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UNDERSTANDING CHILDHOOD ADVERSITY AND RESILIENCE: PERSPECTIVES OF AUTISTIC ADULTS

BY

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Submitted by

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Dedication

For Asher—my playmate, entertainer, and source of joy throughout this work.

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Abstract

The purpose of this thesis project was to better understand the effects of childhood adversity on autistic individuals and the role of resilience in mitigating those effects. A review of the literature indicated that, despite vast research on these phenomena in the general population, little is known about their influence on the well-being of individuals on the autism spectrum. To understand these phenomena better, I employed interpretative phenomenological analysis (IPA), integrating participatory methods to ensure the research question, design, and analysis were congruent with the wishes and perspectives of the autistic community. Four autistic adults volunteered for this study and, through semi-structured interviews, described their experiences of adversity and resilience in childhood and adolescence. Adversity had long-term negative effects on the well-being of participants, while resilience meant an improvement in well-being in young adulthood. Autism/autistic characteristics interacted with both adversity and resilience to contribute to the well-being of participants.

Keywords: autism, childhood adversity, ACEs, resilience, mental health, interpretative phenomenological analysis, participatory methods, ethical autism research

Preface

The following thesis is comprised of three manuscripts prepared for publication in academic journals. The first is a review of the literature on the topic of childhood adversity and resilience in individuals on the autism spectrum. It has been submitted and is under review with *Disability & Society.* The second article is a methodological reflection on integrating participatory methods into interpretative phenomenological analysis and has been prepared for *International Journal of Qualitative Methods*. The third and final article describes the findings of this study and has been prepared for the journal *Autism.*

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Chapter I — Introduction

The effects of childhood adversity in the non-autistic population is well documented. There is a demonstrated correlation between adversity in childhood and poor mental and physical health outcomes in adulthood (Bright et al., 2016; Felitti et al., 1998; Hughes et al., 2017). There is also evidence that these outcomes can be mitigated by internal and external protective factors, which are developed in childhood. The mitigating effect of protective factors on physical and mental health outcomes is called resilience (Herrman et al., 2011; Moore & Ramirez, 2016; Rigles, 2017). Children diagnosed on the autism spectrum experience more adversity in childhood than non-autistic children (Berg et al., 2016; Rigles, 2017) yet the impact of these experiences is relatively unstudied, as is the concept of resilience. Epidemiological studies that analyzed the relationship between resilience and adversity in children on the autism spectrum have had inconsistent results (e.g., McCrimmon et al., 2016; Rigles, 2017), pointing to a need to understand how resilience is experienced by children on the autism spectrum.

Additionally, there is an emerging trend to make autism-related research more ethical by including members of the autism community in the research process by seeking their input on research priorities and study design, and by including them in dissemination activities (Chown et al., 2017; Pellicano, 2014; Pellicano & Stears, 2011). Historically, autism-related researchers have excluded autistic perspectives and often explored issues in autism through a non-autistic lens, perpetuating the power imbalance experienced by autistic individuals in society (Milton & Bracher, 2013). As such, it is important to engage in research that includes the perspectives of autistic individuals with a focus on minimizing power imbalances between researchers and participants

(Pellicano, 2014; Pellicano & Stears, 2011). Furthermore, researchers often rely only on their singular perspectives in contributing to knowledge production about autism. It is important that they consider that other stakeholders in the autism community, including autistic self-advocates, parents and caregivers of individuals on the autism spectrum, and practitioners working with the community have valuable insights that can inform the direction and implementation of autism-related research (Orsini & Davidson, 2013; Pellicano, 2014).

Statement of Problem

If children on the autism spectrum are to be provided with sufficient and effective mental health supports, practitioners need to understand better how adversity and resilience are experienced by children on the autism spectrum and the potential effects of those experiences on their well-being. Furthermore, these experiences need to be understood from an autistic perspective, privileging the expertise of autistic individuals in their own lived experiences.

Purpose

The main purpose of this study is to understand how autistic adults describe and make meaning of their childhood experiences of adversity and resilience, particularly in relation to their emotional well-being in both childhood and adulthood. Additional objectives, however, are to add to the growing body of literature on conducting ethical and participatory autism-related research, through the integration of participatory research approaches into an interpretative phenomenological analysis (IPA) methodology.

Research Question

How do autistic adults, who experienced adversity in childhood, understand the influence of those experiences on their well-being and the meaning of resilience in their lives?

Definition of Terms

The following terms relate to the conceptualization of this study:

Autism is a developmental disorder that is neurologically based and occurs in all races, genders, ethnicities, and social classes (Centers for Disease Control [CDC], 2020, National Institute of Mental Health [NIMH], 2020). The prevalence of autism has increased dramatically in the last two decades, from 1 in 150 children diagnosed in 2000 to 1 in 54 currently (CDC, 2020). Those who are diagnosed on the autism spectrum demonstrate a range of functioning levels and abilities (American Psychiatric Association [APA], 2013a). Autism is characterized by two main areas of impairment: (a) difficulty with social communication and (b) restricted, repetitive patterns of behaviour (NIMH, 2020). The impairment in social communication often manifests as difficulty with the pragmatics of social interactions, that is, engaging others, expressing or recognizing feelings, understanding relationships, and adjusting to different social contexts (Lord & Jones, 2012; NIMH, 2020). Restricted, repetitive behaviours may appear as unusual motor movements, speech patterns, hyper-focused interests, or resistance to changes in routines (NIMH, 2020). The current diagnostic label identified in the 5th edition of *Diagnostic and Statistical Manual* (*DSM-5*; APA, 2013a) is ***autism spectrum disorder***. However, prior to the publication of *DSM*-5, the diagnostic criteria and labelling system were different and included diagnoses of ***autistic disorder***, ***Asperger's syndrome***, and

pervasive developmental disorder-not otherwise specified (PDD-NOS; APA, 2013b). For the purposes of this study, given that participants will have received their diagnoses in childhood, which was likely prior to the publication of *DSM-5*, participants with any autism-related diagnosis were included. For consistency of language throughout this thesis, the term autism will be used to refer to autism spectrum disorder or any other autism-related diagnosis.

Neurodiversity refers to the understanding of autism, attention deficit hyperactivity disorder (ADHD), and learning disabilities as neurological differences, rather than disorders or pathologies that need to be treated. Furthermore, the neurodiversity movement promotes autism as a unique way of being and characterizes many autistic characteristics as strengths rather than deficits (Baron-Cohen, 2017; O'Dell et al., 2016; Silberman, 2015). As such, in this thesis, I will refer to autism as a difference, which may have co-occurring disorders, such as language delays or intellectual disability (Baron-Cohen, 2017).

For the purposes of this study, I will use the terms ***autistic*** and ***on the autism spectrum*** to describe a person diagnosed with autism. While there is controversy within the autism and autistic communities regarding the use of *person-first* (i.e., person with autism) and *identity-first* (i.e., autistic person) language (Brown, 2011; Kenny et al., 2016), many autistic individuals have identified identity-first language to be preferable to traditional person-first language (Kenny et al., 2016; National Autistic Society [NAS], 2018). This terminology is congruent with the neurodiversity perspective.

Neurotypical refers to individuals who are not neurodivergent, that is, do not possess the neurological differences associated with autism (Baron-Cohen, 2017).

Childhood refers to the period from birth to an individual’s 18th birthday.

The ***autistic community*** refers to individuals who identify as being on the autism spectrum, while the ***autism community*** includes individuals on the spectrum and their allies and supporters, such as family members, practitioners, and researchers (Iraeidle, 2019; Kenny et al., 2016; Pellicano et al., 2014).

Chapter II — Research Paradigm and Interpretive Framework

Social Constructivism

In qualitative research, we have the opportunity to explore aspects of human experience through different perspectives, or paradigms. I conducted this study from the social constructivist paradigm, as my goal was to gain insight into the individual and collective understandings of specific phenomena. From the social constructivist perspective, the nature of knowledge, or ontology, is not universal nor singular (Creswell & Poth, 2018). In interpretative phenomenological analysis (IPA), my chosen methodology for this study, researchers place an emphasis on understanding the meaning participants make of their experiences, rather than looking for universality of described experiences (Smith et al., 2009). As such, there is room in IPA to hold space for multiple ways of interpreting the same phenomenon, without privileging one reality over another. One of the underlying philosophies of IPA is that the meaning participants attribute to their experiences is constructed through interaction with the researcher, which the researcher in turn interprets through their own lens (Smith et al., 2009). This is congruent with the epistemological stance of social constructivists—knowledge is created in a given context through the interactions of those individuals experiencing it (Creswell & Poth, 2018). Axiologically, social constructivists understand values to be socially created and understood within historical and cultural contexts; socially constructed values will influence both researchers and participants in their interpretations of meaning (Creswell & Poth, 2018). Through a social constructivist lens, IPA researchers pay attention to context and recognize that experiences and interpretations exist only within that context (Smith et al., 2009).

Critical Autism Studies

Critical autism studies is an area of study that has been influenced by the emancipatory approach to research of disability studies (O'Dell et al., 2016) and through which autism is viewed as a socially constructed concept, with expression and understanding of it fluctuating across contexts (Orsini & Davidson, 2013; O'Dell et al., 2016). While critical autism studies are an evolving and complex area of study, Orsini and Davidson (2013) identified three key features of critical autism studies:

1. Careful attention to the ways in which power relations shape the field of autism
2. Concern to advance new, enabling narratives of autism that challenge the predominant (deficit-focused and degrading) constructions that influence public opinion, policy, and popular culture
3. Commitment to develop new analytical frameworks using inclusive and nonreductive methodological *and* theoretical approaches to study the nature and culture of autism (p. 24-25)

I used the principles of critical autism studies and social constructivism to guide my methodological decisions throughout the research process, particularly in attending to power imbalances and approaching autism from a strengths-based narrative. Additionally, I viewed autism through the lens of neurodiversity, considering autism as a diagnostic label but not as a pathology or problem, instead conceptualizing autism as a neurological difference and cultural identity. Reflexivity, collaboration, and consultation with members of the autism and autistic communities helped to keep me grounded in the philosophical assumptions of social constructivism and the principles of critical autism studies.

Chapter III — Literature Review Article

Childhood adversity, resilience, and autism: A review of the literature

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Abstract

The long-term, negative physical and mental health effects of childhood adversity are well-documented in the literature, as are the mitigating effects of resilience factors. However, for those on the autism spectrum, these phenomena are relatively unstudied and not well-understood. Articulating the concept of mental health as a function of childhood adversity, resilience, and autistic identity provides a foundation from which to conduct research and provide clinical mental health supports to individuals on the autism spectrum. Research on adversity and resilience in this population must consider neurodiversity and foreground the perspectives of the autism and autistic communities in research design, study implementation, and findings dissemination.

Points of Interest

- The prevalence of mental health disorders and rates of childhood adversity are higher in children on the autism spectrum when compared to the general population, which points to a need to understand this relationship from the perspective of autistic individuals.
- The development of resilience in children on the autism spectrum is not well-understood but is potentially necessary to mitigate the impacts of childhood adversity in this population.
- In this paper, I argue that researchers and clinicians developing and offering mental health supports to individuals on the autism spectrum need to consider the

influence of childhood adversity and resilience factors within the context of an autistic identity.

- Understanding these phenomena and their relationships to each other is best accomplished by seeking the insight and input of the autistic community as participants and partner researchers

Keywords: autism; adversity; resilience; children; mental health; research

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Introduction

The effects of childhood adversity on individuals in the general population is well-documented. There is a demonstrated correlation between adversity in childhood and poor mental and physical health outcomes in adulthood (Bright et al., 2016; Felitti et al., 1998; Hughes et al., 2017). There is also evidence that these outcomes can be mitigated by internal and external protective factors, which are developed in childhood — a phenomenon known as resilience (Bellis et al., 2018; Gartland et al., 2019; Herrman et al., 2011; Liu et al., 2020; Moore & Ramirez, 2016). The role of resilience in promoting the wellbeing of children and adults who have faced adversity is important because experts have noted that facilitating the development of resilience is an easier task than trying to avoid adversity (Avdagic et al., 2018). However, the influence of adversity and resilience on the health outcomes of children on the autism spectrum has not been as thoroughly studied and is not well-understood. Children diagnosed on the autism spectrum experience more adversity in childhood than their non-autistic peers (Berg et al., 2016; Rigles, 2017), yet the impact of these experiences is relatively unstudied, as is the concept of resilience. Epidemiological studies that analysed the relationship between resilience and adversity in children on the autism spectrum have had inconsistent results (e.g., McCrimmon et al., 2016; Rigles, 2017; Schneider et al., 2019), pointing to a need for further research that explores how resilience is experienced by children on the autism spectrum.

The experiences of mental health in individuals on the autism spectrum are complex. The literature on the prevalence of mental health disorders has shown varied results and has highlighted the diversity of these experiences (Lai et al., 2019). While there is evidence indicating that children on the autism spectrum experience mental disorders at a high rate (Centers for Disease Control and Prevention [CDC], 2020; Joshi et al., 2010; Madden et al., 2017; Soke et al., 2018; Wijnhoven et al., 2019), there is a paucity of literature on the factors that influence the development of mental health disorders in this population. For example, epidemiological studies have only provided insight into the higher rates of adversity faced by children on the autism spectrum and have not described the long-term influence of these phenomena on mental health (e.g., Berg et al., 2016; Rigles, 2017).

Furthermore, there is a tendency among researchers to identify mental health disorders as co-morbid to autism (e.g., Joshi et al., 2010; Madden et al., 2017; Soke et al., 2018), implying that autism is a disorder that occurs alongside other mental health diagnoses. The perspective that autism is a separate, independent disorder to be treated does not account for the possible influence that being autistic has on one's mental health. Understanding autism through a *neurodiversity* lens, that is, as a neurological difference with unique strengths, rather than a disorder characterized by deficits (Baron-Cohen, 2017; Silberman, 2015), allows us to conceptualize autism as an identity that may influence how one experiences adversity and resilience, and the subsequent impact on mental health. The purpose of this literature review is to discuss the mental health outcomes of children on the autism spectrum, conceptualized as a function of their experiences of adversity, resilience, and autistic identity. Their unique experiences of these phenomena and the potential influence on mental health must be considered when determining appropriate and effective mental health supports for both autistic children and adults. Implications for future research are also discussed.

Considering Neurodiversity: Autism as Identity Not Pathology

How researchers and clinicians view an autism diagnosis is important in the development of mental health supports. The current health system pathologizes autistic characteristics, leading clinicians and researchers to focus on the treatment of autism (Baron-Cohen, 2017; O'Dell et al., 2016; Ripamonti, 2016). When autism is pathologized and viewed as a co-morbidity to other mental health disorders, clinicians and researchers focus on interventions that reduce autistic characteristics and make autistic individuals appear 'more normal' (Hodge, 2013). In contrast, a more wholistic approach to mental health can be achieved by embracing a *neurodiversity* lens when conceptualizing mental health challenges in individuals on the autism spectrum.

Neurodiversity suggests that autism is not a disorder, disease, or problem to be fixed; rather, it is a neurological difference that fosters distinct abilities (Baron-Cohen, 2017; O'Dell et al., 2016; Silberman, 2015). Baron-Cohen (2017) suggested that viewing autism through a neurodiversity lens is analogous to discussing handedness — being left-handed or right-handed is neither good nor bad, functional nor dysfunctional; it is simply a difference. Additionally, for those on the autism spectrum, symptoms resulting from traumatic experiences can manifest as an increase in autistic behaviours (Wood & Gadow, 2010), which may mask the significance of traumatic experiences on autistic individuals. Rather than taking a pathologizing perspective and thus focusing on changing autistic behaviours, clinicians and researchers embracing neurodiversity can be attuned to the possible influence of childhood experiences on an autistic individual's presenting behaviours.

Through a neurodiversity lens, autism is both a diagnosis and an identity, developed within a sociocultural context (O’Dell et al., 2016), and comes with unique strengths (Silberman, 2015). Ripamonti (2016), paraphrasing Stanley Hauerwas, noted the sociocultural belief that those with disabilities are distressed by their disability. However, often the distress people with disabilities feel is due to being different, in this case autistic, within a society that does not value or accept difference (Hodge, 2013). This sociocultural belief that disability is a problem that exists within a person is misplaced and leads to the pathologizing of autism and the need to fix that problem (Hodge, 2013). Thus, embracing neurodiversity invites *neurotypical* (non-autistic) researchers, clinicians, and supporters to identify and provide supports that respect and integrate a person’s unique autistic traits into the process, rather than trying to change them.

Furthermore, by moving away from pathologizing autism to focusing on a person’s autistic identity, researchers and clinicians can explore the interaction of an autistic identity, childhood adversity, and the development of resilience on the mental health of individuals on the autism spectrum. From a neurodiversity perspective, autistic individuals are the experts of their own neurodivergent experiences and are best suited to interpret their experiences for a neurotypical audience (Silberman, 2015). As such, neurotypical researchers and clinicians must rely on autistic individuals to make meaning of their own experiences of childhood adversity and resilience and provide us with their insights.

Adversity

In 1998, Felitti and colleagues published a ground-breaking study in which they demonstrated the link between adversity, or *adverse childhood experiences (ACES),* and poor physical and mental health outcomes in adulthood. Subsequently, many researchers have studied this relationship in a variety of contexts and populations. A Google search revealed how ubiquitous the research on adversity and health has become. A search of Google Scholar for articles on ACEs in the last 20 years showed 327,000 results, suggesting it is a topic that is well-studied in the general population. However, there are significantly fewer studies exploring the effects of adversity on children on the autism spectrum. From the available research, it is apparent that individuals on the autism spectrum experience adversity at a higher rate than their neurotypical peers (Berg et al., 2016; Rigles, 2017), which suggests that adversity negatively impacts the mental health of children on the autism spectrum.

Traumatic Effects of Adversity

In the current literature on adversity in childhood, researchers used various terminology to describe these experiences, including *trauma/traumatic events* (American Psychological Association [APA], 2008; Kerns et al., 2015; Kisiel et al., 2009; Mehtar & Mukaddes, 2011; Taylor & Gotham, 2016; Van der Kolk, 2005), *adverse childhood experiences* (Bellis et al., 2018; Felitti et al., 1998; Hughes et al., 2017; Moore & Ramirez, 2016; Rigles, 2017; Thakur et al., 2017), *adversity* (Berg et al., 2016; Bright et al., 2016), and *stressors* (Wood & Gadow, 2010). Regardless of the chosen terminology, these researchers have similarly described childhood experiences of sexual, physical, or psychological abuse (Felitti et al., 1998; Hughes et al., 2017; Kerns et al., 2015; Mehtar

& Mukaddes, 2011; Moore & Ramirez, 2016; Van der Kolk, 2005), domestic or community violence (Berg et al., 2016; Felitti et al., 1998; Hughes et al., 2017; Kerns et al., 2015; Mehtar & Mukaddes, 2011; Moore & Ramirez, 2016; Taylor & Gotham, 2016; Thakur et al., 2017; Van der Kolk , 2005), parental death or injury (Berg et al., 2016; Hughes et al., 2017; Taylor & Gotham, 2016), parental mental illness or addiction (Berg et al., 2016; Felitti et al., 1998; Moore & Ramirez, 2016; Taylor & Gotham, 2016; Thakur et al., 2017), bullying/victimization by peers (Hughes et al., 2017; Taylor & Gotham, 2016; Wood & Gadow, 2010), parental divorce or separation (Berg et al., 2016; Hughes et al., 2017; Taylor & Gotham, 2016), poverty (Berg et al., 2016; Hughes et al., 2017; Moore & Ramirez, 2016), and natural disasters (Kerns et al., 2015; Mehtar & Mukaddes, 2011; Van der Kolk, 2005). According to the American Psychological Association (2008) "a traumatic event is one that threatens injury, death, or the physical integrity of self or others and also causes horror, terror, or helplessness at the time it occurs" (p. 2).

Trauma can be acute, happening only once, or can occur repeatedly over time (APA, 2008; Kerns et al., 2015). The severity of trauma can vary, but there is consensus that the effects of prolonged trauma are more destructive than the effects of a single traumatic event (APA, 2008). As such, any of the above examples could be traumatizing to an individual, with the perceptions and impacts of such events varying from person to person (APA, 2008; Kerns et al.,2015). Given this variability, I use the more general term *adversity* to describe experiences that have the potential to be traumatizing, except in instances that require the above terminology for clarity.

Adversity Among Children on the Autism Spectrum

The evidence for the assertion that children on the autism spectrum are exposed to adversity at greater rates is found in the 2011-2012 National Survey of Children's Health (NSCH), in which researchers gathered parent reports of children's health from participants across the United States (U.S.); and, when compared with the general population, parents reported that their children on the autism spectrum had experienced more ACEs (Berg et al., 2016; Rigles, 2017). ACEs that were most commonly experienced by children on the autism spectrum were related to family distress, including financial issues, divorce, death of a parent, and parental mental health disorders (Berg et al., 2016; Rigles, 2017). Berg and colleagues (2016) also identified a significantly higher incidence of neighbourhood violence for children on the autism spectrum.

In addition to the high prevalence of ACEs in children on the autism spectrum, there is also the potential for them to experience adversity in the form of victimization by their peers (Hoover & Romero, 2019; Pfeffer, 2016; Rowley et al., 2012). Parents reported high rates of physical assault and bullying directed toward their children diagnosed with autism (Pfeffer, 2016), and children on the autism spectrum, aged 8-14, self-reported teasing and bullying as the most common experiences of adversity in their lives (Hoover & Romero, 2019). Furthermore, children on the autism spectrum in inclusive education settings experienced more bullying than those who attended specialized sites (Rowley et al., 2012). Inclusive education is a right granted to all students diagnosed with autism by the United Nations' Convention on the Rights of Persons with Disabilities (2006) and, in 2017, 58% of U.S. students diagnosed on the autism spectrum attended inclusive education classes at least 40% of the time, with

39.7% of students attending inclusive classes 80% of their day or more (U.S. Department of Education, 2019). This means that almost half of autistic students in the U.S. are at high risk of being victims of bullying at school. Most concerning about this is that children on the autism spectrum were likely to experience more than one instance of victimization in their lifetimes (Pfeffer, 2016), which is known to have more damaging effects than experiencing only one adverse or traumatic event (APA, 2008).

Evidence that children on the autism spectrum face more adversity than their neurotypical peers compels us to understand how these stressors impact their wellbeing. While the effects of adversity on children on the autism spectrum is unclear, we know from studies of neurotypical children that adversity is negatively correlated with both physical and mental health (Bellis et al., 2018; Bright et al., 2016; Rigles, 2017). For example, adversity is correlated with childhood illnesses such as digestive problems, allergies, headaches, asthma, and reports of overall poor health (Bellis et al., 2018). Children with ACE scores of one or more are also significantly more likely to have a mental, physical, or developmental disorder, with higher ACE scores being associated with multiple disorders (Bright et al., 2016).

It is clear that adversity is associated with a lack of physical and mental wellbeing in children, with increased incidence being related to a greater number and severity of problematic outcomes (Bright et al., 2016). Given the significant exposure to adversity that many children on the autism spectrum experience, it is reasonable to conclude that adversity has a serious impact on the mental health of children on the autism spectrum; this, however, has not been studied. Instead, we look to the extensive literature on the presentation and prevalence on mental health disorders in children on the autism spectrum to inform our understanding of their experiences.

Experiences of Mental Health Disorders in Children on the Autism Spectrum

The prevalence of mental health disorders in children and adolescents on the autism spectrum is alarmingly high (CDC, 2020; Joshi et al., 2010; Madden et al., 2017; Soke et al., 2018), The relationship between mental health disorders and autism is complicated and varied, particularly across developmental stages (Ryan et al., 2018; Soke et al., 2018; Vasa et al., 2020). Additionally, mental health professionals have often ignored the relationship, underdiagnosing mental health disorders in children on the autism spectrum (Stadnick et al., 2017), which points to a need for a better understanding of the influence of adversity and resilience on the mental health of children on the autism spectrum.

Common Mental Health Disorders Experienced by Children on the Autism Spectrum

The most commonly occurring mental disorders in children on the autism spectrum are attention disorders, anxiety disorders, depression, and behavioural disorders, which occur at higher rates than in neurotypical children (Joshi et al., 2010; Madden et al., 2017). For instance, children on the autism spectrum are 2.5 times more likely to experience depression than their peers (Madden et al., 2017). Especially troubling is that children on the autism spectrum with diagnosed anxiety self-reported high rates of depressive symptoms and suicidal ideation (Wijnhoven et al., 2019). It is also important to be aware of the variability in the presentation of mental disorders as children age. Older children on the autism spectrum are more likely to be diagnosed with disorders such as anxiety, attention deficit hyperactivity disorder (ADHD), aggression, oppositional behaviours, and mood disorders; while younger children on the autism spectrum exhibit behaviour challenges, such as temper tantrums or sleep disturbances, and developmental disorders, such as language disorders (Soke et al., 2018). These developmental differences are also evidenced in parental reports of mental health crises among children and adolescents (Vasa et al., 2020). In children under age 12, mental health crises were most often related to self-injurious behaviours, while in adolescents, physical and verbal aggression were the most common behaviours associated with a mental health crisis. Further, there is evidence that as children on the autism spectrum develop into adolescence, their needs shift from requiring behavioural supports to requiring mental health supports (Ryan et al., 2018). Given the prevalence and complexities of mental disorders in children on the autism spectrum, it is important to consider these confounding diagnoses when developing interventions and implementing supports.

Underdiagnosing of Mental Health Disorders in Children on the Autism Spectrum

Despite the research evidence demonstrating the prevalence of mental disorders in children on the autism spectrum, mental health professionals seem to under-diagnose mental health disorders in children diagnosed with autism (Stadnick et al., 2017). For example, Stadnick and colleagues (2017) noted that while mental health diagnoses were higher among children on the autism spectrum, there was also incongruence between the prevalence rates that were reported by clinicians and the results they gathered using a diagnostic tool that relied on parent-report. The clinicians were not likely to diagnose any mental disorders in children on the autism spectrum who met the criteria for a disorder according to the diagnostic tool. Stadnick et al. suggested that this finding could be due, in part, to a phenomenon in which clinicians are prone to attribute symptomology solely to autism once the child has that diagnosis. For example, ADHD is diagnosed more often in children who have not yet received a diagnosis of autism than those who have (Soke et al., 2018), and psychotropic medications are frequently prescribed to children on the autism spectrum, even when a corresponding diagnosis is not present (Madden et al., 2017). These examples demonstrate what Stadnick and colleagues referred to as "search satisficing" (p. 847), which is apt to occur in the absence of structured interviews in the diagnostic process (Jensen-Doss et al., 2014). The tendency of clinicians to under-diagnose mental health disorders in children on the autism spectrum is problematic; if these disorders are not identified, the underlying contextual contributors (such as adversity) cannot be addressed, potentially exacerbating the impact on the child's mental health.

Current research has clearly indicated that children on the autism spectrum are more likely than their non-autistic peers to experience mental disorders (CDC, 2020; Joshi et al., 2010; Madden et al., 2017; Soke et al., 2018). Coupled with the understanding that experiences of adversity are also higher in this population (Berg et al., 2016; Rigles, 2017), it is possible that mental health symptoms are related to experiences of adversity in childhood. Furthermore, by understanding the effects of adversity on children on the autism spectrum, clinicians may be encouraged to address mental health disorders in this population, rather than attributing them solely to the autism diagnosis. When combined, these findings reinforce that understanding the potential effects of childhood experiences on mental health is imperative, and that clinicians and researchers need to consider these effects in developing and offering mental health supports to individuals on the autism spectrum.

