suicidality was present in 10.9–50% of the ASD samples identified, and individuals with ASD comprised 7.3–15% of suicidal populations. The authors of the review determined this to be a substantial subgroup. Peer victimization, behavioral problems, being Black or Hispanic, being male, lower socioeconomic status, and lower levels of education were identified as predictive factors for suicidality. A statewide study in Utah also revealed higher suicide risk and incidence in that state's ASD population compared to non-autistic individuals; the risk of suicide death in Utah is higher for females with ASD (Kirby, Bakian, Zhang, Bilder, Keeshin, & Coon, 2019).

Early Mortality

Hirvikoski et al. (2016) studied a large cohort of individuals with ASD (n = 27, 122) diagnosed between 1987 and 2009 to determine evidence of early mortality. Individuals in the control group died at a mean age of 70.20 years, and the corresponding figure for the entire ASD group was 53.87 years. Individuals classified as low functioning died at a mean age of 39.50 compared to a mean of death of 58.39 for their peers classified as high functioning. Suicide occurred more often for those labeled high functioning. The entire ASD population was more likely to die from things like mental and behavioral disorders, nervous, circulatory, respiratory, and digestive system complications, and congenital malformations than the control group. The

study's authors concluded that ASD accounts for substantial health loss across the lifespan (Hirvikoski et al., 2016).

Maltreatment

Fisher et al. (2018) investigated maltreatment referrals and substantiation specific to children with ASD. The authors proposed the following definition of maltreatment:

> Any child who is suffering from or has sustained any wound, injury, disability, or physical or mental condition… and the harm is of such a nature as to reasonably indicate that it has been caused by brutality, abuse or neglect or that, on the basis of available information, reasonably appears to have been caused by brutality, abuse or neglect. (Fisher et al., 2018, p.2)

Samples were drawn from a population-based dataset of 24,306 children born in 2008 in Tennessee. The dataset, including 387 children with ASD, was identified through the Autism and Developmental Disabilities Monitoring network and links to state child protection records. Rates of maltreatment referrals, screening for further action, and substantiated maltreatment were examined for children with ASD versus those without ASD. The sample of children with ASD were referred to the Child Abuse Hotline at a rate of 17.3% compared to children without ASD, who were referred at a rate of 7.4%. Only 62% of referrals for children with ASD were screened for further action compared to 91.6% of the control population. Girls with ASD were more likely to have substantiated maltreatment at a rate of 13.6% versus 1.9%, respectively. The authors called for an increase focus on the risk factors contributing to the maltreatment of children with ASD.

Challenges with Transition to Adulthood

In their landmark National Autism Indicators Report, Roux et al. (2015) determined that approximately 500,000 U.S. students with autism would transition from high school in the next decade. The study focused on adolescents with ASD ages 15 to 17 and revealed several adversity factors common to those youth in transition to adulthood. Fifty percent of autistic youth surveyed reported being victims of bullying during high school. Only 58% of young adults with ASD reported working for pay outside the home, and 36% attended postsecondary education. In addition to their diagnosis of ASD, 60% of youth had at least two health or mental health conditions. Independent living rates were approximately 20% and 25% of young adults with ASD were socially isolated. Though federal law mandates the creation of a transition plan by age 14 for students receiving special education services (Finn & Kohler, 2009), only 42% of youth surveyed reported receiving a transition plan by the federally required age. Autistics often discuss the "services cliff" they encounter when leaving public school and entering adulthood (Paradiz, Kelso, Nelson, & Earl, 2018). When coupled with maltreatment and other adversities, these social, independent living, post-secondary, employment, and personal health factors tied to transition illuminate the pressing need for resilience approaches to ASD support.

Existing Literature on Autistic Resilience

Research related to resilience in autism is scarce (Kantor et al., 2011). McCrimmon and Montgomery (2014) claimed their search of the literature on resilience, protective factors, and ASD failed to yield any additional published research on this topic. After a literature search in 2016, Szatmari (2018) stated, "PubMed offered no citations on resiliency in ASD" (p. 225). Preparation for this dissertation yielded three results on ASD and resilience.

Montgomery, Schwean, Burt, Dyke, Thorne, Hindes, McCrimmon, and Kohut (2008) wanted to learn more about the connections between Asperger's Disorder (AD), emotional intelligence, and resilience. Males with AD were the target sample, and participants completed five assessments designed to measure emotional intelligence and resilience. Once assessments were completed, means, standard deviations, and t-scores were used to compare target scores with norm groups. Respondents with AD self-reported much lower scores in emotional intelligence and resilience than the normative group. The authors determined that males with AD understand complex emotions and emotional transitions, but struggle to apply these to everyday interpersonal interactions. Researchers concluded the study by suggesting the practice of emotional intelligence and resilience skills in real-life settings.

McCrimmon and Montgomery (2014) generated a narrative summary of the implications of a resilience theory approach to ASD. This study did not add quantitative data to the field but did provide inferred ASD specific risk and protective factors. For example, social deficits, sensory hyper-hypo sensitivity, uneven cognitive skills, aggressive tendencies toward self or others, and resistance to new experiences were labeled as internal risk factors. Conversely, behavioral flexibility, cognitive flexibility, high IQ, hyper-focus, attention to details, systematic approaches, novel problem solving, and areas of marked strength or talent were listed as internal protective factors.

Szatmari (2018) presented a reflection piece on risk and resilience and ASD. While the journal article was mostly an overview of the topic, it did suggest the power of supported employment and inclusive education as external protective factors. Like Szatmari (2018), each of the three reviewed studies provided best guesses about resilience factors based on assumed experiences of those with ASD. None of the studies, however, worked deeply and thoroughly to

understand the essential risks and protections autistics experience. This study is the first to attempt to use emic approaches to generate rich, authentic data on autistic resilience.

Resilience Approaches to ASD

Taking a resilience-based approach benefits autistic individuals and their allies both. Positive psychology and strengths-based models offer teachers and caregivers new perspectives on their students or loved ones. Seeing the strengths of a person or student makes it easier to imagine them in valued roles (Kantor et al., 2011). McCrimmon and Montgomery (2014) were acutely aware of the unbalanced profile of strengths and weaknesses in ASD saying "it is important to use a 'resilience lens' when trying to understand people on the spectrum, to think about the 'flipside' of identified risk factors to identify characteristics or skills that may be useful in building protective skills/factors" (p. 377). Professionals collaborating with the autism community should be well informed about strengths-based approaches and presume competence in those they support (Donaldson, Krejcha, & McMillin, 2017). Autistic individuals themselves benefit when they build on their talents and move away from a singular focus on areas of deficit or weakness (Wong, Donelly, Neck, & Boyd, 2018). Despite broad calls for strengths-based approaches from the ASD community and some progressive organizations, research continues to highlight deficit and disorder while ignoring potential protective factors of ASD (McCrimmon & Montgomery, 2014).

Positive Psychology and Resilience

Positive psychology is a strengths-based approach employing positive emotions, positive character traits, and enabling institutions in order to move away from a focus on remediating one's deficits (Seligman, Steen, Park, & Peterson, 2005). Schools and institutions are experimenting with positive psychology techniques to help individuals increase achievement,

engagement, social support and belonging, self-esteem, hope, well-being, and overall life satisfaction. Given the data on adversity and ASD and a cultural tendency to see the disorder strictly as a deficit, positive psychology approaches could help autistics become more engaged, hopeful, and satisfied.

Brunzell, Stokes, and Waters (2016) examined a positive education paradigm for students who have experienced complex trauma resulting from abuse, neglect, violence, or being witness to violence. Their work made the important distinction between repairing regulatory abilities and disrupted attachment in students versus building on those psychological resources students already had that were likely to promote future success. The authors developed a strengths-based trauma-informed positive education (TIPE) program. Students with ASD are frequently exposed to trauma; a TIPE approach that targets their strengths for support is encouraging.

Shoshani, Steinmetz, and Kanat-Maymon (2016) completed a 2-year longitudinal study of the effects of a school-based positive psychology program on students' subjective well-being, school engagement, and academic achievements. A positive psychology-based classroom-level intervention was implemented with 2517 seventh- to ninth-grade students in 70 classrooms across Israel. Classes were randomly assigned to intervention and control conditions matched for age, gender, and socio-economic status. Data analyses revealed positive intervention effects on positive emotions, peer relations, emotional engagement in school, cognitive engagement, and grade point average scores.

Luo, Yang, Gong, and Lu (2019) used a positive psychology perspective to explore the relationships among university students' social support, belonging, self-esteem, hope, and learning outcomes. Participants (n = 739) enrolled at a university in Taiwan completed written questionnaires assessing the positive psychology variables. Results suggested that students'

perception of social support affected learning outcomes through self-esteem and belonging, which then affected their hope. In addition, social support given by teachers affected students' hope differently than that given by peers. Teacher support effectively predicted the goal orientation, pathways thinking, and agency thinking dimensions of students' hope. Social support, belonging, self-esteem, hope, and learning are essential elements of support systems for students with ASD; this study provides evidence for positive psychology approaches in post-secondary environments.

Authentic Input from ASD Community

Although little research has been conducted to investigate specific resilience factors related to ASD (McCrimmon & Montgomery, 2014), it does not mean one should shy away from building such data and best practices. In fact, the opportunity for feedback and data gleaned directly from the lived experiences of those in the autism community has never been better. A community-based participatory research framework provides an opportunity to partner with the autism community (Donaldson et al., 2017), and the authentic knowledge and experiences of individuals with ASD must be incorporated into resilience research.

Becca Lory is an autistic adult who works as a professional consultant, public speaker, and public relations expert. In addition to her professional work, she participates in research studies about autism and shares her reflections on those experiences. Her recent article For the Love of Science? highlighted the essential reason autistics need to be involved in research about them:

> Besides being assets to any research team, autistic persons have one vital thing that nobody else has, and it happens to be the one thing that researchers need above all else, the data. It is our information to share. It is our time and energy to spend. In fact, the

> future of research is in our hands simply because we control the data. It is our future and we must be active participants in our own research, from its inception to its conclusion. (Lory, 2019, p.3)

The work of Lory and many others is reshaping how ASD research is conducted; meaningful and thoughtful inclusion in the research process is at the core of that shift. The autistic community is asking researchers to utilize their lived-experience to help make small adjustments to the world to “create a more comfortable place for autistic persons” (Lory, 2019, p.3). This study was designed to do just that: focus on the resilience experiences of autistics, learn about their experiences through careful listening, and use that data to make small adjustments to systems in hopes of creating a more comfortable world.

CHAPTER 3: RESEARCH METHODS

A thorough review of the literature revealed the need for deeper exploration of connections between ASD and resilience, as the field is currently making best guesses about resilience factors. This study was informed by disability research frameworks (Jupp, 2006), and was designed to conform to established qualitative practices (i.e., narrative descriptions, inductive data analysis, and participant perspectives).

Data Overview

This study had one primary data collection goal: to ascertain what autistic adults believe about factors that contribute to their resilience. A small handful of studies have looked at ASD and resilience; no previous research has addressed this topic by directly asking members of the community. The abundant resilience research outside of the ASD-specific realm often examines aspects of resilience across four dimensions: internal and external risks and internal and external protections affecting adversity. By design, this study attempted to align with this framework to make data analysis and cross-referencing more meaningful.

To establish a sound theoretical foundation for comparison purposes, this study had a secondary data collection goal: to conduct an in-depth review of resilience literature to create a composite list of accepted resilience factors. An exhaustive, broad range of resilience studies and reports were specifically targeted to create this list, and results were sorted into the four risk and protection dimensions for cross-analysis.

Research Design

Qualitative methods featuring data collected directly from sources, rich narrative descriptions, inductive data analysis, and participant perspectives (McMillan, 2015) were well suited to answer the central and research questions of this study. A phenomenological research

design was employed to generate emic data needed to "describe, clarify, and interpret everyday life experiences of participants to understand the 'essence' of the experience consciously perceived by and described by participants" (McMillan, 2015, p. 319). Groenewald (2004) presented guideposts for phenomenological studies including problem selection, establishing epistemology, sampling, informed consent procedures, detailed data analysis, and checks for validity and truthfulness. These guideposts were blended with Giorgi's five-step phenomenological progression to create a research plan: 1) collect verbal data; 2) read the data; 3) break the data into some kind of parts; 4) organize and express the data from a disciplinary perspective; and 5) make a synthesis and summary of the data for purposes of communication to the scholarly community (Richards & Morse, 2012).

