The Thought Process in Planning for the Adult Lives of Adolescents With Autism Spectrum Disorder

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I have no conflicts of interest to disclose.

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Abstract

The current study examined the lived experiences of six participants raising adolescent children with autism spectrum disorder. Using the phenomenological framework, the researcher explored the thought process involved in planning adulthood transitions by parents. To represent the distinct perspectives of study participants, semistructured interviews with open-ended questions were used to apprehend the core of participants' lived experiences. Data collected from these interviews were coded and analyzed to distinguish significant themes relevant to the research questions. The data analysis yelled the following emerging themes: (a) Considerations for Future Planning; (b) Faith, Culture, and Values; and (c) Parents' Lived Experiences. With the inclusion of subordinate themes, these three emerging themes serve as a framework for the discussion in the current study and future exploration of related topics. Results from the current study illustrated parents' considerations of their child's current functioning, needs, faith, culture and value-based factors, adjustments of expectations, and available services and support. Results suggest parents continued effort to meet the current needs of their children while projecting future needs and outcomes. Furthermore, findings and data collected from the participants may serve as a validating resource for parents in similar situations.

Keywords: autism spectrum disorder, diagnosis, thought-process, lived experiences, adulthood planning, transitions

List of Abbreviations

ASD	Autism Spectrum Disorder
ADHD	Attention-Deficit Hyperactivity Disorder
CDC	Centers for Disease Prevention and Control
CD	Communication Disorder
COS	Circle of Security
DSM-5	Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition)
DCD	Developmental Coordination Disorder
HFA	High Functioning Autism
ID	Intellectual Disability
IDD	Intellectual Developmental Disability
IPA	Interpretative Phenomenological Analysis Coding
IQ	Intelligence Quotient
LFA	Low Functioning Autism
OCD	Obsessive Compulsive Disorder
SSD	Schizophrenia Spectrum Disorder
VAP	Volunteer Advocacy Program

Chapter 1

Problem Statement

The birth of a child with a developmental disorder or later diagnosis of a developmental disorder often leaves parents with little or no hope about their child's future (King et al., 2006). In addition to losing visions of themselves as stereotypical parents, some parents reported losing future expectations of their children living independently (King et al., 2006). For these parents, having precise information on the long-term prognosis of their children is critical in helping them acknowledge the diagnosis, explore available daily resources, and develop functional coping strategies (Howlin et al., 2004). Undoubtedly, autism spectrum disorder (ASD) is one of such developmental disorders, considered highly complex as presentations of autism impairments in every individual diagnosed with ASD vary from person to person and change from time to time (Howlin et al., 2004). However, extended years of research on ASD have shown that early intervention programs like applied behavior analysis (ABA), pretend play interventions, and speech therapy have helped young children with ASD develop social and communication skill sets (Al-Khateeb, 2021). Developing social and communication skills at a younger age is not a direct prediction of adulthood prognosis, as variance in socio-communication symptoms of children with ASD manifests at different stages of development (Alkire et al., 2020). Individuals like Doctor Temple Grandin, who had no speech before the age of 5 with all signs of severe autism, are an example of an adult with ASD whose adulthood prognosis is different from their childhood functioning (Grandin, 2008).

Unfortunately, compared to other disability groups, it is not surprising that adolescents and adults with ASD exhibit poor social, educational, and vocational outcomes as ASD is characterized by impairments in related areas (Oswald et al., 2017). It is estimated that most children and adolescents living with ASD with an IQ below 50 will most likely become highly dependent adults living with parents, caregivers, assisted living establishments, state institutions for people with disabilities, and psychiatric hospitals (Howlin et al., 2004). In a long-term study on adults with ASD, Chamak and Bonniau (2015) concluded that two thirds of adults with moderate to severe autism lived in residential accommodations for highly dependent adults. Their research findings were similar to other international-level research that predicted adults with ASD dependency rate as two-thirds of the general autism population (Chamak & Bonniau, 2015). However, predicting the adult lives of every child or adolescent with ASD is highly uncertain, considering the complexity of the broad spectrum of cognitive, social, linguistic, and behavioral functioning of every individual with ASD (Howlin et al., 2004).

Autism spectrum disorder (ASD) is a lifelong neurological disorder characterized by impaired social, language, behavior, and communication skills (Boshoff et al., 2016). Poslawsky et al. (2013) described ASD as “A neurodevelopmental disorder characterized by atypical and delayed development of reciprocal social interaction and communication, and the presence of stereotyped or restricted behaviors and interests” (p. 294). Other authors like Gyawali Nanda (2019) categorized ASD as a neurodevelopmental condition that impacts an individual’s ability to interact and communicate socially with repetitive behaviors. The DSM-5 diagnostic criteria include deficits in social communication and social interaction across multiple contexts, restricted, repetitive patterns of behavior, interests, and activities (DSM-5). The manifestations of characterized defects in social interaction, communication, and stereotyped behaviors and interests vary with age and ability from person to person (Frith & Happe, 2005). Although presentations of ASD impairments are liable to change, symptoms of these impairments must be present from early childhood, and they must be clinically and significantly impaired in a child's present functioning (DSM-5).

Epidemiology of ASD

The earliest epidemiologic studies on ASD were first conducted between 1960 and 1970, of which the yearly prevalence rate was lower than current estimates (Baio, 2014). Between 1960 and 1970, it was estimated four in every 10,000 persons were diagnosed with autism (Frith & Happe, 2005). However, in recent years, the Center for Disease Control and Prevention (CDC) has reported increasing the number of individuals diagnosed with ASD. Other prevalence studies in America have also suggested an upward trend in prevalence (Baio, 2014). Presently, according to the CDC (2021), the increase is at 1 in 44 children or 23 per 1,000 children, compared to the 2014 overall prevalence estimate of 16.5 per 1,000 children. Similarly, the global prevalence of ASD has also increased based on extensive surveys of children (Baio, 2014). These studies have progressively suggested a continued increase in the prevalence rate with no definite underlying reason (Baio, 2014). However, some studies have attributed the following to heightened ASD prevalence: increased general awareness, the adoption of universal screening at 18 to 24 months of well-child check-ups, and resource availability (Baio, 2014). In addition to recent changes in the diagnostic concept of ASD, which broadened the diagnostic criteria of ASD by including Asperger syndrome and pervasive developmental disorder, these factors contributed to the increase in the number of persons diagnosed with autism (Frith & Happe, 2010). With this change in diagnostic criteria, more people who were never included in the 1960's criteria are now considered on the autism spectrum (Frith & Happe, 2010).

Aside from changes to the diagnostic criteria, the gender differences in prevalence rate and the etiology of ASD have also undergone several reconsiderations (Gyawali & Nanda, 2019). ASD is considerably higher in males than females, with a male to female ratio of 4:1 (Shuck et al., 2019). In the United States, among 8-year-olds, current report from the CDC estimates one autism diagnosis in 38 boys and one diagnosis in 152 girls (Shuck et al., 2019). There are no definite reasons behind the gender imbalance in the prevalence rate, but some studies have suggested possibility of ASD bias toward males (Shuck et al., 2019). Other studies have speculated the masking of less intense autism impairments by some females who learn social skills and coping strategies in their natural environments (Shuck et al., 2019). Similar studies suggested ASD might be more challenging to identify in females than in males as females with less severe impairments when compared to their male counterparts with similar impairments can cover up some autism traits (Shuck et al., 2019). With no definite conclusions on the underlying cause of the gender imbalance in prevalence rate, countless studies have also questioned the underlying cause of autism as inconclusive findings on the etiology of autism have become infinite (Frith & Happe, 2005).

The underlying cause of autism implicated several risk factors, which genetics has been the most accepted among multiple researchers (Sandin et al., 2017). With a 50% risk factor, siblings of those with autism were found to have a higher chance of ASD (Frith & Happe, 2010). In pursuit of the underlying cause of autism, several studies evidenced higher heritability rates among families with ASD children (Gyawali & Patra, 2019). Twin studies have suggested a higher risk of ASD in identical twins than fraternal twins (Frith & Happe, 2010). With greater than 88% risk in identical or monozygotic twins and less than 30% risk in fraternal or dizygotic twins, more studies have extensively considered other sets of multiple births like triplets (Frazier, 2014). Stauffenberg et al. (1989) found 91% and 0% consistency in risk factors among monozygotic and dizygotic sets of twins. On the other hand, some studies have suggested that the primary cause of

ASD is not solely genetics but a combination of hereditary and environmental factors (Sandin et al., 2017). Known as the phenotype variance, which consists of genetic and environmental variance, some studies have suggested the 90% heritability risk of ASD was exaggerated by previous studies that only considered the single gene associated with ASD (Gyawali & Patra, 2019). In previous studies, heritability of autism was found to be significantly higher than the environmental causes of ASD, with 50% heritability risk and 4% environmental risk (Sandin et al., 2017). Recent studies have also associated higher prevalence rate of autism with unstudied environmental triggers impacting young children (Gyawali & Patra, 2019). Other studies have also proposed a combination of genetic and environmental factors by arguing that individuals genetically predisposed to ASD have a higher risk of ASD when exposed to environmental triggers (Frith & Happe, 2005). These suggestions have contributed to the belief that influenza and the measles-mumps and rubella vaccines could trigger autism in toddlers (Gyawali & Patra, 2019). Other environmental triggers associated with autism include mercury toxicity, viruses, allergens, and gastric inflammation (Frith & Happe, 2005). To understand genetic and environmental interactions that could cause autism, Sandin et al. (2017) reanalyzed specific data collected from a previous study that found the heritability rate of ASD at 90%. Conclusions from their study found the heritability risk higher than the environmental risk except that theirs was at 83% risk, although previous studies estimated a 90% risk (Sandin et al., 2017). Although slightly lower than 90%, the Sandin et al. (2017) findings suggested that the risk and causes of ASD may only be explained by genetic factors. Presently, there is limited evidence for any environmental pathogen that causes autism; however, unlimited evidence has shown that the developmental impairments associated with ASD are consistent amongst individuals with ASD but vary in severity from person to person (Frith & Happe, 2010).

Comorbid Disorders

ASD is a broad spectrum of varied presentations of impairments in social, language, behavior, and communication skills (Gyawali & Patra, 2019). Depending on the severity of impairments, behavioral presentations of these impairments are very similar across the board but yet distinct, hence the famous quote, "When you meet a person with autism, you have met one person with autism" (Flannery & Wisner-Carlson, 2020, p. 1). In children, language development was an early sign of developmental delay by parents who overlooked other behavioral presentations of ASD (Poslawsky et al., 2014). As children age, stereotyped behaviors and restricted interests gradually manifest, and some children may develop self-injurious behaviors (Gulsrud et al., 2018). Impairments in the socio-communication domain are manifested in the inability of an individual with ASD to represent their mental state and others' mental states (Hess et al., 2017). Expressing mental states like thoughts, beliefs, feelings, emotions, and reasons are exceptionally challenging for most individuals with ASD (Hess et al., 2017). Clinically, abnormalities in cognitive domains like learning, memory, attention, impulse control, problem-solving, and flexibility in thought and action are evident in some individuals with ASD (Ring et al., 2017). Deficits in some of these cognitive domains impact executive functioning and adaptive behaviors (Hess et al., 2017).

Studies have shown that ASD co-occurs with other neurodevelopmental disorders and mental health disorders (Nah et al., 2017). In young children with ASD, multiple studies have examined the prevalence of comorbid neurodevelopmental disorders like developmental coordination disorder (DCD), communication disorder (CD), attention deficit hyperactivity disorder (ADHD), and intellectual disability (ID; Dovgan & Mazurek, 2019). Developmental coordination disorder (DCD) is characterized by defects in motor skills and coordination. Several studies have demonstrated presence of comparable deficits in children with ASD (Paquet et al., 2019). Like ASD, because DCD impacts executive functioning, academic achievement, and play, ASD and DCD's comorbidity has remained a debatable topic (Paquet et al., 2019). A communication disorder is another neurodevelopmental disorder co-occurring with ASD (Flusberg & Kasari, 2013). Communication disorders like speech and language disorders impact 30% of school-age children with ASD (Flusberg & Kasari, 2013). Estimates show 25%–30% of children with ASD will remain nonverbal or minimally verbal (Flusberg & Kasari, 2013). However, there are no definite explanations to support why some children remained nonverbal despite speech and language interventions (Flusberg & Kasari, 2013). Although ID co-occurs in some children with ASD regardless of language skills, there are assumptions that all nonverbal and minimally verbal ASD children have intellectual disabilities (Flusberg & Kasari, 2013). However, there are notable contradictions to these assumptions as nonverbal adults like Carly Fleishmann, who defied all odds of severe motor apraxia and cognitive delays, found her voice through typing (Fleishmann & Fleishmann, 2012). Within the last decade, the Autism and Developmental Disabilities Network (ADDM) reported a decrease in nonverbal children below age 8 (Baio, 2014). Aside from neurodevelopmental disorders, mental health disorders like anxiety and mood disorders co-occur with ASD (Baio, 2014).

Developmental Stages

Children With ASD. Anxiety, mood irregularities, insomnia or sleep problems, conduct disorder, and obsessive-compulsive behaviors co-occur in younger children (Baio, 2014). Anxiety disorder happens to be the most common psychiatric condition in most children with autism (Dovgan & Mazurek, 2019). Recent estimates on the comorbidity of problem behaviors and ASD suggests that between 35.8% to 94.3% of children with ASD met the markers for dual diagnosis of conduct disorder and ASD (Raulston et al., 2018). However, with variations in ASD presentations, the severity of these comorbid conditions varies from person to person (Bohnert et al., 2016). For example, with the widened diagnostic concept of ASD, which now includes previously diagnosed Asperger disorder subtypes, ASD impairments are less severe in children without an intellectual disability with an average or above-average intelligence quotient (Baio, 2010). Comparably, data collected from the Autism and Developmental Disabilities Monitoring Network found higher rates of ASD impairments in young children with co-occurring intellectual disabilities (Baio, 2010). Children with severe autism symptoms, considered highly impacted by ASD, may have co-occurring conduct disorders like oppositional defiant behaviors and maladaptive behaviors (Gulsrud, 2018). With severe impairments in communication, cognitive abilities, adaptive functioning, and behavior regulation, the possibility of meeting the risk marker for conduct disorder is more significant in highly impacted children (Gulsrud, 2018). The severity of ASD symptoms affects children's ability to learn, adapt, and manage coping strategies for mental health conditions (Dovgan & Mazurek, 2018). Estimates show 27% to 95% of children with ASD have comorbid psychiatric disorders, which become significant in adolescence (Dovgan & Mazurek, 2018).

Adolescence Stage. The developmental stage of adolescence is often a period of self-discovery and socioemotional adjustments, which is particularly challenging for adolescents with ASD (Bohnert et al., 2016). Unfortunately, compared to their neurotypical peers, adolescents with ASD are at a higher risk of being associated with one or more psychological conditions (Stice & Lavner, 2018). Adolescents with ASD do not follow similar developmental trajectories like their neurotypical peers (Hess et al., 2017). With social and communication defects, which impact the ability to process certain information globally instead of locally, some adolescents with ASD struggle with expressing and representing their mental states and others' mental states (Hess et al., 2017). This social challenge is familiar to those without intellectual disability, whom studies have suggested there is a 50% chance of a comorbid diagnosis of major depression, anxiety disorder, or both (Stice & Lavner, 2018). With a comorbidity rate so high, Righi et al. (2017) explored the indicators of psychological conditions and psychiatric hospitalizations in a group of children and adolescents with ASD. Findings from their study suggested adolescents with mood disorders were at a higher risk of being hospitalized for psychiatric intervention (Righi et al., 2017). Mood disorders like depression were a significant area of concern in the likelihood of suicidality in adolescents with autism (Shochet, 2019). Because autism is in part marked by continuous social communication and interaction deficits, Stice and Lavner (2018) suggested that poor social connectedness and loneliness may contribute to internalizing symptoms and depression. In their research on broader autism phenotype traits, a cluster of cognitive and sociocommunicative symptoms that are comparable but milder than ASD symptoms, they concluded that individuals with autism traits, regardless of severity, are at a higher risk of having depressive symptoms due to peer social contentedness and loneliness.

At the adolescence stage, symptoms of depression may become more evident among ASD children as the gap between their neurotypical peers widens (Cheak-Zamora et al., 2017). Challenges associated with adjusting to environmental changes and transitions, struggles with new skill acquisition, and limited social networks contribute to increased anxiety and depression symptoms at this developmental stage (Cheak-Zamora et al., 2017). With notably high depression rates among adolescents with autism, Shochet et al. (2019) proposed the need for strength-based parenting intervention programs for depression prevention in this population. Their qualitative research on parenting adolescents with autism affirmed the need for emotional and knowledge-based parenting support to boost both parents' and adolescents' well-being and mental health (Shochet et al., 2019). In addition to parenting intervention for depression prevention, they suggested school-based depression prevention programs, which have been in existence for neurotypical adolescents (Shochet et al., 2019). With continued challenging socioemotional adjustments and limited social networks, Bohnert et al. (2016) suggested youths' involvement with organized activity as an intervention for controlling depression. Although findings from their study were inconclusive on the association between organized activity involvement and improved social networks, they noted correlational evidence between intensive, organized activity involvement and benefits on emotional control deficits (Bohnert et al., 2016).