Interaction of Autism-Related Characteristics and Adversity

Neurotypical children who are traumatized by adverse experiences may demonstrate a variety of symptoms that can direct mental health clinicians to recognize the presenting problem as trauma-based, and subsequently address their needs accordingly. For example, children may demonstrate anger, sleep disturbances, inability to concentrate, re-experiencing of the event, or dissociation (APA, 2008; Kisiel et al., 2009). However, significantly less research exists regarding the presentation of trauma-related symptoms in children on the autism spectrum. The potential interaction between autistic characteristics and adversity (Im, 2016; Kerns et al., 2015) may influence the presentation of trauma-related symptoms, such as an increase in autism-related behaviours (Kerns et al., 2015; Mehtar & Mukaddes, 2011; Wood & Gadow, 2010). This may mask the evidence that an event was traumatic, resulting in mental health professionals missing the opportunity to provide trauma supports to these children.

Children on the Autism Spectrum May Experience Adversity in Unique Ways

Some have argued that neurological differences in individuals on the autism spectrum cause them to experience adverse events differently, which may result in a person on the autism spectrum experiencing an event as more or less traumatic than would a neurotypical person (Im, 2016; Kerns et al., 2015). The variability in the influence of adversity on individuals depends on how a person evaluates a potentially traumatic situation for threat, and their ability to cope with the emotions related to the event (Kerns et al., 2015). Kerns et al. (2015) argued that the neurological differences in individuals on the autism spectrum may prime them to perceive events as traumatic and confound their ability to cope, leading to a more significant impact. Additionally, experiences that result from autism may be highly stressful for children on the spectrum, such as overwhelming sensory experiences or anxiety in social situations (Wood & Gadow, 2010). This means that children on the autism spectrum may experience negative effects of adversity that their neurotypical peers do not face, further impacting their mental health.

Despite the potential for experiencing adversity in unique ways, there is evidence that following a traumatic event, both children on the autism spectrum and non-autistic children present with similar symptoms. For example, children on the autism spectrum have demonstrated symptoms such as behaviour problems, including aggression and temper tantrums, following a traumatic event. Additionally, they may demonstrate post-traumatic stress disorder (PTSD) symptoms such as distractibility, sleep issues, agitation, and avoidance of social interactions (Mehtar & Mukaddes, 2011; Thakur et al., 2017). These are similar to the symptoms noted earlier that are often exhibited by neurotypical children who have experienced a traumatizing event (APA, 2008; Kisiel et al., 2009); however, these problems are also prevalent in children on the autism spectrum in general (Joshi et al., 2010; Madden et al., 2017, Soke et al., 2018). Additionally, there is the potential for adversity to increase autism-related behaviours. Wood and Gadow (2010) proposed a model of stress and anxiety for children on the autism spectrum wherein stressful events trigger anxiety, which results in an increase in repetitive behaviours, social avoidance, and behavioural challenges. These symptoms are similar to the differences in social communication and the exhibition of restricted, repetitive behaviours that are characteristic of autism (CDC, 2020; National Institute of Mental Health [NIMH], 2020). Therefore, the appearance of such behaviours in a child on the autism spectrum may not raise red flags or may be dismissed as autism-related behaviour.

Anxiety, Depression, and Suicidal Ideation in Children on the Autism Spectrum

Despite the potentially confounding effects of the interaction between autism and adversity on the manifestation of trauma-related symptoms, there is a clear correlation between adversity and anxiety, depression, and suicidal behaviour in adolescents on the autism spectrum (Storch et al., 2013; Taylor & Gotham, 2016; Wood & Gadow, 2010). For example, Taylor and Gotham (2016) found that a single adverse event in childhood was correlated with the development of mood-related symptoms in adolescence. Notably, not every participant who experienced an adverse event developed symptoms, but when symptoms were present, participants also reported adversity in their histories (Taylor & Gotham, 2016). Storch et al. (2013) found a similar relationship between PTSD, which indicates a history of traumatic events, and suicidal thoughts and behaviours in adolescents on the autism spectrum. Suicidal behaviours (i.e., thoughts, plans to attempt suicide, and previous attempts) are high in youth on the autism spectrum; Storch and colleagues found that both depression and PTSD were predictors of this type of behaviour while comorbid anxiety was not. However, Wijnhoven et al. (2019) found that just over one-third of participants aged 8-15, diagnosed with autism and anxiety, self-reported having thoughts of suicide. Together, the results of these studies suggest that when adversity leads to PTSD symptoms, depression, or anxiety, children and adolescents on the autism spectrum are at risk for suicide.

While the research base is limited, there appears to be a relationship between autism, adversity, and the presentation of trauma-related symptoms and mental health disorders in adolescents (Kerns et al., 2015; Mehtar & Mukaddes, 2011; Storch et al., 2013; Taylor & Gotham, 2016; Wood & Gadow, 2010). When identifying mental health disorders and providing support to those on the autism spectrum, it is imperative to bear in mind the complexities of this relationship, to ensure that mental health needs are not dismissed as autism-related behaviours. Furthermore, the potential influence of adversity on the development of mental health disorders moves us toward deepening our understanding of the development of resilience.

Resilience

Resilience is the ability of a person to prevail over negative, or even tragic, life circumstances (APA, n.d.; Herrman et al., 2011). The research literature on resilience is vast and many definitions of the concept exist; however, there is a common theme of maintaining wellbeing in the face of adversity, and “bouncing back” from difficult experiences (Avdagic et al., 2018, p. 5). Resilience mitigates the potential negative outcomes as the result of the interaction between experiences of adversity and the internal and external protective factors that guard an individual from the potential negative effects of the experience (Herrman et al., 2011). While these protective factors have been identified and studied in the general population, little is known about the role of these factors on the resilience of children on the autism spectrum (Rigles, 2017). A better understanding of the experience of resilience by children on the autism spectrum is necessary to foster protective factors in their lives.

Understanding this relationship is useful in developing supports for children at risk for experiencing high rates of adversity. For example, external protective factors can be added to a child's environment with interventions that target their social supports (Avdagic et al., 2018). Furthermore, resilience can be built in children by facilitating the development of internal factors, such as regulating emotions, social skills, and self-esteem (Avdagic et al., 2018; Gartland et al., 2019; Rigles, 2017).

Resilience in Children on the Autism Spectrum

Unfortunately, it becomes more difficult to rely on this information to develop resilience in children on the autism spectrum, as the relationship between protective factors and the effects of adversity for this population is less clear, and some evidence is contradictory. McCrimmon et al. (2016) found that children on the autism spectrum demonstrated resilience no differently from their neurotypical peers, with protective factors and risk factors for adversity occurring at the same rate in both groups. Conversely, Rigles (2017) found that children on the autism spectrum demonstrated less resilience than neurotypical children. Despite this finding, there was no evidence that having an autism diagnosis impacted the relationship between resilience and potential mental health issues, with the likelihood of better mental health being related to higher resilience (Rigles, 2017). These studies are not fully comparable, as McCrimmon and colleagues only included children with a diagnostic label of high functioning autism in their sample, while Rigles included participants with any of the autism diagnostic labels.

Despite these differences, the inconsistency in results indicates that further research is necessary to identify and describe resilience in children on the autism spectrum. Rigles (2017) concluded that children on the autism spectrum may experience resilience differently, and therefore it is not measurable by assessing for known internal factors. As such, the current data on the phenomenon in autistic children may not be accurate, as evidenced by their finding that resilience rates in these children did not decrease as adversity increased, as it does in samples of the general population. Thus, it is imperative that future research describe potential protective factors for children on the autism spectrum.

Autistic Culture and Resilience

Experts generally agree that the concept of wellbeing is influenced by cultural factors and may be identified differently for different individuals (Avdagic et al., 2018). Understanding autism within a neurodiversity framework gives clinicians and researchers the opportunity to consider the culture of autism and the meaning of wellbeing to those on the spectrum. The epidemiological studies of resilience factors in children on the autism spectrum provide a neurotypical understanding of resilience factors in children diagnosed with autism. However, the cultural definition of resilience may be different than the interpretations presented in the current literature. As such, to adequately facilitate the development of resilience in children on the spectrum, we need to understand how autistic individuals conceptualize resilience and wellbeing.

Building Resilience in Children on the Autism Spectrum

Knowledge of how individuals on the autism spectrum experience resilience will guide interventions to either nurture existing internal factors or facilitate the implementation of appropriate external protective factors for children on the autism spectrum. Some researchers have already identified the need to develop protective factors in autistic children, by adapting interventions designed for neurotypical children. By explicitly teaching skills, such as positive self-talk, managing emotions, and problem-solving, Mackay et al. (2017) found that autistic adolescents improved their self-confidence, social skills, ability to cope, and emotional regulation, all of which are known protective factors among non-autistic children (Gartland et al., 2019). Similarly, Guest and Ohrt (2018) successfully adapted child-centred play therapy to meet the needs of a five-year-old child on the autism spectrum who had experienced an early traumatic event. The child demonstrated some ability to therapeutically process his traumatic experience, as well as an improvement in impairments related to his autism (Guest & Ohrt, 2018). Given a better understanding of the experience of resilience and key protective factors in individuals on the autism spectrum, similar interventions which target the development of these unique protective factors may be adapted and provided to children and adolescents on the autism spectrum.

Implications for Future Research

To understand mental health as a function of an autistic individual's childhood experiences of adversity and resilience, further research is necessary. However, to understand these phenomena through a neurodiversity lens, the research must be conducted accordingly. It is imperative to conduct research that has a positive impact on the community, and most importantly, includes the perspectives of members of the autism and autistic communities (Autism Self-Advocacy Network [ASAN], n.d.; Chown et al., 2017; Pellicano, 2014; Pellicano et al., 2014; Pellicano & Stears, 2011). Given the principles underlying neurodiversity, which value autism as an identity and culture, research that honours neurodiversity must include the perspectives of autistic individuals, creating opportunities for them to have input on all aspects of the process (Milton & Bracher, 2013; Milton et al., 2012; Pellicano, 2014). Milton and Bracher (2013) have argued that autistic voices have been excluded from most autism-related research, which increases the power differentials between autistic and neurotypical groups and perpetuates misunderstandings and myths about autism. It is necessary for autism researchers to create opportunities for autistic individuals to share their insights and lived experiences in research (Milton & Bracher, 2013) and for researchers to foreground their input (Pellicano, 2014). Therefore, to study the interaction of autism, adversity, and resilience, it is vital that researchers go directly to those who have experienced these phenomena—autistic individuals. Research that describes and interprets the lived experiences of autistic individuals is necessary to further our understanding of how adversity, autism, and resilience influence mental health outcomes. Furthermore, most research is predominantly rooted in the biases and agendas of neurotypical researchers and may not be in the best interests of the autism or autistic communities (Milton & Bracher, 2013). Therefore, research that engages the autistic community for their insights on the topic of mental health is to be collaborative, including members of the autistic community as partners in the planning, designing, and implementing of research studies, as well as in dissemination and knowledge translation. This is sometimes achieved through participatory action research or other methods of engaging the autistic community (ASAN, n.d.; Chown et al., 2017; Milton & Bracher, 2013; Pellicano et al., 2014; Pellicano & Stears, 2011). Collaboration and engagement with the autistic community decreases the likelihood that the knowledge gathered from autistic participants about their experiences and their mental health is filtered through a neurotypical (dominant) lens and misrepresented and/or misinterpreted (Milton & Bracher, 2013; Pellicano, 2014). This is important, as neurotypical researchers are apt to favour their dominant perceptions, despite contradictory perspectives from those in the autism and autistic communities. For example, Pellicano et al. (2014) studied the perceived engagement of the autism community in research, gathering perspectives from autistic participants, their families, and researchers. While researchers expressed satisfaction with their level of engagement of the autism community, community members saw their own involvement as minimal and often frustrating (Pellicano et al., 2014). Additionally, all the researchers surveyed indicated that autistic participants should not be partners in the research process (Pellicano et al., 2014). These findings illustrate a power differential and the lack of alignment between autistic and neurotypical discourses. It is important that the research into the mental health experiences of autistic individuals not perpetuate these imbalances and that researchers strive to serve the community by aligning their objectives and methods accordingly.

Collaborative Research Reduces Limitations

Some researchers have suggested that autistic participants are unreliable at self-reporting their experiences, internal psychological states, or impacts of stress (Mehtar & Mukaddes, 2010; Robinson, 2018; Wood & Gadow, 2010). Proponents of the use of participatory or emancipatory methodologies in autism-related research have identified that there are, indeed, issues related to these methodologies; however, engaging participatory methods does not affect the validity of results (Pellicano, 2014). Therefore, researchers can adapt as needed, even viewing these issues not ‘as limitations but . . . different ways of thinking’ (Chown et al., 2017, p. 723). Despite the suggestion that autistic participants may be unreliable, researchers have successfully included them in studies on many topics, including trauma and trauma therapy. For example, autistic youth demonstrated the ability to accurately self-report their experiences and feelings in a qualitative study (Cage et al., 2016), autistic adolescents reported on the effectiveness of a resilience program (Mackay et al., 2017), and an autistic adult reported the effects of childhood bullying as part of a therapeutic group (Robinson, 2018). Robinson (2018) noted that the researcher is responsible for ensuring that participants can fully participate in qualitative research. When the researcher considered the case study participant’s unique way of perceiving the world, the participant successfully shared his experiences and insights.

To fully understand how mental health is shaped by adversity and resilience in children on the autism spectrum, it is imperative that we examine the lived experiences of autistic individuals. It is necessary to engage the autistic community both as partners, and as key decision-makers in how the research is conducted. The phrase *nothing about us without us*, has been embraced by autistic advocates and implies that any discussions, research, policies, or practices related to autism must include autistic voices (ASAN, 2019; Chown et al., 2017). Engaging the autistic community both as participants and as partner researchers is a key component to ethical autism-related research (Chown et al., 2017; Milton & Bracher, 2013; Pellicano, 2014; Pellicano et al., 2014; Pellicano & Stears, 2011) and will help to prevent the perpetuation of potentially harmful discourses about autism and autistic people, as well as help to prevent autistic meaning from being translated through a neurotypical perspective (Milton, 2014; Milton & Bracher, 2013; Pellicano, 2014).

Conclusion

Research exploring the unique experiences of children on the autism spectrum related to adversity and resilience is scant. However, given the known influence of adversity on health outcomes in the general population, and the evidence for mitigating these outcomes through the development of resilience, along with the existing research on the rates of adversity and the prevalence of mental disorders in children on the autism spectrum, it is reasonable to conclude that mental health is influenced by adversity and resilience among autistic individuals. Furthermore, by viewing autism as part of an individual's identity, rather than a pathology to be treated, we can focus on mental health as a function of the interaction between autism, adversity, and resilience, rather than as a co-occurring disorder. Further research is needed to learn, directly from autistic individuals, about the relationships between childhood adversity, resilience, mental health, and autistic identity; and to understand the wider implications of providing mental health supports to children and adults on the autism spectrum. It is imperative that researchers employ the insights and opinions of autistic individuals as both participants and partner researchers, to ensure the findings are relevant and congruent with autistic experiences.

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Chapter IV – Methodology Article

Integrating Community Participation with Interpretative Phenomenological Analysis: Reflections on Engaging the Autism Community

Short Title: Community Participation& IPA in Autism Research

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Abstract

Members of the autistic community have long advocated for more input into and participation with autism-related research. Currently, the power to determine the direction of autism-related research and knowledge production related to autism lies with non-autistic researchers, while the wishes and perspectives of the autistic community are largely ignored. There is a growing trend toward ethical autism-related research, however, in which the perspectives of all stakeholders, particularly those of autistic individuals, are sought and their expertise on autism is foregrounded. In a study exploring the experiences of childhood adversity and resilience among autistic adults, we strove to conduct our research in an inclusive and ethical way, by integrating participatory methods, such as community engagement to inform research design, and credibility checking with participants to validate analysis. Five stakeholders, representing parents of children on the autism spectrum, professionals, and autistic community members were recruited to provide input into the research design and provide insight into autistic ways of communicating, interacting, and being. The recommendations generated through this community engagement were then integrated into an interpretative phenomenological analysis (IPA) framework and implemented with four adult autistic participants. Through reflection on the process of community engagement, development of research design, implementation of the study, and credibility checking, it is clear that incorporating participatory methods into IPA increases rigour and ensures that autistic perspectives are represented through research.

Keywords: autism, interpretative phenomenological analysis, participatory methods, ethical autism research, community engagement, credibility checking

Introduction

Historically, researchers studying autism have excluded the input of autistic individuals into research priorities, aims, and design. As a result, knowledge about autism has been produced by non-autistic stakeholders, leading to misunderstandings and misinterpretations of what it means to be autistic. Furthermore, this has exacerbated power imbalances between non-autistic researchers and autistic participants, where non-autistic researchers are positioned as the experts in autistic experiences, rather than autistic individuals themselves (Milton, 2014; Milton & Bracher, 2013; Milton et al., 2012). Advocates for ethical autism-related research have suggested that including autistic perspectives in the prioritization of research objectives, study design, and implementation of autism-related research are key practices for researchers (Chown et al., 2017; Milton & Bracher, 2013; Pellicano et al., 2014; Pellicano & Stears, 2011).

In a recent study [reference withheld for blind review], an exploration of the influence of childhood adversity and resilience in the lives of autistic adults, we, as non-autistic researchers, strove to conduct ethical autism-related research and honour the perspectives of the autistic community. To do this, we employed interpretative phenomenological analysis (IPA) and integrated participatory methods, including community engagement to inform the research design, and credibility checking with participants, post-analysis. While limited, there is evidence in the literature for incorporation of participatory methods with IPA (Bush et al., 2019; MacLeod et al., 2019). Bush et al (2019) argued that IPA blends well with community-based participatory research (CBPR) given that both methodologies facilitate a joint construction of knowledge by researchers and participants. While we did not engage fully with a participatory methodology like CBPR, we conducted a community engagement phase, prior to designing and implementing the research. This practice is common in IPA research within the health field (Larkin & Thompson, 2012). In this phase, we sought the input of the autism and autistic communities on the value of the research question, appropriate methods for data collection, insight into autistic ways of communicating and interacting, and how best to approach autism-related research in an inclusive, ethical way that honours the autistic community. The community advisors provided rich and detailed feedback that informed all aspects of the study. The objective of the subsequent IPA analysis was to understand, directly from autistic participants, how their experiences of childhood adversity influenced their well-being and the meaning of resilience in their lives. The purpose of this paper is to outline the advisors' recommendations and how we integrated them into an IPA methodological framework, and to demonstrate how the integration of participatory methods into IPA improved rigour.

Process of Engaging Community Advisors

After receiving institutional ethics approval for the community engagement phase of this research, we recruited community advisors directly through the first author's professional network and through snowball sampling. Five advisors were recruited. Several advisors had multiple roles and of the five, two were mental health professionals who work closely with autistic individuals, three were autistic self-advocates, and two were parents of children on the autism spectrum. Parents, professionals, and autistic self-advocates are all stakeholders in the outcomes of autism-related research and have unique and valuable perspectives on conducting research for the autism community

(Pellicano & Stears, 2011). Community advisors were considered study participants, and therefore gave written or verbal informed consent, depending on their preferences, and were provided with the interview guide (see supplementary materials). Advisor participants were given the option to be interviewed by phone or via videoconference. They were not offered in-person interviews due to COVID-19 safety concerns and local restrictions. Recorded interviews lasted between 60 and 155 minutes and were conducted by the first author. One advisor also provided answers to interview questions via email post-interview. Advisors gave concrete suggestions for engaging and communicating with autistic research participants, as well as insight into autistic ways of thinking, knowing, and communicating. Advisors gave feedback on the research question, its value to the autistic and autism communities, and provided insight into the power imbalances that exist between non-autistic researchers and autistic participants. They identified potential pitfalls and potential sources of disconnect between participants and researchers and how to avoid them.

Following the interviews, the first author reviewed the recordings and identified the recommendations from each advisor, combined them into a master list, and categorized them according to research methods, engagement strategies, and overall considerations (see Table 1). We then integrated the recommendations into the research design prior to recruitment of participants for the main study.

Community Advisor Recommendations and Researcher Reflections

Research Design

Research Question

Advocates for ethical autism-related research have noted that excluding the autistic community from research has meant that non-autistic researchers have determined the priorities of autism-related research without consultation (Milton, 2014; Pellicano & Stears, 2011) and that ethical autism-related research needs to focus on making the lives of autistic people better (Chown et al., 2017). As such, it was important to us that the research topic and question had value for all stakeholders in the autism community, but especially for those who are autistic. We asked community advisors to give their feedback on the research question and to offer insight into how this research might be valuable to the groups they represented (i.e., parents, professionals, autistic self-advocates). The community advisors validated that the research had the potential to inform positive change in the lives of autistic individuals, including improved awareness of mental health issues faced by autistic individuals and potential interventions to ameliorate those challenges.

Recruitment

Community advisors were not asked specifically to comment on participant recruitment; however, the topic came up in several interviews. There was some disagreement among advisors about appropriate inclusion criteria to ensure participants had the capacity to give informed consent and provide insight into their childhood experiences. One advisor suggested that limited executive functioning skills could make participation in the study challenging for some participants; thus, executive functioning ability could be a more appropriate exclusion criteria than intellectual disability. However, another advisor proposed that recruiting and then excluding participants based on a test of executive functioning could negatively affect their well-being. Given this disagreement, combined with the input of the institutional research ethics board, we determined that executive functioning would not be an appropriate exclusion criterion for this study. Instead, participants were asked to self-report that they did not have a co-occurring intellectual disability.

Our experiences recruiting community advisors influenced our subsequent recruitment procedure for participants. Recruitment of community advisors was done via email and included a significant amount of text-based information. We discovered that some advisors preferred not to read information, opting instead to review the informed consent form with the first author and give verbal consent. This experience prompted us to consider the best way to engage potential participants, as we were concerned that a recruitment poster with too much information might not be accessible to all members of the autistic community, thus limiting the inclusion of participants who communicate differently. As such, we prepared a recruitment poster with minimal text (see supplementary materials) and a short video introducing the first author, explaining the aim of the study, and outlining the eligibility criteria for participation. A link to the video and the poster were shared together to engage participants through multiple modes of communication.

At the time of community engagement, some elements of the research design had been tentatively planned to meet the requirements of the first author’s graduate program. In the proposed design, participants would be included if they were over the age of 18 but had been diagnosed prior to turning 18. This methodological decision was rooted in the principles of IPA, in which it is desirable to have a small, homogeneous sample (Larkin & Thompson, 2012; Pietkiewicz & Smith, 2014; Smith, 2004; Smith et al., 2009). Furthermore, one of the aims of this study was to understand how a child's autistic identity interacted with experiences of adversity and resilience factors to shape their ongoing well-being. As such, we pre-supposed that an autistic identity would be developed in childhood and adolescence following a diagnosis of autism. When they became aware of this eligibility criteria, some community advisors advised against excluding individuals diagnosed with autism later in life, as the experiences of this demographic hold equal value and their experiences of childhood adversity could stem from being undiagnosed. After significant consideration, we decided to continue with the original eligibility criteria, to maintain the rigour gained by having a homogenous sample, especially considering the necessary small sample size for manageable thesis research.

Interestingly, this decision prompted feedback from the autistic community related to the call for participants. A link to the study recruitment video was shared, without our knowledge, to a social media group populated by members of the autistic community. Several individuals contacted the first author to express their concerns with the exclusion criteria, suggesting that it implied their experiences were not valuable or important. They also expressed concern about the implications of a non-autistic researcher making decisions about whose experiences should contribute to the generation of knowledge about autistic experiences. The first author engaged in dialogue with each of these individuals, explaining the aims of the study and the research design. The conflict was resolved with each individual, however, this experience prompted us to reflect further on the role of non-autistic researchers and methodological decision-making in autism-related research. While our methodological reasoning was sound, it was contrary to the advice we received from community advisors. This is one of the tensions that exist between non-autistic researchers and the autistic community (Pellicano & Stears, 2011) and requires careful consideration by non-autistic researchers, to honor the needs and wishes of the autistic and autism communities, while prioritizing rigorous research design. In this case, given the small sample size and the first author's need for guidance as a novice researcher, it was logical and justified to adhere to the IPA practice of maintaining a small, homogenous sample. However, it is possible that our adherence to IPA methodology disproportionately influenced our decision, and thus caused distress and distrust for some members of the autistic community. Further consultation with community advisors about the eligibility criteria may have led to a different methodological decision or altered our approach to recruitment, while maintaining the original exclusion criteria. By communicating the intent and the aims of the study more clearly, we may have mitigated the potential for harm.

Notably, the age of diagnosis was seemingly irrelevant to understanding the experiences of the participants in this study. They were diagnosed as early as three years old and as late as 17 years old. This broad range did not seem to influence the homogeneity of their experiences of either childhood adversity or resilience. While being autistic did influence their experiences, having a formal diagnosis did not seem to change the effects that being different had on their lives. Furthermore, there were similarities in their experiences, specific to being autistic, regardless of the age of diagnosis that were consistent across participants.

Data Collection

Community advisors were asked for ideas about how to collect data in ways that would create space for participants with communication differences or other neurodivergent traits, to engage in the process more easily and comfortably. The first author was keenly aware that, as non-autistic researchers, we were ignorant to the ways in which some participants may interact, communicate, or think; and that most of the time, the onus falls on the autistic individual to adjust to non-autistic ways of communicating and interacting, which deepens the power imbalance that exists between autistic participants and non-autistic researchers (Milton, 2014). It was important to us not to expect autistic participants to adjust to our non-autistic ways of conducting research; instead, we made it a priority to adjust the research design to their unique ways of being. One advisor noted that communicating in a non-autistic way can be overwhelming to some autistic people and by adapting the process to their ways of communicating, it would make participation more manageable. One advisor noted that language is contextual for many people on the spectrum. Other advisors suggested that traditional interviews might overburden participants and suggested that participants have the opportunity to choose how they would communicate their data. Some advisors also suggested that interviews be structured differently, possibly conducting multiple, shorter interviews or building in breaks for longer interviews.

Based on the advisors' recommendations about data collection, the first author developed a pre-interview survey (see supplementary materials) for participants to identify the best way to engage in the data collection phase of the study. All participants contacted the first author by email to volunteer, therefore we provided them the survey via a Microsoft Forms link, with the offer to conduct the survey verbally, by phone, if they preferred. All participants opted to complete the survey online. Participants were asked what their preferred mode of communication was for answering questions related to the study, including via a video conference interview, phone interview, written narrative, online text-based chat platform, pre-recorded audio files, or through visual images with supplemental narratives or audio recordings. They were also given a space to identify another unlisted mode of communication. As with advisor interviews, in-person interviews were not offered to participants due to COVID-19 safety considerations. Two participants opted for phone interviews, one for a video conference, and one for the text-based chat platform.

Other options on the survey included the best time of day for the interview and the opportunity for breaks, multiple, shorter interviews, the chance to review interview questions ahead of time, either written or audio recorded, inclusion of a support person in the room, inclusion of a pet or other comfort items, and a pre-interview “getting to know you” visit to build rapport, comfort, and trust between the interviewer and participant. While the broad range of options required more flexibility and accommodation from us in terms of scheduling and interview preparation, they were based on specific recommendations by advisors to make the interview experience as accessible and comfortable as possible for participants. For example, the option to choose what time of day the participant would prefer to complete the interview was based on the suggestion of one of the mental health clinicians, who noted that for some autistic individuals, the time of day may affect their ability to access technology in shared living circumstances or lessen the potential for overwhelming sensory stimuli in their environment.

The pre-interview survey also covered two other important preferences. We asked participants to provide their preferred language related to autism. There is debate in the autism community about the use of *person-first* and *identity-first* language to describe a person's autism diagnosis (Kenny et al., 2016). In an attempt to reduce the power imbalance between the interviewer and participants, we wanted to respect their language preferences and not assume that we knew the best way to characterize their diagnosis. Additionally, on the recommendation of one advisor, the survey included a question regarding assistive technology and whether participants required research materials (e.g., interview guide) in another, more accessible, format.

Of the options provided, all participants opted for an interview of some type (phone, video, or text-based), three participants chose a time during the day on a weekday and one on a weekend. All requested that they have access to the interview guide ahead of time. One participant requested a "getting to know you" visit prior to the interview and one opted to take several breaks during the text-based chat interview. Participants chose times of day that worked well for them and all provided their preferred way of identifying in relation to autism.