Connection to Research Questions

The central and individual research questions in this study were designed to move inquiry through the progression described above. Generally speaking, investigation of resilience factors autistics identify based on their lived experiences and how those factors can contribute to established resilience knowledge formed this study's central question. The four specific research questions steering the data collection process were engineered to generate the data needed to answer the central question of this study.

Sample Population

Purposive non-random sampling was used to recruit study participants. This selection method aided in finding the information-rich cases needed for in-depth understanding (Fink, 2015; McMillan, 2015). Snowball sampling was used to recruit additional participants as needed. A sample of adults with an ASD diagnosis was recruited from the autistic population in West Virginia and its contiguous states of Kentucky, Maryland, Ohio, and Virginia. Phenomenologists

recommend sample sizes of $N = 10$ to reach saturation, assuming the gathered data are rich and detailed (Groenewald, 2004). Two participants from each of the five aforementioned states were recruited to achieve a target sample size of $N = 10$. Participants from the sample frame had to meet four criteria for inclusion in the study: (a) be age 22 – 47 at the time of interview, (b) have successful completion of at least a Bachelor's degree or vocational program, (c) live independently, and (d) have a reliable form or forms of expressive communication.

The participant age range of 22 – 47 years old was chosen for its direct connection to the passage of the first version of the Individuals with Disabilities Education Act (IDEA) in 1975, which mandated special education services for eligible students with disabilities (Johnson, 2005). Participants near the upper age range of the sample were some of the first potential recipients of these mandated special education services. Participants near the lower age range of the sample had potentially received similar services and had time and opportunity to meet the other selection criteria. Too often, researchers use techniques that exclude autistics from research (Prosser, 2011). For this reason, participants with reliable expressive communication, vocalized or augmented, were included to open participation to a wider variety of communication styles. Stump (2019), in their research on autistic life in academia, referred to having to "choose a narrow subset of a broad community" (p. 95) in hopes of growing knowledge and expanding support for the entire autistic community. The sample in this study is also a narrow subset of a diverse community. Perspectives of participants who met the age, education, and independent living criteria should reflect resilience and serve as guideposts for developing better supports for all with ASD.

Instrumentation

A semi-structured interview was used to gather information from the sample. The interview instrument (Appendix B) included language to clarify the purpose of the interview and provided basic information about informed consent and Institutional Review Board (IRB) protections in the study. The instrument contained a simple demographic section with five questions to establish the age, sex or gender, highest education level, living situation, and person or identity-first language preference for coding. Interview questions 6 – 9 asked participants to describe their beliefs about their internal and external protections and risks, with a focus on childhood, school, post-secondary or vocational training, and independent living experiences. Questions 10 – 14 asked participants to describe their beliefs about transition services received, important strengths and challenges accompanying a diagnosis of ASD, and the most important environmental supports and threats for autistics. A visual support (Appendix C) was offered to assist participants as they responded to the flow of questions during the interview. Visuals are often used by autistics to assist with information processing, and research indicates the use of visual supports is helpful when working with autistic interviewees and study participants (Harrington, Foster, Rodger, & Ashburner, 2014).

Data Collection

Direct phone calls, emails, and social media messaging were used to contact potential study participants. Once an initial agreement to participate was reached, an interview time was established. During in-person interviews, the participant and investigator signed formal consents. For telephone interviews, verbal consent was obtained according to the procedures established in the study's IRB protocol. In-person interviews with three forms of digital audio capture (phone recorder, iPad, and laptop recording software) was the preferred interview process. Participants

were encouraged to suggest a comfortable and private location of their choosing as well as any accommodations needed during the interview. Telephone interviews with audio recording were used when in-person data collection was not possible. Audio recordings were transcribed by the investigator and sent to participants for their approval. Once transcriptions were approved, all audio recordings were subsequently deleted. Digital files and data for this study were securely stored according to the protocols established by the IRB.

Data Analysis

After the desired $N = 10$ interviews were conducted, the process of data coding began. Phenomenological research methods followed those described by McMillan (2015), Groenewald (2004), and others. First, bracketing and phenomenological reduction occurred to control for personal views and preconceptions. Next, units of meaning were delineated from individual interview responses and clustered into codes. Careful attention was paid to emerging codes with high and low frequencies. Checks for validity were conducted by sending individual interview summaries to select participants. Peer debriefing by a colleague and an external audit by a reviewer who was unaware of the details of the study were used to check for credibility. Those checks came back in favor of credibility. Finally, the composite data summary was completed.

Coded were sorted into a quadrant based on the research questions for ease of analysis. Each code was arranged in a frequency hierarchy so those high and low-frequency responses could be easily tracked. Finally, research question three was answered by merging the interview and literature review data sets to identify themes and codes unique to non-ASD research, those shared by both non-ASD and ASD domains, and those unique to the experiences of adults with ASD.

Three threats to validity were inherent in this study: researcher bias, sampling bias, and confirmability. Bracketing was used to reduce personal bias and preconceptions as much as possible. Sampling bias was monitored during the purposive sampling process to ensure a variety of experiences and backgrounds were included in the study. Confirmability was kept in check with proper credibility procedures, which were a priority in this study. Several procedures described by McMillan (2015) were employed: (1) prolonged engagement to achieve saturation; (2) member checking to review data interpretations and conclusions; (3) peer debriefing by colleagues to review for credibility and data connections; (4) external audits for credibility by a reviewer who is unaware of the study; and (5) researcher reflection to check for biases.

Conclusion

A need for data on autistic resilience factors was identified. This study used the qualitative method of phenomenological investigation to generate authentic data from members of the autistic community. Semi-structured interviews were conducted to gather information from adults with ASD in a five state region of Appalachia. Those interviews were then transcribed, coded, analyzed, compared to existing resilience data, and summarized to determine how autistic resilience overlaps with and diverges from what is generally known about resilience factors. Adults with ASD were central to the design and execution of this study; results were used to conceive of positive supports to build on the strengths of autistics and adapt external environments to make autistic life more enjoyable and sustainable.

CHAPTER 4: PRESENTATION AND ANALYSIS OF DATA

This study proposed to investigate resilience factors autistics identify based on their lived experiences and how those factors can contribute to established resilience knowledge and improve systems of support. Findings are organized accordingly: (a) data collection, (b) participant characteristics, and (c) major findings.

Data Collection

A total of N = 10 participants, two from West Virginia and each of its contiguous states, were included in the study. A semi-structured interview was used to gather information from the sample. The interview instrument contained a simple demographic section with five questions to establish the age, sex or gender, highest education level, living situation, and person or identity-first language preference for coding. Interview questions 6 – 9 asked participants to describe their beliefs about their internal and external protections and risks. Questions 10 – 14 asked participants to describe their beliefs about transition services received, important strengths and challenges accompanying a diagnosis of ASD, and the most important environmental supports and threats for autistics.

In-person interviews with three forms of digital audio capture (phone recorder, iPad, and laptop recording software) was the preferred interview process. Telephone interviews with audio recording were used when in-person data collection was not possible. Transcriptions of audio recordings were coded and analyzed using the ATLAS.ti qualitative analysis and research software. Codes and supporting quotations from participants formed the data used to answer this study's research questions.

Participant Characteristics

Participants ranged in age from 22-47 years old. The sex or gender identity of participants was diverse and balanced with four females, four males, one non-binary, and one agender person participating in the study. Currently, language used to describe those on the autism spectrum is a contested topic. One participant preferred person-first language ("person with autism"), four participants preferred identity-first language ("autistic"), and five participants said they had no preference. A variety of education levels was represented with six participants with Bachelor's degrees, two with Master's degrees, one Juris Doctor, and one Ph.D. candidate with several Master's degrees. Finally, nine participants chose to participate verbally, and one participant asked for an accommodation to type their responses.

Age Range	Sex or Gender Identity	Language Preference	Education Levels
22 – 47 years old	Female (4) Male (4) Non-Binary (1) Agender (1)	Person-first (1) Identity-first (4) No preference (5)	Bachelor's (6) Master's (2) Juris Doctor (1) PhD Candidate (1)

Table 2. Demographic Characteristics of Study Participants.

Major Findings

Major findings from this study are presented within the framework of the research questions proposed in the first chapter of this study. Those questions explore the internal and external protective factors and internal and external risk factors identified by participants as well as how these factors match with, or diverge from, broadly accepted resilience factors from existing literature. Research question four is answered as part of the summary process in Chapter 5. Figures or tables summarizing the data appear after each narrative description.

RQ1: What internal and external factors do autistic adults perceive as protections against adversity?

Internal Protective Factors

Intense fixation and hyper-focus. Fifty percent of study participants (10 codes, $n = 5$) mentioned the benefits of the intense fixation and hyper-focus that can be part of having autism. Diagnostically, these factors are often cited as core deficits. Participants, however, were quick to cite the protective power of intense fixations and hyper-focus and dispel the notion that obsessions should be viewed as negative. For example, intense fixations helped participants find degrees and courses that eventually led to careers:

> I studied in college to get my meteorology degree, and I had an interest in that since I was about five. I always watched the weather channel and educated my high school classmates on meteorology, and my high school teachers…that led to me to getting my college degree in meteorology and therefore a career in the field. (Participant 6)

Once employed, participants noted how fixation and hyper-focus can have an impact on work performance. Being able to focus on tasks for long periods of time was referenced as a strength. When hyper-focus is combined with a decreased desire for socialization, productivity can increase:

> I've noticed even in my work environment that when people are talking amongst themselves or not doing their work that I'm usually the one in the back doing something else because I don't want to talk to people. People point out that I am so hard working and it's because I don't want to talk. I don't want to be with people, I want to be with myself, and working by myself and doing stuff. So there are different characteristics in autistic people that are really good for work environments. (Participant 3)

Intense fixation and hyper-focus can also protect against adversity by providing purpose and coping strategies when executive function challenges occur:

> The whole autistic hyper-fixation thing definitely applies to me. Exactly what it applies to changes throughout my life, but being able to have a singular, or at most maybe focus on three things, that's given my life a consistent purpose that helped counter any executive functioning issues that I may have. (Participant 8)

Intense fixations and hyper-focus can help autistics develop a unique identity. Specialization can lead to a uniqueness that helps define one's self and even connect to others with similar interests. One responder celebrated hyper-fixation and "the fact that we don't feel like we automatically have to blend in with broader culture. We can go out on our lone pedestal and thrive if we want" (Participant 8).

Self-awareness. Many participants (7 codes, $n = 5$) commented on the importance of developing deeper self-awareness to overcome adversity and challenges in their lives. Specific examples expressed were "learning what your triggers are instead of assuming that your triggers are somebody else's" (Participant 2), and breaking down the "social aspects, academic aspects, communication aspects" (Participant 3) and how they are individually relevant. A better understanding of self also helps individuals take more informed action in their lives:

> As I got older, I was able to become a little more self-aware of how I was feeling and what was going on around me. So I was able to hold on to my self-awareness, my ability to think about my actions and what's going on to center myself if there was an issue I was having. (Participant 4)

Some participants mentioned they knew what they needed from a young age but did not make the connection that there was anything different about them until later in life:

> I naturally knew what I needed. I just was always aware of what I needed to be okay. I couldn't use lined paper because it bothered me I used plain paper. I didn't like to write with pencils so I used permanent markers. I wrote everything in boxes and carried them around the room. I took copious notes because I couldn't retain any information, but I knew I couldn't retain information from class. I don't learn through auditory means. But what I would do is take all of that information home and repackage it. But I didn't know I was doing any of that – now I realize it. (Participant 5)

Another important aspect of self-awareness was participants' discovery that autism does not mean one is bad or deficient, just different. The process of self-awareness leading to self-acceptance can take a long time. "Understanding my wiring – not as a deficit, but more in terms of clarifying how it is different from neurotypical experience and expectation – has been very helpful. This did not happen until well into adulthood, but it was game changing" (Participant 9).

Persistence. Persistence, grit, and tenacity were mentioned by almost half of the participants (6 codes, $n = 4$), and was represented by discussions of hardworking attitudes, being go getters, and wanting to accomplish goals. The protective nature of persistence is powerful; some participants said persistence was what helped them, more than anything, to push through challenges. One participant said "the fact that I am in a Ph.D. program at all is an example of perseverance" (Participant 10). Persistence can result from "not knowing when to stop" (Participant 5), and needs to be positively channeled in order to be protective.