Other than depression, which mostly co-occurs due to impaired socioemotional adjustment skills, children and adolescents with ASD are sometimes labeled with externalizing psychological conditions like disruptive behavior disorder (Righil et al., 2017). In a recent study, Righil et al. (2017) examined predictors of inpatient psychiatric hospitalization amongst children and adolescents with ASD whose aggressive behaviors exceeded their families' coping capacity (Righil et al., 2017). The likelihood of psychiatric hospitalization for disruptive behaviors was linked to increased maladaptive behaviors in children and adolescents who received an ASD diagnosis at a later age and those from single caregiver homes with low income (Righil et al., 2017). In this population, prior diagnosis of disruptive behavior disorder and other psychiatric conditions, before an ASD diagnosis, are not uncommon as these caregivers seek emergency room interventions in the event of aggression and self-injurious behaviors (Righil et al., 2017). The comorbidity of disruptive behavior labeling was more prevalent in lower IQ individuals with ASD than those with average or above-average cognitive abilities (Blacher & Baker, 2017). Youths with ASD and ID are 3 times more likely to receive a diagnosis of disruptive behavior disorder than their peers without ASD, ID, or both (Blacher & Baker, 2017). Other comorbid behavioral disorders common to this population are oppositional defiant disorder and conduct disorder (Herpes et al., 2019). Their inability to recognize emotional valences like anger, fear, pride, and surprise was associated with defects in non-verbal communication skills (Herpers et al., 2019). With limited ability to communicate their needs, emotions, and desires, which increases likelihood of being misunderstood or mistreated, some youths may exhibit externalizing behaviors due to challenging communication skills (Herpers et al., 2019). Because externalizing disorders are characterized by maladaptive behaviors toward one's environment, the likelihood of being labeled as aggressive, destructive, irritable, and defiant is not uncommon amongst individuals with ASD and ID with more than one of these behavior patterns (Bours et al., 2018). The severity of ASD symptoms often correlates with the cognitive capacity of most individuals with ASD. Aside from having elevated levels of restricted behaviors and interests, they also struggle with adaptive functioning and behavioral expectations (Elser et al., 2019).

Furthermore, regardless of the severity of ASD impairments, mental health conditions like anxiety were found to be a persistent co-occurring disorder across the autism spectrum (Dovgan & Mazurek, 2018). A meta-analysis on adolescents and young children with ASD suggested that 40% of this population has anxiety disorder as a comorbid diagnosis (Nah et al., 2017). Recent studies on mental health concerns in school-based programs have also suggested a steady increase in anxiety among the ASD population (Kester & Lucyshyn, 2019). Second to anxiety is mood disorders at a 10%–24% comorbidity rate (Nah et al., 2017). Sadly, anxiety persistently increases with age across the lifespan of children with ASD (Dovgan & Mazurek, 2018). Same as anxiety, sleep problems like insomnia, if left untreated, is one such condition that could persist across the lifespan of children with ASD (Hohn et al., 2019). With a prevalence rate ranging from 50%–80%, symptoms of sleep problems in this population are very similar to insomnia, including delayed sleep onset, decreased sleep maintenance, early awakenings, and daytime fatigue (as cited in Hohn et al., 2019). Persistent sleep problems and insomnia have adverse effects on their health and daily functioning across their lifespan (Hohn et al., 2019).

Adulthood Stage. In the adult population, other than the impact of age and environmental conditions on the co-occurrence of additional psychiatric conditions, adults with ASD have comparable comorbid psychiatric conditions with some adolescents (Elser et al., 2019). These factors are also known to heighten the impact of additional psychiatric conditions in children and adolescents as they age (Elser et al., 2019). However, high rates of comorbid psychiatric and behavioral disorders are present in the adult population with intellectual developmental disorder (IDD). Higher rates of co-occurring diagnoses were affirmed in those with ASD and IDD (Elser et al., 2019). Estimates show that 30% to 50% of individuals with IDD have co-occurring psychiatric conditions, including those with ASD and IDD (Elser et al., 2019). Anxiety, depression, insomnia, OCD, and social phobia are common co-occurring conditions in adults. At the same time, affective disorders like psychosis and schizophrenia are known to co-occur in rare cases (Nah et al., 2018).

Social withdrawal, lack of trust, and the possibility of an emergence of psychosis and paranoia were lived experiences of ASD adults with average intelligent quotient (Lugo Marin et al., 2017). Conclusions from the Lugo Marin et al. (2017) study on the comorbidity of ASD and schizophrenia spectrum disorders suggested an overlap in the genetic predispositions of some individuals with autism (Lugo Marin et al., 2017). Environmental changes and sensory stimulation are a few unforeseen stress factors that could trigger psychosis-like symptoms in some adults with ASD (Lugo Marin et al., 2017). Environmental conditions like child abuse have a long-term psychological impact on victims, which individuals with ASD also experience (Brenner et al., 2017). Compared to the general population, individuals with disabilities like ASD were 1.6 times more likely to experience physical abuse and 2.2 times more likely to experience sexual abuse (Sullivan & Cork, 1996, as cited in Brenner et al., 2017). Unfortunately, despite high prevalence rate of abuse in the ASD population, there are no evidence-based assessment tools to measure the impact of these adverse childhood events on behaviors (Brenner et al., 2017). However, some studies on adults with ASD have suggested the comorbidity of social phobia and posttraumatic stress disorder (PTSD) on those with histories of abuse (Brenner et al., 2017). Similar studies have also identified the social communication defects in ASD as potential contributors to the underreporting of incidents of abuse in this population (Brenner et al., 2017). Social communication defects such as underdeveloped expressive language, low recognition of social clues, and the inability to represent mental states are typical barriers limiting the understanding of their constructs (Hess et al., 2017). Sadly, families of individuals with ASD are often confronted with the fear of others taking advantage of their vulnerable child’s social communication deficits, one of the many long-term challenges embedded in raising a child with autism (Brenner et al., 2017).

Parenting Challenges

The long-term challenges of raising a child with ASD are comparable to the challenges experienced by caregivers of adults with ASD, whose adult-life independence lies in the hands of a support system (Cheak-Zamora et al., 2014). These challenges stem from managing their children’s day-to-day lives: the psychological, adaptive, and interpersonal aspects (Lee & Shivers, 2018). The adaptive and interpersonal challenges are primarily embedded in managing the sensory and regulatory impairments, low language development, limited cognitive functioning, and social deficits. In contrast, the psychological challenges stem from managing the behavioral struggles that emerge from these deficits (Lim & Chong, 2017). The psychological challenges of raising a child with ASD are bidirectional with the child's current challenges as parents' stress levels are affected by their child's fluctuating adaptive skills (Raulston et al., 2018). Such bidirectional relationship also exists in families of children with other chronic developmental conditions like Down syndrome, cerebral palsy, Rett syndrome, and ADHD (King et al., 2005). In comparing ASD with other developmental conditions, Vohra et al. (2014) found raising a child with ASD had a higher negative effect on parents' finances, employment, mental health, and time-related burden. The co-occurrence of other comorbid neurological and psychiatric disorders amplifies the parental challenges and stressors as some comorbid conditions emerge with age and environmental changes (Dovgan & Mazurek, 2018). Although the intensity of these challenges is highly dependent on the severity of a child's symptomology, the overall outcome of a child's future is known to be very uncertain as research on predictability of future outcomes based on presenting problems is limited (Dovgan & Mazurek, 2018).

To date, most ASD studies on parents are either focused on parental reactions to their child's ASD diagnosis or parental struggles with providing care for their adult child with ASD (Dovgan & Mazurek, 2018). After the initial ASD diagnosis, parents explore several interventions with hopes of helping their children close the developmental gap between them and their neurotypical peers (Poslawsky et al., 2013). However, children get older and likely comorbid conditions emerge, some parents begin to experience psychological stress due to the socioenvironmental demands on their children (Poslawsky et al., 2013). Simultaneously, others may experience a priority change from closing the developmental gap to adopting a strength-based perspective for the child's abilities (King et al., 2006). Hence, the need for more research on parents' psychological minds within these crucial years cannot be overemphasized, as these years could hold the key to predicting future outcomes (Lee & Shivers, 2018). Estimates on youths with ASD show that less than 25% will become independent adults with typical social lives and competitive employment (Cheak-Zamora et al., 2014). With such discouraging statistics, parents become anxious when visualizing future outcomes of their young children with ASD, as some parents may assume the role of a lifetime caregiver for their children (Spiers, 2015). As challenging as this could be, Spiers (2015) found although some parents chose to embrace adult life transitions one day at a time without planning, others planned ahead by considering the death of parents, loss of insurance coverage, and future financial strains as possible uncertainties (Spiers, 2015).

Regardless of what route a family chooses to undertake, adjusting to changing environmental needs like learning self-advocacy and independent living skills is a terrifying experience for both parents and their children (Cheak-Zamora et al., 2014). To normalize this experience by minimizing adjustment challenges, parents often seek the services of transition planning agencies (Cheak-Zamora et al., 2014). Transition planning services are recommended to begin gradual transition processes at age 12, but due to limited resources, their accessibility often comes at high school completion (Cheak-Zamora et al., 2014). Although some families wait on transition planning agencies, others embrace the present and consider alternative ways of conceptualizing the future (King et al., 2005). Considered as one of the vital factors that impact how families conceptualize transitions, change in family belief systems enable families to focus on the purpose of a transition, create a sense of meaning, and have a sense of control over unfolding transition stages (King et al., 2005). Family values, faith, prioritizing immediate and essential needs, and the sociocultural environment are constructed in belief systems that change over time (King et al., 2005). To understand how families reframe events and experiences in adaptive ways, King et al. (2005) found resilience and general family adaptation as two areas of change in family belief systems that have helped families pull together and face the future with a sense of strength. Beyond changes in family values, some families adopt a positive outlook by focusing on the positives that emerged from parenting their child with ASD (Woodman et al., 2015). Transformational qualities like being thankful for the simple things their children can do, living in the present, and not worrying about the future were some of the positive outlooks that emerged from raising a child with disabilities (King et al., 2006). Woodman et al. (2015) also affirmed positive family processes as a significant variable in predicting adult outcomes of children with ASD. Emerging studies on adults with ASD suggested that parental warmth and tight parent–child relationships were positive family processes linked to improved outcomes (Woodman et al., 2015). Parents embraced the present, adopted a strength-based approach in which they focused on what their children could do, and stopped worrying about their children's future outcomes (King et al., 2006). However, although some parents wait on transition planning agencies and others adopt various conceptualizations of their child's future, some plan intentionally (Cheak-Zamora et al., 2015).

Comparable Studies

There are limited studies on the latter population who chose to plan; yet, only a handful of these studies evaluated the thought and planning processes leading to adulthood transition (Woodman et al., 2015). As transitions are inevitable in all facets of life, Taylor and Seltzer (2010) measured the psychological changes in mother-child relationships at the transition stage but did not consider the thought process leading to the transition stage. The thought process in adulthood planning is so critical because adults with moderate to severe ASD symptoms, when compared to other disability groups, have higher rates of unemployment, dependent living outcomes, and poor educational outcomes (Oswald et al., 2017). The thought process, the critical thinking involved when considering outcomes, was described as a purposeful and self-adjusting process (Jou & Wang, 2015). The thought process involves elaboration, analysis, assessment, prediction, and explanation of the multiple components in parenting a child with ASD (Jou & Wang, 2015). Parents assess possible changes in autism impairments and maladaptive behaviors from one developmental stage to another (Woodman et al., 2014). They analyze and predict sibling relationships, what they might look like in the years ahead, and the relational barriers impacting siblings' quality of life (Noonan et al., 2018). In a phenomenological study that analyzed the lived experiences of siblings of adults with ASD, Noonan et al. (2018) sought to understand the family processes relevant in the lives of brothers and sisters of adults with ASD. Study participants affirmed that to protect themselves and their parents from worrying about the long-term outcomes of their sibling with ASD, they avoided and postponed discussions on adulthood planning (Noonan et al., 2018). Still, sibling relationships in adulthood planning and long-term outcomes cannot be avoided or overlooked, considering parental support for adults with ASD can be interrupted by death, divorce, and declining health conditions (Noonan et al., 2018). Often, parental support and advocacy begin in the younger years and, depending on the severity of ASD impairments, could last across the lifespan (Rispoli et al., 2019). Rispoli et al. (2014) suggested that adult outcomes among severely impacted individuals are often low despite continued parental support at different development stages.

Undoubtedly, with high levels of continuous involvement across the lifespan of a brother or sister with ASD, the lived experiences of families impacted by autism are different from the experiences of an all neurotypical family (Noonan et al., 2018). Although most families affected by ASD share similar parental and sibling support experiences, there are known differences in the levels of involvement, with mothers being the most involved member of a household (Navot et al., 2017). However, despite the levels of involvement amongst siblings and parents, they desire a life of total independence or autonomy for their children or sibling with ASD (Check-Zamora et al., 2017). Furthermore, cognitively processing what independent living could look like outside their homes has remained a challenging undertaking for most parents (Check-Zamora et al., 2017). In a qualitative study on caregivers' perspectives on adulthood transitions, Check-Zamora et al. (2017) reported caregivers affirmed lack of preparedness and understanding of the transition process as a significant challenge in their parenting journeys. In addition to this, parents who had no intention of continuing their legal guardianship roles felt forced to continue in these roles as there were no stipulated transition plans (Check-Zamora et al., 2017). Several studies have documented parents' perspectives on their children's service needs as adults. However, few qualitative studies have examined parents' perspectives on planning ahead to meet these service needs (Check-Zamora et al., 2017).

Similarly, lack of preparedness and understanding of support needs were documented in a phenomenological study of lived experiences of college students with ASD (Harn et al., 2019). With an average or above-average intellectual ability, study participants, who lived independently as college students with ASD, reported inadequate understanding of college needs and insufficient preparedness to cope with some barriers associated with ASD (Harn et al., 2019). Similar issues on insufficient preparedness were reported in another study by Gaona et al. (2019). Their research article titled "I Am Ready for a New Chapter" appeared to be the opposite of their findings, as families and adolescents reported feelings of unpreparedness and limited understanding of adulthood autonomy (Gaona et al., 2019). Like most phenomenological studies on lived experiences, this study provided visible insights into the world of adolescents with ASD, who, although deemed prepared for adulthood, reported inadequate parents' readiness and continued support from immediate family (Gaona et al., 2019). Because these comparable studies have persistently highlighted the need for adequate preparedness for adulthood, other studies have examined the transition period (Noonan et al., 2018).

Despite the degree of preparedness for transitions, parents of children and adolescents with ASD have undergone several changes in their perspectives and thought-processes when considering long-term plans (Noonan et al., 2018). Similar to parents with neurotypical children, these parents also experience perspective changes in the course of their children's development, except that perspective changes in the ASD population begin at the earlier years of a child's life and last across their life span (Woodman et al., 2014). Undeniably, in the course of their physical and developmental growth, parents change their perspectives on what lies ahead as their expectations for their children continue to be altered by the peculiarity of ASD (Woodman et al., 2014). For some parents, the initial ASD diagnosis marks the beginning of their perspective changes, although others may experience this at different developmental stages (Poslawsky et al., 2013). Conclusions from the Poslawsky et al. (2013) study affirmed that the resolution and nonresolution of parents in accepting or not accepting their children's formal ASD diagnosis contributed to parents' long-term plans. Parents, who reacted positively, saw themselves as the most suitable person to advocate for their child's immediate and future needs (Poslawsky et al., 2013).

As the name entails, a suitable person is a general term used to reference the official and unofficial guardians of adults with disabilities (Coles, 2015). A suitable person was evaluated by Coles (2015) in her study, which considered the psychological reasoning in decision-making by parents of adults with ASD. Conclusions from her study suggested parents, by embracing their roles as suitable persons, surround themselves with positive family processes that minimize stress and challenges embedded in special needs parenting (Woodman et al., 2014). Depending on family dynamics, these positive family processes can be manifested in different ways, such as the quality of joint parent–child interactions, mother-child relationships, father-child relationships, sibling/siblings-child relationships, and positive reinforcements parenting (Woodman et al., 2014). With positive family processes, adolescents with ASD had favorable predictive outcomes in their transitions to adulthood than those with negative and non-supportive family processes (Woodman et al., 2014). The undeniable impact of family processes on long-term outcomes cannot be overlooked as it determines the quality of life of those affected by ASD (Blackburn et al., 2019).