One advisor recommendation related to data collection created some tension for the research team and required significant discussion and reflection to determine if it could be integrated into the research design. One advisor noted that some autistic people do not speak, or communicate more effectively using visual images, however most research studies are designed to engage participants in verbal interviews or questionnaires. IPA has received criticism as a methodology for conducting autism-related research, given that autistic participants may use language quite differently than a non-autistic researcher. Howard et al. (2019) argued, "[i]f IPA is so intrinsically bound to the elicitation of voice, questions may well be raised as to whether it can be a legitimately useful tool for autistic individuals with language difficulties" (p. 1874). They also suggested giving participants the opportunity to share data via another mode of communication in IPA studies. To prevent exclusion of potential participants who are non-speaking or who express themselves more effectively through images, the advisor recommended that participants have the option to express themselves through art or photographs, with a trusted person serving as translator between the participant and researcher. While it was important to us not to inadvertently exclude participants, who do not communicate using spoken language, the suggestion posed a logistical, methodological, and ethical quandary. Adding translators to the research design would require additional informed consent considerations, would potentially reduce confidentiality for participants, as there was no guarantee translators would keep the sensitive information shared by participants private, and it could be difficult to schedule the amount of time necessary to conduct an interview in this way.

From a methodological perspective, using a translator to interpret potentially abstract images, seemed to jeopardize the ideographic nature of IPA. The focus on *the particular* by IPA researchers allows them to develop a detailed, in-depth appreciation for a participant's experience, as it occurred in a particular context at a particular time. Researchers give much attention to each case before moving to an examination of the whole data set, comparing and contrasting the interpretations of each case (Pietkiewicz &

Smith, 2014; Smith, 2004; Smith et al., 2009). We were concerned that the details and context would be lost in the translation process. Furthermore, the suggestion posed a problem related to the interpretive nature of IPA. There is a *double hermeneutic* in IPA, that is, multiple levels of interpretation of the participants' experiences (Smith, 2004; Smith et al., 2009; Smith & Osborn, 2015). Firstly, the participant is making sense of their own experiences and sharing that interpretation with the researcher. From there, the researcher interprets the participant's interpretation, therefore interpretation of the experience happens twice, creating a double hermeneutic. Furthermore, interpretation does not end with the researcher and participant, rather it continues to a third level as a reader interprets the research findings through their own lens (Smith, 2004; Smith et al., 2009). Including a translator to the data collection would add another layer of interpretation, potentially changing the meaning intended by the participant or understood by the researchers. By adding translators, we were concerned that we would lose the ability to closely examine and analyze a participant's interpretation of their experience.

In grappling with this dilemma, we considered the insight of another advisor, who explained the concept of an autistic language and the misunderstandings that often occur between autistic and non-autistic individuals. They suggested that autistic people spend time and energy translating the things they want to communicate into the language of a non-autistic communication partner. This can lead to miscommunication and misunderstanding, not unlike those that occur between speakers of English and French. We conceptualized this internal translation as a fourth level of interpretation of a participant's experience; however, it is different in that it is still the interpretation of the participant, not an external person removed from the experience. This advisor posed a similar suggestion to help combat misunderstandings between autistic participants and non-autistic researchers. They recommended employing an autistic individual to read and translate the transcribed participant interviews prior to analysis. This recommendation prompted the same methodological concerns.

Interpretative phenomenological analysis has been used in autism-related research previously, and MacLeod (2019) suggested that the double hermeneutic in IPA could mitigate the potential for misunderstandings by addressing the *double empathy problem*, wherein the lack of understanding of another's perspective occurs in both the autistic and non-autistic communication partner (Milton, 2012). The dominant, non-autistic view of the communication challenges that occur between non-autistic and autistic individuals is that autistic people lack the ability to empathize with others; whereas the autistic perspective is that non-autistic individuals are unable to empathize with those on the autism spectrum, which leads to non-autistic communication partners making assumptions about what an autistic person is saying, feeling, or thinking. This lack of empathy by both communication partners is the double empathy problem. The double hermeneutic in IPA, therefore, addresses this problem as researchers strive to understand and make meaning of a participant's understanding of their experiences (MacLeod, 2019). Additionally, by engaging in the double hermeneutic, the researcher acknowledges that their interpretation of the participant's experience is filtered through their own, non-autistic lens, and thus, does not claim that their interpretation is a purely autistic perspective (Howard, 2019; MacLeod, 2019). Furthermore, by exploring participants' experiences ideographically, researchers describe the particulars of individual experiences and convey their commonalities, rather than deriving a general theory through analysis of a population (Pietkiewicz & Smith, 2014; Smith & Osborn, 2015). It is the shared creation of understanding between the researchers and participants, within a particular context, that makes IPA congruent with the aims of participatory research, in which the meaning of experiences is also co-created (Bush et al., 2019)

Ultimately, we decided that given the ethical and logistical barriers to incorporating these recommendations, as well as the interpretative and ideographic nature of IPA, that we would forego those recommendations for this study. However, these suggestions are not without merit and could be valuable to researchers employing methodologies that are not interpretative or participatory.

Interviews. Community advisors had specific suggestions for conducting interviews with autistic participants. They suggested that participants be provided with the interview guide ahead of time, and that we provide a rationale for each question, to give participants the context of what information we hoped to glean from the question (see supplementary materials). Advisors disagreed on the best types of questions to ask. Some suggested that shorter, concrete questions would be best, while others suggested broader, more abstract questions. One advisor pointed out that many people on the autism spectrum enjoy language and have large vocabularies, and that using rudimentary language would be an insult to some. To meet the needs and preferences of participants who might require different types of questions, we created an interview guide that included broad questions with specific, concrete sub-questions for drawing out detailed recounts of childhood experiences, if needed (see supplementary materials). The interview guide included a rationale for each question, with an explanation of the objective of each. Participants had the opportunity to review the interview guide prior to participating in the interview.

Community advisors provided recommendations for conducting the interviews, with a particular focus on ensuring that participants could be as comfortable as possible when engaging with the interviewer. For example, they suggested that the interviewer provide silent moments so that the participants would have adequate time to cognitively process questions and formulate answers. They also suggested avoiding yes/no questions, as these may not encourage participants to share details beyond the expected yes or no response. Given that participants on the autism spectrum may experience challenges related to sensory overstimulation, advisors suggested that video conference interviews be done with a plain, non-distracting background, and that the interviewer wear solid, non-descript clothing to ease sensory stimulation. Additionally, it was suggested that participants be encouraged to take breaks if needed and to be reminded that their comfort throughout the process is a priority. Lastly, several advisors noted that sometimes autistic people need time to process an experience and will have more to say on a topic after some time has passed. It was recommended that the interviewer follow-up with participants a few days after the initial interview to give another opportunity to add additional thoughts and comments. It was also suggested that this follow-up contact would be an opportunity to check in on the well-being of participants after the potential emotional toll of discussing childhood adversity, a consideration supported in the IPA literature. Exploring one’s lived experiences may create distress for participants and researchers are responsible for ensuring that participants’ emotional well-being is supported (Smith et al., 2009; Pietkiewicz & Smith, 2014). Besides following-up with participants post-interview, we provided participants with a list of mental health resources available in their communities and offered them two free counselling sessions with a counsellor of their choice. One participant took advantage of this benefit.

While integrating the many strategies suggested by the community advisors required more time and effort than traditional semi-structured interviews might have, the benefit of providing options for participants was clear. All the participants expressed that participating in this study was a positive experience and that they felt comfortable in engaging with the first author, who conducted all the interviews. Interestingly, the four participants who volunteered for this study were individuals who had significant insight into their experiences, used language in ways that matched the first author’s way of communicating, and did not require intensive support from the interviewer to participate fully in the interviews. As such, the participants did not choose many of the interview options provided to them. For example, none of the participants requested to do multiple, shorter interviews, to provide data via written narratives or visual images, or to have research materials provided to them in an accessible format. For this particular group of participants, the most useful options were to have the opportunity to review the interview questions ahead of time and to have alternatives to the video conference interview. However, based on the variability of expression of autistic characteristics in people on the autism spectrum, evidenced in the multifarious recommendations from community advisors, the broad range of options was appropriate and necessary.

Researcher Positionality

In addition to the specific research design recommendations and strategies for implementing the study, the community advisors provided insight into how autistic people may experience the world and considerations for us, as non-autistic researchers, for engaging with participants and completing data analysis. These considerations were mainly related to the power imbalance between non-autistic researchers and autistic research participants, a phenomenon that is documented in the research literature (Milton, 2014; Pellicano et al., 2014). The community advisors for this study provided examples of how the first author’s positionality may inherently perpetuate this power imbalance and influence participants, which could subsequently affect the quality and richness of the data and data analysis. One advisor noted that the power imbalance will be greater than the researcher perceives it to be. To ensure rigour, therefore, it was important that the first author strive to create an interview space where participants would feel comfortable and safe to share openly about their experiences and even disagree with the researcher. For example, one advisor noted that the first author’s previous career as a teacher meant that she may represent an authority figure to some participants, particularly if they had experienced negative interactions with teachers in their childhoods. Participants may have had experiences in school where they were discouraged from sharing their opinions, disagreeing with teachers, or avoided negative interactions by acquiescing or deferring to teachers. If participants believed that they could not disagree with her, present a contrary point of view, or felt pressured to respond with answers that would be desirable to her, the rigour of the study and strength of the findings could decrease. The first author was also concerned that she may slip into this role of authority figure and expert, thus amplifying the position of power and influencing interactions with participants.

IPA researchers can increase rigour by maintaining sensitivity to context, which is partially achieved during the interview when the researcher articulates an “appreciation of the interactional nature of data collection within an interview situation” (Smith et al., 2009, p. 180). Smith et al. (2009) indicated that “obtaining good data require close awareness of the interview process—showing empathy, putting the participant at ease, recognizing interactional difficulties, and negotiating the intricate power-play where research expert may meet experiential expert” (p. 180). This is congruent with the recommendations of advisors, who suggested that the interviewer openly acknowledge the power imbalance with participants, encourage participants to ask clarifying questions, reinforce that their data will be included even if a participant disagrees with the interviewer, and take steps to ensure participants feel comfortable throughout the interview. The first author, therefore, opened each interview with transparency about her positionality, the motivation for the study, and the objectives in conducting this research. This included acknowledging the power imbalance inherent between the first author as a non-autistic researcher and the autistic participant. Participants were encouraged to ask questions, disagree, and request breaks or other support as needed. To maintain this openness and equality throughout the interview, the first author frequently checked in with participants about their well-being and comfort level and asked permission before moving to a new question or topic, to give participants the time necessary to answer questions in detail.

During data analysis, the first author addressed the potential influence of her positionality and biases through reflexivity. For example, when reviewing the interviews, the first author noticed instances where it seemed participants were verbally agreeing but their body language or tone of voice did not match that agreement. We wondered if these were occurrences of participants acquiescing to avoid conflict or were deferring to the interviewer's expertise. We were careful to consider that the data generated in those instances was potentially inaccurate or irrelevant, comparing it to the data set as a whole to determine whether it could be used to contribute to the overall analysis and generation of themes.

Credibility Checking

Credibility checking is used to ensure that researcher interpretations in IPA are of a high quality and ensures rigour (Larkin & Thompson, 2012). While there are a variety of methods for engaging in credibility checking, including audit by an external expert or peer sample (Larkin & Thompson, 2012), the most common means of credibility checking in autism-related IPA studies is to invite study participants to validate researcher interpretations (MacLeod, 2019). By engaging in credibility checking non-autistic researchers can minimize the risk that they have inaccurately interpreted the experiences of autistic participants through a non-autistic lens, which reduces power imbalances (MacLeod, 2019). As one community advisor in the present study pointed out, if the findings of an autism-related research study are not validated by autistic people, they are simply hypotheses about autistic people, made by a non-autistic researcher. Credibility checking reduces the power imbalance when researchers give up the role of expert and seek validation from participants with humility. Community advisors in the present study provided feedback on how best to engage participants in this process. Similar to data collection, the recommendations of the community advisors were to ensure that the task of credibility checking would be manageable for participants. They suggested presenting information in small chunks; for example, organizing interpretations for participants to review in smaller pieces, such as by themes.

The participants in this study were eager to engage in credibility checking and the first author scheduled a meeting with each of them to discuss the themes resulting from the data analysis, with supporting data from their individual transcripts. This fits with the development of themes in IPA data analysis as findings reflect the comparison of themes across cases, although themes may or may not be evident in every participant’s experience (Smith et al., 2009). Accordingly, it is appropriate to provide participants the opportunity to comment on the validity of themes generated across cases, as they relate to their own experiences. Three participants opted to meet over the phone and one via videoconference. These credibility-checking interactions with all participants were audio recorded. Participants were provided with a document outlining each theme, sub-theme, and associated supporting quotes from their individual interviews. Credibility checking discussions did not follow a formal structure, however, all participants opted to systematically review the document with the first author and for each theme or sub-theme, validated the interpretation, provided supplemental data to support the theme, and/or clarified details that we had misunderstood. Interestingly, some participants offered new data to support sub-themes that we had not previously interpreted as part of their experiences. During credibility checking it became evident that the sub-themes derived from other participants’ experiences were also relevant to their lives even though they had not been apparent in their original data. Some participants provided additional data with this realization.

As researchers, the credibility checking process was valuable, both in terms of producing rigorous findings but also as validating that the research is important and helpful to autistic individuals and the overall community. This was especially important to the first author, who frequently questioned whether she was the best person to be conducting this research and whether the implementation and findings of the study would be helpful or harmful to the autistic community. Participants expressed pleasure and gratitude for the opportunity to participate in the study and expressed how participation in the study provided them with the opportunity to explore their experiences, gain further understanding of themselves, and continue to heal from adversity. The first author felt honoured to be a witness to the recounted experiences of these participants and is indebted to them for their candid and insightful participation in this study.

Dissemination

Community advisors had minimal recommendations regarding dissemination but validated that the research question was important and that the findings should be disseminated broadly to the autistic and autism communities. Advisors suggested multiple modes of dissemination to reach multiple audiences. For example, dissemination to academic journals to reach researchers and professionals working with individuals on the autism spectrum, and social media to reach the autistic community. Additionally, some advisors requested that they receive acknowledgement through co-authorship on publications and presentations. For this study, advisors will be named in the acknowledgements of academic publications and named as co-authors on lay publications and presentations, as appropriate.

Conclusion

Increasing involvement of the autistic community in autism-related research is a priority for autistic self-advocates and researcher allies who wish to make autism-related research more ethical, inclusive, and valid (Chown et al., 2017; Pellicano et al., 2014). One aim of the present study was to engage the autistic and autism communities to inform the research design of and, ultimately, the knowledge generated by this study. Three autistic and two non-autistic mental health professionals provided insight and feedback into the research methods used for this study, which led to successful engagement of autistic participants and rigorous findings. The recommendations of community advisors outlined in this article will be helpful to other non-autistic researchers in ensuring that their qualitative research designs include the perspectives and wishes of the autistic community.

Table 1

Community Advisor Recommendations

Category	Recommendations
Recruitment	• Executive functioning instead of IQ for exclusion criteria; excluding participants based on executive functioning could be damaging • Include participants who were not diagnosed in childhood
Data Collection	• Have clear goals and motivations for interview questions • Multiple, shorter interviews • Use concrete questions *and* use broad open-ended questions • Give participants a chance to review interview questions in advance • Let people choose their own mode of communicating their data; interviews might be overwhelming to some people • Avoid rudimentary language – often people on the spectrum have big vocabularies and do not like to be talked down to • Follow up with participants after a couple of days so that they can add additional details • Follow up with participants after a couple of days to check on their well-being • Invite participants who communicate differently to include a support person who can serve as a translator. • Follow up with people who work closely with the participant to get further understanding about the participant's meaning
Researcher Positionality	• Researcher as a former teacher might trigger a perceived power imbalance because sometimes autistic individuals generalize bad experiences to others • Explicitly tell people they can ask clarification questions • Participants may see the interviewer as a person with power, causing anxiety, thus may be deferential as a result • Acknowledge the role of non-autistic researchers • Validate that participants' perspectives are valued and important • Researcher can acknowledge and name power imbalances, inviting equality • Power imbalance will be greater than the researcher realizes • Give participants choice of time of day for interviews
Interviewing Strategies	• Use visuals due to challenges with working memory • Provide processing time when waiting for answers • Ask participants what would make the process comfortable for them • Plain background and plain clothes for video interviews

	• Participants may use assistive technology and require alternate format materials • Ensure people know they have permission to take a break • Avoid yes/no questions • Be curious and ask clarifying questions of participants
Credibility Checking	• Conduct credibility checking in manageable chunks over time • Credibility checking could be broken down by theme or idea • Provide manageable chunks of data in separate documents • Interpretations must be validated by an autistic person or it is just another hypothesis by a non-autistic researcher • Credibility checking needs to be accessible
Dissemination	• Disseminate to social media to reach the autistic community • Disseminate to academic journals to reach researchers and professionals

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Chapter V – Findings Article

Realizing the problem wasn't necessarily me": An interpretative phenomenological analysis of the meaning of childhood adversity and resilience in the lives of autistic adults

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Abstract

There is ample evidence that childhood adversity correlates negatively with physical and mental health outcomes across the lifespan. Resilience results when internal and external protective factors in childhood mitigate the effects of adversity and mental and physical health outcomes are improved. However, the phenomena of childhood adversity and resilience among autistic children are understudied and not well understood. In this study, we engaged members of the autism community to advise on the research question, research design, and analysis. Following the engagement phase, three autistic young women and one nonbinary young adult, aged 19-27, participated in semi-structured interviews via phone, video conference, and online chat;. credibility checking interviews followed data analysis. Through interpretative phenomenological analysis we identified themes related to negative effects of adversity, including *social disconnection*, *mental and emotional well-being*, *sense of self*, and *development into young adulthood*. Resilience was developed in *places of refuge* and *identity*, and was evident in their *transitions into young adulthood*. These findings provide direction for fostering resilience in children and adolescents on the autism spectrum and planning and implementing mental health supports to autistic individuals across the lifespan.

Keywords: autism, interpretative phenomenological analysis, participatory methods, credibility checking, childhood adversity, resilience

Lay Abstract

The long-term negative effects of childhood adversity on physical and mental health are well-documented. However, it is not a guarantee that a person will experience negative health outcomes following childhood adversity—the effects can be reduced by resilience, which is fostered throughout childhood when external and internal protective factors are present in a child's life. Unfortunately, not much is known about the effects of adversity or the development of resilience in children on the autism spectrum, despite the fact that they experience significantly more adversity than their typically developing peers. This study aims to describe the effects of childhood adversity on autistic individuals and the meaning of resilience in their lives. We interviewed four autistic young adults, three women and one non-binary participant, about their childhood experiences to gain their insights into how adversity in childhood shaped their well-being into young adulthood, as well as the factors that may have led to growth and improved quality of life. Childhood adversity negatively influenced participants' social disconnection, mental and emotional well-being, their sense of self, and their development into young adulthood. Conversely, resilience was fostered in childhood internally through aspects of their own identities and externally in places of refuge, leading to improved well-being in young adulthood.

Keywords: autism, interpretative phenomenological analysis, participatory methods, credibility checking, childhood adversity, ACES, resilience

Introduction

Adversity in childhood has been understood as a predictor of poor physical and mental health outcomes in adulthood (Bright et al., 2016; Felitti et al., 1998; Hughes et al., 2017). However, these negative outcomes can be ameliorated by internal and external protective factors, yielding resilience (Bellis et al., 2018; Gartland et al., 2019; Herrman, 2011; Liu et al., 2020; Moore & Ramirez, 2016). While these phenomena are well-studied in the non-autistic population, there is little research exploring the relationship between childhood adversity, resilience, and health outcomes for autistic adults. Epidemiological research has shown that children on the autism spectrum endure more adversity than their non-autistic peers (Berg et al., 2016; Rigles, 2017), which may contribute to mental health challenges. Furthermore, limited research on the prevalence of protective factors in the lives of autistic children have described inconsistent findings (e.g., McCrimmon et al., 2016; Rigles, 2017), bringing into question the role of resilience in mitigating the effects of adversity on autistic children. Thus, more research is needed to understand the interaction of adversity and resilience in the lives of autistic children.

The lack of understanding of these phenomena among autistic individuals is concerning given the prevalence of poor mental health in both children and adults on the autism spectrum (Centers for Disease Control and Prevention [CDC], 2020; Joshi et al., 2010; Lai et al., 2019; Madden et al., 2017; Soke et al., 2018). A conceptualization of the interplay between childhood adversity, resilience, and mental health in individuals on the autism spectrum would inform mental health promotion and intervention in autistic individuals, potentially improving their mental and emotional well-being. The aim of this study was to provide insight into the influence of childhood adversity on the well-being of autistic adults, and the meaning of resilience in their lives.

Methods

Methodological Approach

Interpretative phenomenological analysis (IPA) grounded this study, along with methods borrowed from participatory research, to uphold principles of ethical autism-related research (Chown et al., 2017; Pellicano, 2014). IPA is rooted in phenomenology, which focuses on describing human experiences; hermeneutics, which seeks to interpret and make meaning of participants' experiences; and idiography, by which researchers attend to the details and context of a participant's experience (Smith et al., 2009). IPA researchers pay close attention to participants' descriptions and understanding of their lived experiences, interpreting the participants' interpretations of their own experiences. This makes IPA an appropriate methodology for conducting ethical autism-related research because researchers seek to understand and highlight the perspectives of participants, while acknowledging how their own perspectives influence their understanding, thus not claiming to have first-hand knowledge of autistic experiences (MacLeod, 2019). This approach, along with positioning participants as experts and being reflective helps IPA researchers lessen the inherent power imbalances between non-autistic researchers and autistic participants (Howard et al., 2019).

Community Engagement

To further ensure the study design and analysis were conducted ethically and inclusively, we engaged the autism community while designing the study. We interviewed five community advisors, three autistic adults and two non-autistic mental health practitioners who worked within the autism community. Two advisors also identified as parents of children on the autism spectrum. Advisors provided recommendations for recruitment and data collection methods; and insight into autistic ways of thinking, communicating, and interacting, which influenced data generation and analysis.

Procedure

Following approval by the institutional Research Ethics Board (site withheld, #23780), participants were recruited through social media, local autism-community serving agencies, and the first author's university online announcement board. As per the advice of community advisors, participants were offered a variety of participation options (e.g., videoconference interview, phone interview, online chat interview, or written narratives with or without visual images). Two participants participated by phone, one opted for videoconference, and one engaged via online chat. In-person interviews were not offered due to COVID-19 safety concerns. The first author conducted the interviews. All participants opted to preview the interview guide. To enhance transparency and understanding, the interview guide provided detailed explanations of the purpose for each question and contained both open-ended questions and concrete, specific prompts. Interview topics included childhood adversity, resilience, and mental health. Video and phone interviews ranged from 58 minutes to 107 minutes. Participants gave written informed consent prior to the interview. Phone and video interviews were audio recorded and the online chat log was saved. Participants received a $25 gift card following the interview.

Data Analysis

As per IPA, each participant's data were thematically analyzed as a single case, and then analysis was completed across cases to identify common themes (Smith et al., 2009). In the initial noting phase, data were annotated according to descriptive, linguistic, and conceptual elements (Smith et al., 2009). Following initial noting of a single case, annotations and reflexive comments were reviewed to identify emergent themes. Similar themes were then clustered according to adversity or resilience. These themes were tabled, described, and then through abstraction, narrowed further to superordinate themes. Following analysis of each case, the superordinate themes for each single case were compared, grouped, and renamed through abstraction, and then clustered one more time, described, and categorized into new superordinate themes. These final themes were tabled with supporting participant quotations to ensure themes derived across cases were grounded in the details of each participant's recount of their experiences.

Rigour

T To maintain rigour, the first author kept reflexive notes and integrated them into analysis. Reflexivity gives the IPA researcher opportunity to evaluate the influence of their own experiences on the analysis (Smith et al., 2009). To further demonstrate analytic rigour, the second author also completed initial noting and emergent theme development for each case, with ongoing discussions and critical evaluation throughout the process of thematization. Finally, the first author engaged participants a second time for the purpose of credibility checking. Participants were provided with a summary of overall themes and supporting quotations pertaining to their interview. Three participants provided feedback via recorded phone or videoconference, and one responded in writing.

Participants also chose a pseudonym to be identified by in the final report and dissemination. Participants were given another $25 gift card following the credibility check. The discussions were integrated into the findings.

Findings

Four eligible participants, aged 19-27, volunteered for this study; three identified as women and one as non-binary. Participants were diagnosed with autism in childhood or adolescence (see Table 1). Through data analysis, we found themes related to both adversity and resilience.

Adversity

Participants described diverse experiences of adversity including bullying at school by peers and teachers; rejection by peers; verbal, emotional, and physical abuse by parents; growing up in an oppressive communist dictatorship; and internal dysregulation and behaviour challenges. Despite their unique and varied experiences, participants described similar effects of adversity on their lives: *adversity influences social disconnection, adversity influences mental and emotional well-being, adversity influences sense of self,* and *adversity influences development into young adulthood.*

Adversity Influences Social Disconnection

Participants identified social disconnection due to adversity that affected their relationships with friends and romantic partners, even into young adulthood. While participants did not attribute their experiences of social disconnection to autistic characteristics, they were often victimized for being different, which exacerbated social disconnection. Social disconnection occurred in multiple ways, including through *avoidance* of social interactions, *ostracization and stigmatization,* and *rejection* by others.

Avoidance. The negative consequences of social adversity, such as bullying at school, led some participants to avoid social interactions, which increased social disconnection and isolation. Hannah said, “I just tried to stay away from [the other kids].” The social disconnection was not isolated to childhood: Chris described their ongoing avoidance of social connection, “I had a really hard time trusting people around me. . . and so, it’s become really hard for me to reach out to people on my own.”

Ostracization and Stigmatization. Participants described adverse experiences of ostracization, (i.e., exclusion from social groups and activities); and stigmatization, wherein they were negatively labelled and consequently mistreated by others, both of which led to social disconnection. Not surprisingly, participants were ostracized by peers. Hannah recalled being unwelcome among peers: “People were just telling me that I don’t deserve to be here.” Additionally, some participants were ostracized by adults. Shirley recounted an experience with her grandmother: “I started drumming on the table because I was so happy. [My grandmother] asked my mom to escort me out because I was disrupting her pets.”

Participants recounted a range of experiences of stigmatization. They described being negatively characterized and subsequently deemed unworthy and unwelcome. For instance, Hannah recounted the consequences of being labelled as unstable: “[I was] constantly being called a psycho, being beaten up at school.” The stigmatization Chris faced at school by peers was reinforced by teachers: “they were making a point of making sure that everybody knew that I was different and wrong. I had been built up as like this problem child who did everything wrong on purpose." In a follow-up discussion, Saoirse expressed how policies and practices within the school system set her up to be ostracized and stigmatized:

> Because I was in that spec ed/gifted class . . . we were still segregated from the rest, were still the different or the special kids. And while I'm really grateful that we had a specific place for us, why are we the ones that have to be treated as the other?

Rejection. Participants were further disconnected from social relationships through rejection by others. They believed they were rejected because they were different and unworthy of connection. Hannah linked the rejection by her peers to her emotional dysregulation and behaviours:

> Whenever I had a meltdown, they would turn their back on me because they were scared of being beaten up, and I totally understand that, but they were really mean to me. They called me a psycho, a freak everybody hated me.

Adversity Influences Mental and Emotional Well-being

Participants in this study expressed a history of mental health challenges and emotional distress. These issues began in childhood and, for all four participants, continued into adulthood, with varying degrees of severity. Their experiences of childhood adversity influenced their mental and emotional well-being in four ways: *ongoing mental health challenges*, *behaviour challenges in childhood*, *suicidal ideation*, and *emotional distress*. Additionally, the *importance of mental health supports* was evident.