Self-reliance. One third of participants (5 codes, $n = 3$) described the power of self-reliance on their ability to grow and overcome challenges. Having to navigate a world on their own was seen as a powerful stepping-stone to greater independence and success. Overcoming the personal voice of self-doubt "that says 'You're not ready for this. You can't do it. You're not

capable of doing it' and saying 'yes, I can'" (Participant 3) is internally protective. Breaking from family and being "willing to just go…just go do things myself" (Participant 8) was also given importance. College experiences appear to provide an opportunity to test self and develop one's voice while still having some structure and routine:

> In college, it's different. I had to learn to fend for myself and wasn't capable of doing it so that's when I had to learn to be independent and do things for myself. Now my new sense of independence is definitely what I'm winning on because I'm thinking of going out of the country for school I definitely have to be independent. I did study abroad in undergrad so that helped a little bit with the scariness. If you're going to be out there, you do have to be alone essentially. You do have support from people back here but you have to learn how to fend for yourself and self-advocate for yourself. That was something I had to learn…to give myself a voice, because sometimes I let other people give me a voice and I can't do that. You gotta do it yourself! (Participant 3)

Detail oriented. Almost half of this study's participants (5 codes, $n = 4$) cited the power of being detail oriented and how that strength can help overcome challenges. While the general community does recognize autistic tendencies toward details, they tend to see detail orientation as pathological and not beneficial. Autistics can be "very good at specific oriented tasks" (Participant 6) which can lead to fresh perspectives on systems and the world:

> Rather than looking at the whole picture, we may pay attention to the smaller details that no one else may notice. That can be beneficial in situations. Maybe you might have seen an autistic photographer who takes pictures of certain things that maybe most people would not notice – certain angles or certain small little things. (Participant 7)

It is not difficult to imagine how detail orientation can lead to career success. One participant said “I was really good at specific things. I was very good at memorizing minute details. Other more general things were more difficult for me to memorize. So I had attention for details that allowed me to build upon my interests in meteorology. And those interests allowed me to be who I am today” (Participant 6).

Additional findings. Deep empathy and compassion (5 codes, n = 3) were shared as internally protective by one third of participants who described being able to deeply feel the emotions of others and energy that is generated in environments and social situations. Stress management and coping (4 codes, n = 4) were discussed by four participants; engaging in art, music, and special interests were referenced as being especially helpful with stress and coping. Three participants listed people pleasing (3 codes, n = 3) as being something that drives them to succeed in school, careers, and life in general and comes from a deep desire to contribute and make others happy. Intelligence was mentioned by two participants (3 codes, n = 2) who said it was essential to increased access and opportunity. Honesty (3 codes, n = 3), shared by 3 participants, was considered a positive internal aspect that is important in friendships, careers, or other situations where trustworthiness and directness is needed. Creativity (3 codes, n = 2) was seen as an important internal protection that can be leveraged in careers. Self-advocacy skills (2 codes, n =1), rule following (2 codes, n = 2), retaining information (2 codes, n = 2), loyalty (2 codes, n = 2), asking for help (2 codes, n = 1), and having an awareness of one’s diagnosis (1 code, n = 1) were seen as important internal protective aspects as well.

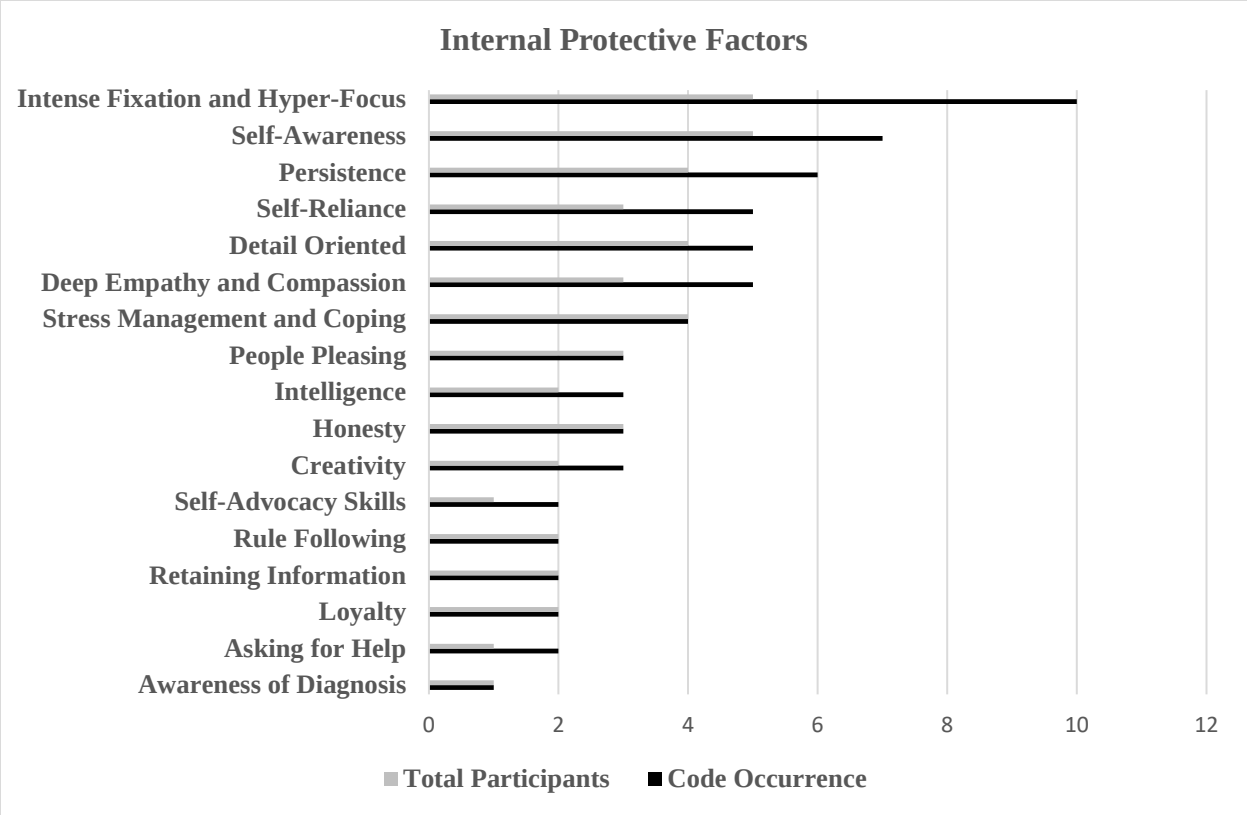

Figure 1. Descriptive Statistics of Code Occurrences and Total Participants for Internal Protective Factors.

External Protective Factors

Supportive family. Eighty percent of participants (15 codes, $n = 8$) responded that the support they received from family was a critical external protective factor. Familial support in the form of moral, ethical, and practical guidance were general themes. More specifically, families provided safe environments for personal growth. Often, families are active in the advocacy process for autistics:

> My parents, I grew up with them a little bit but I was pretty much raised by my grandparents my whole life. So, I had a wide family net that helped support me. To have someone out there advocating for you, especially supportive family and supportive friends, that's amazing. (Participant 3)

Families serving as advocates is especially important when autistics are young. One participant described help from his mom saying “When I was young I didn’t have much input. She was pretty much my advocate at the time” (Participant 6). Another participant shared the importance his mother’s role in fighting for them saying “For one thing I have a very supportive family. My mom’s very supportive and she fought for me” (Participant 10). Families are also integral to helping autistics find important connections with the community and professionals:

> Family is one of the biggest things. My family was very active and very supportive in helping me deal with that. I don’t think I would have gotten to where I am or be as resilient as I am without their active participation. You know, they’re the ones that set me up with the professionals that were able to help me. (Participant 4)

Once community and systems connections are made, families can also play a pivotal role in systems navigation and difficult transitions:

> Without the support of family to help me navigate those systems and transitions, I do not think I would have been able to get in the door, so to speak. It is a similar reason I am able to own a home, and manage basic finances now. Without the support of others to show me how those things worked, and why they are so important, I would not have been able to navigate those things. But with a lot of support up front, I am now able to better understand those systems, and maintain them pretty well on my own. (Participant 9)

Close friendships. Half of those interviewed (7 codes, $n = 5$) said close friendships were vital external factors determining their success. Many noted that they may not have a large circle of friends, that they prefer quality over quantity, and that friendships often take a long time to develop. Friendships are valued for the good influence they have on the participants’ lives and can be especially powerful when they are found in work environments:

> I still have my close friends from high school, but having people in your work environment that are supportive of you is also very good. I tell people about my plans for school and they are all like "oh my gosh, that's so exciting! I can't believe you're going to do that! Success is happening for you! I want to be there for you at every step!" And to have someone who is in that field, who knows how hard it is to be there, is so great. (Participant 3)

In a world that often misjudges autistics, the understanding and unconditional support a close friend provides is externally protective. Friends also share ideas, tips, and tactics that have worked for them. Seeing friends overcome their own challenges and modeling strength is also protective:

> The support and unconditional regard of people who were engaged with me no matter what. It wasn't a lot of people, it was a handful. Even though it may be just a small number of people I have been able to continually trust, people who have supported me, they are strong people. They are really strong people. So, I think witnessing that puts my faith back in being able to think "okay, I can survive through something"…some of those strong people have remained and stayed there and encouraged me to do great things and prevented me from giving up. (Participant 7)

Therapeutic support. Fifty percent of interviewees (6 codes, $n = 5$) described the importance of solid therapeutic support in their lives. Various occupational, speech, and physical therapies were listed. Cognitive behavioral-type therapy was also said to have helped participants learn new skills and perspectives that helped them succeed in their lives. One participant talked about the particular power of finding a therapist who was willing to learn more about their autism:

> I've got a good therapist now. That's been a good external source that – she doesn't really know as much about autism but she is willing to learn. And she doesn't act like I'm crazy. She's always like "I'm learning so much from you!" And I'm like "good, because I'm learning from you." Just not having her treat me and look at me like oh my god you're crazy but have her go "wow, I did not realize this about autistics, I did not realize." So, having her as an external source has been the biggest thing for me. (Participant 2)

Structure and routine. Almost half of the study participants (5 codes, $n = 4$) shared the importance of structure and routine as external protections. One participant said they needed structure to help with executive functioning saying "sometimes I need a guide for what I need to do and trying to get my life in order" (Participant 6). Another participant discussed the power of visual supports and schedules:

> Some of us really rely on visual supports or schedules and knowing what we are going to do next – predictability…we have certain apps that remind us or pull up schedules of what is going on. For example, if you are in a doctor's office they can provide certain examples of the steps they are going to do so you know what is going to happen. (Participant 7)

External structure and routine also impacts college and work environments. College, for example, was supportive in the way it provided a structure for "what you were required to do for your major – so being able to choose from things from a catalog for choices, but you were told you only have two choices…it was like structure, limited choices, scheduling, pattern and routine" (Participant, 5). Another participant talked about needing structure at work and being "put into a work environment I haven't had time to grow accustomed to, or put in to a work

environment that has constantly changing schedules and demands. Routine might be more desirable but not more common" (Participant 4). It was said that the world tends to falsely assume that autistics automatically "know the purpose of the pedagogy" (Participant 5) but instead need more structure like visuals, guides, and clear routines to be successful.

High quality schools. Forty percent of interviewees (5 codes, $n = 4$) conveyed that high quality schools played an externally protective part in their lives. Schools that provided clear academic and social guidance were appreciated. Schools who took bullying prevention and remediation were seen as especially protective. More specifically, one participant went into granular detail about schools providing accommodations, transition supports, and mindful planning to meet student needs:

> Having access to a least restrictive environment in school, that meant being able to take a test or quiz in the hallway or in different rooms where I wasn't surrounded by other students who may have been distracting me. So, having an opportunity tests in a quieter environment where I wasn't surrounded by other people helped me concentrate more. That was a very important thing. Also, having access to a note taker who took better notes than I did helped me to remember everything that the instructor had said in class rather than me trying to jot it all down. The transition planning was essential for going from special education to the regular classroom environment. So, when I was in fourth grade I made a big transition from my special education program to regular elementary school. They did that by doing it one day a week, then two-three-four days a week rather than doing it all at once. So, a gradual mainstreaming approach is good rather than doing it all at once. I think that is very important. (Participant 6)

Additional findings. Similar to supportive families and close friendships, three participants (4 codes, *n* = 3) said community support was essential. Two participants (3 codes, *n* = 2) discussed the importance of having access to safe and solitary spaces during times of stress or dysregulation. Others understanding ASD (3 codes, *n* = 3), finding shared interest groups (2 codes, *n* = 2), having college encouraged (2 codes, *n* = 2), and existing in a culture of acceptance (1 code, *n* = 1) were also important external protective factors shared by participants.