For most parents of children with ASD, the possibility of their child not having an adequate quality of life as adults is a significant area of concern as every parent desires the best for their child (Howlin et al., 2004). Consistent with most functioning variations in the autism population, individuals with severe impairments are projected to have a lower quality of life than those with minimal impairments or higher functioning (Howlin et al., 2004). Minimally impaired students with ASD, who have high social skills and moderate communication skills, are 5.40 times more likely to gain livable employment than their classmates with lower social and communication skills (Walsh et al., 2017). However, among those employed, a significant number of them experience employment termination due to unacceptable social communication behaviors (Bolman, 2008, as cited in Walsh et al., 2017; Hulbutt & Chalmers, 2004; Muller et al., 2003).

The first systemic outcome study on long-term prognosis was discouraging as 3 out of 38 participants lived independently with paid full-time jobs; 61% were considered to have a low quality of life, 25% were rated as the acceptable quality of life, and only 14% attained a moderate quality of life rating (Howlin et al., 2004). With such discouraging statistics, Howlin et al. (2004)

explored the correlations between intelligence quotients in children and adulthood outcomes. Their study is one of the few studies that highlighted autism-related challenges in children and the prognostic indicators used by parents when planning for adult life. Findings from their study suggested that in recent years, improved long-term outcomes witnessed and predicted by parents are due to enhanced therapeutic and educational facilities. However, with recent improvements in prognostic possibilities, most participants in this follow-up study remained very dependent on parents or other caregivers (Howlin et al., 2004).

Emerging Variables in Comparable Studies

Several studies on the autism population have explored parental reactions in the early years of a child's life and high school transitioning from adolescence to adulthood. However, few studies have considered parental reactions at different developmental timelines (Chamak & Bonniau, 2015). In a study on parental resolution post ASD diagnosis, Poslawsky et al. (2013) found that most parents of children with severe autism impairments were classified as unresolved. Despite the severity of autism impairments, some parents reacted positively to their children's initial ASD diagnosis, chose not to allow an autism diagnosis to alter their life plans, and explored immediate intervention resources (Poslawsky et al., 2013). Their study suggested that parents who continued exploring more intervention resources demonstrated a stable reaction to receiving an ASD diagnosis (Poslawsky et al., 2013). However, Poslawsky et al. (2013) affirmed the need for future research on parental reactions at different timelines or defining moments across a child's lifespan. In another study on family experiences at different developmental trajectories, Chamak and Bonniau (2015) suggested noticeable differences in trajectories of long-term outcomes between individuals with mild autism and individuals with severe autism. Their long-term trajectory study on family experiences at different timelines was based on 76 adults with ASD (Chamak &

Bonniau, 2015). The commonality between these two groups of family experiences was parental stress, other comorbid mental health conditions, and inadequate intervention resources (Chamak & Bonniau, 2015).

Undoubtedly, people react differently to receiving a diagnosis, and an ASD diagnosis is no different. However, the sudden fear of the unknown seems to be a common reaction among parents of children with ASD (King et al., 2006). Parents' fearful outlook on their children's future is founded on the inability to predict future outcomes as current autism impairments and maladaptive behaviors may not predict long-term outcomes (Woodman et al., 2015). Knowing this, Woodman et al. (2015) explored the possibility of predicting long-term outcomes in their 8 and half year longitudinal study on a large sample group of adolescence and adults with ASD. Their study suggested that despite the severity of the current autism impairments and maladaptive behaviors, improved long-term outcomes may be predicted based on the family's emotional climate, the parent–child relationship, and changes in parents' perspectives on future expectations (Woodman et al., 2015). Changes in the parent–child relationship, one of the three family processes, was explored in a similar study by Taylor and Seltzer (2010). Findings from their study drew attention to the role of mother-child relationships, unmet service needs, and family expectations on long-term outcomes of youths with ASD (Taylor & Seltzer, 2010). Although other considerations were explored, unmet service needs were suggested to be an early marker for poor long-term outcomes. Youths with no transition plans and negative family processes were at a higher risk of becoming unemployed adults with no vocational activities (Taylor & Seltzer, 2010). Again, these studies explored the possibility of predicting the long-term outcomes of young people with ASD by considering several facets of their growth course (Taylor & Seltzer, 2010).

In a similar study, Navot et al. (2017) explored the effect of gender in mothers' maternal experiences raising teenage girls with ASD. Conclusions from their study suggested the impact of gender and the environment on future outcomes of individuals with ASD (Navot et al., 2017). Most study participants believed that the male counterparts have a better social life outside of their homes than females as more males are diagnosed with ASD than females (Navot et al., 2017). These mothers also suggested that the male counterparts can turn their fixations into a money-making careers like gaming and information technology programming. In contrast, the females do not have those skills and resort to cashier jobs in grocery stores (Navot et al., 2017). On the other hand, in a similar study, male youths with autism reported trying to make friends with female classmates and neighbors, although parents warned them not to come close to their female children (Zamora et al., 2014). Zamora et al. (2014) identified the environment as another variable in their study on the challenges of transitioning to adulthood but added the term supportively. In assessing the future outcomes of their study participants with ASD, Zamora et al. suggested that establishing social relationships outside of their supportive environment seemed like the most challenging aspect of adulthood for these youths. Here, a supportive environment is the people and resources that aid executive functioning as adults in the community (Zamora et al., 2014).

Although gender differences and the existing environment were found to impact long-term outcomes, Taylor et al. (2017) suggested by training parents on these subject matters, parents were more prepared to face the outside world and less vulnerable to their social environments. In their study on advocacy training for adult disability services, Taylor et al. (2017) concluded by training parents on when and how to advocate for adult disability services, parents felt more comfortable, in charge, and empowered confronting adulthood transition (Taylor et al., 2017). Initial exposure to these training on adult disability services cannot be overemphasized as most government-funded resources like Medicaid and school-based services often end at the transition stage (Shea et al., 2018). Knowing this, they examined the Volunteer Advocacy Program as a school-based intervention for transitions and found it relevant in mentally preparing parents for what lies ahead (Taylor et al., 2017). Similarly, Circle of Security intervention (COS), another parent training technique, was evaluated by Fardoulys and Coyne (2016) in their study that considered relational and communication issues synonymous with autism. COS is an attachment-based parenting intervention that promotes safe parent–child relationships and effective parent–child communication (Fardoulys & Coyne, 2016). Given that communication challenges and impaired social skills are significant autism defects, Fardoulys and Coyne found COS potentially helpful to parents in learning how to communicate better with their children at all life stages. In thinking and preparing for the various stages of life, some parents adopt a strengths-and needs-based perspective, in which they focus on what their children can do, rather than dwell on what they cannot do (King et al., 2005). By focusing on the strengths and needs-based perspectives, parents ignore gender differences, the social environment, and transition training programs and embrace the peculiarity of their children's strengths and needs as determining factors in planning for the future (King et al., 2005).

Current Research

Recent studies on adolescents with ASD recognize the need for early conversations on adulthood transitions considering life satisfaction and projected quality of life for both parents and children begins with intentionality (Franke et al., 2018). Several studies on young adults and school-age children with ASD are beginning to explore and evaluate available daytime activities that instill functional skills for independent living and self-efficacy (Knuppel et al., 2019). Three years ago, Ireland et al. (2017) embarked on a pilot study that evaluated available social skill interventions in preparation for employment for young adults with ASD and intellectual disabilities. Findings from their research emphasized the need for early introduction of vocational rehabilitation programs that promote positive employment outcomes and generalized long-term outcomes (Walsh et al., 2017). In the same year, Wertalik and Kubina (2017) analyzed the effectiveness of the latest procedures used in modeling daily living skills for adolescents transitioning to adulthood. Findings from their study, which was synonymous with the Walsh Hollaway and Lydon's study, affirmed the need for early conversations on daily living skills in the autism population.

Furthermore, other studies on young adults with ASD are taking progressive steps to explore daytime activities and employment opportunities irrespective of levels of functioning (Knuppel et al., 2019). In a nationwide survey in Denmark, Knuppel et al. (2019) reported that one fifth of the sample size existed with no daytime activities. In the autism population, the frequency of young adults graduating from high school with no forethought daytime activity is typical because the perceived quality of life is embedded in providing housing and a safe environment (Franke et al., 2018). Current reports on unemployment found that young adults with ASD, 2 years after high school graduation, are at a higher risk of being unemployed than their peers with other disabilities (Rosales & Whitlow, 2018). With young adults waking up each day with little or no daytime activities, the Knuppel et al. (2019) study aimed to compare the present functioning of groups of young adults with or without daytime activities diagnosed with ASD in childhood. Conclusions from their study suggested that young adults with daytime activities like vocational programs and part-time jobs had the highest adaptive behavior level (Knuppel et al., 2019).

As daytime activities promote adaptive functioning, Rosales and Whitlow (2018) evaluated job interview training for young adults with ASD. Findings from their study suggested the need for improved cognitive processes to reduce distressing symptoms like anxiety and depression that interfere with employment opportunities (Rosales & Whitlow, 2018). Hence, early conversations on transitioning to adulthood, adult life, and long-term planning are needed. In light of these findings and hopes of furthering the research on long-term outcomes of young adults with ASD, this research explored parents' thought processes when considering or planning for their children's adult lives with ASD. Regardless of what route parents choose to undertake in embracing their autism journeys, the overarching theme in any consideration or conclusive decision is the thought process. The thought process, the exercise of using the mind to consider a phenomenon carefully, is the driving force behind most human decisions (Jou & Wang, 2015).

To gain in-depth insight into this phenomenon, the researcher proposes a qualitative study in a phenomenological framework that explores parents', and legal guardians' lived experiences raising adolescents with ASD. The broad question in this phenomenological study seeks to answer the question, "What are the thought-processes of parents in their lived experiences raising children with ASD?" The thought process is the underlying cognitive activity behind parents' considerations on life satisfaction and projected quality of life for their children (Franke et al., 2018). The proposed research evaluates the qualitative components of mental activities that become operational when parents consider their children's long-term outcomes. Instincts, generalization, logic, critical thinking, creativity, and judgment are some mental activities that stimulate human reasoning (Lee & Shivers, 2018). Other quantitative components like gender, socioeconomic status of parents, and the severity of autism impairments will also be considered, as these factors are known to influence parents' judgment when considering long-term plans. This qualitative research, which is different from others, promised to explore the many factors that play multiple roles in parents' considerations in the years leading to adulthood.

Rationale

In recent years, the growing number of children diagnosed with ASD have triggered an increased concern amongst family members left with limited research on the long-term prognosis of their loved ones with ASD (Baio, 2014). With the yearly increase in prevalence rates of ASD, researchers have focused on defining times in the lifespan of individuals with ASD. The early years and the transition to adulthood are two of the most frequently studied phenomena (Howlin et al., 2004). There are several studies on childhood autism and parental reactions in the early years (Poslawsky et al., 2013). More studies on young children with ASD have explored parent training and intervention resources to manage and develop functional skill sets (Raulston, 2018). Others have examined ASD impairments and emerging comorbid conditions in young children (Dovgan & Mazurek, 2019). The relevance of these early years studies cannot be undermined, considering the prevalence rate of ASD continues to rise (Baio, 2014).

Furthermore, as a life-changing experience, receiving an ASD diagnosis is one of the many defining moments of parenting a child with ASD as their transition to adulthood is of equal importance as the diagnosis (Woodman et al., 2014). With the growing rate of ASD diagnosis and adulthood being the most prolonged duration of lifespan, adults with ASD will consist of a significant amount of humanity (Woodman et al., 2014). Outcome studies on adults with ASD are not encouraging. Two thirds of adults with ASD were categorized as dependent adults living in care homes, parents' homes, or other assisted living establishments (Chamak & Bonniau, 2015). Parents and siblings are left with no other choice than to remain significant advocates in the lifespan of their loved ones with ASD (Noonan et al., 2018). However, with several studies focused on defining times in their lifespan and limited studies on trajectories to these defining times, it is apparent that these defining moments are informed by parents' lived experiences (Cheak-Zamora et al., 2015).

Knowing this, Chamak and Bonniau (2015) explored the family experiences of adults with ASD in a trajectory study with a goal aimed at retracing their journey from the ASD diagnosis to the defining moments that predicted long-term outcomes. Findings from their study illustrated challenges parents encountered from the initial ASD diagnosis to the years leading to adulthood (Chamak & Bonniau, 2015). With a minimal emphasis on how parents mentally processed these challenges and moved on to the next, the Chamak and Bonniau (2015) study was one of the few trajectory studies that considered the pathway to adulthood but left out parents' thought-processes in these trajectories. Because parents assume a lifetime role of advocacy for their children with ASD, the need to understand the logical choices behind their decisions cannot be overemphasized as these parents are confronted with emerging challenges in their everyday lives. Given this, the current study sought to understand parents' and guardians' lived experiences when considering the adult life outcomes of their children with ASD. Furthermore, the following subordinate research questions addressed some potential qualitative and quantitative factors parents consider in making future plans:

1. How does your child's current functioning impact your thought process when thinking and planning their adult life?
2. How does your child's gender influence your parental experiences when considering adulthood outcomes?
3. In your parenting experience, were there faith, cultural and personal values that influence your thoughts when considering future plans?

Chapter 2

Philosophical Worldview

Phenomenology is a philosophical perspective and a qualitative methodology approach that studies people and how they understand and interpret the world around them (Ellis, 2016). As a school of thought that highlights first-person experiences, phenomenology was created to substitute for the empirically based positivist philosophy (Lambert & Lambert, 2010). Some have considered phenomenology a joint product of more than one related but different philosopher (Hopkins et al., 2016). Others view phenomenology as an emerging yet progressive philosophical stance (Hopkins et al., 2016). Despite the philosophical pluralities, the study of experiences and attitude adaptation are commonalities among all phenomenologists (Hopkins et al., 2016). Hence, exploring lived experiences is the aim of every phenomenologist embarking on a phenomenology study. The philosophical worldview of phenomenology is not founded on problem solving but by understanding a given issue by giving voices to those who have lived through it to narrate their experiences (Hopkins et al., 2016). The second commonality in phenomenology is the obligation to adopt a phenomenological attitude. Although not relevant to this dissertation, the adaptation of a phenomenological attitude considers the concept of time in relation to everyday experiences (Hopkins et al., 2016). The difference between this philosophical perspective and other qualitative research perspectives is that other qualitative research approaches are focused on broader theoretical agendas, but phenomenology centers on understanding the phenomenon as an objective experience (Wilding & Whiteford, 2005).

Purpose Overview

Recent studies on the autism population have shown only about 17% of children diagnosed with autism spectrum disorder (ASD) will live independent adult lives (Heasley, 2013). For most parents of children with ASD, predicting the possibility of their child living an independent adult life presents unique challenges due to the broad spectrum of cognitive, language, social and behavioral functioning correlated with ASD (Howlin et al., 2004). Several follow-up studies and comparative studies on children and adults with ASD have explored long-term prognosis with inconclusive findings as the variability of ASD impairments differs from one individual to another (Howlin et al., 2004). As parents embrace this reality, some begin to make plans for their children's transition to adulthood, and other parents may choose to leave the future in the hands of fate (Chamak & Bonniau, 2015). Whatever route these parents take, the truth remains that their choices are fueled by the thought process embedded in the uniqueness of raising a child with ASD, which can be very challenging.

However, as challenging as this can be, parents embrace the uniqueness of their parenting journeys, which are frequently influenced by multiple factors such as the environment, accessibility of resources, core values, culture, belief systems, religion, and socioeconomic status. To understand how some or all of these factors influenced parents' thought processes when considering the long-term prognosis of their children's adult lives, this research explored rich descriptions of their lived experiences raising a child with ASD. Given this focus, this research considered the qualitative components of lived experiences like motivation, regrets, lessons learned, core values, perception, belief systems, intentions, culture, expectations, and resolutions. In addition to some quantitative components like age, gender, socioeconomic status, and severity of autism impairments as factors that influence the thought process in adult life planning. Unlike most trajectory studies on long-term outcomes, this qualitative research examined the cognitive processes impacted by the many factors that play multiple roles in the years leading to adulthood transition. In light of this, this research aimed to understand the psychological reasoning behind plans made by parents for their children with ASD.

Research Questions

This dissertation explored the thought and planning process involved in preparation for adulthood by parents and guardians of adolescents with ASD. Hence, the research question was, what are parents' and legal guardians' lived experiences when considering the long-term outcomes of their children with autism spectrum disorder?

Other subquestions emanating from this research question were:

1. How does your child's current functioning impact your thought process when thinking and planning their adult life?
2. How does your child's gender influence your parental experiences when considering adulthood outcomes?
3. In your parenting experience, were there faith, cultural and personal values that influence your thoughts when considering plans?

Research Design

The research design of the current study was founded on the framework of methods and techniques chosen by the researcher.