Ongoing Mental Health Challenges. Participants expressed ongoing concerns related to their mental health as they transitioned into young adulthood. Saoirse developed depression in adolescence and suffered for years, “things just kept getting worse and worse in my late teens, and then early 20s. . . . it wasn't until I was 25 that I was really able to get the help that I needed.”

Behavioural Challenges. For Shirley and Chris, adversity led to physically and verbally aggressive behaviours. Shirley experienced abuse by her father and imitated those behaviours: “I remember coming home from my dad's quite often and repeating the verbally and physically hurtful things [my dad] did to me towards my mom.” Chris’s aggressive behaviours were often a reaction to the relentless bullying they experienced:

> I just remember that I saw somebody going towards my backpack and I jumped up and I punched him because I assumed that he was going to steal something from me. I was so used to people doing stuff like that.

Suicidal Ideation. Suicidal ideation emerged as a common experience among participants. Chris’s suicidal thoughts and behaviours began at a young age: “I had first experienced suicidal ideation when I was eight . . . my first suicide attempt was when I was nine. It was rough.”

Emotional Distress. Participants described emotional distress, including emotional pain, sadness, anxiety, anger, and self-hatred. Hannah experienced distress from a young age:

> I hated myself since I was 5, actually. . . . I was really sad all the time. I was angry. I couldn’t control my anger. . . . When I was in high school [I] started therapy because my anxiety was really bad.

Shirley recalled, “As a child I was depressed a lot because I was always bullied at school or by my dad. . . . I'd say my mood was hurt and confused through my childhood.”

Importance of Mental Health Supports. Participants conveyed the importance of mental health supports to manage the pervasive emotional distress resulting from adversity. Shirley noted how valuable it was to have a psychologist to talk to in elementary school who “just let me vent for an hour 1-2 times a week.” Saoirse credited her improved quality of life in adulthood to psychological therapy and medication, “the medication was a literal switch in my head, it was amazing. It truly gave me my life.”

Adversity Influences Development into Young Adulthood

Saoirse frequently characterized her experiences of adversity as “formative,” and this attribution was similarly reflected in the other participants’ accounts. Formative experiences were those that influenced participants’ development, including how they interacted, behaved, and felt in adulthood. Participants expressed that, due to childhood adversity, they had to *unlearn learned behaviours*, experienced *lost time*, had *difficulty with adult relationships*, and that their adversity has had a *lasting influence* on their lives.

Unlearning of Learned Behaviours. The adversities that participants encountered were complex, ongoing, and pervasive. These experiences were interwoven with the development of their attitudes, beliefs, values, and behaviours. Over time, they learned that there were alternatives to these views and behaviours and, in some cases, that they were unhelpful or even unsafe. For example, Saoirse’s father modelled aggression:

> I was using the same awful tactics that my father was. I was using aggression, and hatred and resentment, anger . . . I ended up just like my father. . . . And I was

> like, no, I can't do that . . . . And that's what made me look inside and do a lot more internal work.

Lost Time. Most participants expressed a loss of time, which manifested as either memory loss or a sense that they had not lived fulsome lives. Chris identified their memory loss as a means of coping with their memories of adversity:

> I’ve kind of compartmentalized it in a way so that if I want to get to something specific, I have to go through all the other things first. So, it’s like there’s a lot of stuff that happened that I just either don’t remember or can’t remember right now.

For Saoirse, losing time meant missing out on positive experiences due to her mental health challenges, “I feel like I started my life at age 25 . . . but I missed out on like a good decade, at least, of life.”

The Lasting Influence of Adversity. The effects of adversity persisted in the participants’ lives, regardless of resilience. For Shirley, this was evidenced in self-doubt about her role in the breakdown of relationships, “I’ve had friends move away without explanation or stop talking to me for no reason . . . it does sometimes leave me wondering if it's something I'm doing since it keeps happening.” Chris noted that they expected this influence to last forever, “So, like there’s a lot of stuff that I don’t think I’m ever going to be over.”

Difficulty with Adult Relationships. Adversity influenced participants’ social-emotional development, as evidenced by challenges with initiating and maintaining adult relationships. Shirley said, “I’ve also been in tons of failed relationships and recently got out of an abusive one which I feel is all linked to my past experiences.” Saoirse described how her template for interacting with others developed through interactions with her father:

> Yeah, the relationships I had growing up in my family just did not give to me the tools . . . to communicate properly with people, to have a productive and positive conversation, to make friends, [or] to repair relationships.

Adversity Influences Sense of Self

Childhood adversity shaped participants' negative perceptions of themselves. Participants expressed a *yearning to understand themselves*, f*eelings of shame*, *lack of belonging*, and *powerlessness*.

Yearning to Understand Oneself. Participants commented on how they could not comprehend their own behaviours and feelings as children. Without this insight, they viewed themselves as inferior. Hannah conceptualized this as adverse, "Adversity is . . . misunderstanding yourself—being misunderstood by others."

Shame. Experiences of adversity taught participants that they should be ashamed of themselves because they were different and inadequate. Shirley tried desperately to hide her autistic identity from others:

> Honestly, I felt very claustrophobic trying to hide who I was. Almost like you were trying to physically stuff me into a literal desk drawer at times. . . . I wanted to be normal and 'non autistic' growing up so I studied my peers to try and be like them.

Chris felt unworthy and inferior, "it was a lot of me internalizing that I was a bad person."

Lack of Belonging. Participants viewed themselves as not belonging, or fitting in, with others. Hannah said of her peers, “They always treated me badly because I was weird, I couldn’t talk to people. I was different . . . . I had meltdowns until, like, grade 7.” Chris said, “I constantly felt like I was on the outside. I felt separated from everyone else.”

Feelings of Powerlessness. All participants described feeling that they had no power in their own lives and no capacity to change their circumstances. Saoirse said of her conflict with her father, “it didn't matter what I tried to do with my life . . . . it seemed insurmountable and I wasn't going to be able to do anything, because I wasn't allowed.” Hannah felt powerless to her emotional dysregulation, “I never meant to hurt anyone. It just happened because I lost control.”

Resilience

Resilience was interpreted as the result of positive experiences in childhood that fostered long-term well-being; resilience was evidenced by positive outcomes for participants, despite their experiences of adversity. In speaking about the meaning of resilience in their lives, participants identified internal and external resources that provided them with security, stability, and support. Each participant defined resilience differently; however, their definitions alluded to a perseverance in the face of adversity and resistance to its potentially detrimental effects. From Saoirse:

> Resilience, to me, means fighting back in the face of adversity . . . it sucked, but you had to deal with it, and you had to find a way to either overcome it, circumvent it, or cope with it.

For the participants in this study, resilience was influenced by *places of refuge* and *identity*. Additionally, resilience influenced *transitions into young adulthood.*

Places of Refuge

Resilience was fostered in safe spaces, where participants could escape from the ongoing and relentless stress in their lives—places where they were free to be themselves. These places of refuge were not only physical spaces, but also connection with other people and internal resources. Participants found refuges in *accepting communities*, *a sense of belonging, interests and talents, attentive adults*, and their *use of imagination*.

Accepting Communities. Participants developed resilience when they were accepted unconditionally by others. Shirley recalled feeling safe with her aunt and cousin:

> [My aunt] always made me laugh by being silly and so did my cousin who lived with her. . . . I remember in the summers we'd stay there he'd look through teen magazines with me, do the high school musical sing-alongs with me, etc., and my aunt was always pretending to be clumsier or sillier than she really was.

Sense of Belonging. Beyond acceptance, participants also noted places where they felt they belonged, or fit in, either with particular people, or a safe physical space. Participants felt a sense of belonging with peers with whom they had shared experiences, interests, and sometimes neurodivergent traits. Saoirse highlighted her high school experience in a gifted program:

> Those kids were like me. That was really awesome. That was the first time that I had seen a conglomerate of classmates that had similar characteristics. And then I

> kind of realized, wow, I don't have to cover up anymore, necessarily. I don't have to wear a mask. I don't have to try, and you know, spend the abhorrent amount of energy that I do trying to fit in in a neurotypical world. I could just be with these kids and it would be great.

Interests and Talents. Participants found refuge in the activities they were passionate about. Hannah expressed how she depended on her special interests for stability and security, “having a special interest to rely on . . . I really enjoyed lining up Little Pet Shops and organizing them. I acted out scenes from my life.” Saoirse described how her musical talent helped her, “if I needed to feel good . . . I would just sing and play the piano for hours and pretend. It was a really nice escape.”

Attentive Adults. Participants identified caring adults in their childhoods who were attentive, emotionally supportive, and who intervened to change participants’ circumstances. Hannah spoke of a high school principal, “She is a really nice person and I would often talk to her when I was in high school . . . she’s like the mother I never had—an emotionally stable person.”

Use of Imagination. Participants used their imaginations as a place where their hardships did not exist. Chris recalled, “My favorite thing to do was to go to the pool and just swim. And I would like to imagine I was a fish or a mermaid or whatever because it was like an escapism thing.”

Resilience is Found in Identity

While adversity influenced participants’ sense of self and self-perception, their identities, namely their personal traits and uniqueness, also contributed to their resilience.

The aspects of their identities that promoted resilience were *developing self-understanding*, *determination*, *a sense of pride*, and *personal attributes*.

Developing Self-Understanding. Related to adversity, participants talked about lacking self-understanding and being mystified by their own thoughts, feelings, and behaviours. Conversely, as participants developed self-understanding, they could integrate their uniqueness into a sense of identity, which influenced resilience. For example, Saoirse remembered identifying with Disney characters as a child:

> Most people just think that I am a little bit more to myself, or . . . ‘strange’ or ‘eccentric’ or ‘weird’ are the terms that were used with me as a child . . . but I didn't find anything wrong with being ‘eccentric’ or ‘strange’. . . . I mean, frig, they called Belle in Beauty and the Beast strange and I was like, she's not strange! She just likes to read books. I like to read books, too. What’s weird about that?

Hannah discussed how receiving an autism diagnosis changed her understanding of herself:

> I got diagnosed when I was 17 years old and it was a really eye-opening experience because it finally explained what was going on in my childhood . . . I thought I had a personality disorder because I was so emotionally unstable, but it turned out to be just autism and that my sensory needs weren’t being met.

Determination. The participants in this study demonstrated a drive to change their lives and circumstances and to be heard, despite the negative effects of adversity. As Saoirse’s understanding of her circumstances shifted, she gained the confidence to improve her situation:

> Realizing that the problem wasn't necessarily me . . . after that, I applied to university and college without [my father’s] permission. Because I was like, you know what? I will be damned if I am not allowed to go out and live my life.

Sense of Pride. Participants expressed a sense of satisfaction in their accomplishments and talents, regardless of the other difficulties in their lives. Hannah spoke about her school achievements, “I’ve always been a high achiever academically. I’m a straight A student and always have been. And I work really hard and really enjoy studying and that’s something that I’ve always taken pride in.”

Personal Attributes. These participants noted specific characteristics that helped them manage the effects of adversity. Shirley said, “I've adapted a very dark sense of humor to my life experiences.”

Resilience Influences Transitions to Young Adulthood

For the participants in this study, resilience meant positivity and growth in their young adult lives, despite their experiences of adversity. Considering the participants’ current well-being, *social connection,* the *ability to adapt and change,* and *moving forward* were evident.

Social Connection. In young adulthood, participants expressed newfound social connections, including friendships and romantic relationships. Saoirse expressed gratitude for her current social connections, “I have amazing other supportive friends [and] my partner who I disclosed most of this information to. So, yeah, I've had really great people around.”

Ability to Adapt and Change. As they entered young adulthood, participants worked hard to grow emotionally and make changes in their lives. Hannah happily noted how she had learned to regulate her emotions and behaviour, “On the whole, I am pretty much in control most of the time, I can control the sensory input, and I just don’t have those sensory meltdowns like I used to..”

Moving Forward. Participants were future-focused—making plans and engaging in activities. While their experiences of adversity continued to influence their lives, they were moving forward through young adulthood. Saoirse described her life after leaving home, “I was able to explore the world . . . I started hanging out with people that I otherwise wasn't allowed to hang out with. I started trying different activities.” Chris enrolled in a post-secondary program and engaged in entrepreneurship, “[I’m] starting a small business with my friend.”

Discussion

All study participants experienced childhood adversity and articulated the meaning of resilience in their lives. While participants’ experiences of adversity varied, the effects were commonly destructive to their well-being and sense of self. Furthermore, there was commonality in their experiences of resilience.

Research has indicated a relationship between mental health symptomology and adversity in non-autistic children (Bellis et al., 2018; Bright et al., 2016; Rigles, 2017) and there is limited evidence that children on the autism spectrum also experience mental health challenges related to adverse experiences (Storch et al., 2013; Taylor & Gotham, 2016; Wood & Gadow, 2010). This study examined adversity and resilience through first-hand accounts from autistic adults and therefore provides insight into the immediate and ongoing effects from adversity, as well as the pervasive and complex influence of adversity in their lives. Participants connected their mental health challenges, including depression, anxiety, and suicidal ideation, to adversity, which is similar to symptomology identified in previous research (Storch et al., 2013; Taylor & Gotham, 2016). Additionally, they described how adversity influenced other aspects of their lives, that is their diminished social interactions, lack of connection, and self-concept, and permeated their development beyond adolescence into young adulthood.

Some theorists posit that the neurobiological characteristics of autism influence how adverse experiences are perceived by autistic children, thus mitigating or exacerbating their effects (Im, 2016; Kerns et al., 2015); however, this was not identified by participants in the present study as a feature of their experiences of adversity. Instead, these findings show a complex and contextual interaction of autism with both adversity and resilience that is simultaneously detrimental and protective. For example, autism interacted with adversity to influence social disconnection, as this was often prompted by maltreatment related to participants' autistic traits and differences; rather than autism being adverse in and of itself, or as a confounding variable in their interpretations of adverse experiences. This distinction, however, does not preclude the damaging effects of these experiences on the participants’ overall well-being. In relation to resilience, participants' autistic characteristics carried more significance for them as resilience factors. Participants found safety and comfort in special interests and talents, as well as with peers who understood and experienced the world in a similar way.

Additionally, the present study goes beyond epidemiology and provides an in-depth exploration of the meaning of resilience in the lives of participants. Little is known about the characterization of resilience in children on the autism spectrum, as the available research is predominantly epidemiological and quantitative (e.g., McCrimmon et al., 2016; Rigles, 2017). In non-autistic children, factors such as supportive adults, personality characteristics, and positive social relationships have been shown to mitigate the negative effects of adversity (Gartland et al., 2019; Herrman, 2011). Autistic participants in the current study identified similar protective factors in their childhoods. They described positive internal and external influences on their well-being, including personal attributes, attentive adults, and accepting social groups, but also factors unique to being autistic, such as special interests and talents, a sense of belonging among peers with similar traits and experiences, and self-understanding related to their autistic identities. Notably, participants also described some positive outcomes in young adulthood, which suggests that resilience factors have mediated, to some degree, the negative outcomes predicted by childhood adversity.

Strengths, Limitations, Considerations, and Directions for Future Research

The present study provides new insight into the experiences of childhood adversity and the meaning of resilience among autistic adults. While these findings need to be considered in the context of a small sample size, the sample is reasonable as per IPA methodology. Our findings offer nuanced attention to the details of participant accounts, thus providing an in-depth understanding of these phenomena in the lives of participants. Additionally, IPA provided an opportunity to hear directly from autistic individuals about their experiences, rather than drawing conclusions from non-autistic, outsider observations. This, along with integration of participatory methods into the study design (reference withheld for blind review), aligns this study closely to the principles of ethical autism-related research (Chown et al., 2017).

Consistent with IPA, we engaged a small, homogenous sample of participants, which presented several limitations. Given that there were no male-identifying participants, the findings cannot be generalized to autistic boys and men. However, given the gender bias toward men and boys in the diagnosis of autism, women and non-binary individuals are underrepresented in research (Lai et al., 2015), therefore this study contributes to that gap.

Additionally, several community advisors suggested that limiting recruitment to individuals who had been diagnosed prior in childhood would exclude valuable input from those who went through childhood without a diagnosis. Future research comparing the experiences of autistic participants diagnosed in childhood versus adulthood, or those self-diagnosed in adulthood, could provide understanding of the influence formal diagnosis has on experiences of childhood adversity and resilience.

Lastly, all participants had strong verbal communication skills and their accounts were not limited by expressive language differences. Given that differences in social communication and language use are common place for autistic individuals, the number of autistic individuals who are non or minimally speaking, and the high percentage of individuals on the autism spectrum with co-occurring intellectual disability, the results of this study may not be representative of their experiences. This sub-set of the autistic population is understudied, and future research could explore their unique experiences of childhood adversity and resilience.

Clinical Implications

From the present study, we learned that childhood adversity has significant and long-term effects on the lives of autistic individuals, including their social connectedness, their emotional and mental well-being, their sense of self, and their development into adulthood. Furthermore, from these findings, it is evident that resilience plays an important role in providing safety and escape from adversity, maximizes individuals' strengths to endure and overcome the adversity, and influences positive outcomes in early adulthood.

These findings compel clinicians and caregivers to pay attention to the potential sources of adversity for children, and to attune to the potentially ambiguous effects of those experiences and seek to foster resilience. Being alert and open to the potential root causes of behaviours, challenges with social interactions, and mental and emotional dysregulation could lead to earlier mitigative interventions fostering well-being, and even prevention of the effects of adversity. Furthermore, recognizing the unique attributes and activities of children on the autism spectrum that may be protecting them from the negative effects of adversity primes clinicians and caregivers to nurture the development of such traits and provide opportunities to engage in protective activities. Additionally, constructing external protective factors, such as mental health interventions, safe environments, and places of belonging and acceptance, may promote resilience in children on the autism spectrum.

When identifying and executing formal resilience-building interventions, it is important to recognize the potential pervasive and complex influence of adversity in the lives of autistic children, and be aware that adversity affects more aspects of a child's life than their emotional and mental well-being. There is ample evidence supporting resilience-building programs in non-autistic children to improve their mental health (Dray et al., 2017). Additionally, some researchers have adapted resilience-fostering interventions for use with children on the autism spectrum, successfully fostering internal protective factors in these children (Mackay et al., 2017). However, for children on the autism spectrum, it is important to also address the social disconnection and harm to identity they may have suffered. Accordingly, providing external supports that minimize social disconnection and bolster a child's sense of identity will be as important as promoting the development of internal resilience factors to improve mental health outcomes.

Conclusion

All participants in this study experienced adversity in childhood that negatively influenced many aspects of their lives and well-being. Additionally, they described how they understood resilience and its positive influence in their childhoods and beyond. Their insights give a deeper understanding of how adverse childhood experiences affect young people and how better to support the development of resilience to minimize poor outcomes in adulthood. Clinicians and caregivers must be aware of the complex and pervasive effects of adversity on children on the autism spectrum, strive to minimize potentially adverse experiences, and work to foster internal and external resilience factors in these children.

Table 1

Participant Demographics

Participant	Age	Gender	Age of diagnosis
Shirley	27	Woman	Upper elementary
Saoirse	27	Woman	Preschool
Hannah	19	Woman	Late teens
Chris	20	Non-binary	Early teens

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Chapter VI — Conclusion

This study is the first to explore qualitatively the phenomena of childhood adversity and resilience in adults on the autism spectrum. Previous epidemiological studies have identified high rates of childhood adversity and inconclusive evidence of resilience in children on the autism spectrum (Berg et al., 2016; McCrimmon et al., 2016; Rigles, 2017), however, an in-depth understanding of the immediate and long-term effects of childhood adversity, and the nature of resilience in the lives of autistic individuals was unstudied up to this point. This study provides valuable insight into the harmful consequences of adverse experiences on the well-being of individuals on the autism spectrum, and the potential mitigating effects of protective factors and emergence of resilience in their lives.

My initial motivations for this research were rooted in my experiences with children on the autism spectrum in a school environment, where I witnessed their social, emotional, and behavioural struggles, and wondered if these challenges were at all influenced by adversity, or were, as many professionals asserted, primarily characteristics of autism. From this study, it is clear that children on the autism spectrum experience significant adversities and, most troubling, can experience serious and ongoing damaging effects of these events. Participants in this study described not only poor mental and emotional well-being, which would be expected based on the known effects of adversity on non-autistic children (Bellis et al., 2018; Bright et al., 2016), but also had a long-term influence on their self-perceptions, their relationships, and aspects of their development into young adulthood. Given these pervasive and perpetual effects on multiple aspects of their lives and well-being, it is no wonder that adolescents on the autism spectrum experience high rates of depression and suicidal ideation and/or behaviours (Storch, 2013; Taylor & Gotham, 2016; Wijnhoven et al., 2019), or that autistic adults experience high rates of mental health disorders (Lai et al., 2019). It is clear that there is a critical need for mental health supports for individuals on the autism spectrum across the lifespan, and the present study provides insight into the development of these challenges in autistic individuals. Mental health challenges in children on the autism spectrum can often be viewed as autistic characteristics by mental health professionals (Stadnick et al., 2017), leading to inadequate or inappropriate mental health supports. The participants in this study have provided us with an understanding of the importance of attending to context and viewing autistic individuals holistically when challenges emerge. For example, some participants described difficulty regulating their emotions and behaviours as a result of their adverse experiences, rather than as a characteristic trait of autism. Professionals and caregivers can better support individuals on the autism spectrum by considering the multiple factors that may be contributing to their challenges, rather than focusing solely on autism and autistic characteristics.

Furthermore, the participants in this study have shown how being autistic is not necessarily a problem in their lives, rather it can be the catalyst for maltreatment by others, which is the source of their problems. For example, some participants described their autistic identities as a factor in their experiences of victimization by others or lack of belonging. This prompts us to consider the importance of attending to context when providing mental health supports to individuals on the autism spectrum. Rather than targeting autism as a problem to be fixed, it could be valuable to explore the implications of being autistic in a primarily non-autistic world. More so, it compels us to evaluate the sociocultural discourses, policies, and practices that underlie such maltreatment. Our rigid sociocultural narratives of what is “normal,” as well as our understanding of ability, influences our perception of what it means to be human or subhuman and potentially underpins our (mis)treatment of others (O’Dell et al., 2016). It is incumbent on researchers, practitioners, parents, and other supporters to combat such discourses, advocate for change at the community and systems levels, and reflect on our own assumptions and biases about autism, particularly when providing support to autistic individuals or contributing to knowledge production about autism through research.

The philosophical assumptions of social constructivism and the theoretical framework of critical autism studies provided a lens through which to view this study, from research design to analysis and dissemination. From this perspective, our understanding of autism is rooted in a particular context, at a particular time, and more than one understanding of autism can be true simultaneously (Creswell & Poth, 2018; O’Dell et al., 2016). O’Dell and colleagues (2016) noted that autism can be both a diagnostic label and an identity, a notion that I embraced throughout this project. O’Dell et al. have suggested that the neurodiversity movement, which has bloomed in certain sociocultural contexts, provides a counter-narrative to the pathologizing, deficits-based conceptualization of autism, instead characterizing autism as a neurobiological difference and cultural identity. Given the harm that has been perpetrated against the autistic community by researchers in the past (Milton, 2014; Milton & Bracher, 2013), it was important for me to conduct my work in a way that would challenge the dominant deficits-oriented view of autism, as well as strive to minimize the extent to which I foregrounded my perspectives and ways of knowing, opting instead to privilege the perspectives and expertise of individuals on the autism spectrum. This was achieved by conducting a qualitative study that focused on the lived experiences of autistic adults, by engaging the autism and autistic communities to inform research design and provide some understanding of autistic ways of communicating, interacting, and being, and through credibility checking directly with participants following data analysis.

Despite taking these steps and aspiring to a high standard of ethical and inclusive autism-related research, ultimately, my biases have undoubtedly influenced my interpretations of the data, as in IPA it is understood that the meaning of participants' recounted experiences is contextual and temporally-bound, constructed between the researcher and participant (Smith et al., 2009). Therefore, the understanding of autistic identity not as a source of stress for participants in and of itself, rather as a target for maltreatment by others, given the sociocultural context in which there is a narrow understanding of normal, is only one interpretation and way of perceiving the interplay between autism and childhood adversity. However, through credibility checking, this interpretation was validated by the participants, as it fit their understanding of their lived experiences. Accordingly, while the insight provided by participants in this study cannot be generalized to all individuals on the autism spectrum who have experienced adversity, we are behooved to consider how being autistic, or more broadly, different, may be interacting with experiences of childhood adversity and the overall consequences of that on the well-being of autistic individuals and the broader autism community. This can inform change in how we view autistic identity and the effects of childhood adversity, at the individual and personal level, the community level, and systems level. This applies not only to adversity, but also to the fostering of resilience in children on the autism spectrum, a discussion of which follows.

The phenomenon of resilience was also interpreted through a neurodiversity lens, and, as such, an autistic identity proved to be a key factor in participants emerging as resilient in young adulthood. I conceptualized resilience as a phenomenon that becomes evident over time, as individuals experience positive outcomes, despite their experiences of adversity; and that resilience occurs when internal and external protective factors are present to mitigate its harmful effects (APA, n.d.; Herrman et al., 2011; Moore & Ramirez, 2016; Rigles, 2017).

For participants in this study, resilience was evident in their young adult lives as they demonstrated the ability to adapt to their circumstances and make change in their lives, in the development of social connections, and in moving forward into young adulthood with hopes and goals for the future. Participant accounts of their current mental and emotional well-being, their involvement in activities, and their social lives, while “not perfect,” as one participant described it, were mostly positive and characterized by hope for the future. All participants identified having at least one significant, healthy relationship, and were embracing change, including working towards improved mental health, emotional regulation, and trying new experiences. It is encouraging to know, that despite significant adversity in childhood, and the ongoing distress associated with such events, participants were able to find their way into young adulthood and experience improvements in their well-being.

The protective factors that may have led to resilience, were interpreted as the positive, comforting, safe, and supportive childhood experiences they recounted.

Participants described aspects of their identities that were interpreted as protective, as well as places, physical or internal, where they were shielded from the ongoing adversity they faced. Through the neurodiversity lens, autistic traits can be conceptualized as strengths—one participant referred to her, “superpowers.” As such, the protective factors that were internal to participants could be attributed to being autistic, such as special interests and talents, or their own determination. Regardless of whether these protective traits and behaviours were autistic characteristics, they were strengths and sources of comfort for participants. Accordingly, to foster resilience in children on the autism spectrum, it is logical that we attend to their strengths and interests, providing space and support to develop them further. Additionally, participants identified their own sense of pride in their accomplishments as being positive in their young lives. Instilling a sense of pride in children’s abilities may help to increase their opportunity for resilience.

External factors that were positive and potentially protective for the participants in this study were affirming of their neurodivergent identities. Just as being victimized for their differences had a damaging effect on participants, being embraced and accepted wholly, and valued as a community member, fostered growth and belonging. This finding holds two distinct but interconnected considerations for fostering resilience in children on the autism spectrum. Firstly, it is important to help children find people and places where they feel that they belong. For the participants in this study, this was often, but not always, with people that they described as being “like them,” that is, neurodivergent, or who had had similar experiences. For these participants, it was important to build relationships with people who truly could understand them. However, this needs to be done with caution, as segregating neurodivergent children in the hopes that they find belonging, will further distance them from their peers and characterize them as outsiders, an experience relayed by one participant during credibility checking. By forcing children on the autism spectrum into out-groups, even with the best of intentions, we perpetuate the discourse that being different is wrong or a problem. Therefore, encouraging children to build social relationships with other children who will understand them is important, it needs to be done concurrently with working toward changing sociocultural discourses of normalcy and the pathologization of autistic traits. Children on the autism spectrum should be accepted and included in all spaces, as well as have the opportunity to connect with other children who perceive the world as they do.