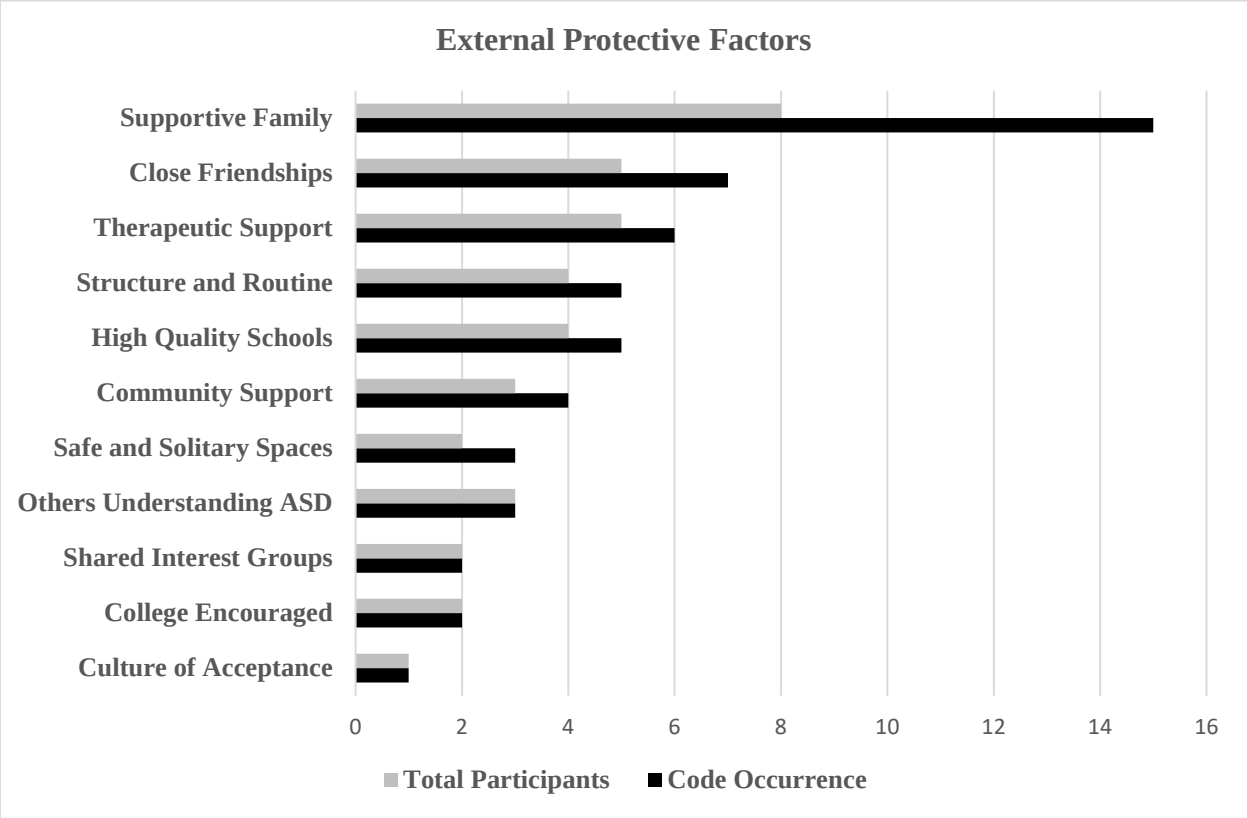

Figure 2. Descriptive Statistics of Code Occurrences and Total Participants for External Protective Factors.

RQ2: What internal and external factors do autistic adults perceive as contributors to risk of adversity?

Internal Risk Factors

Sensory sensitivity. Sixty percent of interviewees (14 codes, $n = 6$) said sensory sensitivity was a critical internal risk factor that often leads to challenges and adversity. Though it has long been known that autistics endure many sensory struggles, the depth and complexity of those challenges is still underestimated by others. Sounds ranging from loud and sudden crashes to "unpleasant eating sounds that other people make" (Participant 6) can require the use of headphones or leaving environments all together. Sight-based sensory challenges can result from fluorescent or harsh lighting in buildings, stores, and classrooms. One participant noted that fluorescent lighting is "something that really affects my thinking. It hard to focus and concentrate" (Participant 7). Unpredictable and sudden changes created by things like caution lights or lightning storms startling and problematic**.** Tactile sensitivities were described as having a limiting effect on clothing options, food choices, and even food consumption.

Participants were clear in their description of the cumulative effect of sensory events stacking up on one another. One interviewee said to "keep in mind that when we get overwhelmed sometimes it is a combination of sensory elements that can contribute, intensify, and become overwhelming" (Participant 7). Another person also described the problematic internal risks associated with negative sensory accumulation:

> I hate the sound of hammering. I don't really like the sound of beeping. But, if things like that happen and they keep going on…that I can probably answer. If it's a set of things that are all added together, then I can't differentiate. I can't give you a plan because I am too overwhelmed processing what I am processing to be able to tell you what I want. I

> wish I could tell people what I wanted, and I normally can if you give me time and help me get out of the immediate environment. (Participant 5).

Sometimes escape from troublesome environments is not possible as noted by one participant who illustrated "being in spaces when you can't escape from it. Whether it's sensory overload, or if you have a lot of people, you are trying to soak in too much information and processing a lot and you can't do it. It's overwhelming" (Participant 7).

In addition, the coping strategies some autistics use to regulate are discouraged or not allowed:

> I struggled with self-regulation. Big time. And the ways I coped were often not allowed in places like school or public settings. But I followed direction well. If I was redirected, I complied, and took note of all that was not allowed. However, I did not really replace the non-allowed things with anything. So…I stayed dysregulated. (Participant 9)

When autistics do try to stay regulated and comfortable in settings where they are the minority people tend to misunderstand their needs "since the default expectations and methods for interaction are centered around neurotypical experience" (Participant 9).

Over-trusting others and naivety. Seventy percent of participants (9 codes, $n = 7$) relayed that over-trusting others and naivety are internal characteristics that often lead to increased risk and adversity. In a broad sense, participants said this can manifest as people taking advantage of them without being able to detect it right away. They also said their desire to follow rules can set them up for vulnerability. One respondent said they were a "very straight laced person. If you tell me to do something I will do it. I'm not rebellious" (Participant 3). Autistic honesty exacerbates this phenomenon. Participant 5 said "I'm not often aware of how vulnerable I am because I am so honest. It's not that I am unaware of myself. I don't have ill motives. I don't see other people as having ill motives."

Manipulation can occur as a result of this naivety. An interviewee shared the risks they experience as a result:

> I don't like to think the worst in people. It's hard for me to tell right away about red flags. So, if someone is acting charming it's harder for me to detect if they are actually being manipulative or if they're trying to flirt with me…I like to give people chances but sometimes I get into situations where I give too many chances. So that can lead me to greater risk and to pitfalls. (Participant 7).

Exploitation was also a theme expressed by participants. Over-trusting others, especially in business transactions, can have exploitative consequences. A participant who is a small business owner said "I've learned how hard it is to know when someone puts on the trusting act but really just wants to rip you off…there are some areas where maybe it does make it easier for us to get in those traps" (Participant 8). Participants also described having their personal and private information shared on the internet without permission by people they thought were trustworthy. The connection between over-trusting and naivety to the risk of sexual, physical, and mental abuse was mentioned by several participants. One participant summarized this internal risk factor with haunting precision:

> There are very manipulative bad people out there, but because I'm not bad I don't have the theory of mind to process that somebody else could be looking at me that way. I don't process it, so it's not real. So, I don't take it into consideration when I am factoring the social dynamics of the situation. It's easy to hurt me at work or interpersonally, take advantage of me sexually, professionally…because I am probably honest with you in a way that you are not used to but I'm not aware of that because that's how I am. If you have that awareness of both what I'm doing not being normal and what your motives are,

> it's like Pinocchio and the Cat in the Box…they are able to get him to come to Pleasure Island to take advantage of him. It's not that he has ignorance. He does have agency. What he doesn't know is that other people are terrible. That's different. He did make the choice to go. He made the choice to go based on the idea that the people who were telling him to go were as good as he was. That's the difference. (Participant 5)

Decoding social information. Half of those interviewed (7 codes, $n = 5$) said difficulties with decoding social information was an internal risk factor they have experienced. Being able to read people, discern between joking and bullying, and determine where social lines intersect or evaporate was mentioned. Also, participants discussed the difficulty with navigating various social environments and the shifting social rules in places like schools and workplaces. Deciphering between social hierarchies like "how you're supposed to interact with your co-workers or your boss in a social way" (Participant 4) was shared. To add to the social confusion, participants highlighted a "disconnect between what we are taught in autism therapies and then go out in the real world and realize that the social rules literally change every day. It's hard to know what rulebook to play by" (Participant 8).

Over-empathy. One third of participants (5 codes, $n = 3$) communicated challenges with over-empathy as internal risks they experience. For example, feelings of deep empathy led some interviewees to become over bearing with people who were grieving the recent loss of loved ones. Others reported taking in overwhelming amounts of energy from large crowds or social settings and being unable to process the gravity of all of the incoming emotional energy. One participant described this phenomenon:

> We still have empathy where we really do feel emotions very deeply and I would argue that sometimes it does look like we are cold or we appear to limit contact with other

> people or struggle to express emotions – it's not because we don't have them. It's because we experience them so deeply that it's too overwhelming. Those are things that people need to understand. (Participant 7)

These instances of deep over-empathy can manifest as physical pain as well. A respondent called their experience compassionate empathy and said "When I see somebody hurting, actually injured, I actually feel it behind my knees…like feel it…I'll actually feel the pain in certain places" (Participant 10). Therefore, the physical and emotional toll over-empathy can take led some participants to note it as a complex internal risk factor.

Feelings of alienation. Forty percent of interviewees (5 codes, $n = 4$) said feelings of alienation were common internal risk factors in their lives. Feelings of alienation were described as not having anywhere to fit in, and feeling wrong and bad. One participant shared their perspective by saying "I don't go out and make those connections. I am not naturally a person that goes out and makes those things unless those were already happening by accident…plus my interests right now are not things I could talk about as much" (Participant 5). Many said they felt it was hard to be fully included and were not included in outside activities like school functions, parties, social outings, and dinners. A participant said "I still feel like people at work hang out amongst themselves more than I do. I feel like sometimes I am excluded, and I feel let down when I don't get wedding invitations that I hear that other co-workers get" (Participant 6). Several communicated the desire to feel accepted, to belong, to fit in, and understand the world around them.

Additional findings. Two participants (4 codes, $n = 2$) said missing the big picture was an internal risk factor. Being detail oriented but failing to see how all of the details combine into big pieces of information was noted. Compulsive rule following was shared by three people (4

codes, *n* = 3) who said that being overly driven by rules presents challenges when life requires deviation. Driving was given as an example where rules need to be bent or broken sometimes to ensure safety. Tactical empathy challenges were described by three participants (3 codes, *n* = 3) as internal struggles with understanding how one's actions will impact another person or situation, and gauging what others are thinking or feeling in social exchanges. Three participants (3 codes, *n* = 3) listed over-fixation, especially on romantic interests, as internal risk factors. Finally, the need for external validation (3 codes, *n* = 2), masking (2 codes, *n* = 2) or hiding one's autism, managing unfamiliar stimuli (2 codes, *n* = 1), and not seeking help or advice (1 code, *n* = 1) rounded out the participants' list of internal risk factors.