Population and Sample

The population and sampling of study participants were derived from a purposive framework. Purposive sampling is a technique in which the researcher chooses a sample group that best represents the population studied (Peoples, 2019).

Recruitment. With a combination of purposive and snowballing sampling, participants were recruited from three different sources. First, the initial study participants were recruited using purposive sampling that targeted a diverse group of parents and guardians of children with ASD in a special education school. These study participants, which made up the first four participants, originated from a Seattle-based all-inclusive K–12 private school. Before the current study, the researcher had an existing relationship with the school as a parent of a former student. Study participants were recruited via an introductory letter about the study emailed to all parents on the parent-support platform. Using snowballing sampling, the researcher recruited additional participants with the help of existing participants who recommended other parents who met the study's inclusion criteria. The researcher emailed an introductory letter to referred parents, after which those that indicated interest were recruited (see Appendices C and D).

Participants. Synonymous with studies of this nature, the current sample group was derived from the autism community in the greater Seattle area and an additional participant from Ireland. As an inclusion criterion, all participants are parents of adolescents with ASD, who have maintained the parent/parents' role from the initial ASD diagnosis. All participants received a formal ASD diagnosis in the early years of their children's lives.

Sampling. Initial study participants were derived from a purposive framework. Purposive sampling is a technique in which the researcher chooses a sample group that best represents the population studied (Peoples, 2019). However, considering the researcher was open to receiving referrals for potential participants from the initial participants, additional participants were recruited using snowballing sampling. Hence, the primary sampling technique was a combination of purposive and snowball sampling.

Sample Size. A sample size of six to 10 participants was the projected number of participants to yield data saturation at the data analysis stage. However, with data saturation as an overarching goal, the exact number of study participants was determined by the saturation point at the data analysis stage.

Criteria. As an inclusion criterion for this study, each participant self-identified with all of the following criteria:

- A parent or legal guardian to one or more adolescents with ASD
- Maintained the parent or legal guardian role from the initial ASD diagnosis to the time of the interview
- The adolescent or adolescents must be between ages 10 and 19
- The adolescent or adolescents must have a formal ASD diagnosis from toddler years

The following criteria were not considered while recruiting participants:

- Gender of the parent/legal guardian
- Race of the parent/legal guardian

However, as diversity in study participants increases study representation of different identities, the researcher included parents/legal guardians from different demographics and culture. In addition to variations in demographics and cultural background, the researcher included one participant in another geographic location outside of the greater Seattle area and the United States.

Furthermore, other selection criteria that were considered to increase the generalization of research findings included:

- Variation in the gender of the adolescent or adolescents
- Socioeconomic status of the parent/legal guardian
- The severity of ASD impairments of the adolescent/adolescents or current level of functioning

Research Design and Methodology

To answer the above research questions, the researcher used the phenomenological framework of Heidegger. A phenomenological framework is a qualitative methodology that examines consciousness patterns experienced from the first-person perspective (Lambert & Lambert, 2010). This phenomenological research design unveiled an in-depth understanding of parents' lived experiences from the initial ASD diagnosis to explore the thought process in planning for adulthood. By asking parents who have lived through the various stages of acceptance and resolution of their experiences, it evoked meaning in comprehending their parenting journeys' uniqueness. With this in mind, rather than generalize or categorize parents' lived experiences by using other phenomenological research frameworks, Heidegger's phenomenological framework was preferred because it considers the relationship between human beings and the world we live in (Hopkins et al., 2017). The overarching concept in Heidegger's research approach is the need to understand a phenomenon rather than describe it (Lambert & Lambert, 2010). This research approach also considered analyzing and interpreting lived experiences by recognizing that every human experience can be interpreted (Heidegger, 1988). Precisely, an experience is a product of what has happened, and the interpretation an individual puts on that experience distinguishes one experience from another (Ellis, 2016).

Furthermore, the fundamental constructs of Heidegger's research approach are founded on the researcher exploring the meanings in people's experiences within the context of our world (Ellis, 2016). The concept of being, which is being-in-time is a major concept in Heidegger's research approach that separates it from other phenomenological research designs, as being-in-time refers to our existence within that world (Lambert & Lambert, 2010). In other words, a researcher will not and cannot understand a phenomenon solely from an objective position

(Lambert & Lambert, 2010). Undoubtedly, our reality is constructed from our experiences within that world. Considering the researcher is raising a child with ASD, no better research approach allows for personal biases other than Heidegger's phenomenological framework. However, to control personal bias from interrupting test validity, the researcher explicitly noted any personal bias on related topics on a different platform. This research approach allows researchers to do so before analyzing data. Considering this research approach recognizes that lived experiences are distinctive interpretations of an individual's experiences with a phenomenon, the data collection strategy was founded on first-person accounts of parents of adolescents with ASD. With one-on-one interviews, the study participants shared their experiences from their lenses through open-ended questions presented to them (Lambert & Lambert, 2010).

Instrumentation

The researcher used the following research instruments at different stages of this dissertation process to discover descriptive findings as combining all five instruments sufficiently answered the research questions.

Semistructured Interviews

Considered the sole data source for most qualitative research, semistructured interviews raise broad questions followed by probes for more clarification (see Appendix A; Brod et al., 2009). In choosing to use semistructured in-depth interviews, the researcher considered the qualitative nature of this dissertation and semistructured interviews as the traditionally used interviewing platform for qualitative research (DiCicco-Bloom & Crabtree, 2006). The researcher further considered the benefits of semistructured interviews in allowing participants to share detailed descriptions of their individual experiences raising their children with ASD. In addition to the above two considerations, semistructured in-depth interviews allowed the researcher to delve deeper into the meanings lived experiences hold for each participant (DiCicco-Bloom & Crabtree, 2006).

Follow-up Interviews

Follow-up interviews addressed any descriptions in the initial individual interview that needed further clarity and conclusions. The use of follow-up interviews assumes that some participants may forget or leave out essential details in their responses to research questions or display limited vocabulary and short explanations (Peoples, 2019). Individual follow-up interviews allowed the researcher to clarify preliminary information and collect additional data from enriching study findings.

Field Notes

Field notes are vital instruments in qualitative research as they provide observational and reference platforms that aid the validity of findings (Brod et al., 2009). During interviews, the researcher employed field notes to note detailed and accurate observational contents like behaviors, body language, activities, comments, and other observational features. Field notes served as reference points at the data interpretation and analysis stage.

Journaling

Describing the researcher's biases in the dissertation or a separate journal prior to data analysis is a concept of the Heideggerian framework (Peoples, 2019). With this in mind, the researcher explicitly noted any preconceived notion or biases related to the studied phenomenon. Besides being a reference platform, journaling also served as an additional instrument for validity and reliability. Journaling as an additional instrument for measuring the validity and reliability of data is discussed further in a later section.

Video Recording

Ideally, most qualitative interviews are in-person as in-person contact may enable relationship building and increase the richness of research findings (DiCicco-Bloom & Crabtree, 2006). However, with the COVID-19 global pandemic, the researcher used the Microsoft Teams platform closest to an in-person interview session. Both audio and video recordings are geared toward producing verbatim responses and eliminating distractions at the data collection stage (DiCicco-Bloom & Crabtree, 2006). The permission to video record each session was included in the informed consent (see Appendix B), and further discussion on video recording was also included in the data collection section.

Data Collection Process and Procedures

With approval from the institutional review board in place, the researcher combined purposive and snowball sampling by contacting coparents at the ABC school. The researcher introduced her dissertation in the parents' email group. As a former coparent, the researcher needed no formal introduction, aside from introducing her dissertation and inviting interested participants to respond to the email. Based on responses, interested participants who met the inclusion criteria were emailed a link to the informed consent which described the study. Participants read and signed the consent forms and confirmed their voluntary participation. To fully understand the current research and what participation entailed, participants had the right to ask further questions about the data collection process. Similar to ABC school plan, the researcher posted an invite on two Facebook platforms for parents with ASD children. Synonymous with all purposive sampling, members of both SCSN (a Facebook group) and Raising Autistic Kids of Washington best represented the study population because most of the members were raising children with ASD. The researcher asked all interested participants to leave a private message with their email addresses on Facebook messenger. Based on the inclusion criteria and with an email address at hand, the link to the informed consent was sent to interested members of the group. A combination of purposive and snowball sampling was used as interested participants referred the researcher to potential participants, and referred participants were contacted via emails.

The COVID-19 global pandemic and the need for social distancing increased the need for virtual meetings, of which one-on-one-interviews are not excluded. Given the risk of meeting in person and considering other precautionary steps, all interviews were virtually done on Microsoft Teams. Microsoft Teams is a collaboration and communication software designed to integrate video meetings, communication chats, and file storage. With present changes to telehealth requirements, Microsoft Teams has become a telehealth and HIPPA compliant platform in view that all security features must be in place to protect users. With Microsoft Teams, the researcher successfully recorded all sessions and generated transcripts for all recorded interviews. All interview sessions were conducted one-on-one using open-ended questions that addressed the research questions. With a time duration of 45 minutes to 60 minutes for each interview session, all participants had an equal amount of time to respond to the research questions. Participants' confidentiality was identified with a code that accurately represented the participant (example: A, B, C, D, E, and F). Field notes were used at all interview sessions and as a reference platform while analyzing data to keep track of observations and reflections. The data collection process began 4 weeks post institutional review board approval. At the end of the data collection process, interview transcripts from Microsoft were transcribed and coded using the ATLAS. ti 22 software.

ATLAS. ti 22 Software

The ATLAS. ti 22 coding software, a qualitative data analysis tool, was the predominant analysis tool used in the current study. The ATLAS. ti software enables researchers to analyze qualitative data in transparent and organizational format (Friese, 2019). The ATLAS.ti 22 software does not automatically generate codes; instead, it provides researchers with a platform to query collected data, in verbatim transcripts, by assigning codes generated by the researcher through meanings attached to each data segment (Friese, 2019). Furthermore, ATLAS.ti 22 does not analyze generated codes. Instead, it organizes generated codes into groups and themes created by the researcher such that it displays a well-designed visual concept of the researcher's thoughts in a single platform (Barry, 1998). Using the ATLAS.ti 22, the researcher created a well-designed interface for every transcript in a single platform that supported the efficient analysis of emerging themes across all transcripts.

Interpretative Phenomenological Analysis Coding

Interpretative phenomenological analysis (IPA) coding is a data interpretation technique informed by the principles of phenomenology, hermeneutics, and ideography (Smith et al., 2009). IPA coding centers on pulling out themes on how participants make sense of their personal and social experiences within the research phenomenon (Mackie et al., 2021). Coding in IPA entails several levels; the first level involves identifying and writing down the initial analytic observations about the data on an analytic diary. At this level, which is also considered the open or accessible coding stage, the researcher developed themes based on her initial analytic observations of the data or transcripts (Smith, 2007). At the second level, the researcher, on a line-by-line basis, identified objects of concern, relationships, concepts, events, and processes that mattered to each participant. The contextual meanings of identified objects were grouped into principal codes and subordinate codes. At the third level, the researcher discussed and evaluated the groups in supervision meetings with members of her dissertation team. At this level, the researcher reorganized code groups based on their relevance to the research questions and identified overlapping themes, and further condensed them under more significant themes. For example, codes for “finding a good fit for educational and vocational advancement” were categorized under the theme “services and support” and further condensed into a more significant theme, “parenting challenges.” The outcome of these levels of coding, reevaluation, and reorganizing is to depict the conceptual analysis of all aspects of the raw data by developing them into categories of emerging themes. Informed by the purpose of this research, which was to understand the psychological reasoning behind adulthood plans made by parents for their children ASD, the researcher brought to light the unique experiences and perspectives of each participant in the narratives in Chapter 3.

Credibility, Validity, and Reliability

To address any threats to the credibility, validity, and reliability of study findings, the researcher explained the researcher’s bias and detailed descriptions in a research journal. These two practical phenomenological framework procedures assure validity in qualitative dissertations.

Explanation of the Researcher’s Bias

The Heideggerian framework, the phenomenological research design chosen for this dissertation, considers the researcher’s bias or prior understanding of the phenomenon (Peoples, 2020). Also known as preconceptions, the researcher’s bias is assumed to be present in all Heideggerian research designs because appropriately incorporating the researcher’s prior biases is valuable in the data analysis process (Peoples, 2020). However, for validity and reliability assurance purposes, all personal biases or judgments must be explicitly declared on the dissertation or by journaling about them before analyzing collected data. The researcher used the journaling platform to address all personal bias or preconceptions on various topics by tracking revisions in her thoughts on related topics. Field notes and descriptive journals eliminated any overshadowing of personal bias as all phenomenological studies' credibility depends on the end goal, discoveries (Peoples, 2020).

Supporting Study Reliability and Validity

To support the reliability and validity of the current study, the researcher used the following statistical measures.

Credibility and Flexibility. The researcher has had extensive experience in the ASD community professionally and personally. The researcher is currently raising an adolescent son with ASD and has, over the years, worked and interacted with parents and guardians of children with ASD at different ages, from different racial backgrounds. The researcher completed contracted clinical training at a neurological assessment clinic as a requirement for a doctoral degree. The researcher's present contract for a doctoral internship at a community mental health clinic has included individual, family, and couples' therapy. Some of the researcher's clients have been individuals and parents of children with ASD. The researcher has also provided voluntary services at several autism-related settings such as developmental preschools, nonprofit foundations for autism awareness in Nigeria, and online parent support groups for autism and related disorders.

Peer Debriefing. Debriefing, which originated in the military, describes the narrative account of individuals exposed to the same event (Fanning & Gaba, 2007). Peer debriefing in qualitative research is used to establish the data analysis procedure. Peer debriefing, if executed accurately, improves the credibility and quality of the research by uncovering the researcher's errors and biases (Fanning & Guba, 2007). Peer debriefing for this study involved the researcher meeting with another impartial colleague to critically review and provide feedback on the methodological activities implemented by the researcher. The researcher provided a colleague with two versions of transcripts generated from Participant E, bare and coded, for critical review.

Intra-rater Reliability. To verify the consistency of the coding technique using interpretative phenomenological analysis (IPA), the researcher adopted the test retest correlation procedure by recoding one transcript twice at a 2-month interval. This type of reliability assessment is known as intra-rater reliability. It entitles repeated assessment of one or more diagnostic tests, sampling units, or transcripts by a single rater (Nutter et al., 1993). Determining the reliability of the coding technique used in generating the emerging themes in this research was informed by research on intra-rater testing as a valuable assessment tool that affirms the consistency or inconsistency of a rater testing technique (Vance et al., 2020). Knowing this, the researcher randomly selected the transcript of Participant C, which was different from the peer debriefed transcript and recoded the transcript using the same IPA coding style as was initially coded. A sample of the statistical index for Transcript C is found in the data analysis section in Chapter 3.

Data Triangulation. Multiple data sources are essential to guarantee external validity (Carter et al., 2014). The researcher used multiple participants and methods such as video recordings of interviews, verbatim transcripts, and field notes to promote data triangulation across all data sources. The researcher obtained a widened and more accurate view of the research topic by comparing themes and patterns of highly similar existing research. Furthermore, when needed, the researcher referenced notes on behavioral observations, personal journals, and field notes as additional support instruments for emerging themes generated from the transcripts (Brod et al., 2009).

Protection of Human Subjects

Due to the sensitive nature of the research question, “What are parents’ and guardians’ lived experiences when considering the adult lives of their children with autism spectrum disorder?" the researcher anticipated possible emotional challenges with participants, who may be subjected to the thought of narrating their stories by participating in this dissertation. Behind the emotional challenges lie the psychological stress of discussing their child's future and some pending adjustments, which could lead to feelings of anxiety, worry, shame, or embarrassment. Considering that some parents may never have openly discussed this topic, the interviews could be a reality check that may or may not be needed at the time. However, although participants' vulnerability fueled the authenticity of data collection in discussing sensitive topics, the researcher recognized this in the research procedures.

To protect participants from these risks, the researcher:

- Included participants' right to end the interview, the right to rephrase a question, and the right to skip a question in the informed consent
- Ensured data privacy and security by using self-generated identification codes representing data from every respondent without identifying information linked to the data

To protect participants from any adverse emotional events related to their participation in this study, the researcher included the following information in the informed consent: 24-hour Crisis Response Hotline (1866-427-4747), Psychology Today (1-800-234-8361), and Psychology Today's website (www.psychologytoday.com). These steps gave participants the leverage to protect themselves from any emotional risk from the interviews.

Furthermore, to lessen the risk associated with the sensitivity of some research questions, the researcher chose an alternative procedure that did not include the subjects of the conversation, the children. Earlier, the researcher considered including participants' children while interviewing their parents or guardians because of the need for more than one perspective. After considering the risk of discussing this topic, as some families may never have openly discussed it with their children, the researcher decided to interview only the parents, as the latter procedure will lessen possible emotional risks.