Through this project, I aimed to understand better the potential influence of childhood adversity and the development of resilience in individuals on the autism spectrum. As a non-autistic researcher, I approached this task cautiously, careful to ensure that every aspect of the project would be helpful and valuable to the autism community, and especially to autistic children, adolescents, and adults. As a result, I have conducted a rigorous research study and generated findings that may inform approaches to supporting the mental health of autistic individuals, as well as supporting the development of resilience in the lives of children on the autism spectrum. Also important is the onus on us, given these findings, to change sociocultural discourses of autism and to alter both our personal biases, assumptions, and behaviours, as well as deconstructing the structures that perpetuate these discourses. This study lays the groundwork for future research, including investigations into the process of resilience development and the effectiveness of interventions to support mental health or foster resilience in children and adolescence on the autism spectrum.

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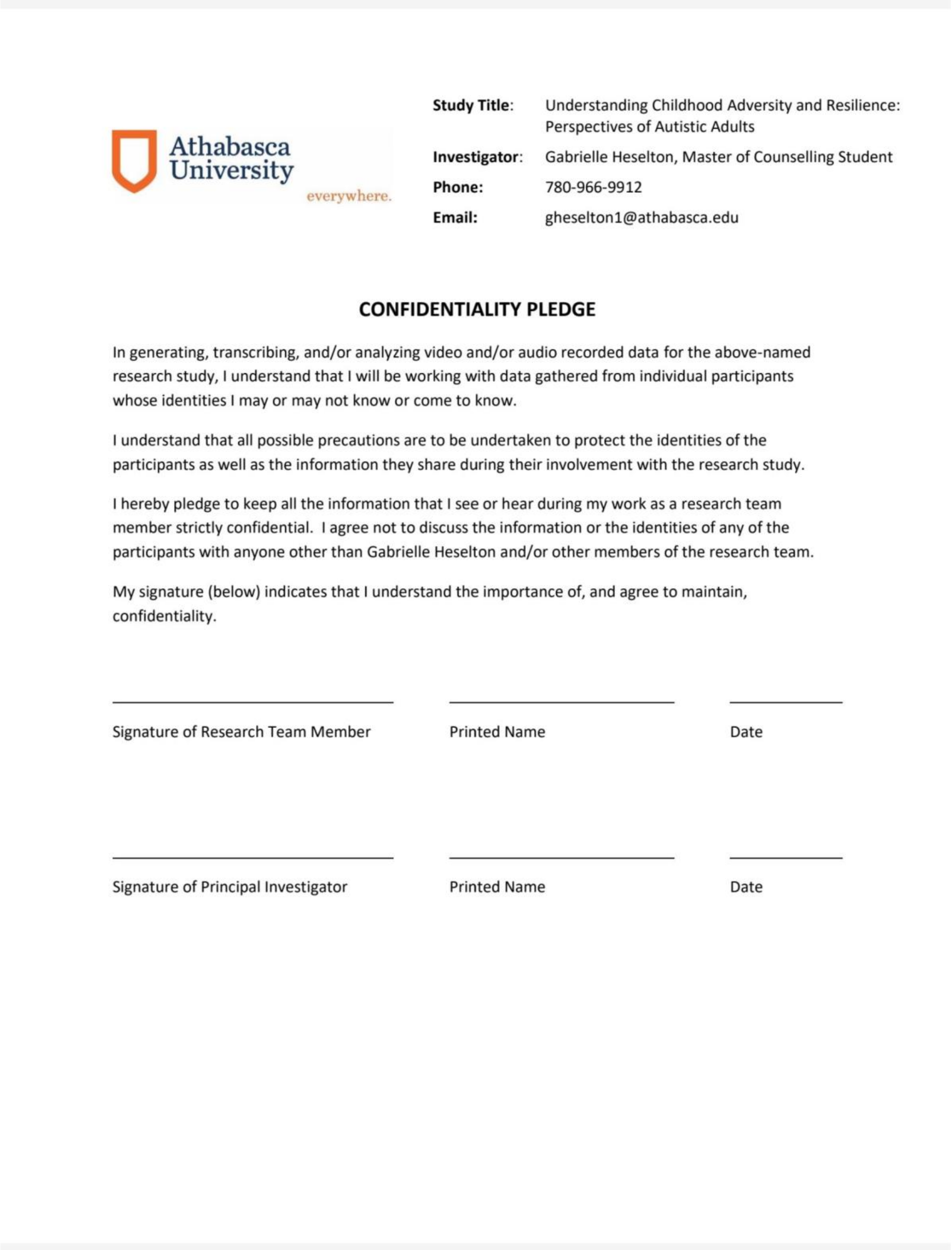
Appendix A: Confidentiality Pledge



Athabasca University
everywhere.

Study Title: Understanding Childhood Adversity and Resilience: Perspectives of Autistic Adults
Investigator: Gabrielle Heselton, Master of Counselling Student
Phone: 780-966-9912
Email: gheselton1@athabasca.edu

CONFIDENTIALITY PLEDGE

In generating, transcribing, and/or analyzing video and/or audio recorded data for the above-named research study, I understand that I will be working with data gathered from individual participants whose identities I may or may not know or come to know.

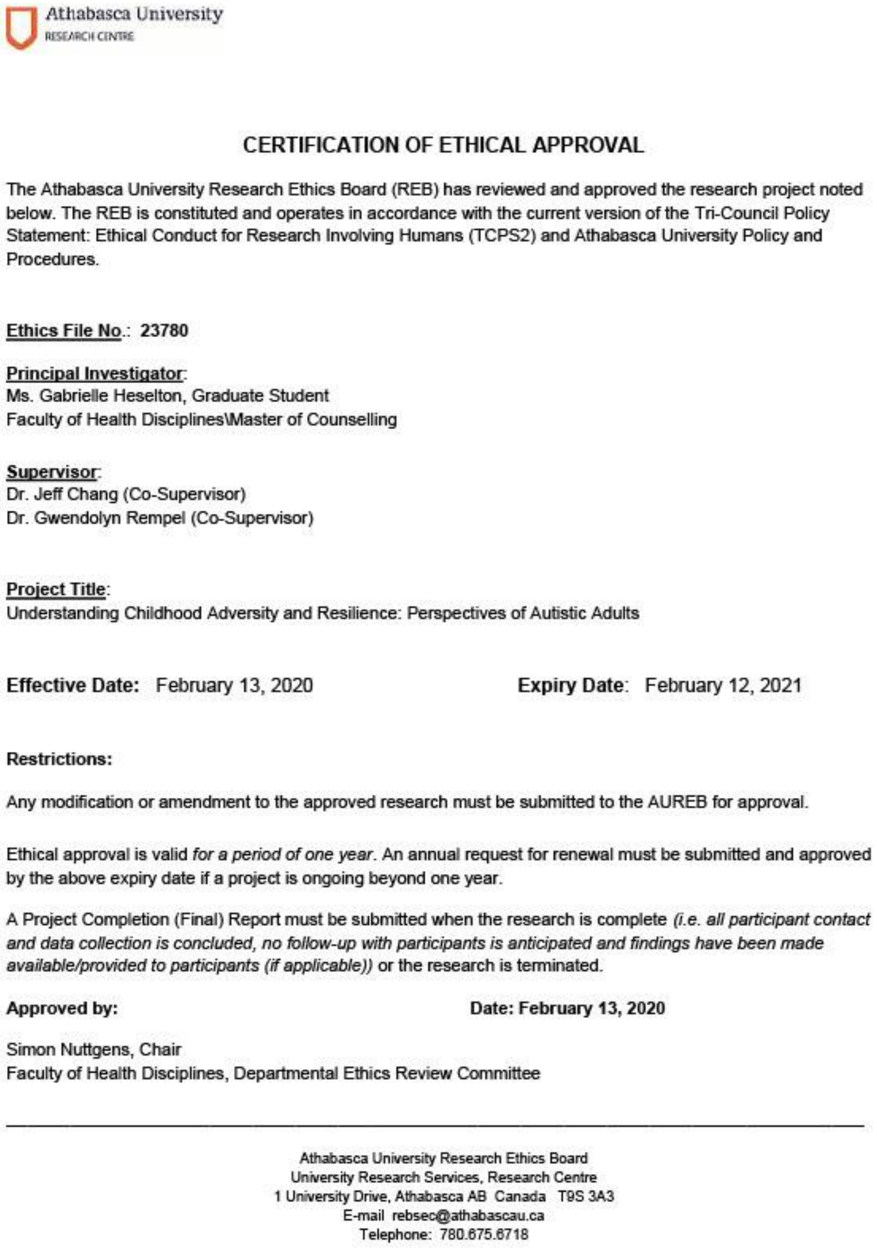
I understand that all possible precautions are to be undertaken to protect the identities of the participants as well as the information they share during their involvement with the research study.

I hereby pledge to keep all the information that I see or hear during my work as a research team member strictly confidential. I agree not to discuss the information or the identities of any of the participants with anyone other than Gabrielle Heselton and/or other members of the research team.

My signature (below) indicates that I understand the importance of, and agree to maintain, confidentiality.

______________________	______________________	__________
Signature of Research Team Member	Printed Name	Date
______________________	______________________	__________
Signature of Principal Investigator	Printed Name	Date

Appendix B: Ethics Approval



Athabasca University
RESEARCH CENTRE

CERTIFICATION OF ETHICAL APPROVAL

The Athabasca University Research Ethics Board (REB) has reviewed and approved the research project noted below. The REB is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) and Athabasca University Policy and Procedures.

Ethics File No.: **23780**

Principal Investigator:
Ms. Gabrielle Heselton, Graduate Student
Faculty of Health Disciplines\Master of Counselling

Supervisor:
Dr. Jeff Chang (Co-Supervisor)
Dr. Gwendolyn Rempel (Co-Supervisor)

Project Title:
Understanding Childhood Adversity and Resilience: Perspectives of Autistic Adults

Effective Date: February 13, 2020 **Expiry Date**: February 12, 2021

Restrictions:

Any modification or amendment to the approved research must be submitted to the AUREB for approval.

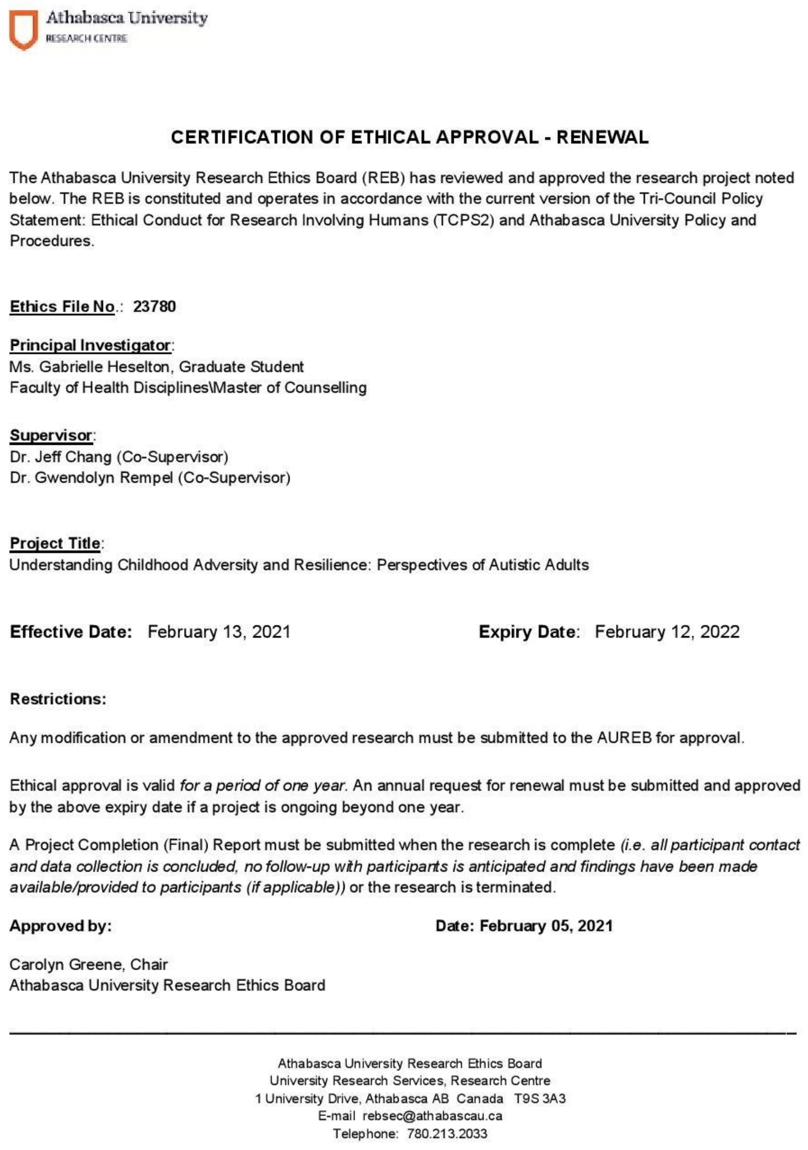
Ethical approval is valid *for a period of one year*. An annual request for renewal must be submitted and approved by the above expiry date if a project is ongoing beyond one year.

A Project Completion (Final) Report must be submitted when the research is complete *(i.e. all participant contact and data collection is concluded, no follow-up with participants is anticipated and findings have been made available/provided to participants (if applicable))* or the research is terminated.

Approved by: **Date: February 13, 2020**

Simon Nuttgens, Chair
Faculty of Health Disciplines, Departmental Ethics Review Committee

Athabasca University Research Ethics Board
University Research Services, Research Centre
1 University Drive, Athabasca AB Canada T9S 3A3
E-mail rebsec@athabascau.ca
Telephone: 780.675.6718



Athabasca University
RESEARCH CENTRE

CERTIFICATION OF ETHICAL APPROVAL - RENEWAL

The Athabasca University Research Ethics Board (REB) has reviewed and approved the research project noted below. The REB is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) and Athabasca University Policy and Procedures.

Ethics File No.: **23780**

Principal Investigator:
Ms. Gabrielle Heselton, Graduate Student
Faculty of Health Disciplines\Master of Counselling

Supervisor:
Dr. Jeff Chang (Co-Supervisor)
Dr. Gwendolyn Rempel (Co-Supervisor)

Project Title:
Understanding Childhood Adversity and Resilience: Perspectives of Autistic Adults

Effective Date: February 13, 2021 **Expiry Date**: February 12, 2022

Restrictions:

Any modification or amendment to the approved research must be submitted to the AUREB for approval.

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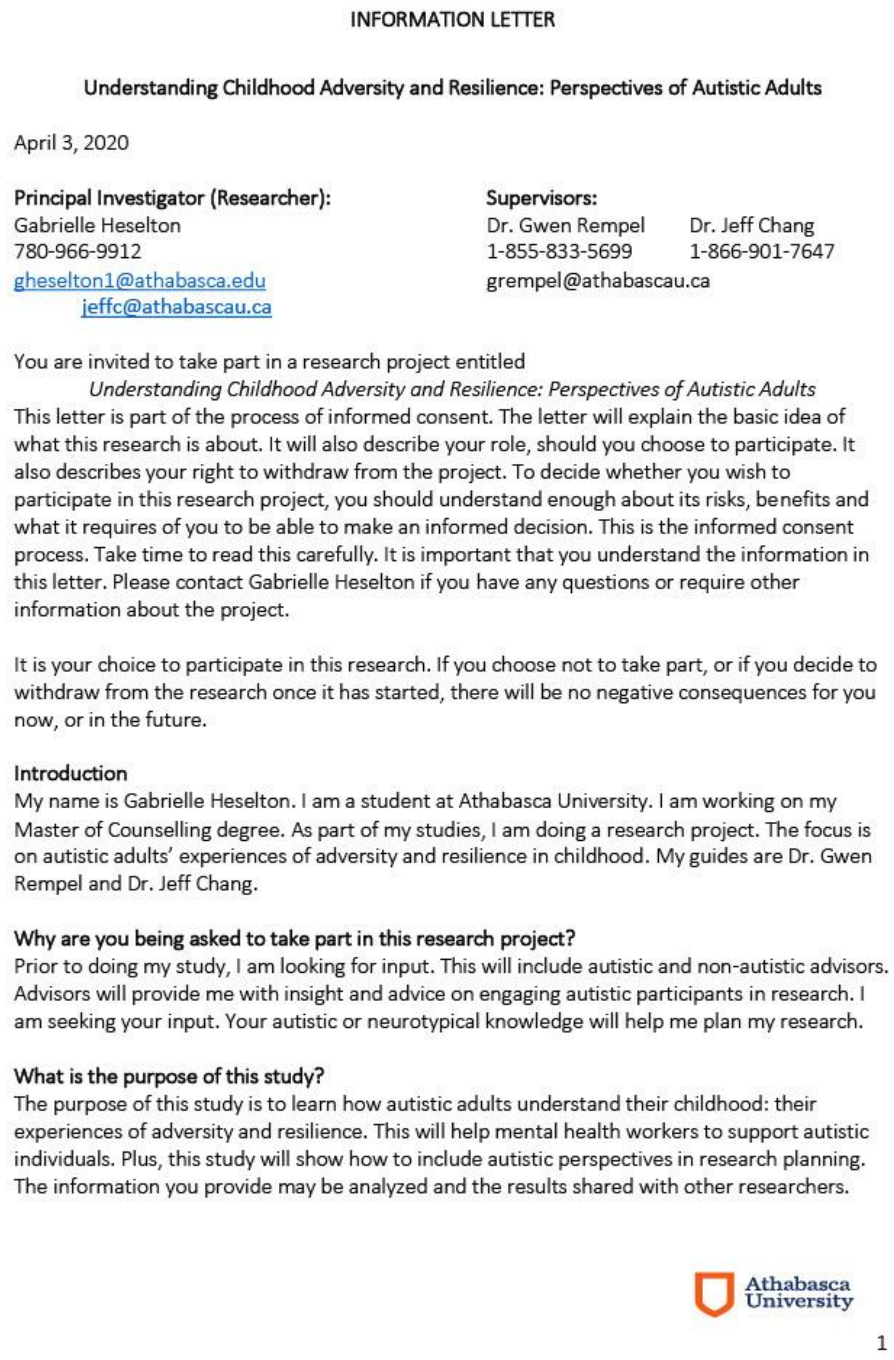
A Project Completion (Final) Report must be submitted when the research is complete *(i.e. all participant contact and data collection is concluded, no follow-up with participants is anticipated and findings have been made available/provided to participants (if applicable))* or the research is terminated.

Approved by: **Date: February 05, 2021**

Carolyn Greene, Chair
Athabasca University Research Ethics Board

Athabasca University Research Ethics Board
University Research Services, Research Centre
1 University Drive, Athabasca AB Canada T9S 3A3
E-mail rebsec@athabascau.ca
Telephone: 780.213.2033

Appendix C: Information Letter and Informed Consent—Advisors



INFORMATION LETTER

Understanding Childhood Adversity and Resilience: Perspectives of Autistic Adults

April 3, 2020

Principal Investigator (Researcher):	**Supervisors:**	
Gabrielle Heselton	Dr. Gwen Rempel	Dr. Jeff Chang
780-966-9912	1-855-833-5699	1-866-901-7647
gheselton1@athabasca.edu	grempel@athabascau.ca	jeffc@athabascau.ca

You are invited to take part in a research project entitled
Understanding Childhood Adversity and Resilience: Perspectives of Autistic Adults
This letter is part of the process of informed consent. The letter will explain the basic idea of what this research is about. It will also describe your role, should you choose to participate. It also describes your right to withdraw from the project. To decide whether you wish to participate in this research project, you should understand enough about its risks, benefits and what it requires of you to be able to make an informed decision. This is the informed consent process. Take time to read this carefully. It is important that you understand the information in this letter. Please contact Gabrielle Heselton if you have any questions or require other information about the project.

It is your choice to participate in this research. If you choose not to take part, or if you decide to withdraw from the research once it has started, there will be no negative consequences for you now, or in the future.

Introduction
My name is Gabrielle Heselton. I am a student at Athabasca University. I am working on my Master of Counselling degree. As part of my studies, I am doing a research project. The focus is on autistic adults' experiences of adversity and resilience in childhood. My guides are Dr. Gwen Rempel and Dr. Jeff Chang.

Why are you being asked to take part in this research project?
Prior to doing my study, I am looking for input. This will include autistic and non-autistic advisors. Advisors will provide me with insight and advice on engaging autistic participants in research. I am seeking your input. Your autistic or neurotypical knowledge will help me plan my research.

What is the purpose of this study?
The purpose of this study is to learn how autistic adults understand their childhood: their experiences of adversity and resilience. This will help mental health workers to support autistic individuals. Plus, this study will show how to include autistic perspectives in research planning. The information you provide may be analyzed and the results shared with other researchers.

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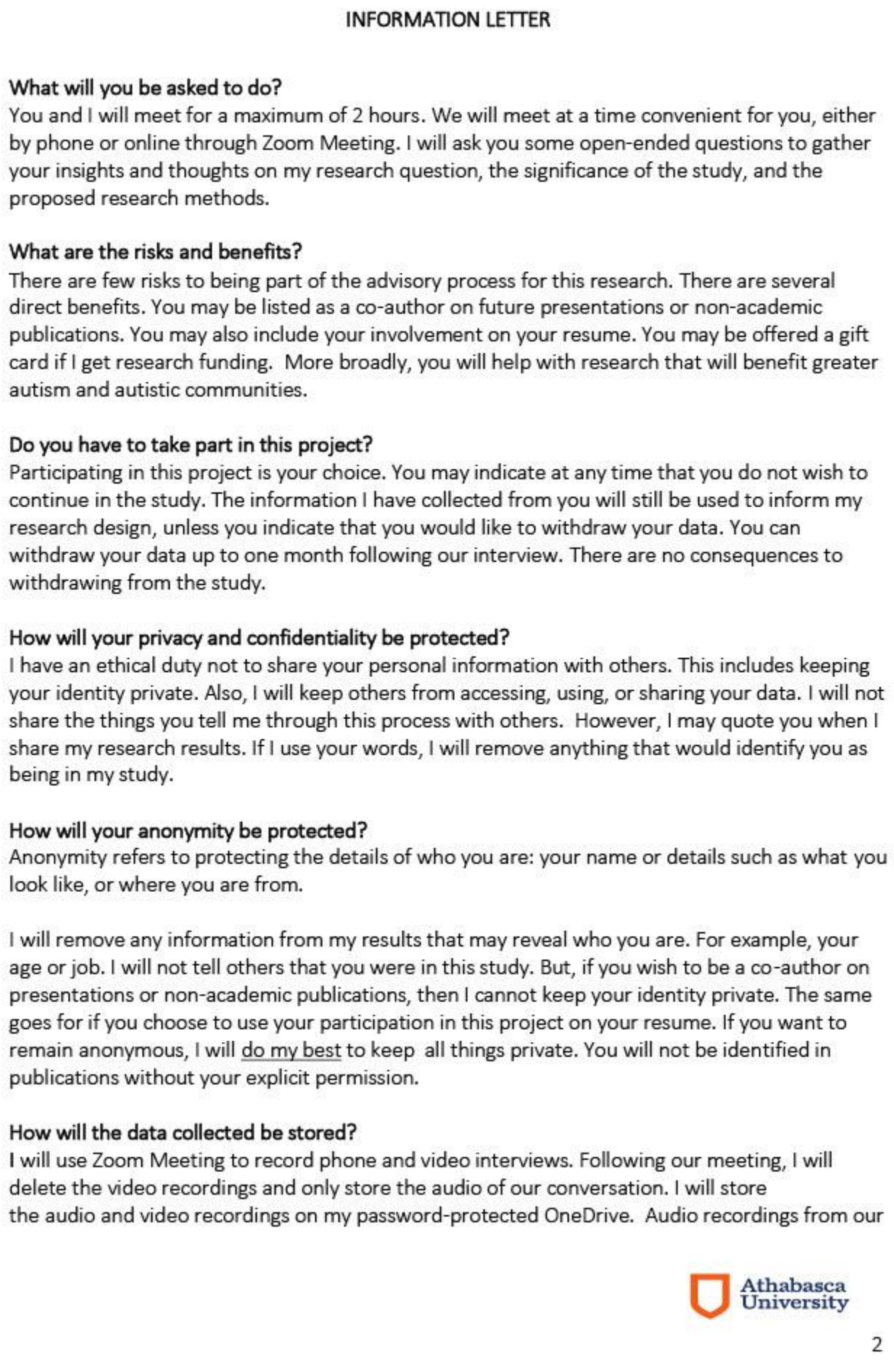

INFORMATION LETTER

What will you be asked to do?
You and I will meet for a maximum of 2 hours. We will meet at a time convenient for you, either by phone or online through Zoom Meeting. I will ask you some open-ended questions to gather your insights and thoughts on my research question, the significance of the study, and the proposed research methods.

What are the risks and benefits?
There are few risks to being part of the advisory process for this research. There are several direct benefits. You may be listed as a co-author on future presentations or non-academic publications. You may also include your involvement on your resume. You may be offered a gift card if I get research funding. More broadly, you will help with research that will benefit greater autism and autistic communities.

Do you have to take part in this project?
Participating in this project is your choice. You may indicate at any time that you do not wish to continue in the study. The information I have collected from you will still be used to inform my research design, unless you indicate that you would like to withdraw your data. You can withdraw your data up to one month following our interview. There are no consequences to withdrawing from the study.

How will your privacy and confidentiality be protected?
I have an ethical duty not to share your personal information with others. This includes keeping your identity private. Also, I will keep others from accessing, using, or sharing your data. I will not share the things you tell me through this process with others. However, I may quote you when I share my research results. If I use your words, I will remove anything that would identify you as being in my study.

How will your anonymity be protected?
Anonymity refers to protecting the details of who you are: your name or details such as what you look like, or where you are from.

I will remove any information from my results that may reveal who you are. For example, your age or job. I will not tell others that you were in this study. But, if you wish to be a co-author on presentations or non-academic publications, then I cannot keep your identity private. The same goes for if you choose to use your participation in this project on your resume. If you want to remain anonymous, I will do my best to keep all things private. You will not be identified in publications without your explicit permission.