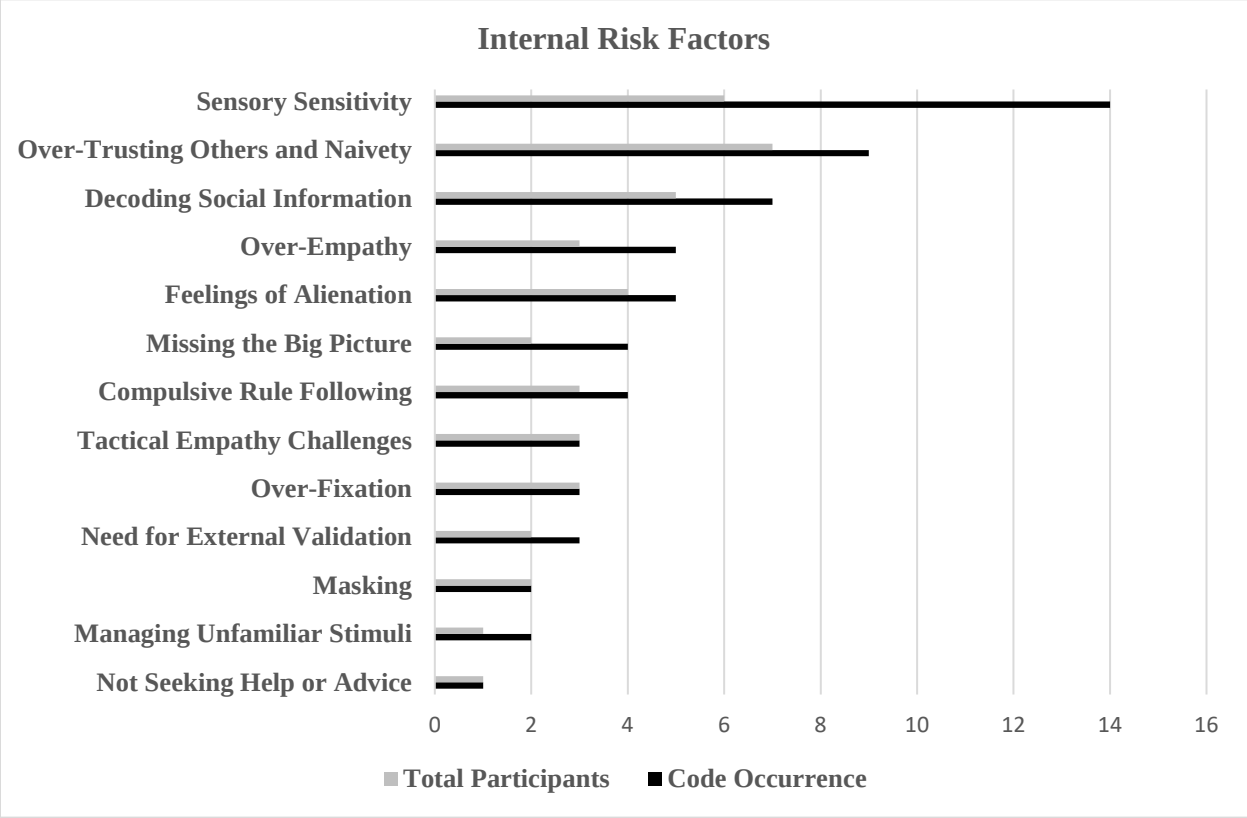

Figure 3. Descriptive Statistics of Code Occurrences and Total Participants for Internal Risk Factors.

External Risk Factors

False ASD myths and misunderstanding. Eighty percent of interviewees (18 codes, *n* = 8) discussed the risks false ASD myths and misunderstanding create. First, participants shared how a surface level understanding of ASD can lead to challenges. For instance, many said non-autistics do not seem to know "how the autistic experience works. People are aware of the word autism but don't really understand how it can really affect a person…we don't get as much empathy and it makes it hard for us to be accepted and understood" (Participant 7). This shallow understanding can be especially challenging when crisis or overload happens and those around autistics do not know how to provide quality support.

Participants have struggled when institutions like colleges have not understood their needs. One person said "College was horrible. College was probably worse than grade school and high school because it was a lot of professors that just weren't even understanding. That was what broke me honestly" (Participant 2). Another participant had a similar experience saying "One thing that I have found in my PhD program is no one is really willing to learn about autism and understanding what it is. For me, personally, I don't necessarily need them to adapt themselves completely but just understanding what I go through is helpful" (Participant 10). These experiences seem to be reflected in employment myths; one participant said "I think most people may not see us as good employees or people in society. Most people think we are not able to be by ourselves, able to do things on our own" (Participant 3).

Autistics shared that they sometimes encounter people who say they understand ASD, but that understanding does not always translate to flexibility:

> One of the biggest challenges and threats is not necessarily a lack of understanding, but a lack of flexibility. So, people may say "I understand if you have ASD, or I understand if

> you're autistic" but they might not be willing to really give flexibility or leeway to those with it. So, you're at work, right, and you start to get some sensory overload going on and it can be difficult to say "hey, I'm going to head home for the rest of the day or take a little break or whatever." That can be hard for some people to understand. They can't really relate with it. (Participant 4)

According to interviewees, disclosing their diagnosis to others who may believe in certain myths or have misunderstandings about ASD can result in being treated with less respect and can even lead to others accusing them of faking their autism.

Participants shared beliefs about the role they believe media has played in the creation and perpetuation of myths about ASD. Several people referenced movies like *Rain Man* and more recent shows like *The Good Doctor* and *Atypical* as contributing to the myths about autism. Specifically, one person said:

> People with autism, because it presents so differently, if your construct and concept is based on Dustin Hoffman in a movie from decades ago, who also didn't have autism, then what happens is it's hard for people to conceptualize difference in presentation. The most difficult challenges are living as a person within a disability that is hard for people to contemplate and understand because it presents itself socially and behaviorally. And it presents differently in every single person. And it doesn't match any of the cultural identifiers that we ascribe to other things like race or gender, where we have expectations of what something looks like that do match up to some degree. (Participant 5)

Participants talked about a future where people on the outside looking in at autism accept autistic communication as different not faulted, and "accept that most people want to be good, most people want to be employed, most people want purpose, and most people want to be loved"

(Participant 5). A final note of summary on this particular external risk factor was shared by one study participant:

> Lack of understanding in society about Neurodiversity Paradigm. This is a big one. For so long, differences in wiring have been pathologized, and seen as abnormal and/or in need of correction. Expectations in society and within systems (school, work, etc.) that prioritize and reaffirm concepts of "normal" create great challenges and risks to all people who do not naturally operate within those parameters. (Participant 9)

Sensory triggers and distraction. Six out of ten respondents (12 codes, $n = 6$) discussed sensory triggers and distraction as external risks that lead to greater challenges and adversity. Things like bright lights, sharp, loud or unexpected sounds, agitating colors, and chaotic and crowded environments were frequently recapitulated codes. Participants talked about the negative effect sensory triggers and distractions have on their daily lives. One person said they would "go into their office at midnight and work until 3 or 4 in the morning, and now I'm realizing because it was quiet and there were no distractions" (Participant 5).

Discrimination and devaluing. Forty percent of those interviewed (8 codes, $n = 4$) described some experience with external risks related to discrimination and devaluing. Specific discrimination from professionals were shared. One person communicated a situation with their pharmacist who as soon as they said they were autistic, would not make eye contact with them and started to talk to her friend over her. They said they "left there fighting a meltdown" (Participant 2). Participants described feeling like they had to prove they came into this world and were allowed to live in it. Discrimination and devaluing made one respondent think "Well, maybe I'm not worth being here, maybe I'm not worth being with these people" (Participant 3). These external threats also tend to devalue autistics' concepts of self-identity. One person

expanded on this idea by saying “Stop challenging other people’s identity. If a person comes to you and tells you who they are, unless you are a neuroscientist who tells you who they are to diagnose them, really their diagnosis is not your business” (Participant 5). Finally, one interviewee detailed the external risks that come with the discrimination and devaluing of autistics:

> False constructs and concepts of what is “acceptable” assume that there are right and wrong ways to experience and interact in the world, regardless of whether a person is causing harm. The result is that people who are NOT neurotypical (who do not fall in the majority in terms of how their brains operate) are at an automatic disadvantage. Not only are they at a disadvantage by being overlooked in the planning/development phases of all systems that affect them, but they are seen as being or doing “wrong” just by the fact that their ways of doing things are already considered “inappropriate” if outside of the norm.

Poor design and architecture. Half of those interviewed (6 codes, $n = 5$) discussed external risks as a result of poor design and architecture. Similar to conversations about sensory triggers, participants shared how environments are frequently chaotic, loud, bright, crowded, and overwhelming. The use of harsh fluorescent lights and agitating colors was also noted. Participants talked about how it seems designers of spaces and environments have created barriers to society and hazards without realizing it. Small changes to create better environments were often suggested:

> I do think in general, where I work, we have tons of empty office spaces…there should be a room where I should be able to leave that is not marked, where you cannot find me, where you cannot ask for my help, where I should be able to escape from time to time, so that I am not visible and not being called upon…maybe in 20 minutes I will feel like

going back to be called upon. I think a safe space would be helpful. And that could accommodate a lot of needs as you could have a lot of things in there. (Participant 5)

Another simple solution suggested by an interviewee was a public alert system in malls or buildings if a planned, predictable loud noise or major sensory event was about to occur. Participants talked about the changes in mindsets needed to make better environments, and one person concluded by saying if "we would just find those little things to adjust we could all fit in together and it would work well and we wouldn't have so many autistics unemployed…struggling" (Participant 2).

Bullying. Fifty percent of participant (6 codes, $n = 5$) said bullying was an external risk factor they had experienced. The forms described ranged from cyberbullying through social media to actual physical threats and attacks. Some participants felt being different made them stand out as targets as "people don't like things that are different necessarily. It scares them. So when someone notices something different they may poke fun at it, and may see it as something like 'Oh, I can make fun, I can bully' because that's their way of looking at it" (Participant 1). Instances of bullying were said to have occurred across the educational span from elementary school to college. The effects of bullying are lasting as one person said "when I was bullied it would really stick with me even if it was something little or minor I would dwell on that" (Participant 8).

Abuse. Thirty percent of those interviewed (6 codes, $n = 3$) communicated they had experienced abuse in their lifetimes. Manipulation by others was often not realized until months-worth of the abuse had been occurring. One person reported not being able to recognize occurrences of abuse until "it's over and I have to reflect on it" (Participant 5). Sexual assault and abuse by medical professionals were described as external risks that led to complex cases of

post-traumatic stress disorder, and one participant said “I hope that the odds of me encountering more of those sociopaths I would hope are low considering the relative frequency when I was younger. I would hope that ends” (Participant 5).

Additional findings. Large crowds or social gatherings (5 codes, *n* = 4), and a lack of safe spaces for regulation (5 codes, *n* = 4) were listed as external risk factors by 40% of participants. Finally, poverty, low quality schools, loss of a parent, law enforcement interaction, and difficulties with housing (1 code, *n* = 1) were each shared by at least one participant.