Record Keeping

To ensure optimum confidentiality from the start of this study:

- All participants were assigned an identification number that replaced their names throughout the interview.
- Participants were asked not to divulge any identifying information during the recorded interview. Identifying information like a child's name was deleted from participants' transcripts who inadvertently offered their child's name or other identifying information.
- Included in the informed consent, each participant had the right to stop the interview at any time.
- The recorded responses were downloaded on a password-protected file on a secure Google drive created for this study at the end of each interview.
- Original recordings were destroyed after the download.
- Access and viewing of the downloaded files were given to the researcher and the faculty sponsor.
- All recordings were transcribed, and the transcription files were saved on a password-protected Google drive account.
- Filed notes were stored in a password-protected cabinet at the researcher's home.
- The researcher had exclusive access to the field notes, which could be granted to the dissertation chair if needed. Furthermore, signed consent forms were given to the

dissertation chair, and access to the consent forms could only be granted to the researcher, faculty sponsor, and authorized personnel.

Data collected from participants were only for this dissertation, including the write-up, dissertation defense, and possible future publication of an article or book. Lastly, consistent with the phenomenological framework, which is based on a first-person perspective, this dissertation did not involve access to participants' files, deception, and any formal testing.

Summary

To gain a comprehensive understanding of parents' remarkable lived experiences with raising their children with ASD, the current research interviewed parents of students at a local all-inclusive K–12 school in Washington state. Founded on the Heideggerian phenomenological framework, the researcher acknowledges the researcher's perspectives, assumptions, and personal bias from parenting her child with ASD, and efforts are accounted for in a separate journal. These factors were detailed to reduce or eliminate their impact on data reliability and validity. Participation in this study was entirely optional, and study participants' responses guided the contents of the study outcomes. Lastly, study participants who volunteered to lend their thoughts and share their stories affirmed the desire to contribute to autism research. In addition to contributing to the autism community, study participants affirmed gaining personal insights into themselves by reflecting on their journeys and acknowledging their unique parenting experience.

Chapter 3

Results

Using Heidegger's phenomenological framework, this study explored the lived experiences of parents raising children diagnosed with autism spectrum disorder (ASD). The catalyst for this research was the recognition of deficiencies in previous research on parents with ASD children, and the minimal credit on parents' thought processes years leading to adulthood. Considering the unique presentations of ASD in every individual diagnosed with ASD, this research framework examined the consciousness patterns as experienced from the first-person perspective (Lambert & Lambert, 2010). To explore the thought process in planning for adulthood and adulthood transitions, this phenomenological research unveiled an in-depth understanding of parents' lived experiences from the initial ASD diagnosis to the present day. In comprehending the uniqueness of their parenting journeys, these parents shared their lived experiences and the various stages of acceptance, denials, resolutions, and realistic expectations with hopes that their stories would bring to light the internal and external factors that influenced their thought processes. Accessibility of resources, the environment, parents' core values, culture, socioeconomic status, and the child's level of functioning are a few of the internal and external factors known to influence parents' planning when considering adulthood resources. Given all of these, the current study is guided by this overarching research question: What are parents' and legal guardians' lived experiences when considering the long-term outcomes of their children with autism spectrum disorder?

Furthermore, the subquestions provided meanings for some parts of the research question.

1. How does your child's current functioning impact your thought process when thinking and planning their adult life?

2. How does your child's gender influence your parental experiences when considering adulthood outcomes?
3. In your parenting experience, were there faith, cultural and personal values that influence your thoughts when considering future plans?

This chapter confers the findings that emerged from data collected from six participants in Washington state in the United States and in the United Kingdom. The interview protocol that directed the individual interviews with each participant provided an opportunity for participants to think through their lived experiences and convey them in their own words. Each interview was conducted one-on-one via a computer-based software application (i.e., Microsoft teams) and video recorded.

Description of Participants

As an inclusion criterion for this study, all participants self-identified as parents of adolescents with a formal diagnosis of ASD from toddler years. Interested participants with children outside of the adolescent age (10 and 19) were excluded, and parents that did not play the parent or legal guardian role from the initial ASD diagnosis. The description of the six participants was conveyed to protect the confidentiality and anonymity of each individual. See Table 1 for the characteristic feature of each participant.

Table 1

Description of Participants

Participant	Gender	Race	Gender of child	Current age of child	Age at ASD diagnosis
A	Female	White	Male	16	3
B	Male	Multiracial	Female	14	3
C	Female	White	Female	16	3
D	Female	Black	Male	13	3
E	Female	Asian	Male	16	2
F	Male	White	Male	17	3

Participants A, C, D, and E identified as females, and Participants B and F identified as males. Three participants identified themselves as White, and the other three self-identified as Black, multiracial, and Asian. Five out of the six participants were biological parents of their children, except for Participant B, who adopted his daughter in infancy. In addition to having raised their children from infancy, all participants were legally married or living together in the same household with their children and spouses. Five of the six participants received a formal diagnosis of ASD for their children at age 3, except for Participant E, whose son was diagnosed at age 2 but sought professional help at 18 months. Consistent with the gender disparity in the male to female ratio in ASD diagnosis, with higher number of males diagnosed with ASD than females, four participants were parents of male children, and the remaining two participants had female children. Excluded in the inclusion criteria but essential in the description of participants, there were variations in the following domains: sexual orientations of participants, chronological ages of participants, economic status of participants, children's chronological ages, and children's levels of functioning. These variations provided diverse and rich data to the current study as it increases the possibility of generalizing findings from this study across the ASD community.

Data Analysis

The researcher systematically evaluated collected data by using the following interpretative coding technique**.**

Interpretative Phenomenological Analysis Coding

Interpretative phenomenological analysis (IPA) coding is a data interpretation technique informed by the principles of phenomenology, hermeneutics, and ideography (Smith et al., 2009). IPA coding centers on pulling out themes on how participants make sense of their personal and social experiences within the research phenomenon (Mackie et al., 2021). Coding in IPA entails several levels; the first level involves identifying and writing down the initial analytic observations about the data on an analytic diary. At this level, which is also considered the open or accessible coding stage, the researcher developed themes based on her initial analytic observations of the data or transcripts (Smith, 2007). At the second level, the researcher, on a line-by-line basis, identified objects of concern, relationships, concepts, events, and processes that mattered to each participant. The contextual meanings of identified objects were grouped into principal codes and subordinate codes. At the third level, the researcher discussed and evaluated the groups in supervision meetings with members of her dissertation team. At this level, the researcher reorganized code groups based on their relevance to the research questions and identified overlapping themes, and further condensed them under more significant themes. For example, codes for “finding a good fit for educational and vocational advancement” were categorized under the theme “services and support” and further condensed into a more significant theme, “parenting challenges.” The outcome of these levels of coding, reevaluation, and reorganizing is to depict the conceptual analysis of all aspects of the raw data by developing them into categories of emerging themes.

Peer Debriefing

The researcher provided a colleague, who had no interest in this research, with two versions of transcripts from Participant E, bare and coded for critical review. The colleague critically reviewed the two versions of Participant E's transcript and provided feedback to the researcher. With the bare transcript, the peer debriefer read through the transcript and noted some possible codes and themes. He went further to review the coded transcript and noted some over emphasized coded lines like the following code names: neurotypical tendency, intentional transition plans, finding a good fit for support services, and using available resources. He noted the following under emphasized points: security and safety, culture, the early years and involving siblings. Based on his notes from the bare and coded transcripts, he discussed his perspective on some under emphasized and over emphasized points with the researcher. The researcher discussed the reasoning behind some of coded lines and code names, processed bias assumptions on these two code names: (a) neurotypical tendency and (b) using available resources. Lastly, the researcher and the debriefer explored reviewing transcripts from other participants and integrating the code names culture, services and support in the coding schema.

Intra Rater Reliability

To verify the consistency of the coding technique using IPA, the researcher adopted the test-retest correlation procedure by recoding Participant C's transcript twice. The researcher transferred the results of the transcripts into an excel spread sheet and conducted a kappa analysis to assess the degree of agreement between the codes in the initial and recoded transcript. The weighted kappa, derived from the kappa analysis, is the statistical value that assigns less weight to agreement if coded categories are dissimilar (Viera & Garrett, 2005). The kappa analysis reported the weighted kappa as .83 with a *p* value (probability value) less than .001. *p* values of less than 0 indicate less than chance agreement, and *p* values between 0.81–0.99 indicate almost perfect agreement (Viera & Garrett, 2005). Therefore, with the weighted kappa at 0.83, which is within the range of almost perfect agreement, it is evident that the researcher established adequate intra rater reliability with consistency in the coding technique.

Emerging Themes

Emerging themes were derived from a combination of the three levels of IPA coding, feedback from peer debriefing, and field notes. Informed by the purpose of this research, which is to understand the psychological reasoning behind adulthood plans made by parents for their children ASD, the researcher brought to light the unique experiences and perspectives of each participant in the following narratives (see Table 2).

Table 2

Coding Schema

Code names	Parents' Lived Experiences	Values, Faith and Culture	Executive Functioning	Adaptive Functioning	Gender – Related Issues
Subordinate theme (1)	The Early Years	Family Values	Cognitive Flexibility	The Conceptual Domain	
Participants	Participant D	Participant D	Participant A	Participant A	Participant C
Quotes	When he turned two, we took him for a well-child visit, and the public health nurse said he wasn't meeting all his	We value togetherness more than our space or freedom. Having him at home gives us peace of mind, which	But in junior high, it suddenly felt like the wheels kind of fell off because the learning	He's also extremely intelligent, like super high IQ, and it's been like this since he was born.	I am not against any gender or sexual identity, I just want her to identify with one,

Code names	Parents' Lived Experiences	Values, Faith and Culture	Executive Functioning	Adaptive Functioning	Gender – Related Issues
	developmental milestones at that age	to us is better than space.	pace is much faster. He just couldn't keep up with the multi-tasking; it was just too much for him		not because others are doing it, but because it's what she sees herself as.
Subordinate Theme (2)	Services and Support	Faith	Comorbid Disorders and Psychiatric Symptoms	The Social Domain	
Participants	Participant B	Participant B	Participant E	Participant C	
Quotes	The constant hurdle in our experiences with raising her is finding a good resource that meets the specific need at the time	We are not religious, so we do not really rely on that in raising our children. We are open to those kinds of stuff if our children choose to follow that route	My son has several disorders and challenges that come with ASD. He did not speak till after he turned ten	It almost feels like others are non-existent, and such behaviors make me worry about college because she will stand out.	

Code names	Parents' Lived Experiences	Values, Faith and Culture	Executive Functioning	Adaptive Functioning	Gender – Related Issues
Subordinate Theme (3)	Realistic and Unrealistic Expectations	Cultural Diversity and Flexibility		The Practical Domain	
Participants	Participant F	Participant E		Participant F	
Quotes	I just want him to succeed in life, and I wrestle with the idea of what is realistic and unrealistic at this age	In the Sikh religion, we do not trim our hair, and that alone makes him stand out. He is not White, and even if he were from a different race other than an Asian, he looks so different with his patka turban on his head.		I am happy to help him or remind him, but what happens when he goes off to college?	

Theme 1: Parents' Lived Experiences

The Early Years. The overarching research question is founded on lived experiences of parents raising children with ASD, and in sharing their lived experiences, every participant went back to their experiences in the early years of their child's life. All six participants shared their lived experiences before the diagnosis and the role parental instincts played in seeking an evaluation for their children. Both participants A and D were not overly concerned about their son's development before their ASD diagnosis, but the similarities between their lived experiences ended at this stage. Participant C described her daughter as "Very different, a fuzzy toddler who was so difficult to understand. We couldn't tell what made her happy, everything was a guess, and it is still the same till today." In addition to describing her daughter's behavior in the early years, she acknowledged not being concerned about her behaviors, considering she met most developmental milestones like speech and gross motor skills.

But unlike Participant A, whose son was verbal before the age of 3, Participant D's parental instincts were informed by the lack of communication skills at 3 and half years old. Participant D stated:

> When he turned two, we took him for a well-child visit, and the public health nurse said he wasn't meeting all his developmental milestones at that age. I wasn't too concerned because his older brother was a late taker, but after age 3, and yet no form of communication, I started praying.

In another participant's narrative on life before the ASD diagnosis, Participant F stated, "My son was very active the moment he began walking. His preschool teacher complained about his struggles with sitting through circle times and at mealtimes. It felt like he was constantly on the move." However, he emphasized that getting him diagnosed and enrolling him in occupational therapy helped with his sensory needs, which in turn lessened his hyperactivity.

Participant C's lived experiences before and after the diagnosis was an experience, she noted as "Very confusing." To explain the confusing diagnostic impressions of her daughter's ASD symptoms, she said:

> In the early years, my parents pressured me not to get her evaluated, but that didn't keep stop me freedom seeking evaluation. She got thrown out of preschool twice because she went under the table and wouldn't move, and in the second preschool, she refused to move from one activity to another. We've been seeking various diagnostic specialists since she

> was a year and a half. Even John Hopkins didn’t catch it. Well, with females, it’s harder, especially when they are meeting all their milestones.

Similar to Participant C’s experiences with female children and the misdiagnosing that comes with meeting developmental milestones amid autism traits, Participant B described his daughter’s early years, saying, “We adopted my daughter as a toddler, but from the moment she came home, we knew she was different from our son.” He went on to share their experiences with multiple providers who felt his daughter’s behaviors were more environmental than developmental, considering she transitioned from an unstable to a stable environment. In an opposite narrative, Participant E described her son’s autism traits as “Quite evident from an early age.” According to her, “He did everything late. He was almost two when he started walking, and it took him forever to eat solid food. He had little to no eye contact, and he was so unaware of his environment.” She described these developmental challenges as the catalyst that initiated a developmental assessment. She affirmed the unexpectedness that came with the diagnosis by saying, “Although we knew he was delayed on different developmental markers, an autism diagnosis was a far reach.” In all six narratives on early years, the children of Participants B and C were misdiagnosed at the early years, thereby receiving a later autism diagnosis. However, the commonality in their lived experiences pre and post autism diagnosis was their parental instincts about their child not meeting developmental and childhood expectations.

Services and Support. Repeatedly, the exploration of services and support was a familiar narrative in the lived experiences of all six participants, whose search for services dates to the early years. All through the interview process, participants made multiple references to finding available services and support for their children in responding to various research questions. Participant A described leaving the public school for a private that supported her son’s adaptive needs. To describe this experience she said, “And then we got to his current school, suddenly everything just clicked. It was the perfect environment for him in a lot of ways, except for challenging him academically, but we are fine with that.” Participant B stated, “The constant hurdle in our experiences with raising her is finding a good resource that meets the specific need \at the time. You know her needs change as she grows, so it’s a hurdle to try out schools and providers.” In the same vein, Participant C shared her experiences, saying, “We are working with DVR. Learning through the parent group, and I’m trying really hard to apply them in my interactions with her.”

Furthermore, Participant D shared her experiences with navigating intervention resources in a county different from the United States. She said, “Here in Ireland, our case manager from the department of health-connected us with a behavior specialist. When my son was younger, she came to our house twice a week, but she stopped coming after he started school.” In addition to using government-based resources, she has explored other private resources outside of government funding on her own. In explaining this, she said:

> You know I cannot fold my hands and watch my son regress, so I joined several Facebook support groups for parents with ASD, and I have learned so much from there. We have tried working with a nutritionist, we see an autism doctor for nutritional supplements, and we have also gone to Mexico for stem cell treatments. I knew about these resources from the Facebook groups.

In a similar narrative on using social media as a support system, Participants E and F referenced Facebook as a support platform. But similar to Participant D, who used personal funds outside of government resources, Participant E depended on self-funding for behavior, speech, and vocational therapies. In explaining this, she said, “Many years ago, there was very little health insurance coverage for behavior interventions. We basically had to pay for almost every service, including enrolling him in a private school. It’s been an expensive journey for us.” Furthermore, Participant F also referenced Facebook as a support platform. He shared a particular experience saying:

> The last couple weeks have been very challenging. About a week ago, I shared on my Facebook page that I need to hear from friends and associates who struggled with kids that hated high school and didn’t do very well in it. I got a lot of encouragement and suggestions from people.

Furthermore, he shared his experiences with accessing autism services in New York and Washington state and expressed his thoughts on transitional services. According to him, “I am trying to set him up with the Next Steps program, and after that, we will begin the DVR paperwork.” DVR is the Division of Vocational Rehabilitation, a statewide resource under Department of Social and Health Services that provides employment services and support for adults with disabilities. Participants D and F interchanged services and support with resources, but regardless of their chosen language, the narratives of all six participants on services and support were informed by the individualized needs of their children and family.