How will the data collected be stored?
I will use Zoom Meeting to record phone and video interviews. Following our meeting, I will delete the video recordings and only store the audio of our conversation. I will store the audio and video recordings on my password-protected OneDrive. Audio recordings from our

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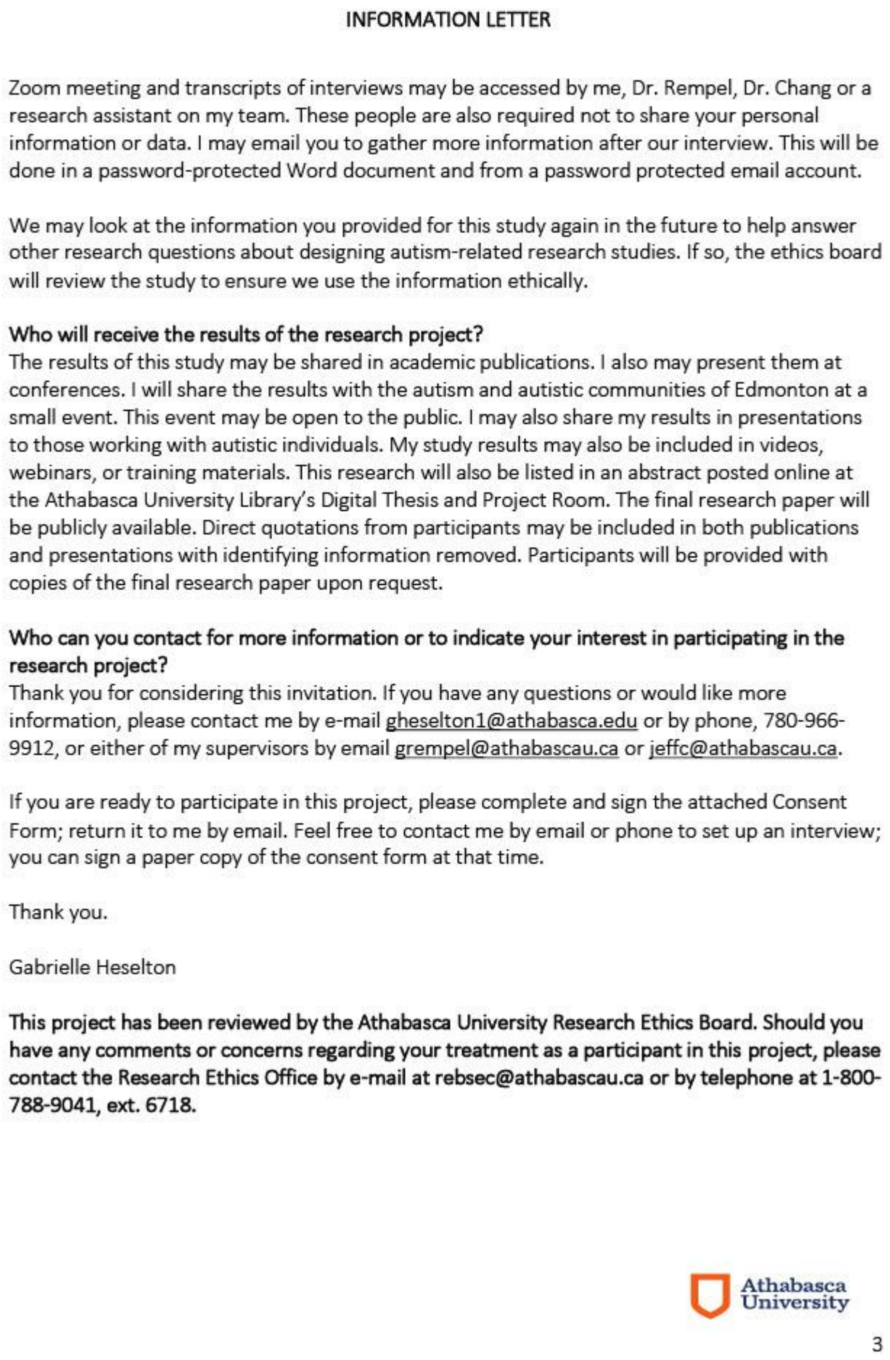

INFORMATION LETTER

Zoom meeting and transcripts of interviews may be accessed by me, Dr. Rempel, Dr. Chang or a research assistant on my team. These people are also required not to share your personal information or data. I may email you to gather more information after our interview. This will be done in a password-protected Word document and from a password protected email account.

We may look at the information you provided for this study again in the future to help answer other research questions about designing autism-related research studies. If so, the ethics board will review the study to ensure we use the information ethically.

Who will receive the results of the research project?
The results of this study may be shared in academic publications. I also may present them at conferences. I will share the results with the autism and autistic communities of Edmonton at a small event. This event may be open to the public. I may also share my results in presentations to those working with autistic individuals. My study results may also be included in videos, webinars, or training materials. This research will also be listed in an abstract posted online at the Athabasca University Library's Digital Thesis and Project Room. The final research paper will be publicly available. Direct quotations from participants may be included in both publications and presentations with identifying information removed. Participants will be provided with copies of the final research paper upon request.

Who can you contact for more information or to indicate your interest in participating in the research project?
Thank you for considering this invitation. If you have any questions or would like more information, please contact me by e-mail gheselton1@athabasca.edu or by phone, 780-966-9912, or either of my supervisors by email grempel@athabascau.ca or jeffc@athabascau.ca.

If you are ready to participate in this project, please complete and sign the attached Consent Form; return it to me by email. Feel free to contact me by email or phone to set up an interview; you can sign a paper copy of the consent form at that time.

Thank you.

Gabrielle Heselton

This project has been reviewed by the Athabasca University Research Ethics Board. Should you have any comments or concerns regarding your treatment as a participant in this project, please contact the Research Ethics Office by e-mail at rebsec@athabascau.ca or by telephone at 1-800-788-9041, ext. 6718.

Athabasca University

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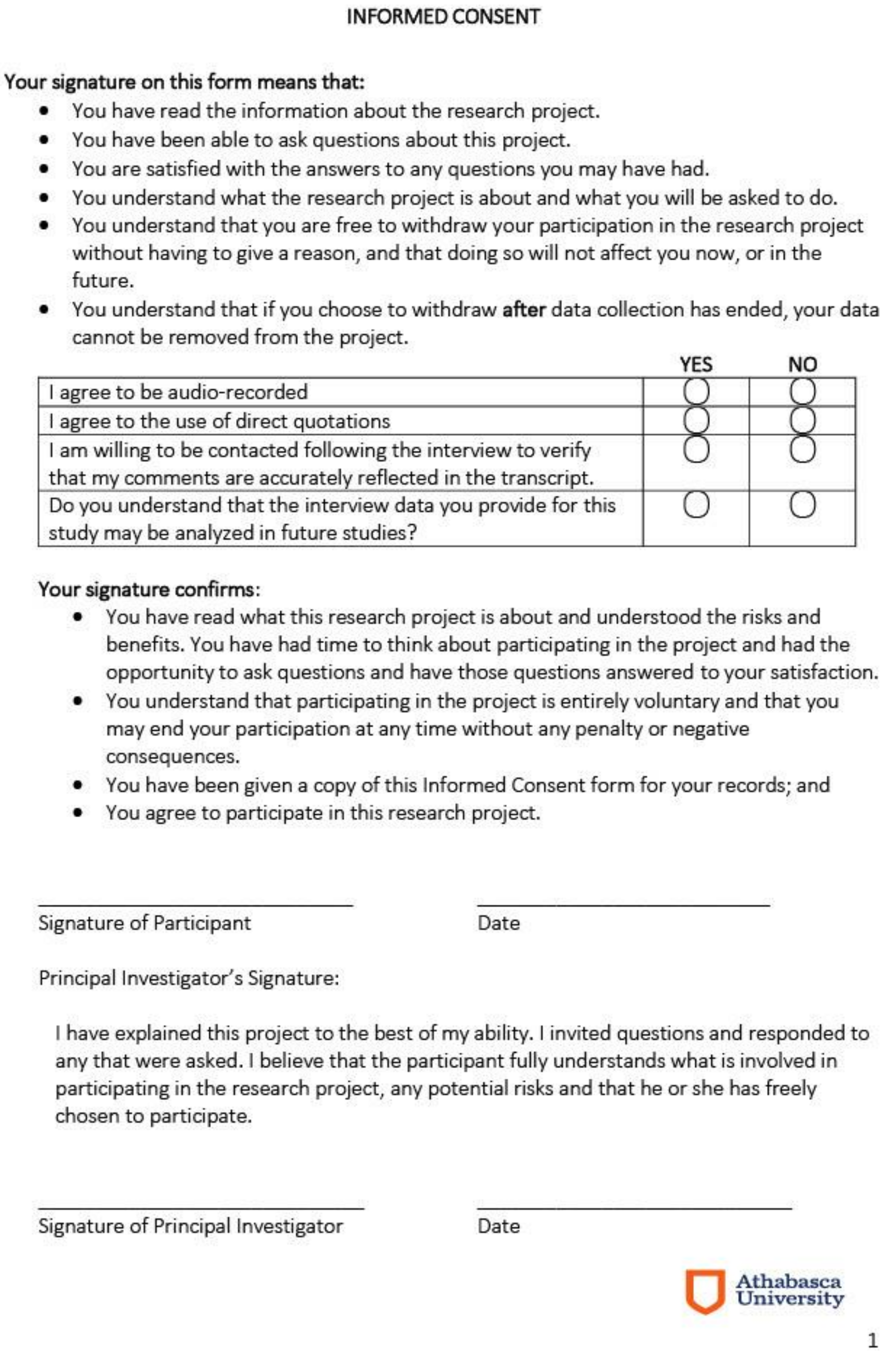


INFORMED CONSENT

Your signature on this form means that:

- You have read the information about the research project.
- You have been able to ask questions about this project.
- You are satisfied with the answers to any questions you may have had.
- You understand what the research project is about and what you will be asked to do.
- You understand that you are free to withdraw your participation in the research project without having to give a reason, and that doing so will not affect you now, or in the future.
- You understand that if you choose to withdraw **after** data collection has ended, your data cannot be removed from the project.

	YES	NO
I agree to be audio-recorded	○	○
I agree to the use of direct quotations	○	○
I am willing to be contacted following the interview to verify that my comments are accurately reflected in the transcript.	○	○
Do you understand that the interview data you provide for this study may be analyzed in future studies?	○	○

Your signature confirms:

- You have read what this research project is about and understood the risks and benefits. You have had time to think about participating in the project and had the opportunity to ask questions and have those questions answered to your satisfaction.
- You understand that participating in the project is entirely voluntary and that you may end your participation at any time without any penalty or negative consequences.
- You have been given a copy of this Informed Consent form for your records; and
- You agree to participate in this research project.

____________________________ __________________________

Signature of Participant Date

Principal Investigator's Signature:

I have explained this project to the best of my ability. I invited questions and responded to any that were asked. I believe that the participant fully understands what is involved in participating in the research project, any potential risks and that he or she has freely chosen to participate.

____________________________ __________________________

Signature of Principal Investigator Date

Athabasca University

1

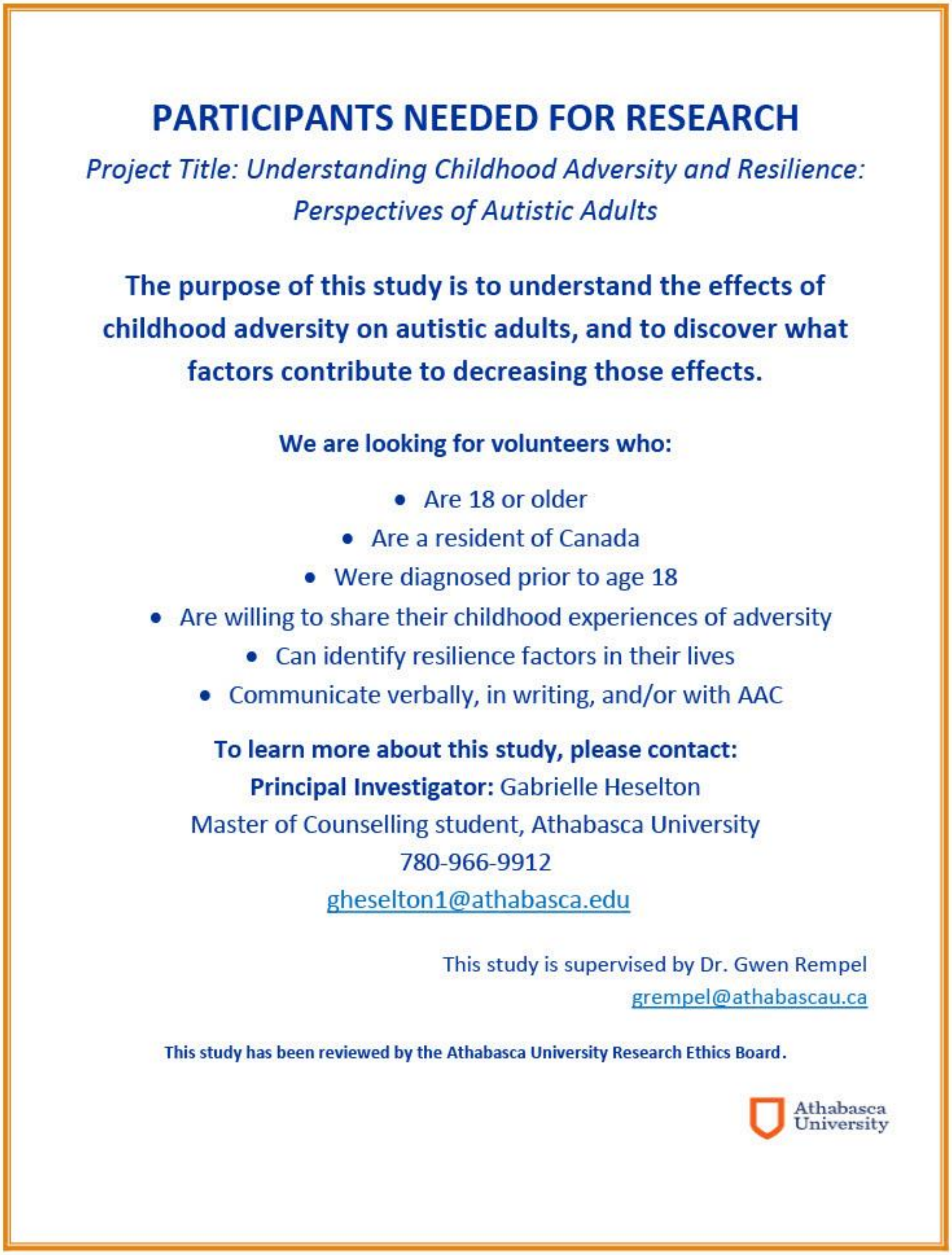
Appendix D: Interview Guide—Community Advisors

The discussions with community advisors will be informal and open ended. However, some prompts may be required to spark conversation. Possible prompts include:

1. Tell me about how you were introduced to autism. How do you identify in relation to autism?
2. What do you think are the most important things for a researcher to know about autism?
3. What do you think should be priorities of autism-related research/researchers?
4. How do you feel about autism-related research and it being conducted by neurotypical researchers?
5. My research question is: *how do autistic adults, who experienced adversity in childhood, understand the influence of those experiences on their well-being and the meaning of resilience in their lives?* What are your thoughts on the value of my research question? How would you change it to make it more valuable to the autism/autistic communities?
6. What do you think the potential impact of my research is for the community you identify with (e.g., parent/caregiver, autistic person, professional)?
7. What do you see as potential applications of my research for the community with which you identify?

8. What methods would you suggest I use to make data collection more congruent with autistic ways of communicating/meet the needs of people who communicate differently?
9. Credibility checking is a method used to ensure the researcher has truly captured the meaning conveyed by participants. Credibility checking typically involves having participants read their transcripts, with the researcher's annotations and a summary of emerging themes and provides their feedback to the researcher about the accuracy of the interpretations[8] What strategies would you suggest for making credibility checking more congruent with autistic ways of communicating/meet the needs of people who communicate differently?
10. What can I do, as the researcher, to make participation in this study the best possible experience for participants?
11. What power imbalances, if any, do you perceive as existing between neurotypical researchers and participants from the autism or autistic communities? What steps can I take to help minimize these imbalances?
12. How can I, as a neurotypical researcher, strive to minimize power imbalances between the autism/autistic communities and the research community?
13. What would be the best ways for me to disseminate my results to you/your identified community?
14. Is there anything else you would like to share with me about conducting research with autistic participants?
15. How was this interview for you?
16. Can I contact you if I have follow-up questions or need clarification?

Appendix E: Recruitment Poster



PARTICIPANTS NEEDED FOR RESEARCH

Project Title: Understanding Childhood Adversity and Resilience: Perspectives of Autistic Adults

The purpose of this study is to understand the effects of childhood adversity on autistic adults, and to discover what factors contribute to decreasing those effects.

We are looking for volunteers who:

- Are 18 or older
- Are a resident of Canada
- Were diagnosed prior to age 18
- Are willing to share their childhood experiences of adversity
- Can identify resilience factors in their lives
- Communicate verbally, in writing, and/or with AAC

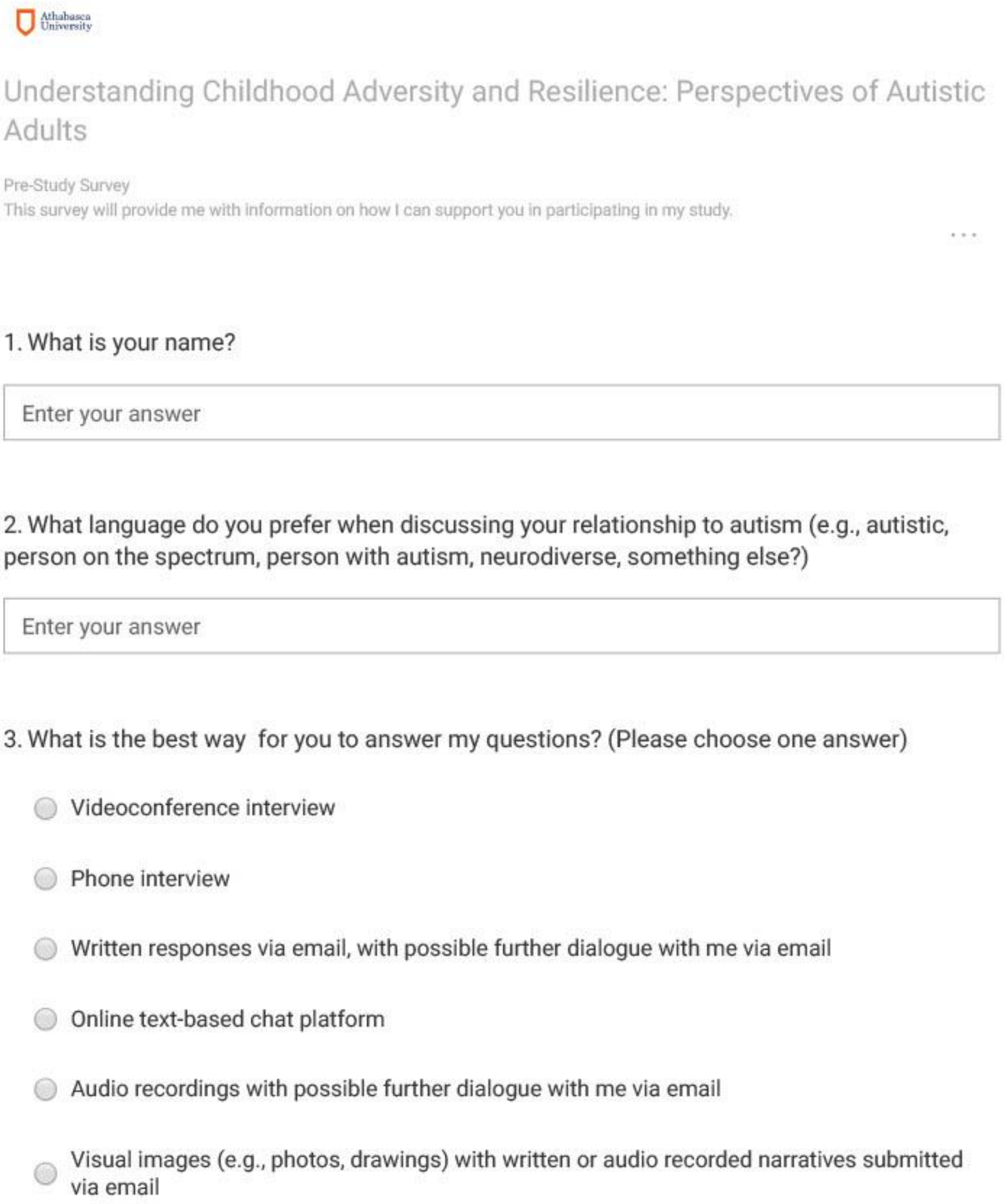
To learn more about this study, please contact:
Principal Investigator: Gabrielle Heselton
Master of Counselling student, Athabasca University
780-966-9912
gheselton1@athabasca.edu

This study is supervised by Dr. Gwen Rempel
grempel@athabascau.ca

This study has been reviewed by the Athabasca University Research Ethics Board.

Athabasca University

Appendix F: Pre-Interview Survey



Athabasca University

Understanding Childhood Adversity and Resilience: Perspectives of Autistic Adults

Pre-Study Survey

This survey will provide me with information on how I can support you in participating in my study.

1. What is your name?

Enter your answer

2. What language do you prefer when discussing your relationship to autism (e.g., autistic, person on the spectrum, person with autism, neurodiverse, something else?)

Enter your answer

3. What is the best way for you to answer my questions? (Please choose one answer)

○ Videoconference interview

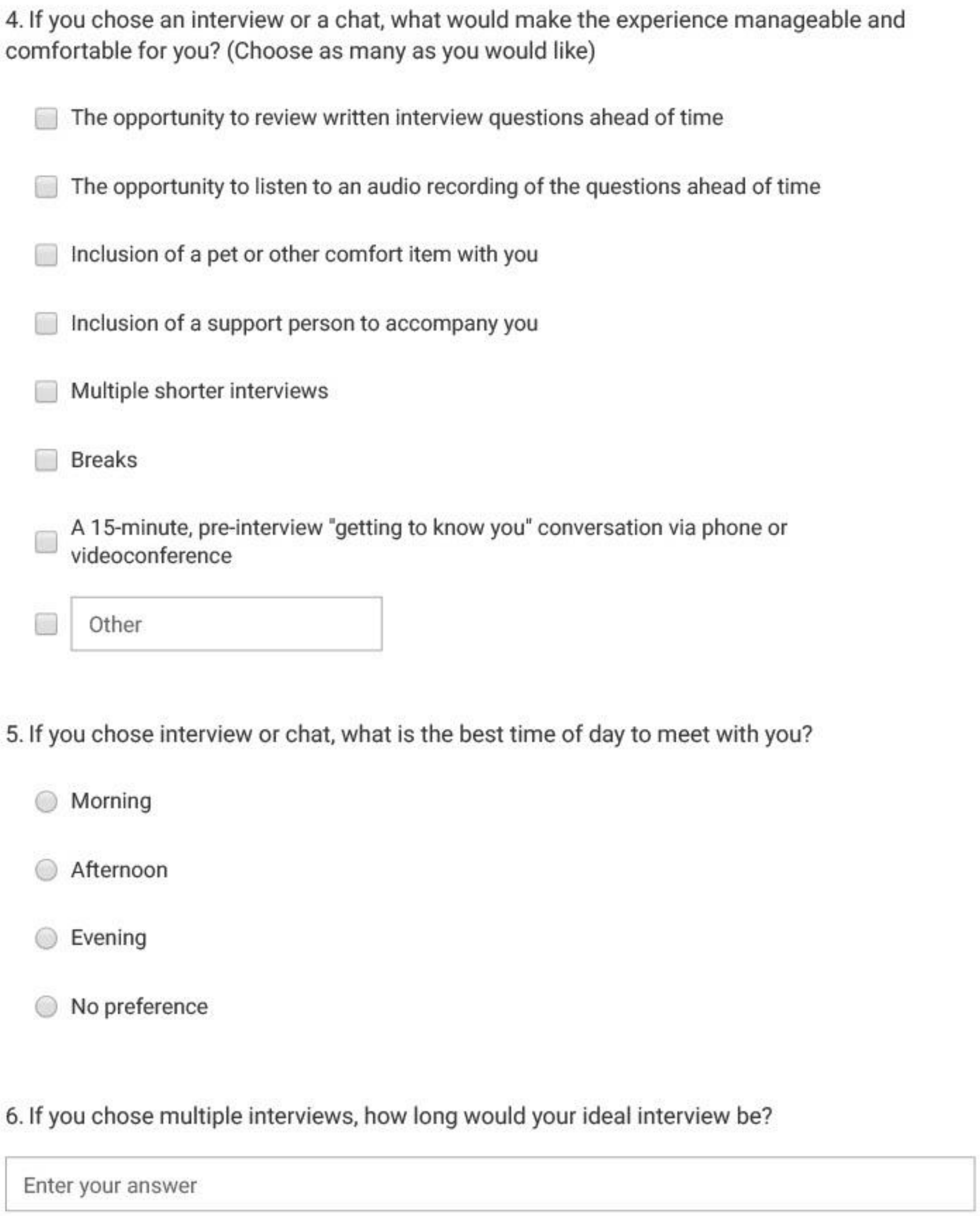
○ Phone interview

○ Written responses via email, with possible further dialogue with me via email

○ Online text-based chat platform

○ Audio recordings with possible further dialogue with me via email

○ Visual images (e.g., photos, drawings) with written or audio recorded narratives submitted via email



4. If you chose an interview or a chat, what would make the experience manageable and comfortable for you? (Choose as many as you would like)

☐ The opportunity to review written interview questions ahead of time

☐ The opportunity to listen to an audio recording of the questions ahead of time

☐ Inclusion of a pet or other comfort item with you

☐ Inclusion of a support person to accompany you

☐ Multiple shorter interviews

☐ Breaks

☐ A 15-minute, pre-interview "getting to know you" conversation via phone or videoconference

☐ Other

5. If you chose interview or chat, what is the best time of day to meet with you?

○ Morning

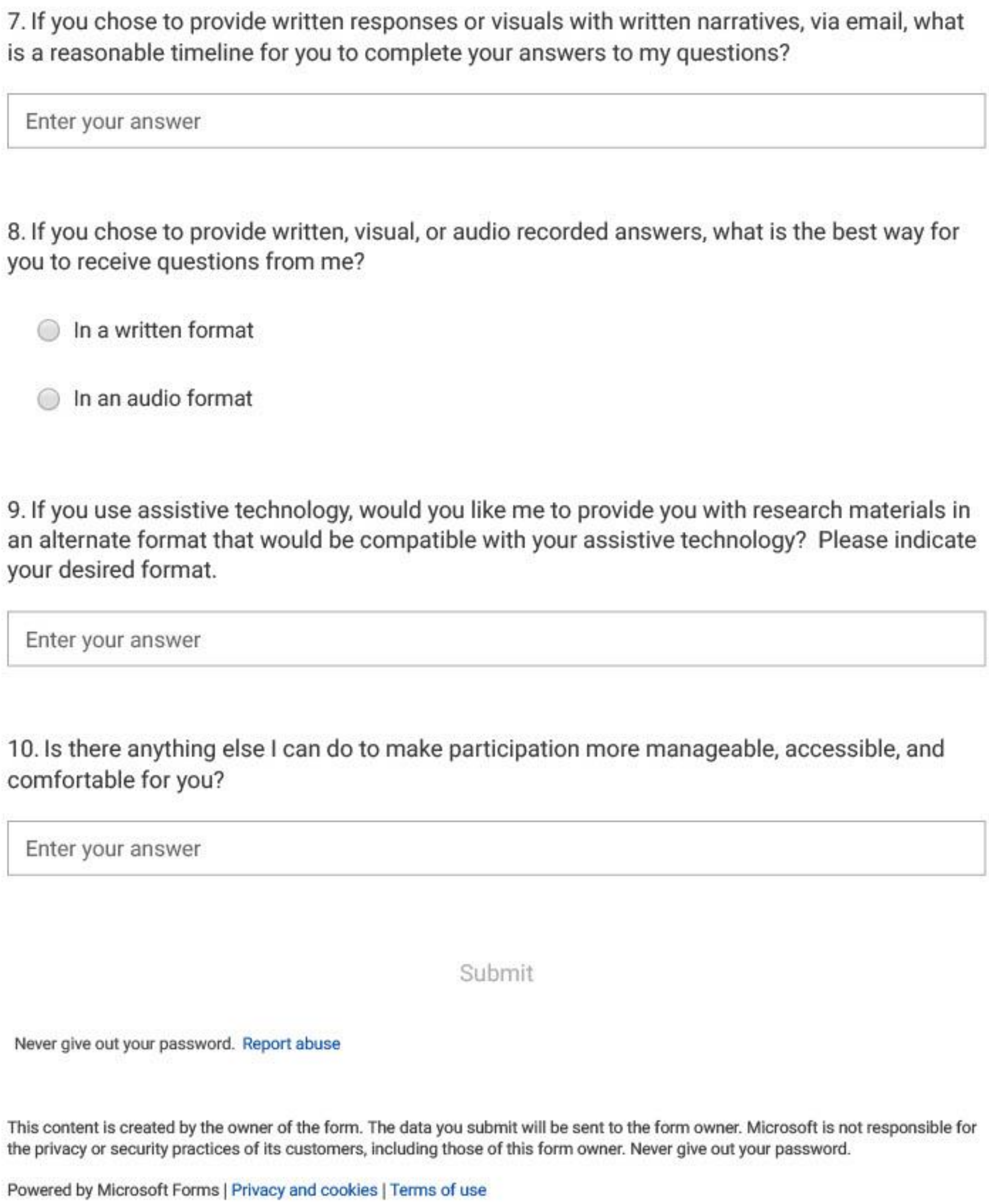
○ Afternoon

○ Evening

○ No preference

6. If you chose multiple interviews, how long would your ideal interview be?

Enter your answer



7. If you chose to provide written responses or visuals with written narratives, via email, what is a reasonable timeline for you to complete your answers to my questions?