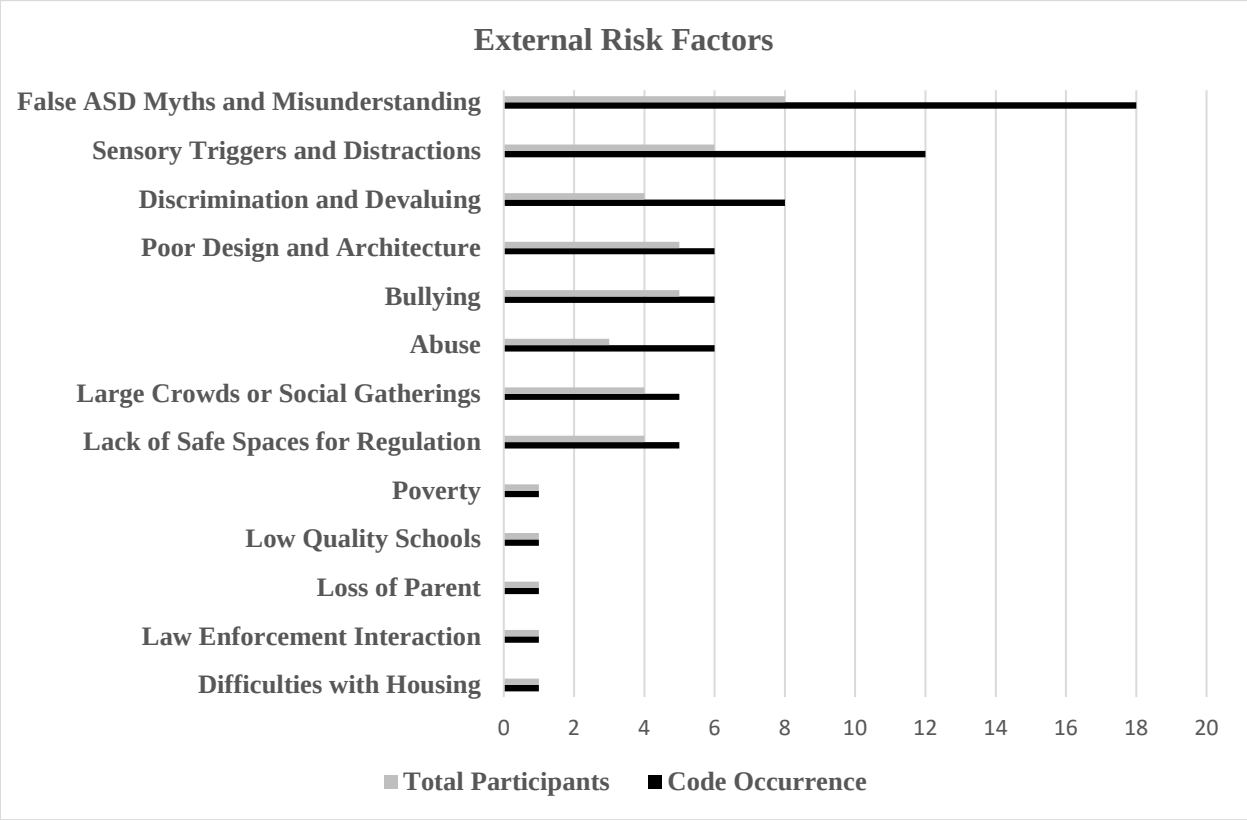

Figure 4. Descriptive Statistics of Code Occurrences and Total Participants for External Risk Factors.

RQ3: How do these factors match with, or diverge from, broadly accepted resilience factors from existing literature?

The literature review in Chapter 2 generated a condensed list of internal and external risks and protections from a variety of well-established sources on resilience. That list from the literature review found in Table 1 of this study was then combined with results from participant interviews and codes from the present study to form Table 3. The table allowed for visual inspection, comparison, and analysis of both sets of data to help answer research question three. Codes from this study on autistic resilience were represented in the table in italics. Autistic resilience codes matching themes from the literature review were blended in the literature and ASD column of the table. Themes from the literature and codes from this study that did not match were charted in their own respective columns.

The first data point of interest was the percentage of overlap between themes from the literature review and the ASD codes generated by this study. Nineteen of the 24 (87.5%) themes pulled from the literature were matched to the ASD codes.

Overlap from the reverse direction was also calculated. Protective internal factor comparison showed 43.8% of the ASD codes overlapped with literature themes, while 56.2% of ASD codes were unique. Protective external factor analysis revealed 45.5% of the ASD codes overlapped with literature themes, and 54.5% of ASD codes were unique. Internal risk factor comparison showed 38.5% of the ASD codes overlapped with literature themes, while 61.5% of ASD codes were unique. Finally, external risk factor analysis revealed 46.2% of the ASD codes overlapped with the literature themes, and 53.8% of ASD codes were unique.

Resilience Domain	**Literature Only**	**Literature *and ASD***	***ASD Only***
Protective Internal	-Social competence	-Agency, motivation to adapt *-Self-reliance and self-advocacy* *-Asking for help*	*-Intense fixations and hyper-focus* *-Detail oriented*

	-Hope, faith, optimism -Meaning making, belief life has meaning	-Problem solving, planning, executive functioning skills *-Intelligence* *-Persistence* -Self-regulation, emotional regulation *-Stress management and coping* -Positive views of self or identity *- Self-awareness* - Routines and rituals *- Rule following*	*-Deep empathy and compassion* *-People pleasing* *-Honesty* *-Creativity* *-Retaining information* *-Loyalty* *-Awareness of diagnosis*
Protective External	-Opportunities to explore and dream	-Nurturing, sensitive caregiving -Skilled parent management and discipline tailored to child *- Supportive family* -Attachment relationships, emotional security, belonging *-Close friendships* *-Community support* *-Shared interest groups* -Schools with high standards and values -Well trained and compensated teachers *-High quality schools* -Opportunities to rest *-Safe and solitary spaces* -External affirmation of worth and capability **Need for external validation*	*-Therapeutic support* *-Structure and routine* *-Others understanding ASD* *-College encouraged* *-Culture of acceptance*
Risks Internal	-Adverse birth factors	-Cognitive challenges *-Missing the big picture* *-Compulsive rule following* *-Over-fixation* -Absence of problem solving and behavior regulation skills *-Managing unfamiliar stimuli*	*-Sensory sensitivity* *-Over-trusting others and naivety* *-Decoding social information* *-Over-empathy* *-Feelings of alienation* *-Tactical empathy challenges* *-Masking* *-Not seeking help or advice*
Risks External		-Parent abuse, divorce, illness *-Abuse* *-Loss of parent* -Schools lacking resources and qualified staff *-Low quality schools* -Low socio-economic status (SES) *-Poverty* -Dangerous neighborhoods *-Difficulties with housing*	*-False ASD myths and misunderstandings* *-Sensory triggers and distractions* *-Poor design and architecture* *-Bullying* *-Large crowds or social gatherings* *-Lack of safe spaces for regulation* *-Law enforcement interaction*

		-Racism and discrimination -*Discrimination and devaluing*	

Table 3. Sorted List of Combined Factors from Literature Review and Participant Interview Codes (***code from internal risks matched with external protection element)**

RQ4: How can resilience factors unique to the autistic experience inform systems design and implementation?

Resilience factors identified by autistic adults based on their lived experience closely match those identified in the extensive research on resilience. To date, however, no exploration has been conducted to determine if and how autistic resilience expands beyond those core factors, and this study was the first attempt to take on that task. Interviews, transcription, coding, checks for credibility, and analysis over the course of this study revealed several unique factors that play an important role in autistic resilience.

As discussed in Chapter 2, people who are autistic can face high levels of risk and adversity which can lead to concerning challenges with transitions to adulthood, bullying, abuse, health risks, and even suicide. Also, the inherent strengths of autistics, many of which were shared by participants in this study, are often overlooked or left out of systems of support all together. Organizing the resilience factors discovered in this study into fresh taxonomies to help schools, colleges, places of employment, and other systems assess needs to help build autistic resilience is paramount.

Building Resilience in Youth and Adults

Tables 4 and 5 are pilot-level tools called the *Autistic Resilience Checklist – Youth* (ARCH-Y) and the *Autistic Resilience Checklist – Adult* (ARCH-A). Each checklist was created using results from this study and differ slightly in language use. While these tools are still in the

early stages of development, each can be implemented by people with ASD or those working with them to help assess how given systems are performing in terms of fostering resilience.

Autistic Resilience Checklist – Youth
ARCH-Y
(Pilot Tool)

Domain	Element	Element Not in Place	Element Partially in Place	Element Fully in Place	I'm Not Sure
Strengths	*Intense fixations and hyper-focus are channeled into many experiences, lessons, and activities*				
	Persistence is encouraged, channeled, and rewarded				
	Creativity is encouraged and creative solutions to tasks or problems are accepted				
	Tendencies for deep empathy and compassion are recognized and valued				
	Honest opinions and viewpoints are sought and included				
Environment	*Adequate stress management and coping options are available*				
	Safe and solitary spaces are available for regulation				
	Sensory triggers and distractions are limited				
	Regulation options are in place during large group or crowded social activities				
	Structures and routines are in place to help with clarity, predictability, and expectations				
	Inclusion with peers and others is ongoing				
Curricular	*Lessons in self-discovery that build self-awareness (strengths, preferences, tendencies, triggers, etc.)*				
	Access to information, peers, or experiences that encourage identity				
	Lessons in self-advocacy: communicating wants, needs, asking for help, etc.				
	Lessons in self-care to mitigate stress, over-fixation, dysregulation, etc.				
	Lessons that build on interests with opportunities to share interests with others				
	Lessons to help with decoding social information, over-trusting others, naivety, etc.				
	Lessons in interpreting the signals and intentions of others				
	Lessons in processing the emotional experiences of others				
	Lessons in applying small details to bigger picture				
	Opportunities to try tasks or experiences without unnecessary help or prompting				
Culture	*Family is supportive and actively engaged*				
	Close friendship(s) exist				
	Community connections and support exist				

	Others deeply understand, accept, and value those with ASD				
	People provide rich and positive external validation of those with ASD				
	Bullying, exploitation, and abuse are not tolerated, and action is taken to prevent and remediate				

Table 4. Sample of the *Autistic Resilience Checklist - Youth* (ARCH-Y) Pilot Tool.

Autistic Resilience Checklist – Adult **ARCH-A** (Pilot Tool)					
Domain	**Element**	**Element Not in Place**	**Element Partially in Place**	**Element Fully in Place**	**I'm Not Sure**
Strengths	*Intense fixations and hyper-focus are channeled into many experiences, lessons, and activities*				
	Persistence is encouraged, channeled, and rewarded				
	Creativity is encouraged and creative solutions to tasks or problems are accepted				
	Tendencies for deep empathy and compassion are recognized and valued				
	Honest opinions and viewpoints are sought and included				
Environment	*Adequate stress management and coping options are available*				
	Safe and solitary spaces are available for regulation				
	Sensory triggers and distractions are limited				
	Regulation options are in place during large group or crowded social activities				
	Structures and routines are in place to help with clarity, predictability, and expectations				
	Inclusion with peers and others is ongoing				
Curricular	*Experiences in self-discovery that build self-awareness (strengths, preferences, tendencies, triggers, etc.)*				
	Access to information, peers, or experiences that encourage identity				
	Support in self-advocacy: communicating wants, needs, asking for help, etc.				
	Support in self-care to mitigate stress, over-fixation, dysregulation, etc.				
	Experiences that build on interests with opportunities to share interests with others				
	Support with decoding social information, over-trusting others, naivety, etc.				
	Support with interpreting the signals and intentions of others				

	Support with processing the emotional experiences of others				
	Support with applying small details to bigger picture				
	Opportunities to try tasks or experiences without unnecessary help or prompting				
Culture	*Family is supportive and actively engaged*				
	Close friendship(s) exist				
	Community connections and support exist				
	Others deeply understand, accept, and value those with ASD				
	Others provide rich and positive external validation of those with ASD				
	Bullying, exploitation, and abuse are not tolerated, and action is taken to prevent and remediate				

Table 5. Sample of the *Autistic Resilience Checklist - Adult* (ARCH-A) Pilot Tool.

Results from completed checklists can help autistics, teachers, administrators, faculty advisors, employers, and consultants identify areas of strengths and needs in a given system and use that information to bolster resilience-based supports. Many more studies and applications are needed to refine these tools and methods, but results from this study have provided the first step in the movement toward resilience-based approaches to ASD.

CHAPTER 5: SUMMARY, DISCUSSION OF FINDINGS, AND RECOMMENDATIONS

The purpose and methods of this study are summarized in Chapter 5. Also included in the chapter is a discussion of the findings for each of the study's research questions, implications, limitations, and recommendations for future research.

Purpose

People with autism are at risk for adversity. Research indicates suicide, early mortality, targeted bullying, underemployment, low rates of post-secondary education, social isolation, and safety concerns make up the core risks associated with a diagnosis of ASD. The study of resilience has focused on both risk and protective factors as they relate to adversity; resilience approaches work to reduce risk and vulnerability through a focus on the strengths and assets of at-risk individuals. Before this study, research and practice in the area of resilience and ASD, however, are virtually non-existent.

To date, approaches to ASD support typically focus on deficits and remediating the perceived challenges accompanying an ASD diagnosis, and those without a diagnosis often define what life is like for those with ASD. The high risk of adversity, lack of data on resilience and ASD, and missing representation of authentic autistic experience in ASD research created a need to answer central questions related to ASD and resilience. This study investigated what resilience factors autistics identify based on their lived experiences and how those factors can contribute to the design of stronger systems of support.