Realistic and Unrealistic Expectations. Changing expectations was a dominant theme in parents’ lived experiences. All participants except for Participant D emphasized the term “realistic expectations” when discussing changes in thought processes, plans, and expectations. Participants A, C, and F interchanged realistic expectations with reasonable or unrealistic expectations when discussing similar views. In describing his daughter’s current progress in school, Participant B stated, “It’s like we are still trying to gauge what is realistic here and what isn’t. So I’m not quite sure yet, but I just want her to be happy and safe. It will be interesting to see how things go in the next couple of years, like whether or not college is a realistic expectation.” Still, on the topic of academic progression, Participants A, C, and F described their current expectations, with Participant A stating, “He has strengths in math and science, and at this time, a reasonable expectation will be to prepare him for smaller colleges where there is support for students in the spectrum.” Disclosing her present thoughts on future expectations for her daughter, Participant C said:

> We all have college degrees in my family, and we want her to follow in those footsteps. But I am not sure if she will thrive in a traditional college environment. At this time, a reasonable expectation will be for her to start up in a local community college, and we will continue reevaluating other options.

In a comparable narrative, Participant F expressed his current expectations saying:

> I just want him to succeed in life, and I wrestle with the idea of what is realistic and unrealistic at this age. I expect him to do his best and go to college, but at the same time, I do not want to push him too hard. I am beginning to recognize some unrealistic expectations I had in the past.

However, although Participant E shared the same views with Participant F on unrealistic expectations, she identified the negative outcomes of overreaching expectations. In identifying this, she said:

> I want to have reasonable expectations, something that he can achieve rather than pushing him beyond his abilities. I pushed him beyond his abilities when he was younger, and that went terribly wrong. He developed defiant behaviors as his way of fighting back, and it took me some time to realize it.

In addition to speaking on overreaching expectations, Participant E described reasonable expectations not from an academic standpoint, like other participants, but in the light of her son's current and future adaptive needs. In discussing this, she said:

> We are hoping that, eventually, he can do some things by himself over time. That is a reasonable expectation for him at this time because he needs a lot of motor skill planning and stuff like that. All his caregivers know this, and we are all working together on this.

Theme 2: Values, Faith, and Culture

Family Values. The last subordinate research question explored the influence of faith, culture, and personal values on parents' thought processes when considering future plans. In response to this research question, all participants shared varying family values, which, in some narratives, intentionally or unintentionally influenced parents' thought processes in their parenting journeys. Participant E described her family values at length, which she was struggling to preserve while working with her son's providers and caregivers. In describing her experiences, she said:

> Here in America, the thought process is that the child goes away, out of the house after a certain age, once he crosses a certain teenage age. For us, the values are different, and we've been planning it like he will live with us as long as we are alive. So, when the school connected us with assisted living programs, we never bothered with that resource.

She further added, "I once had a caregiver say 'Don't say never.'" Participant E explained that they planned on having their son at home with them as long as they could. In her words, "We value togetherness more than our space or freedom. Having him at home gives us peace of mind, which to us is better than space." Comparably, Participant D, while speaking on family values, stated:

> We are beginning to have conversations with my older kids about my son. Hard conversations about guardianship and future shared responsibility between them and us, especially when we get older. As a family, we do not believe in leaving things unsaid.

Participant A described their family values as “very American.” She explained that her family values were nothing outside of the typical American family except for their strong emphasis on getting a college degree, which according to her, “Separates us from typical American families where college degrees are entirely optional.” She further added, “Obviously, my husband and I have graduate degrees and work in professional fields. So we put a lot of value on education, which I’m sure he’s absorbed from us, unintentionally, over the years.” Participant F described comparable family values with Participant A on the value of education, except that Participant F expressed flexibility with the thought of his son not getting an advanced degree. In affirming the recent change in his thought process over college plans, he said:

> You know for me, it’s still the traditional route, right? You finish high school, go to college, finish college, and get a job, right? So, it’s really personally very challenging to picture other routes. But at the same time that this was all going on, I began rethinking our values around the traditional route to success.

He further narrated his lived experiences in college and how he would want his only child to experience that as well.

Faith. In this domain, participants shared very little on faith-based influences on their experiences. Participants B and C had similar experiences with growing up in strict religious families but deciding not to carry on with any faith-based values. Participant B shared some traumatic lived experiences that led him to leave the Methodist church when he openly declared his sexual orientation. While narrating his experiences, he said:

> I am gay, so I grew up being told that I am bad. I am awful, I am going to hell, and I am a demon. But it's just who I am. I didn't choose this. Why would I choose this very difficult path when it's a lot easier to conform to the dominant culture?

In describing any faith-related influence on his parenting, he said:

> We are not religious, so we do not really rely on that in raising our children. We are open to those kinds of stuff if our children choose to follow that route. You know, a while ago, she became interested in going to Sunday school with a friend, and we did not object.

However, Participant B went further to share their family values around extreme Christianity, saying:

> To be honest, my husband and I share the same values on the bad connotation with the word Christianity. One time, we looked at what they were studying in youth group, and it felt extreme to us, so we stopped her from attending the youth group.

Unlike Participant B, Participant D grounded most of her parenting experiences on her faith. In her narrative, she shared her initial response to her son's odd behavior as a toddler and how she declined seeking medical-based resources. Instead, she believed her son's behaviors were spiritual, and with that, she sought after faith-based interventions like prayers, fasting, and spiritual deliverance. In sharing this lived experience, she said:

> You know, when my son was young, he behaved very differently from my other kids. We prayed, did lots of praying and fasting, and casting out any demonic attacks on him. Those sorts of things we do as believers. But it felt like the more we prayed, the worse it got. So, the psychologist and his doctor sat me down and told me what it was, and from there, I had to go and read up about autism because I knew nothing.

While sharing her thoughts on the impact of faith on parenting, she said:

> I still believe that God can heal him, but I am not relying only on just prayers. Fasting without doing anything was me in the past, maybe 8 years ago. But these days, I do all of them, I fast, I pray, I try diet changes, medication, everything. I am now open to everything.

Cultural Diversity and Flexibility. The topic of cultural diversity and flexibility resonated a lot with participants whose life experiences depicted seeking acceptance from the dominant culture. While sharing their life experiences with faith, culture, and values, Participants B, E, and F had a lot say on how their search for an accepting and diverse social environment impacted most decisions they made as a family. In affirming the need for his family to live in a diverse community free from judgment and unacceptance, Participant B said, “Settling in MKZ has helped us connect with other families like us. I can imagine how difficult it would have been for us, as two gay parents, if we choose to live in our hometowns.” In expressing how living in Seattle has helped them navigate resources for their daughter, he described how they transferred their daughter from a public school to a private school that seemed more accepting. However, regardless of the ease at which he described the acceptability of same-sex marriages in Seattle, he said:

> People always assume us to be brothers and not parents, or even partners. Sometimes, they will ask either of us, “Where is the mom?” Sadly, some of these encounters happened at parent-teacher conferences, medical and behavioral appointments, and public parks.

Similarly, although Participant F was in a heterosexual relationship, he shared a comparable experience with Participant B, having moved from Upstate OPD to MKZ in search of an environment that pushed for cultural diversity. In describing this experience, he said:

> We were in OPD for a while, and we were there for 20 years. He was born in OPD, but we moved here 3 years ago. Life here is so different. Although the gay and lesbian population in OPD are pretty prominent, the Trans population and the asexual population and all the

> other kinds of identities are not as much as they are in MKZ. We are comfortable being here. It's been such a great opportunity for him to see the rainbow of differences and the rainbow of opportunities, and it's just like being normal.

Furthermore, he acknowledged the move from OPD to MKZ as intentional step toward entirely helping his son experience the beauty of diversity in his daily life.

Contrary to the experiences of Participants B and F on the diverse nature of the social environment in MKZ, Participant E had minimal experiences with diversity in Seattle. While sharing the impact of culture in her parenting experiences, Participant E went a different route from Participants B and F and described her life as an immigrant who practices a religious concept that automatically separates her from others in any given circumstance. Participant E self-identified as a devote Sikhism woman from Indian heritage. In sharing her life experiences with practicing Sikhism and raising her son, she said, "In the Sikh religion, we do not trim our hair, and that alone makes him stand out. He is not White, and even if he were from a different race other than an Asian, he looks so different with his patka turban on his head." Furthermore, she shared her concerns with her son looking different and how the thought of him being different has become a conversation between her and her in-laws, who do not see the need to trim her son's hair. In explaining the divergent views between herself and her in-laws, she said:

> Trimming my son's hair is a sensitive topic between my in-laws and I, who believes we are going against our religious practices because we want our son to fit in socially. My son's therapists tell me that he will always stand out, and I know that he is an easy target considering his physical appearance and his disability. Right now, he has adults supervising him, so we are not too worried. What happens when he goes off to work as an adult?

She concluded by sharing her hopes in the possibility of the social environment in Seattle becoming more accepting of people that look different, which, according to her, “Will lessen my worries about my son surviving outside my supervision.”

Theme 3: Considerations for Future Planning

Executive Functioning. All through the interview process, each participant referenced the impact of their child’s distinct executive functioning capacity on everyday life. Executive functioning is the cognitive control system in charge of the creation of intentional thoughts and actions and the recognition and attainment of goals (Mason et al., 2021). Individuals with ASD often display deficits in cognitive processes like regulation, control and management of thoughts and actions (Macoun et al., 2020). It was not surprising to observe how most participants referenced executive functioning multiple times while responding to the first subordinate research question. All participants, except for Participant D, described how they frequently considered their child’s ability to process information, pay attention to tasks and inhabit appropriate responses when switching daily routines, like mealtimes, childcare, and community outings. In her words, Participant A described her experience with reminding her son about some self-hygiene routines in the mornings. She said, “Yeah, he’s definitely got executive functioning issues. He needs a lot of help with planning daily self-hygiene routines, especially when there is a change of schedule.” Participant E described the impact of impaired organizational skills on her 16-year-old-son, who still struggled with wrapping his patka around his head. The patka is a protective length of cloth worn by males from the Sikh religion. She explained that although her son has watched her wrap the patka on his head on a daily basis for the last 13 years, he has continued to struggle with placing the patka correctly and rolling the two ends of the cloth that hold it in place. Participant C described her daughter’s organizational and planning skills as advanced but impaired in paying attention to smaller details. When referencing her daughter’s daily life, she stated:

> It’s a little bit concerning that she has mastered all the hygiene things that people think of, like deodorant and showering, but forgets to brush her hair and sometimes her teeth. She’s got all the others down, but I can’t get her to brush her hair. Essentially, she just forgets.

When describing the impact of their children’s executive functioning abilities on future considerations like college planning, living away from home, and using public transportation, five participants, all except for Participant D, shared their individual perspectives on how they are considering multiple options and alternative resources when conceptualizing future plans and outcomes. Participant C described the divide between her daughter’s academic readiness for college and executive functioning challenges saying:

> Her high school teachers think she will excel in traditional colleges based on her current grades, but college is different because she be by herself, and I have always helped her with planning, and organizing her homework, study routines, and study guides. So, we are considering other options, like smaller colleges, which may be less of an academic advancement, but more supportive of her impaired organizational skills. Especially at ABC college, where they have autism navigators who help students on the autism spectrum with organizing their daily college needs.

Participant F noted a similar perspective with his 17-year-old son, for whom he enrolled in a transition readiness program for parents known as Next Steps. The Next Steps Program is targeted at helping parents and guardians consider and plan toward possible options based on their child’s needs, which includes executive functioning. He stated, “Given all of that, he is pretty high functioning, but there are some developmental and processing stuff that is holding him back from integrating some management skills in some cognition tasks." He further shared that based on his impaired management skills, his family was considering possible future options spending additional years in high school, remaining at home after high school and enrolling for running start program, or living at home and enrolling in a local technical school for computer programming. With most participants commenting on executive functioning, but with distinct emphasis on their child's cognitive inflexibility, it became imperative to discuss cognitive flexibility as a subordinate theme.

Subordinate Theme: Cognitive Flexibility. Cognitive flexibility is one of the executive function skills centered on the ability of an individual to shift between more than one task and concept at the same time maintaining appropriate attention at the various tasks at the same time (Cambaz & Unal, 2021). In recent years, cognitive flexibility has been named the focal point in the integration and management of most basic cognitive processes (Mason et al., 2021). Five participants, other than Participant E, emphasized the interference of their child's inability to adequately process information when presented with more than one task or in the event of an unforeseen circumstance. Participant C described an experience where her daughter was hired by a neighbor to clean out a room full of mailing boxes. She said:

> The neighbor told her to break down the boxes and remove them from the room, but my daughter left behind some boxes that were already broken down. When I asked her, she said "I was told to only break down the boxes," so I look at things like that as her inability to give full attention to several tasks because the broken-down boxes needed to be removed from the room as well.

While narrating his parenting experiences with his 13-year-old daughter, Participant B described an overwhelming experience that involved his daughter and their neighbor's child. He described this experience, saying:

> At the peak of the pandemic when people were avoiding close contact with others, we saw my neighbor's daughter, and my daughter gave her a hug. I tried to explain to her that we could no longer give hugs because of the virus, she went into a rage session. She kicked, screamed, and broke things.

In another experience with his daughter's inflexibility with changes, he stated:

> A good example of this was this morning. She was playing with some sand-art-thing while eating breakfast. Then she started pushing the sand from the table to the floor, and I said to her, "Oh no, we can't do that, we don't want the sand on the floor." That seems like a very simple instruction, right? But that didn't go well because she did not understand why she should stop doing that. So, she ran to her room and slammed the door.

Participant A narrated her son's struggles with managing and processing multiple academic and organizational tasks when he transitioned from elementary school to junior high. She described this experience saying, "But in junior high, it suddenly felt like the wheels kind of fell off because the learning pace is much faster. He just couldn't keep up with the multi-tasking; it was just too much for him." Similarly, while sharing his family's experiences with transition stages, Participant F identified his son's rigid thinking as an aspect of cognitive processing that might pose challenges in his future career. He said:

> But from another piece of cultural standpoint, the other thing that I am trying to prepare him for is teaching him the basic skills of shifting and maintaining attention from one task to the other. That is just super hard with these kids because they are so rigid in their thinking

> and views about things. We are constantly exposing him to fluctuating tasks that could instill some flexibility in him so that he can get a job in the future and keep it. Such that he doesn't put himself in a situation he feels he can't get out of.

Comorbid Disorders and Psychiatric Symptoms. All participants shared the impact of co-occurring disorders in both present and future plans. The existence of one or more co-occurring disorders is not uncommon in the ASD population (Dovgan & Mazurek, 2019). These co-occurring disorders range from neurological disorders to psychiatric conditions (Dovgan & Mazurek, 2019). In her parenting experiences narrative, Participant D identified her son's neurodevelopment disorder, known as speech apraxia, as the dominant consideration when thinking about his future. While describing her son's inability to communicate verbally, she stated:

> The current situation is scary. He is 13 years old and looking at him, you can tell that he has his own mind, just like other teenagers, but he cannot express what he is thinking. His speech challenges are quite concerning, and I am afraid to think of him as a grown man.

Furthermore, while responding to the research question on the impact of culture, faith, and values on parenting experiences, Participant D revisited the topic of co-occurring disorders, saying:

> As a person of faith, I have never stopped trusting God with my son's speech. I believe God can heal him from speech apraxia, but I find myself afraid of the future and thinking about what opportunities are out there for him if he becomes an adult with limited verbal skills.

Correspondingly, Participant E described her son's impaired verbal skills as one out of other considerations in her deciding to live with him for the rest of her natural life. She described this saying:

> My son has several disorders and challenges that come with ASD. He did not speak till after he turned ten. In fact, his speech therapist and the school had given up on his speech because studies have shown that it is harder to develop speech after age ten. But you know, at age 16, I am hoping to make him as independent as possible despite his severe speech challenges. In the foreseeable future, we do not plan on having him live elsewhere other than our home, as long we both are alive.

Participant D described other co-occurring disorders as limiting factors in her son's development. She stated:

> He also has severe sensory issues and elevated obsessive-compulsive disorder (OCD) symptoms. He does not have a formal diagnosis of OCD, but it is definitely impactful on his daily functioning. He is constantly flapping his hands and rocking back and forth, and his obsessions are so challenging.

In sharing the interference of psychiatric symptoms on his daughter's daily life, Participant B echoed the comments of Participant E and the challenges of obsessive behaviors, saying:

> Her present behaviors are so challenging and the obsessiveness she has with some things are becoming so unmanageable because you can't tell what obsessions she will wake up with. It feels like every day comes with a new thing to obsess about.

Contrary to Participant B, Participant A had minimal interference with OCD but heightened interference with anxiety. She stated, "He's pretty high functioning, but you know anxiety has probably been the biggest thing we've had to deal with all the way through. Earlier, he had some OCD-like symptoms, but thankfully his OCD never became severe." Similar to Participant A's parenting experiences with his son's anxiety, Participant C narrated her experiences with anxiety, saying:

> Yeah, it’s so tricky because academically, she is doing quite well, and I can see her getting through college just fine. But my daughter gets so anxious, and a lot of her anxiety manifests as irritability or withdrawal, and because of that, I worry a lot about how she will handle things in the future.