Enter your answer

8. If you chose to provide written, visual, or audio recorded answers, what is the best way for you to receive questions from me?

○ In a written format

○ In an audio format

9. If you use assistive technology, would you like me to provide you with research materials in an alternate format that would be compatible with your assistive technology? Please indicate your desired format.

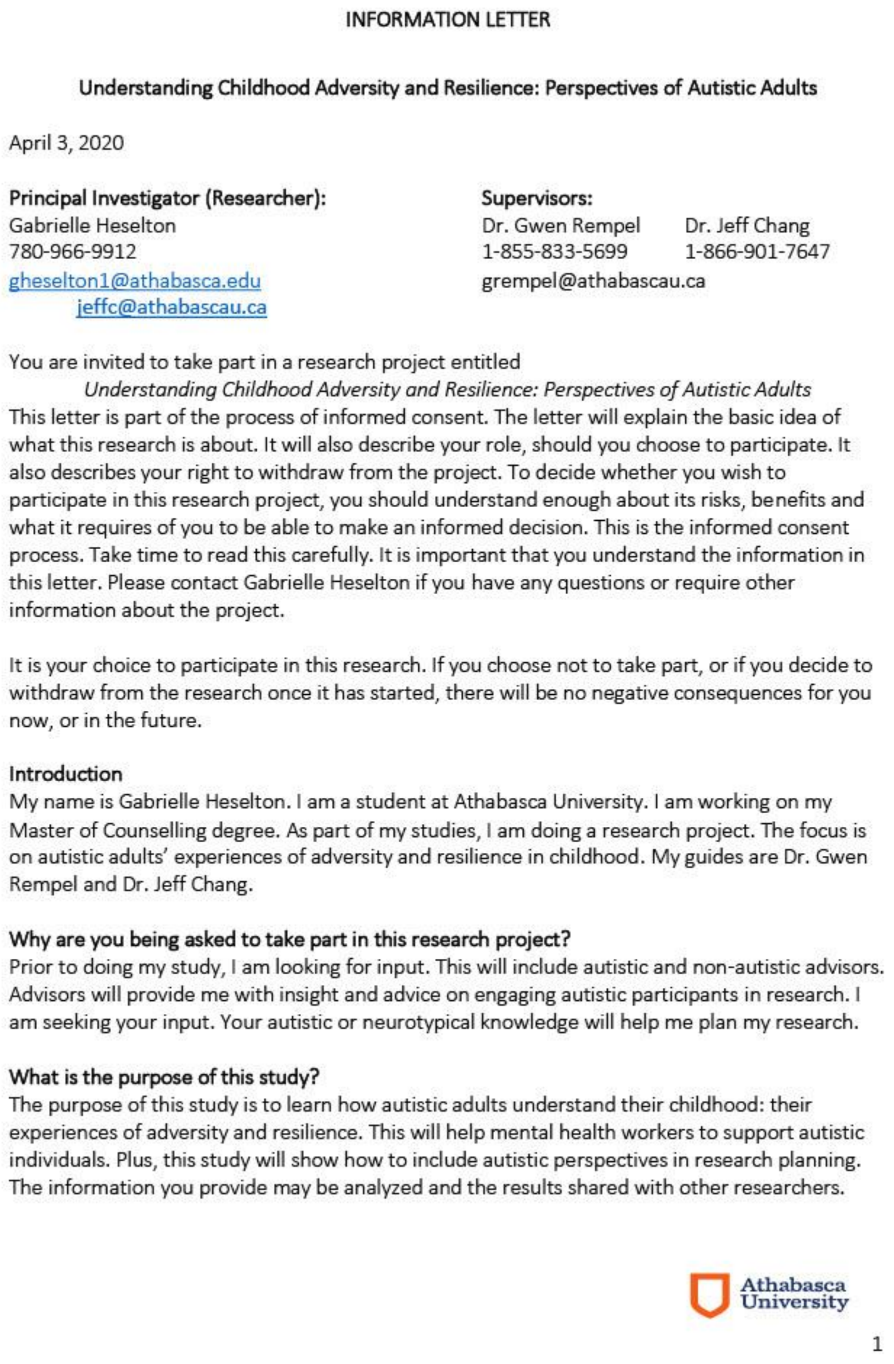
Enter your answer

10. Is there anything else I can do to make participation more manageable, accessible, and comfortable for you?

Enter your answer

This content is created by the owner of the form. The data you submit will be sent to the form owner. Microsoft is not responsible for the privacy or security practices of its customers, including those of this form owner. Never give out your password.

Appendix G: Information Letter & Informed Consent—Participants



INFORMATION LETTER

Understanding Childhood Adversity and Resilience: Perspectives of Autistic Adults

April 3, 2020

Principal Investigator (Researcher):
Gabrielle Heselton
780-966-9912
gheselton1@athabasca.edu
jeffc@athabascau.ca

Supervisors:
Dr. Gwen Rempel 1-855-833-5699 grempel@athabascau.ca
Dr. Jeff Chang 1-866-901-7647

You are invited to take part in a research project entitled
Understanding Childhood Adversity and Resilience: Perspectives of Autistic Adults
This letter is part of the process of informed consent. The letter will explain the basic idea of what this research is about. It will also describe your role, should you choose to participate. It also describes your right to withdraw from the project. To decide whether you wish to participate in this research project, you should understand enough about its risks, benefits and what it requires of you to be able to make an informed decision. This is the informed consent process. Take time to read this carefully. It is important that you understand the information in this letter. Please contact Gabrielle Heselton if you have any questions or require other information about the project.

It is your choice to participate in this research. If you choose not to take part, or if you decide to withdraw from the research once it has started, there will be no negative consequences for you now, or in the future.

Introduction
My name is Gabrielle Heselton. I am a student at Athabasca University. I am working on my Master of Counselling degree. As part of my studies, I am doing a research project. The focus is on autistic adults' experiences of adversity and resilience in childhood. My guides are Dr. Gwen Rempel and Dr. Jeff Chang.

Why are you being asked to take part in this research project?
Prior to doing my study, I am looking for input. This will include autistic and non-autistic advisors. Advisors will provide me with insight and advice on engaging autistic participants in research. I am seeking your input. Your autistic or neurotypical knowledge will help me plan my research.

What is the purpose of this study?
The purpose of this study is to learn how autistic adults understand their childhood: their experiences of adversity and resilience. This will help mental health workers to support autistic individuals. Plus, this study will show how to include autistic perspectives in research planning. The information you provide may be analyzed and the results shared with other researchers.

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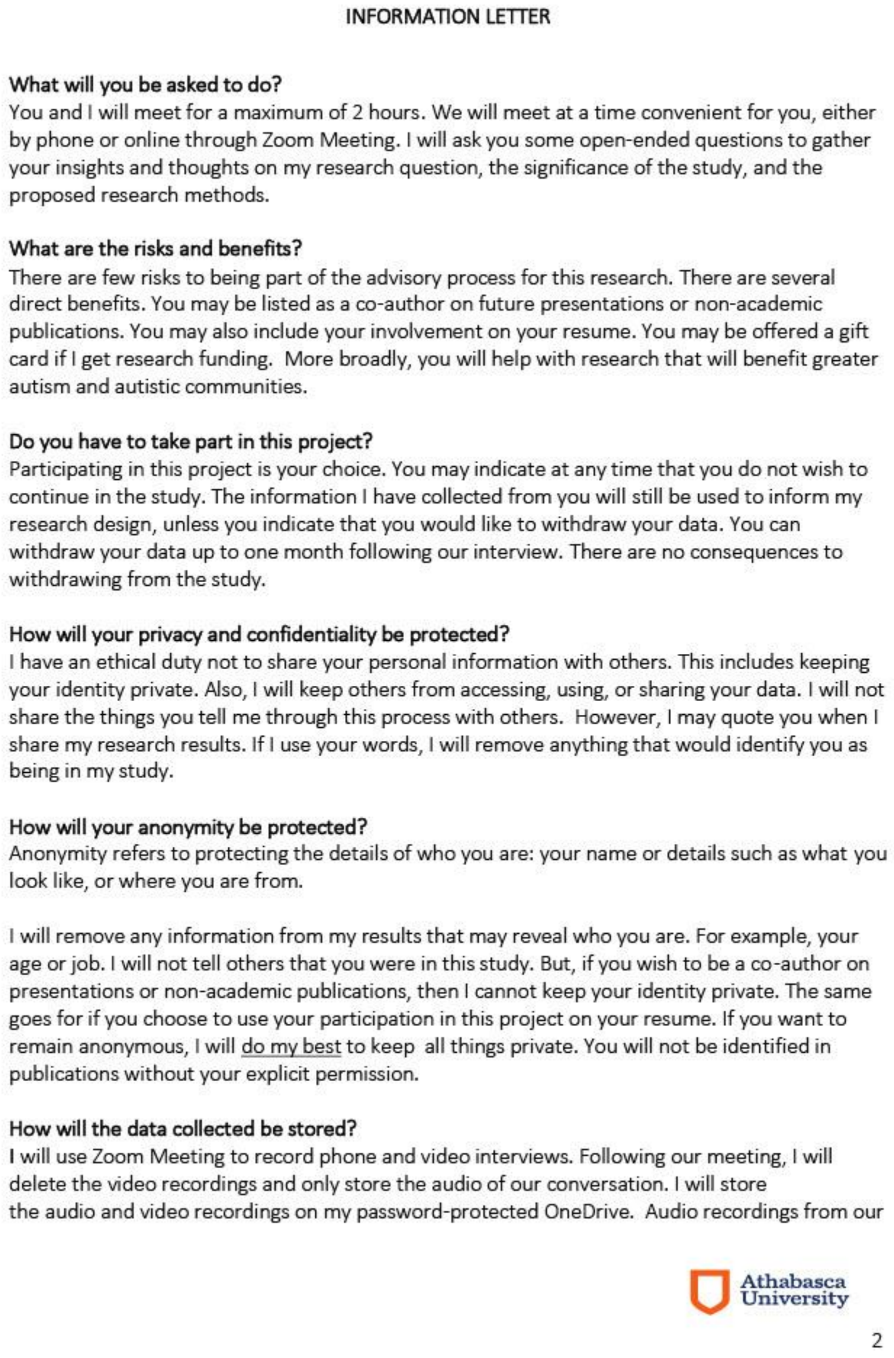


INFORMATION LETTER

What will you be asked to do?

You and I will meet for a maximum of 2 hours. We will meet at a time convenient for you, either by phone or online through Zoom Meeting. I will ask you some open-ended questions to gather your insights and thoughts on my research question, the significance of the study, and the proposed research methods.

What are the risks and benefits?

There are few risks to being part of the advisory process for this research. There are several direct benefits. You may be listed as a co-author on future presentations or non-academic publications. You may also include your involvement on your resume. You may be offered a gift card if I get research funding. More broadly, you will help with research that will benefit greater autism and autistic communities.

Do you have to take part in this project?

Participating in this project is your choice. You may indicate at any time that you do not wish to continue in the study. The information I have collected from you will still be used to inform my research design, unless you indicate that you would like to withdraw your data. You can withdraw your data up to one month following our interview. There are no consequences to withdrawing from the study.

How will your privacy and confidentiality be protected?

I have an ethical duty not to share your personal information with others. This includes keeping your identity private. Also, I will keep others from accessing, using, or sharing your data. I will not share the things you tell me through this process with others. However, I may quote you when I share my research results. If I use your words, I will remove anything that would identify you as being in my study.

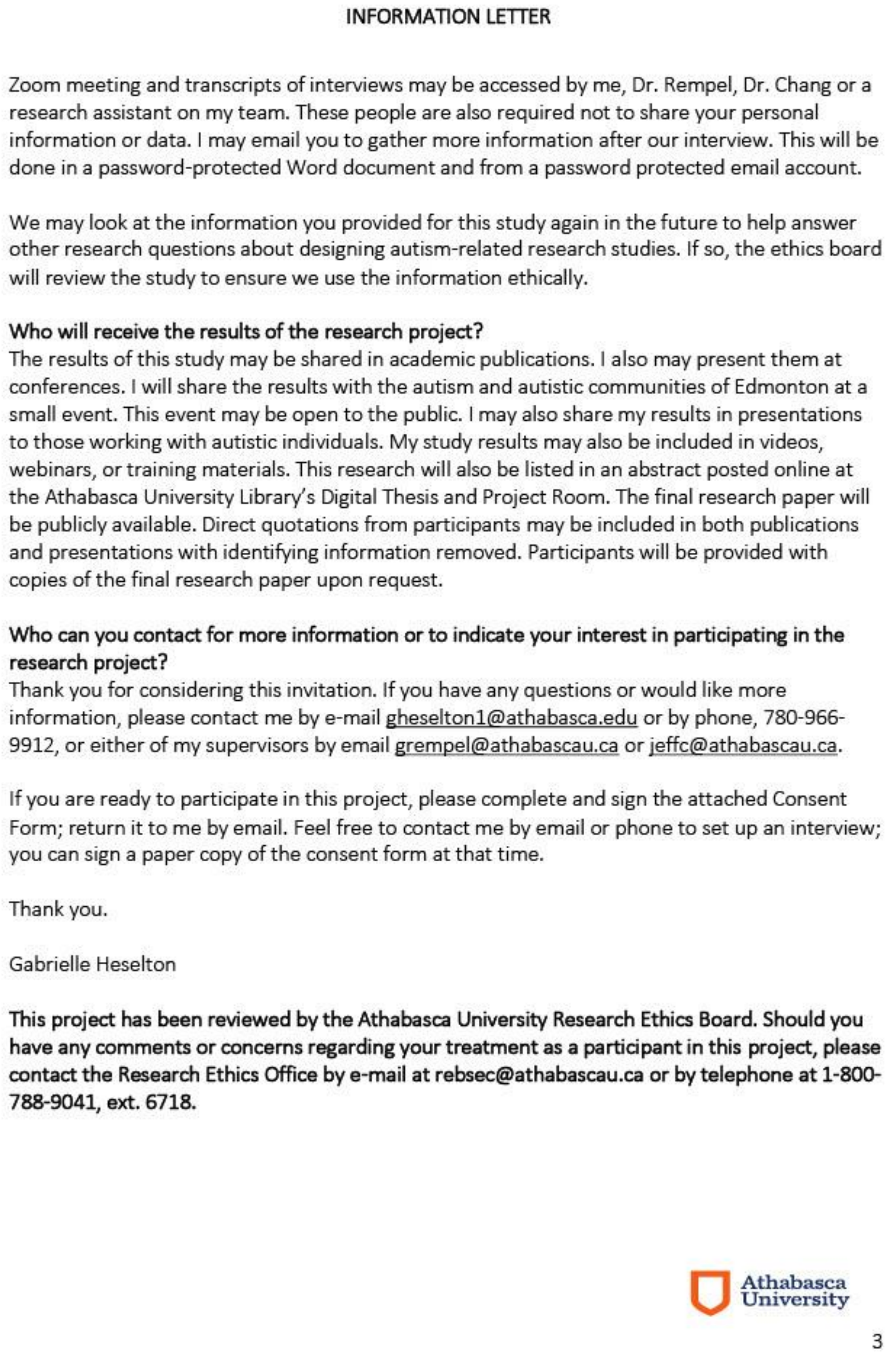
How will your anonymity be protected?

Anonymity refers to protecting the details of who you are: your name or details such as what you look like, or where you are from.

I will remove any information from my results that may reveal who you are. For example, your age or job. I will not tell others that you were in this study. But, if you wish to be a co-author on presentations or non-academic publications, then I cannot keep your identity private. The same goes for if you choose to use your participation in this project on your resume. If you want to remain anonymous, I will <u>do my best</u> to keep all things private. You will not be identified in publications without your explicit permission.

How will the data collected be stored?

I will use Zoom Meeting to record phone and video interviews. Following our meeting, I will delete the video recordings and only store the audio of our conversation. I will store the audio and video recordings on my password-protected OneDrive. Audio recordings from our



INFORMATION LETTER

Zoom meeting and transcripts of interviews may be accessed by me, Dr. Rempel, Dr. Chang or a research assistant on my team. These people are also required not to share your personal information or data. I may email you to gather more information after our interview. This will be done in a password-protected Word document and from a password protected email account.

We may look at the information you provided for this study again in the future to help answer other research questions about designing autism-related research studies. If so, the ethics board will review the study to ensure we use the information ethically.

Who will receive the results of the research project?

The results of this study may be shared in academic publications. I also may present them at conferences. I will share the results with the autism and autistic communities of Edmonton at a small event. This event may be open to the public. I may also share my results in presentations to those working with autistic individuals. My study results may also be included in videos, webinars, or training materials. This research will also be listed in an abstract posted online at the Athabasca University Library's Digital Thesis and Project Room. The final research paper will be publicly available. Direct quotations from participants may be included in both publications and presentations with identifying information removed. Participants will be provided with copies of the final research paper upon request.

Who can you contact for more information or to indicate your interest in participating in the research project?

Thank you for considering this invitation. If you have any questions or would like more information, please contact me by e-mail gheselton1@athabasca.edu or by phone, 780-966-9912, or either of my supervisors by email grempel@athabascau.ca or jeffc@athabascau.ca.

If you are ready to participate in this project, please complete and sign the attached Consent Form; return it to me by email. Feel free to contact me by email or phone to set up an interview; you can sign a paper copy of the consent form at that time.

Thank you.

Gabrielle Heselton

This project has been reviewed by the Athabasca University Research Ethics Board. Should you have any comments or concerns regarding your treatment as a participant in this project, please contact the Research Ethics Office by e-mail at rebsec@athabascau.ca or by telephone at 1-800-788-9041, ext. 6718.

Athabasca University

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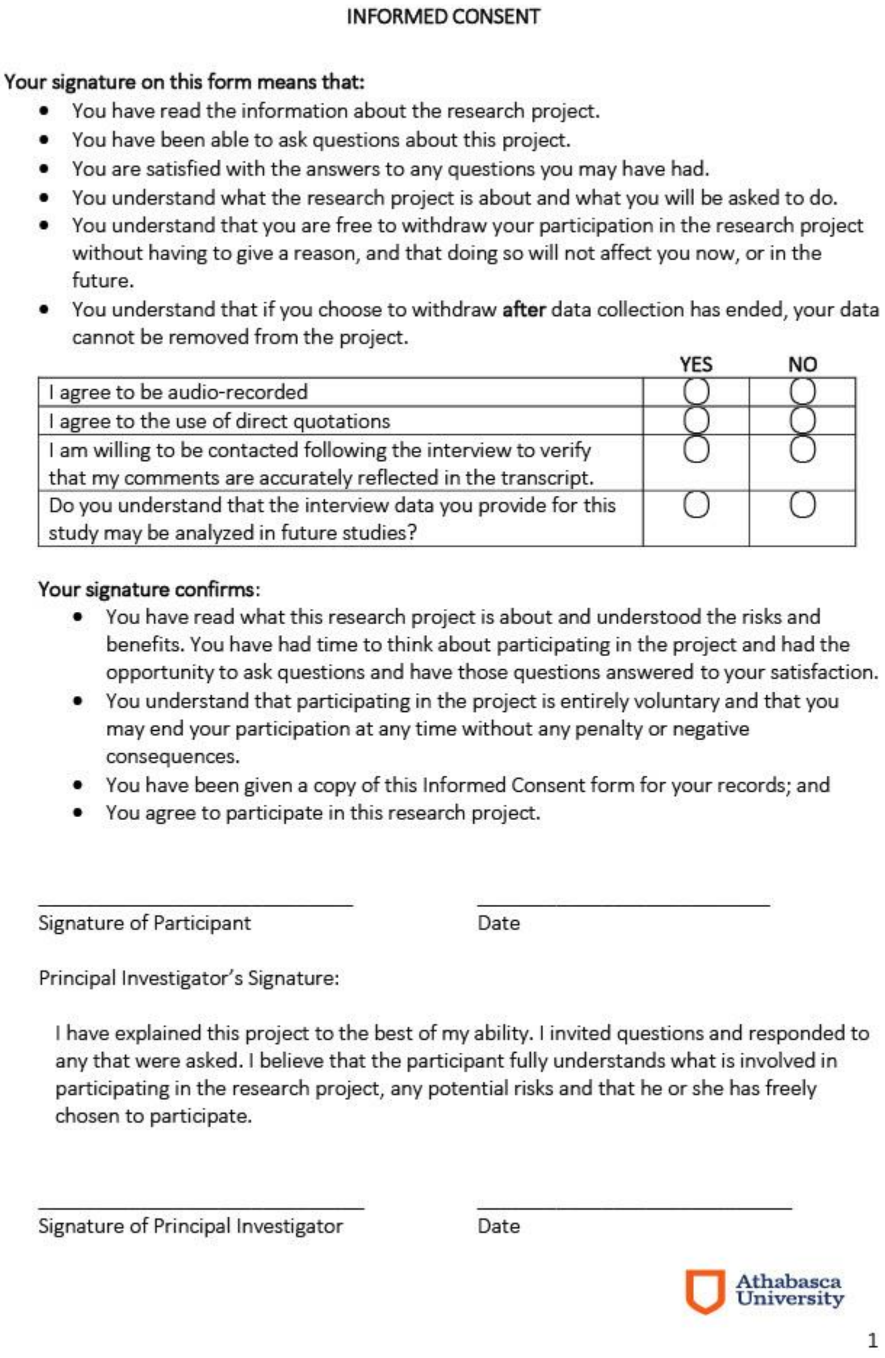

INFORMED CONSENT

Your signature on this form means that:

- You have read the information about the research project.
- You have been able to ask questions about this project.
- You are satisfied with the answers to any questions you may have had.
- You understand what the research project is about and what you will be asked to do.
- You understand that you are free to withdraw your participation in the research project without having to give a reason, and that doing so will not affect you now, or in the future.
- You understand that if you choose to withdraw **after** data collection has ended, your data cannot be removed from the project.

	YES	NO
I agree to be audio-recorded	○	○
I agree to the use of direct quotations	○	○
I am willing to be contacted following the interview to verify that my comments are accurately reflected in the transcript.	○	○
Do you understand that the interview data you provide for this study may be analyzed in future studies?	○	○

Your signature confirms:

- You have read what this research project is about and understood the risks and benefits. You have had time to think about participating in the project and had the opportunity to ask questions and have those questions answered to your satisfaction.
- You understand that participating in the project is entirely voluntary and that you may end your participation at any time without any penalty or negative consequences.
- You have been given a copy of this Informed Consent form for your records; and
- You agree to participate in this research project.

__________________________ __________________________

Signature of Participant Date

Principal Investigator's Signature:

I have explained this project to the best of my ability. I invited questions and responded to any that were asked. I believe that the participant fully understands what is involved in participating in the research project, any potential risks and that he or she has freely chosen to participate.

__________________________ __________________________

Signature of Principal Investigator Date

Athabasca University

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Appendix H: Interview Guide—Participants

Participant Written Responses

Thank you so much for agreeing to share your stories and insights with me! I'm excited to read your responses. Before you start, I would like to share with you some background about myself and my motivation for doing this research.

I am a neurotypical researcher working on my Master of Counselling (MC) degree. This is my thesis research and it is a study that was inspired by my own experiences with people on the autism spectrum. Before enrolling in the MC program, I taught special education for many years, working primarily with preschool and elementary aged children on the autism spectrum. I was often frustrated that there did not seem to be adequate mental health supports for my students and I wondered how their experiences of adversity might affect their mental health. I decided to return to school to gain the necessary skills to provide mental health supports to children, adolescents, and adults on the spectrum, as well as their families. When it came time to develop my research, I knew that it was not enough to assume that mental health supports developed for neurotypical children would be adequate for autistic children. I decided that I needed to hear directly from autistic individuals about what was, is, and would be most helpful to them.

This research is based on the principles of neurodiversity, with a deliberate focus on autism as a difference rather than a disorder. I recognize that there are many perspectives on neurodiversity within the autistic community, however because so much research has been done already on autism as a disorder and a deficit, I wanted to honour neurodiversity and the unique perspectives of those who identify as autistic. Prior to finalizing my research design, I consulted autistic members of the community for their feedback on the study. They provided me with ideas about how I could make the study fit with autistic ways of communicating and interacting. I realize that neurotypical researchers doing autism-related research is not ideal, however I strive to conduct my research respectfully and ethically. I hope this study is an opportunity for autistic perspectives to be acknowledged and valued.

I have learned that it can be difficult for research participants to feel safe to disclose their true thoughts and opinions, especially with a neurotypical researcher, like myself, who may represent others who have done harm to you (e.g., teacher, researcher, counsellor). I hope you feel safe and comfortable to be honest and open with your answers to my questions. I value all that you wish to share—nothing about your experiences will be considered insignificant. I welcome diverse perspectives and invite you to disagree with me or tell me why a question does not fit with your experience. I also do not want you to have to guess about my meaning or my motives for any of the questions. I have provided an explanation for each question, but I also encourage you to contact me with any questions you have along the way. 😊

Gabrielle

There are 13 questions, with most having multiple sub-questions. Please read the following instructions before starting.

Instructions

1. Most of these questions are open-ended and invite you to reflect on specific aspects of your experiences. Many of the questions are followed by more specific sub-questions. If a sub-question does not feel true for your experience, please indicate that, and tell me why it does not apply.
2. Some questions have prompts in italics. It is not necessary that you answer these prompts directly, however, if you are struggling to respond to the question, you may refer to the prompts to focus your ideas. Use as many or as few of the prompts as you would like to aid you in responding to the question.
3. You may write as much as you want for each answer.
4. When you have completed the entire questionnaire, please return it to me by email.

Questions

The purpose of these questions is to get to know you and understand the context you grew up in.

Tell me about your childhood.

a) Where did you grow up?
b) What was the makeup of your family?
c) What kind of elementary school/program did you attend? What kind of junior high did you attend? What kind of high school? (*Prompt: **you do not have to answer these questions unless you choose to. They are simply prompts to help you decide what to say in response to this question** Were you included in a regular classroom? Did you attend a special program or classroom for parts or all of your day?)*
d) What kind of things did you like to do in your free time as a child?
e) Tell me about any lessons or extracurricular activities that you participated in as a child.
f) Tell me about your childhood pets.

2. The purpose of this question is to develop an understanding of how you characterize your current emotional and mental well-being, as later I will be asking how childhood experiences may have influenced your mental health.

How would you describe your current mental health?

(Prompts: Do you have any co-occurring mental health diagnoses? If yes, what are they and how do you feel about those diagnoses? Do you have concerns about your mental health (whether you have a formal diagnosis or not)? What is your mood like? How do you feel when you wake up in the morning? How do you think your mental health could be better than it is? How does your mental health impact your day-to-day functioning? How do you manage your mental health? What do you think would help you? What supports do you wish you had?

3. The purpose of this question is to understand your challenges with mental health as a child, and to identify any supports you may have had in place. Again, this relates to understanding the influence of your childhood experiences on your mental health at the time.

How would you describe your mental health as a child?

a) What was your mood like as a child?
b) What was your mood like as an adolescent?
c) Tell me about any diagnosed mental health issues in childhood or adolescence.
d) How did you feel about those diagnoses at the time?
e) How do you feel about those diagnoses now?
f) Tell me how you managed your mental health at that time?
g) Who supported you and how?
h) What supports do you wish you had?

4. The purpose of this question is to make sure I understand the meaning you attribute to the word adversity. If you and I have different definitions of adversity, then we will not understand each other as we proceed with understanding your experiences together. Your answer may also provide insight to how adversity may be experienced by autistic children similarly to or differently from neurotypical children.