Methods

This study had one primary data collection goal: to ascertain what autistic adults believe about factors that contribute to their resilience as no previous research had addressed this topic

by directly asking members of the community. An in-depth review of resilience literature was completed, and a composite list of accepted resilience factors was used to compare against factors identified by study participants.

A phenomenological research design was employed to generate emic data through participant interviews. Purposive non-random sampling was used to recruit study participants; snowball sampling was used to recruit additional participants as needed. A sample of adults with an ASD diagnosis was recruited from the autistic population in West Virginia and its contiguous states of Kentucky, Maryland, Ohio, and Virginia. Two participants from each of the five aforementioned states were recruited to achieve a target sample size of $N = 10$. Participants from the sample met four criteria for inclusion in the study: (a) be age 22 – 47 at the time of interview, (b) have successful completion of at least a Bachelor's degree or vocational program, (c) live independently, and (d) have a reliable form or forms of expressive communication. Participants with reliable expressive communication, vocalized or augmented, were included to open participation to a wider variety of communication styles.

After the interviews were conducted, the process of data coding began. Phenomenological research methods followed those described by McMillan (2015), Groenewald (2004), and others. First, bracketing and phenomenological reduction occurred to control for personal views and preconceptions. Next, units of meaning were delineated from individual interview responses and clustered into codes. Careful attention was paid to emerging codes with high and low frequencies. Checks for validity were conducted by sending individual interview summaries to select participants. Peer debriefing by a colleague and an external audit by a reviewer who was unaware of the details of the study were used to check for credibility. Codes were sorted into a quadrant based on the research questions for ease of analysis. Each code was

arranged in a frequency hierarchy so those high and low-frequency responses could be easily tracked. Finally, research question three was answered by merging the interview and literature review data sets to identify themes and units unique to non-ASD research, those shared by both non-ASD and ASD domains, and those unique to the experiences of adults with ASD.

Findings

RQ1: What internal and external factors do autistic adults perceive as protections against adversity?

Internal Protective Factors. Fifty percent of study participants (10 codes, $n = 5$) mentioned the benefits of the intense fixation and hyper-focus that can be part of having autism. For example, intense fixations helped participants find degrees and courses that eventually led to careers. Fixation and hyper-focus can have an impact on work performance. Being able to focus on tasks for long periods of time was referenced as a strength. Intense fixation and hyper-focus can also protect against adversity by providing purpose and coping strategies when executive function challenges occur. Intense fixations and hyper-focus can help autistics develop a unique identity. Specialization can lead to a uniqueness that helps define one's self and even connect to others with similar interests.

Many participants (7 codes, $n = 5$) commented on the importance of developing deeper self-awareness to overcome adversity and challenges in their lives. Specific examples expressed were "learning what your triggers are instead of assuming that your triggers are somebody else's" (Participant 2), and breaking down the "social aspects, academic aspects, communication aspects" (Participant 3) and how they are individually relevant. A better understanding of self also helps individuals take more informed action in their lives.

Persistence, grit, and tenacity were mentioned by almost half of the participants (6 codes, *n* = 4), and was represented by discussions of hardworking attitudes, being go getters, and wanting to accomplish goals. The protective nature of persistence is powerful; some participants said persistence was what helped them, more than anything, to push through challenges. One third of participants (5 codes, *n* = 3) described the power of self-reliance on their ability to grow and overcome challenges. Having to navigate a world on their own was seen as a powerful stepping-stone to greater independence and success.

Almost half of this study's participants (5 codes, *n* = 4) cited the power of being detail oriented and how that strength can help overcome challenges. While the general community does recognize autistic tendencies toward details, they tend to see detail orientation as pathological and not beneficial. Autistics can be "very good at specific oriented tasks" (Participant 6) which can lead to fresh perspectives on systems and the world.

Deep empathy and compassion (5 codes, n = 3) were shared as internally protective by one third of participants who described being able to deeply feel the emotions of others and energy that is generated in environments and social situations. Stress management and coping (4 codes, n = 4) were discussed by four participants; engaging in art, music, and special interests were referenced as being especially helpful with stress and coping. Three participants listed people pleasing (3 codes, n = 3) as being something that drives them to succeed in school, careers, and life in general and comes from a deep desire to contribute and make others happy. Intelligence was mentioned by two participants (3 codes, n = 2) who said it was essential to increased access and opportunity. Honesty (3 codes, n = 3), shared by 3 participants, was considered a positive internal aspect that is important in friendships, careers, or other situations where trustworthiness and directness is needed. Creativity (3 codes, n = 2) was seen as an

important internal protection that can be leveraged in careers. Self-advocacy skills (2 codes, n =1), rule following (2 codes, n = 2), retaining information (2 codes, n = 2), loyalty (2 codes, n = 2), asking for help (2 codes, n = 1), and having an awareness of one's diagnosis (1 code, n = 1) were seen as important internal protective aspects as well.

External Protective Factors. Eighty percent of participants (15 codes, *n* = 8) responded that the support they received from family was a critical external protective factor. Familial support in the form of moral, ethical, and practical guidance were general themes. More specifically, families provided safe environments for personal growth. Often, families are active in the advocacy process for autistics. Half of those interviewed (7 codes, *n* = 5) said close friendships were vital external factors determining their success. Many noted that they may not have a large circle of friends, they prefer quality over quantity, and that friendships often take a long time to develop. Friendships are valued for the good influence they have on the participants' lives and can be especially powerful when they are found in work environments.

Fifty percent of interviewees (6 codes, *n* = 5) described the importance of solid therapeutic support in their lives. Various occupational, speech, and physical therapies were listed. Cognitive behavioral-type therapy was also said to have helped participants learn new skills and perspectives that helped them succeed in their lives. Almost half of the study participants (5 codes, *n* = 4) shared the importance of structure and routine as external protections. One participant said they needed structure to help with executive functioning saying "sometimes I need a guide for what I need to do and trying to get my life in order" (Participant 6). Another participant discussed the power of visual supports and schedules.

Forty percent of interviewees (5 codes, *n* = 4) conveyed that high quality schools played an externally protective part in their lives. Schools that provided clear academic and social

guidance were appreciated. Schools who took bullying prevention and remediation were seen as especially protective. More specifically, one participant went into granular detail about schools providing accommodations, transition supports, and mindful planning to meet student needs.

Similar to supportive families and close friendships, three participants (4 codes, $n = 3$) said community support was essential. Two participants (3 codes, $n = 2$) discussed the importance of having access to safe and solitary spaces during times of stress or dysregulation. Others understanding ASD (3 codes, $n = 3$), finding shared interest groups (2 codes, $n = 2$), having college encouraged (2 codes, $n = 2$), and existing in a culture of acceptance (1 code, $n = 1$) were also important external protective factors shared by participants.

RQ2: What internal and external factors do autistic adults perceive as contributors to risk of adversity?

Internal Risk Factors. Sixty percent of interviewees (14 codes, $n = 6$) said sensory sensitivity was a critical internal risk factor that often leads to challenges and adversity. Sounds ranging from loud and sudden crashes to "unpleasant eating sounds that other people make" (Participant 6) can require the use of headphones or leaving environments all together. Sight-based sensory challenges can result from fluorescent or harsh lighting in buildings, stores, and classrooms. Unpredictable and sudden changes created by things like caution lights or lightning storms startling and problematic**.** Tactile sensitivities were described as having a limiting effect on clothing options, food choices, and even food consumption.

Seventy percent of participants (9 codes, $n = 7$) relayed that over-trusting others and naivety are internal characteristics that often lead to increased risk and adversity. In a broad sense, participants said this can manifest as people taking advantage of them without being able to detect it right away. They also said their desire to follow rules can set them up for

vulnerability. The connection between over-trusting and naivety to the risk of sexual, physical, and mental abuse was mentioned by several participants.

Half of those interviewed (7 codes, $n = 5$) said difficulties with decoding social information was an internal risk factor they have experienced. Being able to read people, discern between joking and bullying, and determine where social lines intersect or evaporate was mentioned. Also, participants discussed the difficulty with navigating various social environments and the shifting social rules in places like schools and workplaces. One third of participants (5 codes, $n = 3$) communicated challenges with over-empathy as internal risks they experiences. For example, feelings of deep empathy led some interviewees to become over bearing with people who were grieving the recent loss of loved ones. Others reported taking in overwhelming amounts of energy from large crowds or social settings and being unable to process the gravity of all of the incoming emotional energy.

Forty percent of interviewees (5 codes, $n = 4$) said feelings of alienation were common internal risk factors in their lives. Feelings of alienation were described as not having anywhere to fit in, and feeling wrong and bad. Two participants (4 codes, $n = 2$) said missing the big picture was an internal risk factor. Being detail oriented but failing to see how all of the details combine into big pieces of information was noted. Compulsive rule following was shared by three people (4 codes, $n = 3$) who said that being overly driven by rules presents challenges when life requires deviation. Driving was given as an example where rules need to be bent or broken sometimes to ensure safety. Tactical empathy challenges were described by three participants (3 codes, $n = 3$) as internal struggles with understanding how one's actions will impact another person or situation, and gauging what others are thinking or feeling in social exchanges. Three participants (3 codes, $n = 3$) listed over-fixation, especially on romantic interests, as internal risk

factors. Finally, the need for external validation (3 codes, *n* = 2), masking (2 codes, *n* = 2) or hiding one's autism, managing unfamiliar stimuli (2 codes, *n* = 1), and not seeking help or advice (1 code, *n* = 1) rounded out the participants' list of internal risk factors.

External Risk Factors. Eighty percent of interviewees (18 codes, *n* = 8) discussed the risks false ASD myths and misunderstanding create. First, participants shared how a surface level understanding of ASD can lead to challenges. For instance, many said non-autistics do not seem to know "how the autistic experience works. People are aware of the word autism but don't really understand how it can really affect a person…we don't get as much empathy and it makes it hard for us to be accepted and understood" (Participant 7). This shallow understanding can be especially challenging when crisis or overload happens and those around autistics do not know how to provide quality support.

Six out of ten respondents (12 codes, *n* = 6) discussed sensory triggers and distraction as external risks that lead to greater challenges and adversity. Things like bright lights, sharp, loud or unexpected sounds, agitating colors, and chaotic and crowded environments were frequently recapitulated codes. Participants talked about the negative effect sensory triggers and distractions have on their daily lives.

Forty percent of those interviewed (8 codes, *n* = 4) described some experience with external risks related to discrimination and devaluing. Specific discrimination from professionals were shared. Participants described feeling like they had to prove they came into this world and were allowed to live in it. Half of those interviewed (6 codes, *n* = 5) discussed external risks as a result of poor design and architecture. Similar to conversations about sensory triggers, participants shared how environments are frequently chaotic, loud, bright, crowded, and overwhelming. The use of harsh fluorescent lights and agitating colors was also noted.

Participants talked about how it seems designers of spaces and environments have created barriers to society and hazards without realizing it. Small changes to create better environments were often suggested.

Fifty percent of participants (6 codes, $n = 5$) said bullying was an external risk factor they had experienced. The forms described ranged from cyberbullying through social media to actual physical threats and attacks. Thirty percent of those interviewed (6 codes, $n = 3$) communicated they had experienced abuse in their lifetimes. Manipulation by others was often not realized until months-worth of the abuse had been occurring. Sexual assault and abuse by medical professionals were described as external risks that led to complex cases of post-traumatic stress disorder,

Large crowds or social gatherings (5 codes, $n = 4$), and a lack of safe spaces for regulation (5 codes, $n = 4$) were listed as external risk factors by 40% of participants. Finally, poverty, low quality schools, loss of a parent, law enforcement interaction, and difficulties with housing (1 code, $n = 1$) were each shared by at least one participant.

RQ3: How do these factors match with, or diverge from, broadly accepted resilience factors from existing literature?

The literature review in Chapter 2 generated a condensed list of internal and external risks and protections from a variety of well-established sources on resilience. That list was then combined with results from participant interviews and codes from the present study to visually inspect, compare, and analyze both sets of data to help answer research question three.