In addition to social anxiety, she explained currently deliberating on previous college plans due to her daughter’s anxiety toward longer commutes and public transportation. She shared her concerns saying:

> I have a daughter who doesn’t have the confidence to drive. She’s too anxious about it right now, and she’s left with the option of public transportation. Literally, even our plans for next school year was impacted by this because we considered the running start program, and the only bus she could take that was within a decent distance is the XXX Community College route. But when I went with her on the bus to test if she could do the commute herself, she became very anxious about the number of people on the bus and the multiple stops. So, we are looking at other options currently.

Participant F described his parenting experiences with co-occurring psychiatric conditions as “pretty manageable.” He described this, saying, “Since he began taking anti-anxiety medication, he has done so well in regulating himself and his anxiety is almost a thing of the past. Well, as long as he continues taking his medication.” He further explained that although his son was experiencing beneficial outcomes with psychotropic medication, his experiences with various interventions for learning disability had not been quite successful. In sharing his family’s experiences with navigating available high school options with resources for learning disabilities, he said:

> Just so you know, he's dyslexic, so that's a challenge for reading and writing, and it frustrates him. Since first grade, we've tried several interventions for dyslexia, but his reading has picked up way better than his writing. So, when it was time for him to go to high school, we decided on his current school as a good fit for him because they had typing as an alternative for writing.

Participant F, at the onset of the interview, described the week as a "a good one" and added that same time last week, his son's frustrations with dyslexia were so heightened that he refused to go to school for 2 weeks. According to him, "I thought we were done with school, and I went on Facebook to share my pain with other autism dads." Participant F received encouragement from others, and he was able to get back to helping his son navigate his struggles.

Adaptive Functioning. Adaptive functioning refers to the daily expression of an individual's ability to meet the skill set required for environmental demands (Cote et al., 2020). Adaptive functioning is divided into three domains: conceptual, social, and practical, of which most participants referenced their experiences with two or three of these domains.

Subordinate Theme A: The Conceptual Domain. The conceptual domain embodies the acquisition of concepts, knowledge, and academic skills (Cote et al., 2020). In explaining their children's current functioning, Participants A, C, and F described their children as high functioning with high IQ and great academic skills. Participant A affirmed the ease at which her son learns new academic concepts with very minimal effort from him. She stated, "He's also extremely intelligent, like super high IQ, and it's been like this since he was born." She further narrated the confusion his elementary school teacher had with trying to understand why his son was academically gifted but yet, struggled with keeping his desk area organized. In her words:

> My son has never had to study for any test. He barely remembers to study for them. Sometimes, he tells me, on the way to school, "oh! I have a test today." That worked for him in elementary school, but high school was different because it takes more than academic excellence to be a successful human

Knowing this, it was not surprising to hear Participant C share similar experiences with her daughter's ease at understanding academic concepts and being academically gifted. She shared this saying: "The school is assuring us that she does not need a transition program. They believe that she's ready to get out of school, go into college and move on to her career, but having all A's does not guarantee success in college." Furthermore, she explained that her daughter's grades in high school and SAT scores could get her good college admissions, but they were considering other limiting factors outside of academic excellence. Participant F described the confusion with his son's adaptive functioning skills, saying:

> My son did not qualify for disability benefits from the state because he did not meet the disability criteria for intellectual and learning disabilities. He has a high IQ, although, on paper, he has a formal diagnosis of dyslexia, which is a learning disability. Yeah! Quite confusing.

Contrary to the experiences of the above participants, Participants B, D, and E narrated their children's struggles with understanding, processing, and applying academic concepts and skills. Participant E shared her perspective, saying:

> I do not think my son has the academic skillsets for college or even to be in a higher education setting. He is not functioning at that level, and we as a family, are beginning to put that into consideration when deciding on what will benefit him the most.

She added, “Surprisingly, he understands some basic math problems like single-digit addition and subtraction problems.” She shared that, although her son was minimally verbal, he responded to basic math problems on paper without verbalizing the step-by-step process. She hoped that his understanding of basic math problems would be the stepping ground for further growth in this domain. Sadly, Participant D was less hopeful about the possibility of her son transitioning to advanced academic settings. At age 13, she described her son’s academic journey as possibly ending after high school. Adding to her experiences with her son’s challenging conceptual domain, she stated, “Here in XYZ, the state provides vocational programs for adolescents, like my son, for advancement in other skills, in the absence of academic skills. We are not looking at them right now because it is depressing to think of, but we will eventually.”

But somewhere in the middle between high and low academic giftedness, Participant B considered his daughter as average IQ. He described her ability to conceptualize academic concepts as average, although he was of the opinion that her current struggles with OCD were limiting her from meeting her potential. In describing this, he said:

> If only she can focus on the learning materials rather than obsessing over tiny details in the classroom, I think that she will be an average student. Before the onset of her OCD, we were not too concerned with her learning, but these days, it is becoming harder to focus on only OCD because her obsessions are interfering with learning.

He shared a recent experience when her daughter refused to go into the classroom because the seating arrangements changed to accommodate new students.

Subordinate Theme B: The Social Domain. The social domain is centered on adaptability in social environments and the ability to thrive in interpersonal relationships and leisure activities (Cote et al., 2020). Participants B, C, and E shared their experiences navigating their children’s ability to thrive in social settings. Participant B shared an experience that depicts the Impact of cognitive flexibility on adaptive functioning. In describing his daughter, Participant B stated, “She is overly social, up to the extent of obsessing over a friend or someone in her classroom. It is extremely scary, and we have tried to teach her some social skills, but she does not seem to get it.” He shared a difficult experience between his daughter and a neighbor kid, saying:

> Like a couple of years ago, a neighbor kid, another girl, got a haircut. And you know this was just before the beginning of the school year, and we had just given my daughter a haircut. She went over to play with this neighbor and saw her hair. When she came home, she asked that her hair be cut just like the neighbor’s, but we explained to her that it won’t be possible. At bedtime, she took her scissors and cut off a big chunk of her hair because she wanted to look like the girl next door with the short hair.

He described his daughter’s social skills as one that scares people away. Furthermore, he explained, “I love that she is social and likes being around people, but we’ve had to tell people, at social gatherings, that she has autism in case she displays any awkward behavior.”

Participant C shared contrasting experiences with her daughter, who is different from Participant B’s daughter. She described her daughter’s ability to adapt in social settings or accommodate others as “extremely concerning” while describing her interpersonal relationship skills as “awful.” In illustrating her daughter’s inability to grasp socially acceptable behaviors, she shared a story about her daughter’s constant complaining about a baby in their home. According to her:

> Right now, we have a family that just recently migrated from Germany in our home. They have an 18-month-old baby who was born in our home, but my daughter has never tried to come close to this baby since she was born. I’ve tried to explain to my friend, the baby’s

> mother, but it's very uncomfortable for me as a mother. I think for me, the hardest part of it all is my daughter complaining openly about the baby in the presence of the mother.

Participant C further explained that although she has tried on various occasions to tell her daughter that such behaviors make others uncomfortable, she keeps doing it. She added, "It almost feels like others are nonexistent, and such behaviors make me worry about college because she will stand out." Similarly, in continuing with the conversation on social skills, Participant C described how she has had to constantly educate her daughter on the impact of her external appearance on others. In sharing this, she said, "She doesn't seem to understand how her appearance influences what people think of her. She can go days without brushing her hair, and when I try to explain to her, she struggles with understanding why her appearance matters."

Participant E's adaptive social skill experiences were quite different from Participant B and C's narratives. Although all three participants shared similar experiences with challenging social skills and interpersonal relationships, Participant E's experiences were centered on bullying and her son's inability to understand and express basic social clues. She stated:

> My son is extremely vulnerable to discrimination and being bullied. As a Sikh, he wears his patka to school daily, and that attracts attention to him. I have witnessed kids laughing at him and making fun of his appearance without him recognizing it. I've also seen other kids imitating his flapping of hands, and the teachers did not stop them because my son does not recognize basic social clues like others making fun of him.

Given this vulnerability tendency, she added, "I find myself worrying about the possibility of others misleading him and getting him into trouble, or even worse."

Subordinate Theme C: The Practical Domain. The practical domain involves an individual's ability to adequately manage domestic abilities, personal care, health, and safety concerns (Cote et al., 2020). In this domain, all six participants shared their distinct parenting experiences in instilling age-appropriate practical skills in their children. For some of the Participants like A, C, and F, their children's challenges with practical skills seem more manageable compared to Participants B, D, and E, who compared their children's domestic abilities as that of a toddler or a little above toddler skills. Participant A, while describing her son's adaptive functioning skills, stated, "We recently talked with his psychologist, kind of to give us a perspective on where he is at, and she told us that his adaptive skills are comparable to a 14-year-old. So, you see at 16, he has some catching up to do." She added that the possibility of her son moving out of their home is not realistic, considering his personal and practical skills are not age-appropriate. On a similar note, Participant F shared his experiences with helping his 17-year-old son with grooming hygiene. He stated, "I am happy to help him or remind him, but what happens when he goes off to college?" Outside of personal care, Participant C shared her concerns with her daughter's inability to recognize and apply needed health and safety measures. In describing her concerns, she stated, "On multiple occasions, while returning from school, my daughter slept off on the bus. One particular incident was rather scary, she got home four hours later than her usual time, and she didn't see the need to call us or respond to our calls when she woke up."

Contrastingly, Participants B, D, and E, whose children were not as independent as Participants A, C, and F, shared their parenting experiences with instilling practical, personal, health, and safety skills in their children. Participants D and E shared similar experiences with helping their teenage boys, ages 13 and 16, with personal hygiene routines like bathing and brushing their teeth. Participant E stated, "My son knows and says when it is time to bathe and brush his teeth, but I think it's more of a ritual to him than personal hygiene concerns." While describing her son's practical skills with managing domestic needs, she explained that her son has chores in their home, but he has not understood the responsibility that comes with chores, and neither has he remembered to execute them without reminders. Participant A's parenting experiences as a same-sex two-dad home raising a teenage daughter were unique. In addition to teaching his daughter feminine personal hygiene routines, which was a struggle for him and his partner, he has had to help her with almost all feminine personal hygiene routines. According to him:

> It is becoming obvious that we need the help of a good female role model that can help her with some personal care things. She also struggles to understand the need for some routine hygiene stuff, which prolongs the learning period. I am guessing at this point; we need external help with someone that relates to all that.

Given the narratives of all six participants and their distinct experiences with the three domains of adaptive functioning, it seems evident that their children's current and speculated adaptive functioning skills were subjects of consideration.

Gender-Related Issues. In responding to the subordinate research question, which was focused on the influence of gender in parenting experiences, two participants, D and E, responded directly to the research question, and others, Participants A, B, C, and F, redirected the question from gender to sexual identity and orientation. Given the divergent patterns of responses, it became eminent to analyze the two response styles starting with the first group, those who gave a direct response to the question. In discussing gender, Participant D stated, "I've never really considered my son's gender when making plans or resourcing. I am guessing with girls, it might be a lot different because of their needs, but yea, it's not something that comes to my mind." In addition to stating that there was no gender interference in her parenting experiences, she emphasized the possibility of focusing more on the things that mattered, like helping her son gain skillsets for independent living rather than gender. Participant E, while explaining her views on gender-related experiences, shared a similar perspective with Participant D on no gender interference, but speculated that parents with female children are more conscious those with male children. In describing her parenting experiences with raising a male child with ASD, she said:

> For my son, it might not be very different because of his communication challenges, but I still would say I am concerned with any gender-like issues. If it were a girl, I would, of course, be concerned, considering females are more liable to molestation factors. I've heard that from others raising girls, a lot of people that have females are more conscious for some reason.

Similar to Participant D, she explained her son's impairments outweighed her gender concerns when considering future plans.

The second group of responses diverted from gender to sexual identity and orientation. Participant A, while responding to the question, stated, "He has not expressed a lot of interest in dating. He hasn't said anything about his sexual orientation. It hasn't happened yet, but I am guessing its coming." Similarly, Participant F shared his perspective on his son's sexual identity saying, "I don't know his sexual identity. Yeah, I don't know that he fully knows it yet. I don't have to worry about him getting pregnant, but I might have to worry about him getting somebody pregnant." In addition to sexual identity, he shared his views on sexual orientation amongst individuals with autism. He said:

> The issue of sexual identity and orientation has probably evolved in the last few years. Just as we've started recognizing gender fluidity, I know that there are concerns about kids on the spectrum and potential vulnerability and gullibility with knowing their sexual orientation.

He considered his son as fully protected from any form of vulnerability as they have continued to have conversations with him on issues of sexual identity and orientation.

Participant C, on the other hand, expressed concerns with the possibility of her daughter being confused with her sexual identity. In her narrative, she explained that most of her daughter's friends had declared themselves as gender fluid, and as a result of this, she is not sure if her daughter might follow suit considering her impaired social skills. In addition to not knowing her daughter's sexual identity, she stated, "I am not against any gender or sexual identity, I just want her to identify with one, not because others are doing it, but because it's what she sees herself as." Furthermore, she said:

> Even neuro-typical kids seem confused. I think they are discovering themselves. I see a 21-year-old without autism say goodbye to a different sexual orientation at different stages of their life. I hear that these days, they go by dates, not gender.

Participant B had a lot to say about sexual identity and orientation. Coming from a same-sex marriage, he echoed the nonexistence of gender identity in his household. He referred to his family as "a gender-fluid household." According to him, "Her gender identity, sexual identity, and orientation have never been a conversation in our home because we believe people are allowed to express themselves in any way they want to." However, he shared his experiences in a two-dad household as a constant struggle in the social environment, as people are constantly judging their parenting skills with raising a girl. He added that they do not seem to have such judgments and assumptions with their other male child. Given the varying patterns of responses from the two groups of participants, it seems obvious that participants responded to the question based on their experiences with gender-related issues.

Field Notes and Behavioral Observations

Field notes are vital instruments in qualitative research as they provide observational and reference platforms that aid the validity of findings (Brod et al., 2009). The researcher documented field notes and behavioral observations during and after each interview, and these instruments strengthened the interpretation and analysis of participants' experiences. The inclusion of these instruments gave meaning and aided the understanding of this phenomenological research. The researcher's field notes and behavioral observations had detailed information on participants' behaviors, comments, voice tone, and other observational features that were missed in the written transcripts. The analysis of both the field notes and the raw data provided the foundational reasoning for the emerging themes that were discussed in the current study.

Hesitation and Willingness

Three participants hesitated to respond to the first research question. For example, Participant F took a long pause before saying, "The last few weeks have been rough." Participant E was hesitant to respond to the research question on culture. She commented on the question as being a sensitive topic in her family. Participant B struggled with the research question on gender. He appeared a bit apprehensive, but he gradually relaxed as he continued to speak. Participants A, C, and D seemed to have a neutral reaction to any of the questions. In her opening comments, Participant A stated that she was very familiar with phenomenological studies of this nature. Participant C did not comment on any hesitation or willingness to participate, but her body language conveyed full engagement. Although three participants conveyed their hesitation at the onset of different research questions, all participants seemed willing to share more information once they began speaking. Participant C shared resources, timelines, and own experiences outside of parenting. Participant B had comments like "I hope I am not talking too much?," "Am I diverting?," and "Please let me know if I've answered your question?" Participant D started the interview with few words and low energy, but she gradually became talkative as the interview proceeded. At the end of each interview, after the researcher thanked them for agreeing to partake in the study, all participants expressed future willingness if needed. For example, Participant B said, "You can email me if you have more questions." Other participants used sentences like: Let me know if you need more help, absolutely, anytime, no thank you for doing this.

Sincerity and Openness

All participants appeared to convey sincere responses in their narratives. Their body language, facial expressions, and voice tones spoke to the sincerity of their stories. They reflected on the questions before responding, and this conveyed their digging deeper to process and produce authentic responses. Their transparency was evident in their comments and remarks. For example, Participant A's remark after the first researcher question was, "Oh this easy, I can tell my story even when I am sleeping." Participant F said, "He is my only child, and my parenting experience is just with him." Participant B commented on the third research question by saying, "That's a good one; let me think about it first." Overall, the researcher did not observe any behavior or verbal response that portrayed deceit, insincerity, or pretense.

Emotionality

While narrating his lived experience as a father in a same-sex marriage, Participant B became very emotional speaking on the judgments and comments he receives from people. He took a long pause and asked for a few minutes to get his thoughts together before continuing to speak. All through the interview process, the researcher observed some elements of emotionality based on the participants' obvious facial expressions. Participant A smiled at odd times, and the researcher noted her smiles, which did not correspond with her responses, could be a way to ease off some painful emotions. Participants D, E, and F were teary at different times during their individual interviews. Participant F's response to the first interview question was so emotional that the researcher asked if he would prefer to pass on the question. But he took a long pause and commented on the challenges of the last few weeks before responding to the research question. Participant E fought back tears when discussing her son's bullying encounters in high school. She paused at different times, raised her head up, and adjusted her sitting positioning. Furthermore, Participants B, D, E, and F became teary while speaking and took some long pauses before continuing.