What does the term adversity mean to you? *(Prompts: tell me what the word adversity makes you think of? What is another word you would use to describe adversity? What would you imagine if somebody told you they had experienced adversity?)*

5. The purpose of these questions is for me to develop a picture in my mind of how you experienced adversity as a child, and what the wholistic impact of that adversity was on you. I also want to know how you view yourself in the context of that adversity.

Tell me about a specific experience from your childhood that you would consider to be adverse.

a) How old were you?
b) Where did this experience occur (e.g., school, home)?
c) Who else was involved?
d) Describe the incident.
e) How often did this, or a similar incident, occur?
f) How did you feel at the time?
g) How did this adverse experience impact your behaviour?
h) How did this adverse experience impact your relationships?
i) How did this adverse experience impact your feelings about yourself?
j) What did you do in the adverse situation?
k) Tell me about anyone who may have helped you in that adverse situation. Who were they?
l) Did you hide your feelings about this experience from others? If so, how did you do that? Why did you hide your feelings?

6. The purpose of these questions is to understand the long-term influence of childhood adversity in your life.

Thinking about that adverse experience, how has it influenced your life now?

a) How do you feel about that experience now?
b) How often do you think about that experience?
c) How has that childhood experience affected your feelings now?
d) How has that experience affected your behaviour now?
e) How has that experience affected how you feel about yourself now?
f) How has that experience affected your relationships now?
g) How has that experience affected your daily life now?
h) How has that experience affected your mental health now?
i) How has that experience influenced how you interact with others now?
j) How has that experience influenced your adult relationships?
k) Has that experience had any other effects on you that you would like me to know about?

7. The purpose of this question, again, is to make sure that I understand what resilience means to you. This will give us a common language for our discussion of resilience. Your answer to this question might also provide insight into how your understanding of resilience may be similar to or different from the neurotypical perspective.

What does resilience mean to you? *(Prompts: what do you think of when you hear the word resilience? What is another word you would use to describe resilience? What would you imagine if somebody you were speaking with used the term resilience?*

8. The purpose of these questions is to help me understand what resilience factors you have within you that may have helped you get through an adverse experience. I also want to understand the meaning of those factors for your well-being and your life.

   What do you think it is about you that helped you get through that adverse situation you described earlier? (*Prompts: what are some traits you possess that helped you in that situation? Give me an example of something you did in that situation that helped you?)*

   a) How did you feel about that aspect of yourself at the time?
   b) How do you feel about that aspect of yourself now? Why?
   c) Did you realize at the time that you were helping yourself? If you did, how did you know?
   d) What do you do as an adult to help you get through hard things?

9. The purpose of this question is to determine if you view the internal factors you described in the last question as something that built resilience in you.

How do you think that these traits helped or did not help to lessen the impact of the adverse experience you described?

   a) What were some positive results of u using those aspects of yourself in the adverse situation, if any?
   b) What were some negative effects of using those aspects of yourself in the adverse situation, if any?

10. The purpose of these questions is to understand what factors outside of yourself were influential in helping you get through adversity and what influence they may have had on your well-being and your life.

Tell me about who or what in your life helped you get through the adverse experience you described.

   a) How did you feel about that person or thing now?
   b) How does your experience with that person/thing in the past influence your life now?
   c) Do you think that this person or thing helped lessen the effects of the adverse experience you described? If so, how?

11. The purpose of this question is to understand what safety looked like for you as a child. I am curious if you felt safe as a child and if so, what contributed to that

feeling. I am also curious if safety plays a role in the impacts of adversity and /or resilience.

Describe a place that you could go to feel safe as a child.

a) Was the safe space internal or external (e.g., a physical place or somewhere you would go in your mind?)?
b) Who else, if anyone, was in this space?
c) How did you feel when you were in this space?
d) Did you access this safe space when you experienced the adverse experience you described above?
e) How did being in your safe space help you?

12. The purpose of this question is to understand how you viewed your autism diagnosis and how you view it now. I am curious how being autistic interacted with your experiences of adversity to influence your emotional and mental well-being.

How did you view your autism diagnosis as a child?

a) What was the influence of autism on your experience of adversity?
b) What was the influence of adversity on the role of autism in your life?
c) Do you think having an autism diagnosis and/or autistic identity influenced how you felt about the adverse experience at the time?
d) Do you think your autism diagnosis and/or autistic identity influenced how you viewed yourself at the time?
e) How do you think your autism diagnosis and/or autistic identity influenced how you managed the adverse experience?
f) How do you think your autism diagnosis and/or autistic identity influences your current mental health?

13. The purpose of this question is to create space for you to share anything else you want me to know.

Is there anything else you would like me to know about your experiences?

14. The purpose of this question is to give me feedback on the experience of participating in this study so that I can improve these types of experiences for participants in the future.

How was this experience of participating in research for you?

Final Thoughts

Thank you again for providing me with your thoughtful and honest answers to these hard questions. I am so grateful for your willingness to participate in my study and honouring me with your stories. There are a few final things I would like to remind you of:

- I will contact you in a few days to follow-up on our conversation, to give you a chance to ask any questions or tell me anything else you think is important. What is the best way to contact you?
- If answering these questions has brought up difficult emotions and thoughts, please reach out to your support systems and make sure you do the things you normally do to take care of yourself. Your well-being is the most important thing to me!
- You have access to two free counselling sessions. You are welcome to see any counsellor you choose, or I can refer you to someone. You can pay for the session yourself and send me the receipt. I will e-transfer you the amount you paid. Alternatively, you can ask the therapist to contact me and I will pay them directly. They do not need to reveal your name to me. You have six months following our interview to claim this.
- I will follow-up with you in 4-8 weeks so that you can offer feedback on the accuracy of my understanding of what you have shared with me.

Appendix I: Sample Summary of Themes Document for Credibility Checking

Understanding Childhood Adversity and Resilience:
Perspectives of Autistic Adults

November 25, 2020

Principal Investigator (Researcher):
Gabrielle Heselton
780-966-9912
gheselton1@athabasca.edu

Supervisors:

Dr. Gwen Rempel	Dr. David Nicholas
Athabasca University	University of Calgary
855-833-5699	780-492-8094
grempel@athabascau.ca	nicholas@ucalgary.ca

This project has been reviewed by the Athabasca University Research Ethics Board. Should you have any comments or concerns regarding your treatment as a participant in this project, please contact the Research Ethics Office by e-mail at rebsec@athabascau.ca or by telephone at 1-800-788-9041, ext. 6718.

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University

Theme: Adversity Influences Social Disconnection

Sub-Theme: Avoidance

"I had a really hard time like trusting people around me… And so, it's become really hard for me to reach out to people on my own"

Sub-Theme: Ostracization and Stigmatization

"But my teacher just really didn't like me, to the point that anytime we went on a field trip, she made sure … that I was left back at school and they would keep me in a conference room in like the office for the entire day."

"And because I was the quote unquote problem kid, they wouldn't let me get my own food"

Sub-Theme: Rejection

"…a part of me is always saying, well, if they didn't do so on their own, then they really don't want you around. And you know, they are just humoring you, which was how a lot of my relationships were in elementary school"

"I was constantly being like treated like crap by my classmates, even the ones that I thought were my friends"

Theme: Adversity Influences Mental and Emotional Well-Being

Sub-Theme: Behavioural Challenges

"…that was a trend where like people would hurt me, and I would fight back. And I would get in worse trouble than them."

"I just remember that like I saw somebody going towards my backpack and I like jumped up and I like punched him because I assumed that he was going to steal something from me. I was so used to people doing stuff like that."

Sub-Theme: Importance of Mental Health Supports

"I'm on medication that makes it a lot easier"

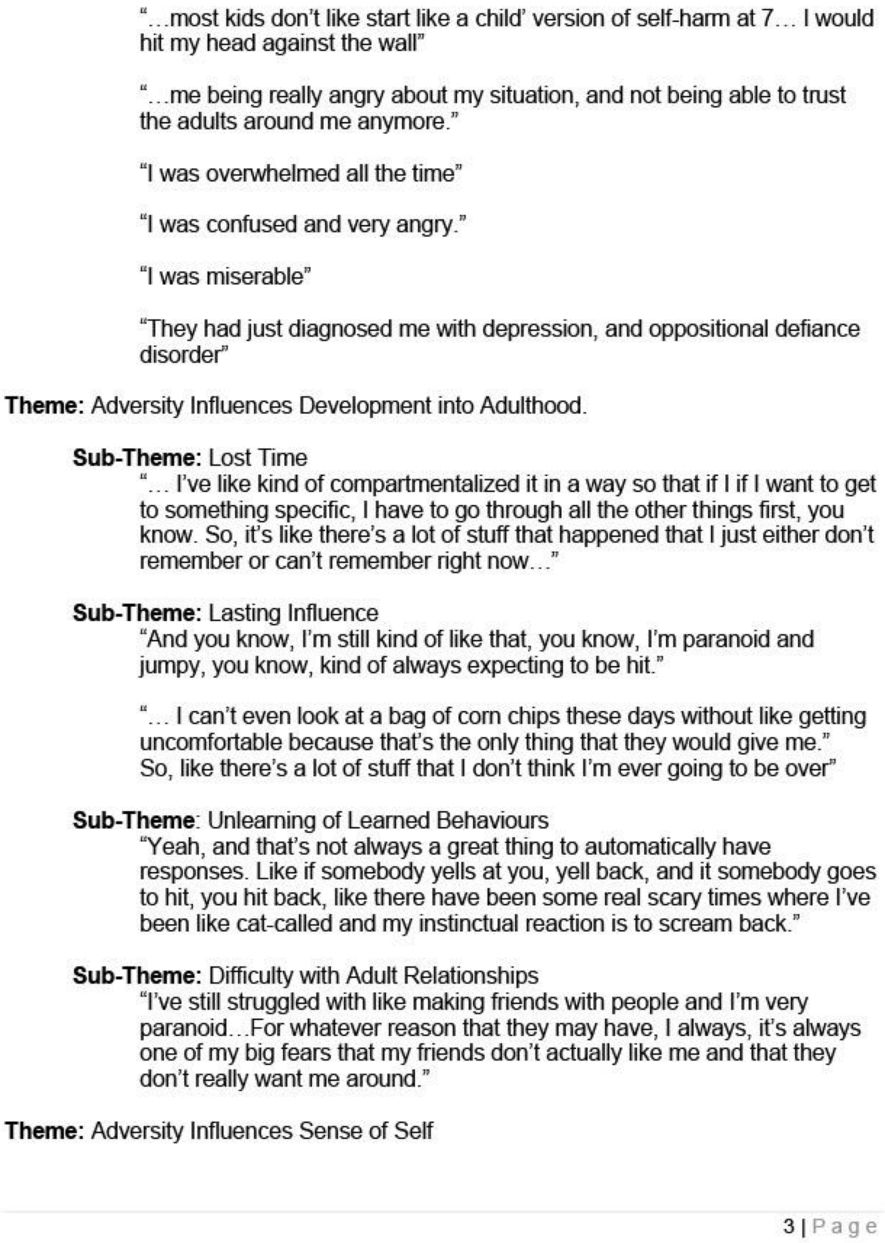
"…I do see a therapist through my school"

Sub-Theme: Suicidal Ideation

"I had first experienced suicidal ideation when I was eight…my first suicide attempt was when I was nine. It was rough."

Sub-Theme: Emotional Distress

"I became really reactive, like if somebody came at me too fast, I would like get ready to get hit"



"…most kids don't like start like a child' version of self-harm at 7… I would hit my head against the wall"

"…me being really angry about my situation, and not being able to trust the adults around me anymore."

"I was overwhelmed all the time"

"I was confused and very angry."

"I was miserable"

"They had just diagnosed me with depression, and oppositional defiance disorder"

Theme: Adversity Influences Development into Adulthood.

Sub-Theme: Lost Time

"… I've like kind of compartmentalized it in a way so that if I if I want to get to something specific, I have to go through all the other things first, you know. So, it's like there's a lot of stuff that happened that I just either don't remember or can't remember right now…"

Sub-Theme: Lasting Influence

"And you know, I'm still kind of like that, you know, I'm paranoid and jumpy, you know, kind of always expecting to be hit."

"… I can't even look at a bag of corn chips these days without like getting uncomfortable because that's the only thing that they would give me." So, like there's a lot of stuff that I don't think I'm ever going to be over"

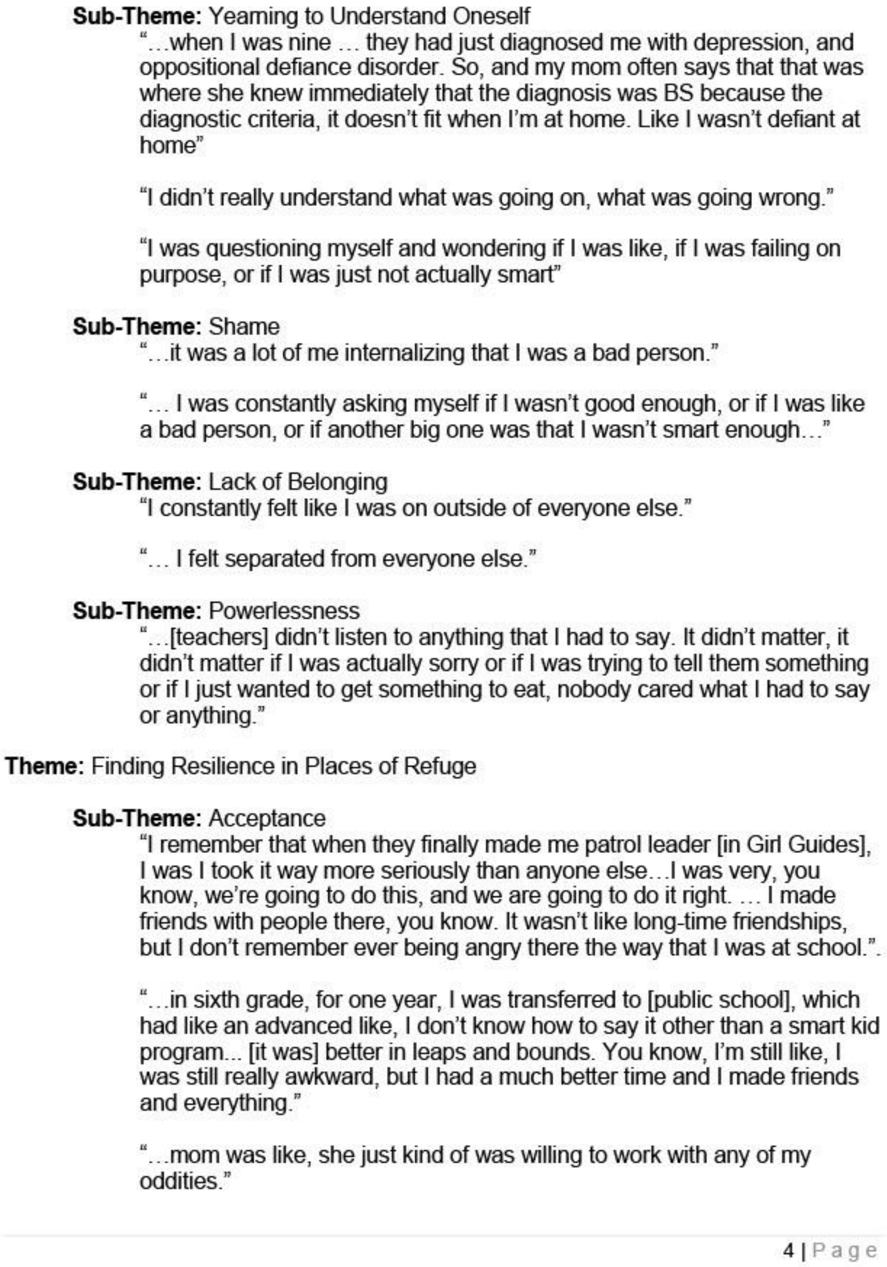
Sub-Theme: Unlearning of Learned Behaviours

"Yeah, and that's not always a great thing to automatically have responses. Like if somebody yells at you, yell back, and it somebody goes to hit, you hit back, like there have been some real scary times where I've been like cat-called and my instinctual reaction is to scream back."

Sub-Theme: Difficulty with Adult Relationships

"I've still struggled with like making friends with people and I'm very paranoid…For whatever reason that they may have, I always, it's always one of my big fears that my friends don't actually like me and that they don't really want me around."

Theme: Adversity Influences Sense of Self



Sub-Theme: Yearning to Understand Oneself

> "…when I was nine … they had just diagnosed me with depression, and oppositional defiance disorder. So, and my mom often says that that was where she knew immediately that the diagnosis was BS because the diagnostic criteria, it doesn't fit when I'm at home. Like I wasn't defiant at home"
>
> "I didn't really understand what was going on, what was going wrong."
>
> "I was questioning myself and wondering if I was like, if I was failing on purpose, or if I was just not actually smart"

Sub-Theme: Shame

> "…it was a lot of me internalizing that I was a bad person."
>
> "… I was constantly asking myself if I wasn't good enough, or if I was like a bad person, or if another big one was that I wasn't smart enough…"

Sub-Theme: Lack of Belonging

> "I constantly felt like I was on outside of everyone else."
>
> "… I felt separated from everyone else."

Sub-Theme: Powerlessness

> "…[teachers] didn't listen to anything that I had to say. It didn't matter, it didn't matter if I was actually sorry or if I was trying to tell them something or if I just wanted to get something to eat, nobody cared what I had to say or anything."

Theme: Finding Resilience in Places of Refuge

Sub-Theme: Acceptance

> "I remember that when they finally made me patrol leader [in Girl Guides], I was I took it way more seriously than anyone else…I was very, you know, we're going to do this, and we are going to do it right. … I made friends with people there, you know. It wasn't like long-time friendships, but I don't remember ever being angry there the way that I was at school.".
>
> "…in sixth grade, for one year, I was transferred to [public school], which had like an advanced like, I don't know how to say it other than a smart kid program... [it was] better in leaps and bounds. You know, I'm still like, I was still really awkward, but I had a much better time and I made friends and everything."
>
> "…mom was like, she just kind of was willing to work with any of my oddities."

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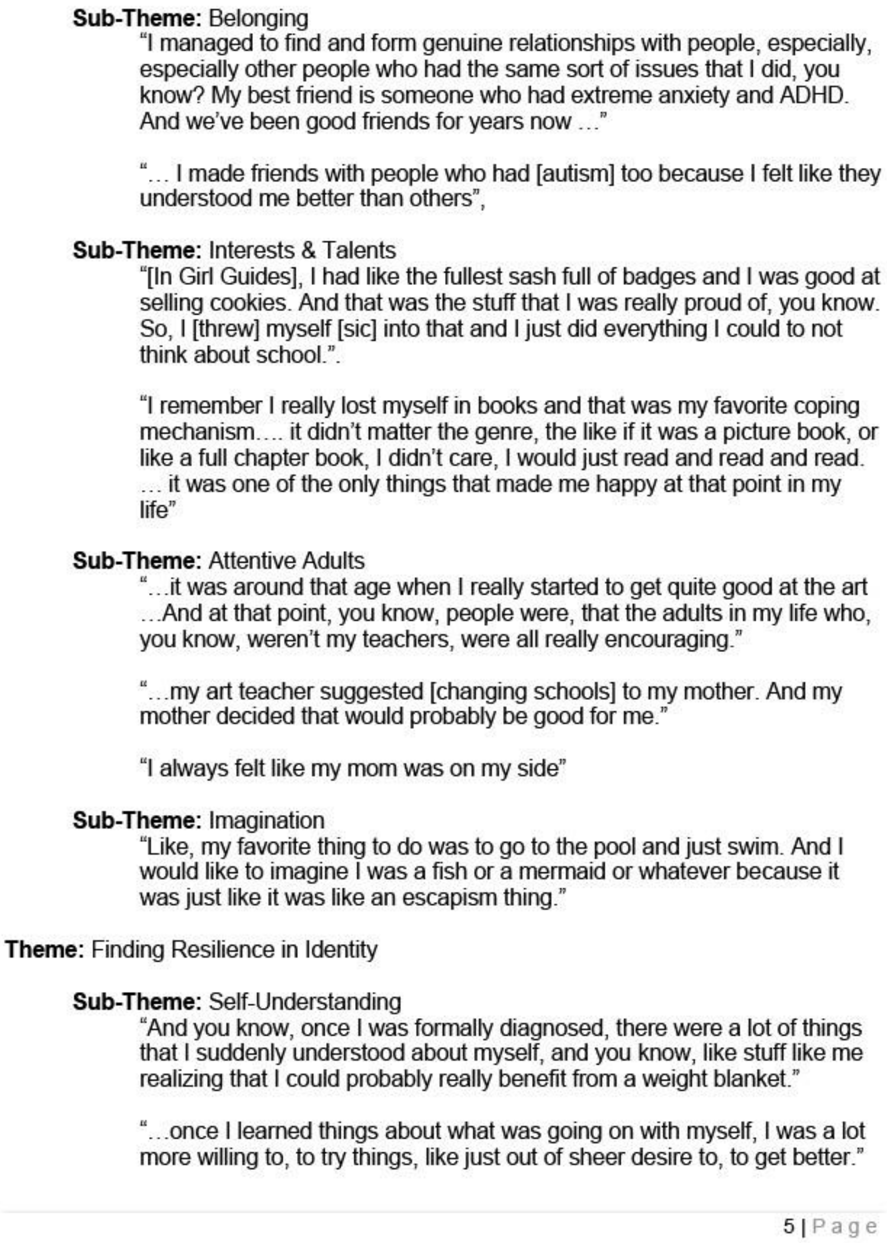


Sub-Theme: Belonging

> "I managed to find and form genuine relationships with people, especially, especially other people who had the same sort of issues that I did, you know? My best friend is someone who had extreme anxiety and ADHD. And we've been good friends for years now …"
>
> "… I made friends with people who had [autism] too because I felt like they understood me better than others",

Sub-Theme: Interests & Talents

> "[In Girl Guides], I had like the fullest sash full of badges and I was good at selling cookies. And that was the stuff that I was really proud of, you know. So, I [threw] myself [sic] into that and I just did everything I could to not think about school.".
>
> "I remember I really lost myself in books and that was my favorite coping mechanism…. it didn't matter the genre, the like if it was a picture book, or like a full chapter book, I didn't care, I would just read and read and read. … it was one of the only things that made me happy at that point in my life"

Sub-Theme: Attentive Adults

> "…it was around that age when I really started to get quite good at the art …And at that point, you know, people were, that the adults in my life who, you know, weren't my teachers, were all really encouraging."
>
> "…my art teacher suggested [changing schools] to my mother. And my mother decided that would probably be good for me."
>
> "I always felt like my mom was on my side"

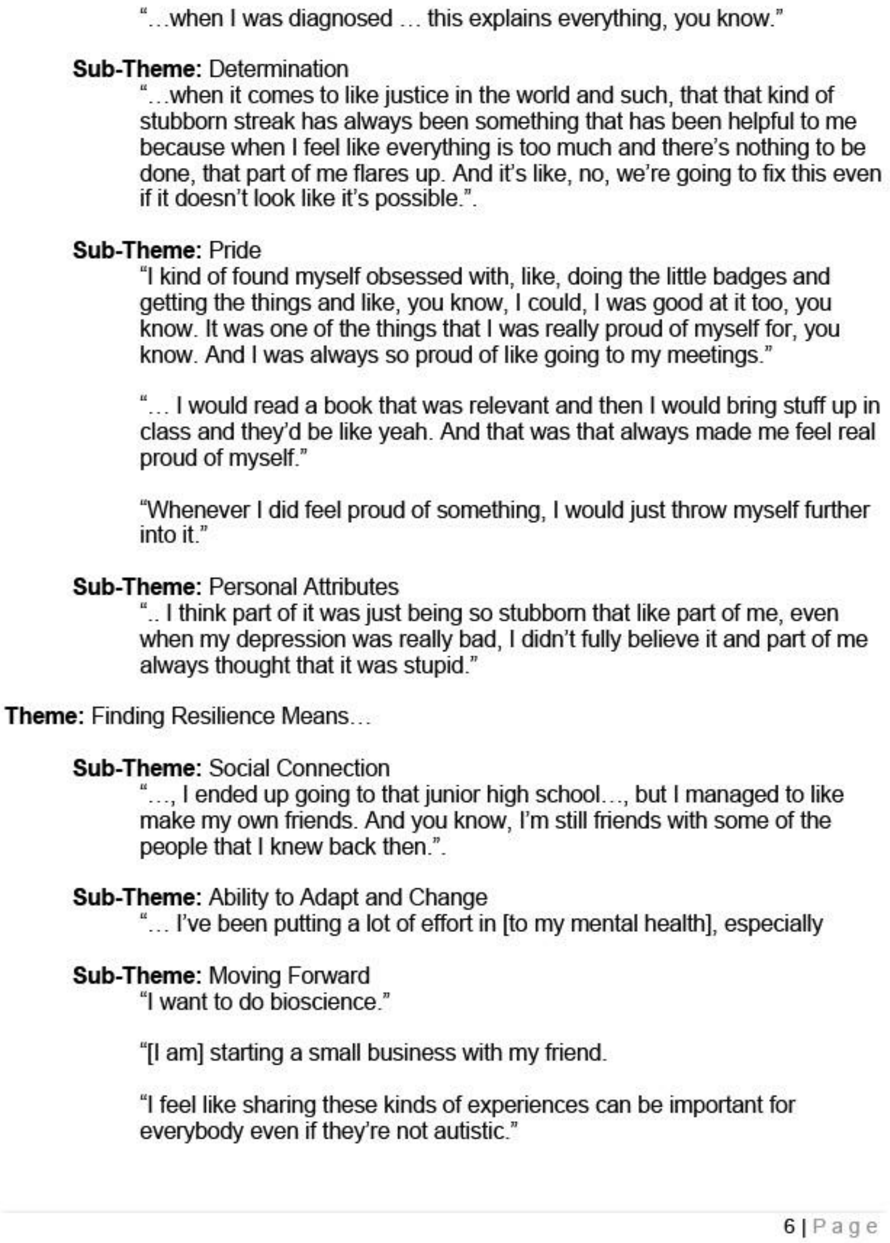
Sub-Theme: Imagination

> "Like, my favorite thing to do was to go to the pool and just swim. And I would like to imagine I was a fish or a mermaid or whatever because it was just like it was like an escapism thing."

Theme: Finding Resilience in Identity

Sub-Theme: Self-Understanding

> "And you know, once I was formally diagnosed, there were a lot of things that I suddenly understood about myself, and you know, like stuff like me realizing that I could probably really benefit from a weight blanket."
>
> "…once I learned things about what was going on with myself, I was a lot more willing to, to try things, like just out of sheer desire to, to get better."



"…when I was diagnosed … this explains everything, you know."

Sub-Theme: Determination

"…when it comes to like justice in the world and such, that that kind of stubborn streak has always been something that has been helpful to me because when I feel like everything is too much and there's nothing to be done, that part of me flares up. And it's like, no, we're going to fix this even if it doesn't look like it's possible.".

Sub-Theme: Pride

"I kind of found myself obsessed with, like, doing the little badges and getting the things and like, you know, I could, I was good at it too, you know. It was one of the things that I was really proud of myself for, you know. And I was always so proud of like going to my meetings."

"… I would read a book that was relevant and then I would bring stuff up in class and they'd be like yeah. And that was that always made me feel real proud of myself."

"Whenever I did feel proud of something, I would just throw myself further into it."

Sub-Theme: Personal Attributes

".. I think part of it was just being so stubborn that like part of me, even when my depression was really bad, I didn't fully believe it and part of me always thought that it was stupid."

Theme: Finding Resilience Means…

Sub-Theme: Social Connection

"…, I ended up going to that junior high school…, but I managed to like make my own friends. And you know, I'm still friends with some of the people that I knew back then.".

Sub-Theme: Ability to Adapt and Change

"… I've been putting a lot of effort in [to my mental health], especially

Sub-Theme: Moving Forward

"I want to do bioscience."

"[I am] starting a small business with my friend.

"I feel like sharing these kinds of experiences can be important for everybody even if they're not autistic."