The first data point of interest was the percentage of overlap between themes from the literature review and the ASD codes generated by this study. Nineteen of the 24 (87.5%) themes pulled from the literature were matched to the ASD codes. Overlap from the reverse direction

was also calculated. Protective internal factor comparison showed 43.8% of the ASD codes overlapped with literature themes, while 56.2% of ASD codes were unique. Protective external factor analysis revealed 45.5% of the ASD codes overlapped with literature themes, and 54.5% of ASD codes were unique. Internal risk factor comparison showed 38.5% of the ASD codes overlapped with literature themes, while 61.5% of ASD codes were unique. Finally, external risk factor analysis revealed 46.2% of the ASD codes overlapped with the literature themes, and 53.8% of ASD codes were unique.

RQ4: How can resilience factors unique to the autistic experience inform systems design and implementation?

Resilience factors identified by autistic adults based on their lived experience closely matched those identified in the extensive research on resilience. To date, however, no exploration has been conducted to determine if and how autistic resilience expands beyond those core factors, and this study was the first attempt to take on that task. Interviews, transcription, coding, checks for credibility, and analysis over the course of this study revealed several unique factors that play an important role in autistic resilience.

People who are autistic can face high levels of risk and adversity which can lead to concerning challenges with transitions to adulthood, bullying, abuse, health risks, and even suicide. Also, the inherent strengths of autistics, many of which were shared by participants in this study, are often overlooked or left out of systems of support all together. RQ4 was answered through the process of organizing the resilience factors discovered in this study into fresh taxonomies. Pilot-level tools called the *Autistic Resilience Checklist – Youth* (ARCH-Y) and the *Autistic Resilience Checklist – Adult* (ARCH-A) were created using results from this study. These tools are still in the early stages of development but were designed to be implemented by

people with ASD or those working with them to help assess how given systems are performing in terms of fostering resilience**.** Results from completed checklists can help autistics, teachers, administrators, faculty advisors, employers, and consultants identify areas of strengths and needs in a given system and use that information to bolster resilience-based supports.

Implications

This study is the first attempt to gather input directly from autistics on their experiences with resilience and, subsequently, the first touchstone in the literature from which new research can be built. Findings indicate that people who are autistic build resilience much in the way others do: through a combination of strong external supports and internal, personal factors. However, autistics experience a fair portion of external and internal risks that are not shared by the population-at-large. Many of those autistic-specific factors were identified in this study. It appears that a blanket approach to resilience may miss some of the unique factors affecting those with ASD. This uniqueness requires unique approaches.

Currently, there is no proven way to assess the adequacy of a given system in terms of its fostering of resilience in autistics. This study at the very least provides a starting point; the ARCH-Y and ARCH-A may begin to serve as useful tools in that assessment process. More research with continued input from the ASD community will be needed to grow and refine this field.

The information generated by this study may help shift focus away from deficits to include autistic strengths. Also, knowing more about the positive environmental and cultural supports that increase resilience, and doing more to build those supports may affect quality of life. It is possible this knowledge may be used to reduce bullying, prevent abuse, help with transitions, and ultimately lead to longer, happier lives for people who are autistic.

Limitations

Several limitations were inherent in this study. Participants were required to have certain communication and language skills to complete the semi-structured interview. As a result, limitations with external validity were possible, as the responses provided by the sample may not fully represent those with certain learning and communication differences in the ASD population. The relatively small sample size of 10 participants, though rich enough to achieve saturation, is another limitation. Additionally, the geographic boundary used to focus recruitment may have introduced certain biases based on region-specific variables.

Limitations with this study's measures and methods also require discussion. For example, participants' ability or willingness to describe their experiences through the interview may have varied, resulting in challenges with validity and reliability. The conceivable limitations of subjectivity of coding and researcher bias common in qualitative studies also deserve attention.

Recommendations for Future Research

- Replications of this interview and data collection process should be conducted in unique geographic locations to check the reliability and credibility of this study's findings.
- Delphi-type studies should be conducted using the identified factors to determine how autistics rank internal and external factors on the basis of importance and if those rankings match the frequency distributions discovered through interviews.
- Studies testing the validity and reliability of the ARCH-Y and ARCH-A should be completed to build stronger, more accurate assessments.
- In-depth studies of environmental design and architecture should be conducted to learn more about creating spaces that are more socially and sensory friendly to autistics.

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APPENDIX A: IRB APPROVAL LETTER

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IRB2 #00003206

October 25, 2019

Dennis Anderson, Ph.D.
Leadership Studies Department

RE: IRBNet ID# 1513779-1
At: Marshall University Institutional Review Board #2 (Social/Behavioral)

Dear Dr. Anderson:

Protocol Title:	[1513779-1] Authentic Perspectives on Autistic Resilience: Implications for Schools and Society	
Site Location:	MU	
Submission Type:	New Project	APPROVED
Review Type:	Exempt Review	

In accordance with 45CFR46.104(d)(2), the above study was granted Exempted approval today by the Marshall University Institutional Review Board #2 (Social/Behavioral) Designee. No further submission (or closure) is required for an Exempt study **unless** there is an amendment to the study. All amendments must be submitted and approved by the IRB Chair/Designee.

This study is for student Andrew Nelson.

If you have any questions, please contact the Marshall University Institutional Review Board #2 (Social/Behavioral) Coordinator Anna Robinson at (304) 696-2477 or robinsonn1@marshall.edu. Please include your study title and reference number in all correspondence with this office.

Sincerely,

Bruce F. Day, ThD, CIP
Director, Office of Research Integrity

APPENDIX B: SEMI-STRUCTURED INTERVIEW

AUTHENTIC PERSPECTIVES ON AUTISTIC RESILIENCE: IMPLICATIONS FOR SCHOOLS AND SOCIETY

Semi-Structured Interview

Andrew Nelson

This interview is designed to gather information from autistic adults on various aspects of adversity, risk, and resilience in their lives to understand unique experiences. The interview will be digitally recorded, transcribed, coded, and analyzed. Some interviewees may be asked to review results later in order to check the validity of coding and analysis. All recordings and data will be stored and protected according to the confidentiality protocol established by the study's Institutional Review Board (IRB). Contact information for the IRB is available should you have any questions or concerns regarding your rights as a subject in this study.

Interview Questions

1. What is your age?
2. What is your sex or preferred gender identity?
3. What is your highest level of education?
4. What is your current living situation?
5. Do you have a preference for person-first or identity-first language?

6. What personal, internal aspects within you do you believe have helped you succeed and overcome challenges in your life?
   a) how did those positive internal aspects play a role in your childhood/school, post-secondary, and independent living experiences?

7. What personal, internal aspects within you do you believe led to increased challenges or risks in your life?
   a) how did those challenging internal aspects play a role in your childhood/school, post-secondary, and independent living experiences?

8. What external or environmental aspects outside of you do you believe helped you succeed

and overcome challenges in your life?

a) how did those positive external aspects play a role in your childhood/school, post-secondary, and independent living experiences?

9. What external or environmental aspects outside of you do you believe led to increased challenges or risks in your life?

a) how did those challenging external aspects play a role in your childhood/school, post-secondary, and independent living experiences?

10. Do you recall if you participated in transition planning as part of your school supports as you prepared for graduation?

11. What do you believe are the most important strengths of autistics or people with ASD?

12. What do you believe are the most critical challenges that come with a diagnosis of ASD?

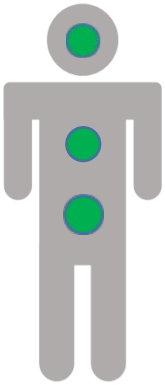
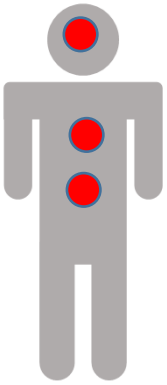
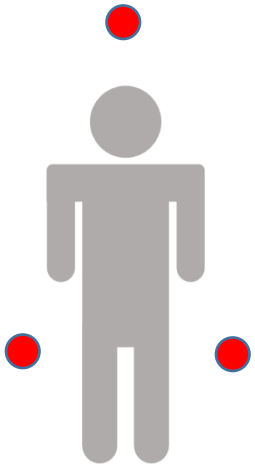
13. What do you believe are the most important environmental supports for autistics or people with ASD?

14. What do you believe are the biggest environmental threats or challenges for people with ASD?

APPENDIX C: SEMI-STRUCTURED INTERVIEW VISUAL GUIDE

AUTHENTIC PERSPECTIVES ON AUTISTIC RESILIENCE: IMPLICATIONS FOR SCHOOLS AND SOCIETY

Semi-Structured Interview Visual Guide

Internal - Protections  Childhood-School? Post-Secondary? Independent Living?	**Internal - Risks**  Childhood-School? Post-Secondary? Independent Living?
External – Protections  Childhood-School? Post-Secondary? Independent Living?	**External - Risks**  Childhood-School? Post-Secondary? Independent Living?

APPENDIX D: AUTISTIC RESILIENCE CHECKLIST – YOUTH (ARCH-Y)

Autistic Resilience Checklist – Youth
ARCH-Y
(Pilot Tool)

Domain	Element	Element Not in Place	Element Partially in Place	Element Fully in Place	I'm Not Sure
Strengths	*Intense fixations and hyper-focus are channeled into many experiences, lessons, and activities*				
	Persistence is encouraged, channeled, and rewarded				
	Creativity is encouraged and creative solutions to tasks or problems are accepted				
	Tendencies for deep empathy and compassion are recognized and valued				
	Honest opinions and viewpoints are sought and included				
Environment	*Adequate stress management and coping options are available*				
	Safe and solitary spaces are available for regulation				
	Sensory triggers and distractions are limited				
	Regulation options are in place during large group or crowded social activities				
	Structures and routines are in place to help with clarity, predictability, and expectations				
	Inclusion with peers and others is ongoing				
Curricular	*Lessons in self-discovery that build self-awareness (strengths, preferences, tendencies, triggers, etc.)*				
	Access to information, peers, or experiences that encourage identity				
	Lessons in self-advocacy: communicating wants, needs, asking for help, etc.				
	Lessons in self-care to mitigate stress, over-fixation, dysregulation, etc.				
	Lessons that build on interests with opportunities to share interests with others				
	Lessons to help with decoding social information, over-trusting others, naivety, etc.				
	Lessons in interpreting the signals and intentions of others				
	Lessons in processing the emotional experiences of others				
	Lessons in applying small details to bigger picture				
	Opportunities to try tasks or experiences without unnecessary help or prompting				
Culture	*Family is supportive and actively engaged*				
	Close friendship(s) exist				
	Community connections and support exist				
	Others deeply understand, accept, and value those with ASD				

	People provide rich and positive external validation of those with ASD				
	Bullying, exploitation, and abuse are not tolerated, and action is taken to prevent and remediate				

APPENDIX E: AUTISTIC RESILIENCE CHECKLIST – ADULT (ARCH-A)

Autistic Resilience Checklist – Adult
ARCH-A
(Pilot Tool)

Domain	Element	Element Not in Place	Element Partially in Place	Element Fully in Place	I'm Not Sure
Strengths	*Intense fixations and hyper-focus are channeled into many experiences, lessons, and activities*				
	Persistence is encouraged, channeled, and rewarded				
	Creativity is encouraged and creative solutions to tasks or problems are accepted				
	Tendencies for deep empathy and compassion are recognized and valued				
	Honest opinions and viewpoints are sought and included				
Environment	*Adequate stress management and coping options are available*				
	Safe and solitary spaces are available for regulation				
	Sensory triggers and distractions are limited				
	Regulation options are in place during large group or crowded social activities				
	Structures and routines are in place to help with clarity, predictability, and expectations				
	Inclusion with peers and others is ongoing				
Curricular	*Experiences in self-discovery that build self-awareness (strengths, preferences, tendencies, triggers, etc.)*				
	Access to information, peers, or experiences that encourage identity				
	Support in self-advocacy: communicating wants, needs, asking for help, etc.				
	Support in self-care to mitigate stress, over-fixation, dysregulation, etc.				
	Experiences that build on interests with opportunities to share interests with others				
	Support with decoding social information, over-trusting others, naivety, etc.				
	Support with interpreting the signals and intentions of others				
	Support with processing the emotional experiences of others				
	Support with applying small details to bigger picture				
	Opportunities to try tasks or experiences without unnecessary help or prompting				
Culture	*Family is supportive and actively engaged*				
	Close friendship(s) exist				
	Community connections and support exist				

	Others deeply understand, accept, and value those with ASD				
	Others provide rich and positive external validation of those with ASD				
	Bullying, exploitation, and abuse are not tolerated, and action is taken to prevent and remediate				