Language

The reoccurring language which became one of the emerging themes was realistic, reasonable, and unrealistic expectations. All six participants made multiple references to one or more of the two when describing current thoughts and future planning. Participants A, C, and F interchanged realistic with reasonable expectations at different times. In all six field notes, the researcher quantified the frequency of this language by the number of times referenced by each participant and came up with six times for Participant E as the highest number of uses. Although Participant D did not out rightly use the term realistic expectation, she described some of her previous expectations as unrealistic.

Careful Consideration

Based on the researcher's presumptions, each of the participants appeared to have carefully considered their response to the research questions. Behavioral observations like short pauses and looking away from the computer screens conveyed their initial considerations to the questions. Participant F often began his responses with comments like "Let's see." Before responding to the questions, Participants A and C observed short pauses before speaking, whereas Participant B nodded his head as the researcher read out the questions. Participant B's nodding of the head was interpreted to be either a sign of agreement or careful consideration to the sequencing of the questions. Participant D occasionally asked for a repeat of the questions and ended her responses with, "I hope I answered your question." Similarly, in addition to wanting clarity, Participant E often broke eye contact with the researcher when she appeared to be processing her thoughts.

Chapter 4

Discussion

This phenomenological study explored the lived experiences of six parents raising adolescent children with autism spectrum disorder (ASD). The purpose of this study was to bring to light the psychological reasoning behind plans made by parents for their children with autism. This research provided in-depth perspectives into the uniqueness of each participant's parenting journeys and the multiple factors that influenced their parental judgments, parental decisions, and future plans. To illuminate the impact of external and internal factors on parents' thought-processes, when considering the long-term prognosis of their children's adult lives, the researcher examined the qualitative components of lived experiences such as motivation, hope, regrets, lessons learned, core values, perception, belief-systems, intentions, culture, expectations, and resolutions, and some quantitative components like age, gender, socioeconomic status, and severity of autism impairments as factors that influenced parenting experiences. The current study was one of the few trajectory studies on autism parenting that examined parents' thought processes as impacted by the many factors that play multiple roles in the years leading to adulthood. With several studies focused on defining moments in the lifespans of children with ASD, and limited studies on trajectories to these defining times, it seemed apparent that these defining moments were informed by parents' lived experiences (Cheak-Zamora et al., 2015).

Interpretation

This chapter aims to interpret and integrate data collected with existing literature and research findings. Interpretation of data involves the assignment of meanings to analyzed data to arrive at a relevant conclusion. Furthermore, the research examined the strengths and limitations of the current study and provided recommendations for further research exploration, on a similar topic, in this population

Impact of Diversity and Inclusion on Adulthood Planning

The first finding that emerged from the current study is parents' pursuit of a diverse and inclusionary social environment for their children. Participants reported this pursuit of diversity and inclusion as going both ways, for themselves and then for their children. Participants sought a social environment with limited to no stigmatization and exclusionary behaviors. Four participants in the current study reported experiencing racial, religious, and sexual discrimination. Two participants, D and E, identified as members of a minority racial group, Black and Asian, of which Participant E (Asian) also identified with the Sikh religion. Sikh is an Indian religion that includes a spiritual code of conduct that involves wearing their hair long and covering them with turbans males or headscarves depending on gender (Khalsa, 2018). Head covering with a headscarf for religious purposes is sometimes interpreted as stigmas of group identity by mainstream society (Weichselbaumer, 2020). Stigma often leads to social bias and discrimination (Weichselbaumer, 2020). Participant E reported currently conflicted on the possibility of shaving her son's hair and eliminating head covering as a measure to minimize exclusionary tendencies from mainstream society. She affirmed witnessing religious and racial discrimination targeted at her son by a group of high schoolers who made fun of her son's physical appearance.

Diversity widely refers to the natural and perceived physical and sociocultural characteristic differences of people and the portrayal of these differences in society (Arsel et al., 2022). Inclusion, according to Arsel et al. (2022), is the creation of a culture that promotes belonging and the incorporation of diverse groups, which is operationalized as opposition to marginalization. A new study on diverse socioecologies has suggested that pronounced social adaptability, flexibility, and the breaking of social tiers could result from the increasing number of present-day migration and cultural exchange with others (Wood et al., 2022). Social adaptability and flexibility afford members of such societies considerable access to resources and services in a diverse social environment. Findings from Wood et al. (2022) research speculated the willingness to make friends and build social networks by individuals from more diverse populations. Sadly, regardless of countless research studies on the need for diversity and inclusion in societies, individuals from minority groups have continued to experience discrimination.

Discrimination of any form is the differential treatment based on race and external differences that are unfavorable to an individual or group (Shavers, 2020). In their findings, Mutmainnah et al. (2022) affirmed the long-term discrimination of Black people and minority groups by the dominant group. In their exploration of Langston Hughes's poems, they referenced physical differences not being the only domain of discrimination, but the implementation of discriminatory practices in social services, educational settings, and the social environment (Mutmainnah et al., 2020). Discrimination isolates individuals experiencing it and prevents them from the process of exploring decent lives for themselves (Mutmainnah et al., 2022).

In addition to racial and religious discrimination, sexual discrimination has continued to be an essential topic of conversation since the 1964 Civil Rights Act (Turner, 2020). Years and decades later, in June of 2020, the Supreme Court, under Title VII of the Civil Rights Act of 1964, banned workforce discrimination based on race, sexual orientation, and gender identity (Johnson, 2022). However, with the exclusion of workforce discrimination, societal discrimination against this minority group, lesbian, gay, bisexual, transgender, and queer (LGBTQ) communities, have continued to perpetuate less diverse societies (Johnson, 2022). Although Participant B was neither Black, Asian, nor Sikh, he reported experiencing traumatic discriminatory acts from the church at his hometown due to his sexual orientation as a gay White male. This lived experience informed his decision to relocate to Seattle with his partner upon becoming a parent to his daughter with ASD. They needed a culturally diverse social environment where they were not judged or isolated due to their sexual orientations. He described needing a diverse social environment and equal access to available resources for his daughter without any form of denial. He also reported continued overt and covert discriminatory comments from supposedly culturally aware members of his current society.

In their narratives, all participants of the current study identified with a particular culture, implicitly and explicitly, when referencing their interactions with the social environment. Participants A through F described how the dominant culture in the social environment influenced the following: lived experiences at the early years of their children’s lives, access to services, resources, support, migration decisions, choice of transitional programs, and indigenous family culture and values. At varying degrees, Participants B, D, E, and F expressed the impact of either the dominant culture or the culture they identified with on their parenting experiences. Participants B and F reported relocating from other cities to Seattle to pursue a diverse and welcoming social environment for their families. Participants B, D, and E narrated their disappointments with the public due to the noticeable external differences between them and the dominant culture. Given the reports of these participants, which align with new studies on diversity and inclusion, it is imperative to consider the impact of a diverse and inclusionary society on adulthood planning (Arsel et al., 2022). Participants B, D, and E affirmed searching for a society that paid no attention to their external features.

In contrast, Participants B and F affirmed leaving their previous geographical locations for Seattle. They considered MKZ to be a more diverse and inclusionary city for themselves and their children. In anticipating their children's futures, and possibly their children's children, participants shared their current state of mind, fears, and worries about discrimination and its impact on their adult lives. As continuous social communication and interaction deficits are synonymous with autism, most participants are worried about poor social connectedness and loneliness, which contributes to internalizing symptoms like depression (Stice & Lavner, 2019). With this in mind, participants affirmed reflecting on the diversity and inclusionary elements of their current or future geographical locations when considering transitionary and adulthood plans for their children with ASD.

Adjusting Expectations

Studies on long-term outcomes of individuals with ASD have suggested parents' changes in perception of their child's needs as they get older (Chamak & Bonniau, 2015). Some studies proposed several developmental trajectories that could predict the severity of autism symptoms and impairments at an older age. Some studies suggested steady improvement in children with minimum autism symptoms, at the initial diagnosis, compared to the severely impaired group (Chamak & Bonniau, 2015). Although intensive early intervention therapies were found to improve autism symptoms of young children at different severity levels, it does not guarantee an absolute outcome at an advanced age (Haglund, 2021). Considering several factors that impact development and growth, the severity of symptoms at a young age does not predict long term outcomes for children with ASD.

Given this, all participants in the current study reported adjusting the developmental and adaptive expectations they had for their children at different stages of parenting. Participants A, C, and F identified their children as high-functioning autism with high IQ, and Individuals categorized as high functioning autism (HFA) are grouped under the neuropsychiatric functionally impaired category, characterized by an absence of social cognition (Hedegaard et al., 2021). These participants described constantly adjusting their sociocognitive and practical expectations for their children by focusing on adequate support and realistic expectations. Some individuals with HFA experience challenges managing domestic and personal care activities associated with impairments in the practical domains (Cote et al., 2020). Furthermore, despite their elevated abilities in acquiring and conceptualizing academic skills, they have impaired abilities in planning and cognitive flexibility (Hedegaard et al., 2021). Participant A considered her son as impaired in the practical domain, while Participant C described her daughter as very inflexible and but needing help in the sociocognitive domain. Although Participant F identified his son as HFA, he described him as dyslexic and impaired in the practical domain.

On the other side of the autism spectrum, Participants D and E identified their children as severely impaired. In the absence of psychiatric symptoms, Participant B considered his daughter moderately impaired. All three participants at the other side of the spectrum also reported adjusting developmental and adaptive expectations at different stages of their children's lives. For these parents, the chronological ages of their children were not the standard of expectation, and neither was it based on academic needs. Instead, they adjusted their expectations based on their child's current adaptive abilities and speculated future needs. In addition to being impaired in the three domains of adaptive functioning, Participants D and E described their children as highly vulnerable members of society due to their inability to understand essential social cues. The three domains of adaptive functioning are the conceptual, social, and practical domains, which are centered on academic functions, social adaptability, and planning skills (Cote et al., 2020). Although Participant B's daughter was not severely impaired in the three domains, she struggled to conceptualize social clues, in addition to other comorbid disorders. Reports from these three participants are synonymous with findings from other ASD studies that suggested challenges in both executive and adaptive functioning by severely impaired individuals with ASD (Chamak & Bonniau, 2015).

The second finding that emerged was participants' reports on adjusting developmental and adaptive expectations for their children at the adolescence stage. Adolescence, the transitional stage between childhood and adulthood, is known as the stage with lesser services for children with ASD (Shea et al., 2018). All participants reported struggling to harness limited resources, which they speculated could result from more emphasis on early intervention and adulthood transition services. With limited intervention resources and the current state of their child's adaptive needs, participants found themselves adjusting and readjusting some expectations they earlier had for their children. These adjustments of expectations by all participants led to a reoccurring terminology, realistic and reasonable expectations, which was used by most participants in describing their current thought process about their children's future needs.

The third finding was the differences in the direction of realistic expectations. Study participants that identified their children as HFA, while describing their realistic expectations, focused mostly on adjusting academic expectations based on their child's social adaptability needs. For example, while describing their earlier expectations about their children transitioning to mainstream colleges, Participants A, C, and F affirmed adjusting their earlier expectations to smaller colleges like community colleges. These participants considered it realistic to enroll their children in an environment with smaller number of students. They recognized that although their children could meet the academic needs of mainstream colleges, the possibility of struggling socially and adaptively is higher for them in mainstream colleges.

Furthermore, while describing their realistic expectations, Participants D and E, who identified their children as severely impaired, focused on a particular domain in adaptive functioning, the practical domain. The practical domain centers on skillsets for self-care, home living and community use, health, safety, and work (Cote et al., 2020). They both affirmed the adolescence stage as the period in their children's development when they came to terms with realistic expectations for their sons considering their impairments. Both participants recognized that although their sons have significant impairments in the three domains of adaptive functioning, they choose to readjust their expectations to more realistic ones. The other two domains are focused on academic and social needs (Cote et al., 2020). They affirmed not completely leaving out academic and social needs but deciding on readjusting their expectations from broad to narrowing them down to the exact needs of their children at this time.

Clinical Implications

The current study may provide further support for families of younger children with ASD approaching adolescence or in the early years of ASD. Parents and siblings of individuals with ASD are often their direct and most consistent support system (Noonan et al., 2017). Across the lifespan of an individual with ASD, it is not uncommon to witness the high levels of involvement and connection by parents and siblings (Noonan et al., 2017). In addition to existing studies on lived experiences of families impacted by ASD, the current study offers a resource platform for families seeking relatable research publications. Similar studies founded on insider perspectives are often sought by those impacted by the same phenomenon when seeking resource ideas, emotional support, or relatable viewpoints. Other than those impacted by ASD, the current study could be a source of reference guide for interventions, support, educational and vocational services that cater to the needs of individuals with ASD. Intervention and support services like behavior, speech and occupational therapists, respite care providers, and classroom support personnel, who work side by side with families, can conceptualize the needs of these families with resources like this.

Findings from the current study and data collected from the participants may serve as a validating resource to parents in similar situations. The current study embodies authenticated and vulnerable responses from six participants, who provided first-person narratives into their lived experiences before and after their children's ASD diagnosis. Study participants shared personal experiences with several highs and lows encountered in their parenting journeys. The highs and lows of raising a special needs child were linked to an increasing prevalence of psychological stress amongst families impacted by it (Boshoff et al., 2016). In addition to psychological stress, increasing relational stress on marriages, friends, and extended family were linked to the challenges of having a child with ASD (Lashewicz et al., 2018). However, as a validating resource platform, given the genuine responses provided by each participant, families in similar situations may find the current data helpful, relatable, and affirming to their emotional, physical, and psychological wellbeing.

Limitations and Recommendations for Future Research

A critical limitation to the current study was the purposive sampling of participants from an all-inclusive private school for children with ASD. Four participants emerged from the purposive sampling, and the other two participants were selected based on snowballing sampling from the initial sampled respondents. Considering the target sample group being a self-paid special education private school and the assumption that study participants are financially stable, their lived experiences could be different compared to parents with limited finances. Given that more disposable funds are generally equal to higher accessibility to services and support, it would have been advantageous to learn more about the lived experiences of parents from lower-income families who are dependent on government-funded resources like public schools.

Another limitation was the small number of study participants. With this being a phenomenological study of lived experiences of parents, the need for more narratives on lived experiences was needed to accurately generalize findings to a larger population. Although the participants in this study differed in cultural backgrounds, demographic locations, gender, age, and sexual orientations, additional variations outside of these, could prompt further generalization to larger groups.

The current study did not have an equal representation of male to female ratio in both the participants and their children. Participants' male to female ratio was 2:4, and 4:2 for the children. It would have been more beneficial to have an equal male to female ratio for participants and their children. The current study only explored the lived experiences of two fathers and two daughters with ASD. Nevertheless, considering ASD diagnosis is higher in males than females with a male to female ratio of 4:1, the researcher deliberated on varied gender representations of the children at the sampling stage. Future research with an equal number of male to female ratio could shed more light on the unique experiences of fathers, which undoubtedly may be different from the parenting experiences of mothers. In addition to this, because girls are often underrepresented in most autism studies, increasing the number of participants with daughters could unveil a comprehensive knowledge of parents' lived experiences.

Lastly, due to the COVID-19 global pandemic, which led to restrictions on in-person meetings, data collection for the current study was accomplished on a computer-based platform rather than face-to-face meetings. Because accurate documentation of field notes on behavioral observations are essential in most qualitative studies, the researcher was aware of the possibility of not capturing some behavioral observations more visible with in-person interviews. Given this, in-person interviews are highly recommended, hereafter, for similar research.

Conclusions

The results from the current study offered the lived experiences of six parents raising adolescent children with ASD. By sharing their lived experiences and the thought processes in adulthood planning, familiar threads or shared themes were identified, discussed, and analyzed, summing up the general message. When considering parents' experiences raising children with ASD, the general message from the current study is the need for increased awareness on diversity and inclusion in our communities to support these children with sociocognitive impairments. Increased social support from others other than parents and providers could come in less discriminatory behaviors from strangers, bystanders, fellow students, and employers. Although more people are becoming aware of the need for diversity and inclusion in societies, increased awareness of inclusionary behaviors will lessen the burden on parents when considering the social support their children will need in the future.

This study joins the host of other studies that saw the need for more conversations on the lived experiences of those impacted by ASD and the different factors that influence their unique experiences. Findings from the current study affirm the popular quote, "When you meet a person with autism, you have met one person with autism," as the lived experiences of every participant in this study were similar but uniquely different (Flannery & Wisner-Carlson, 2020). In understanding the uniqueness of every parenting experience, the current study delved into parents' thought processes when considering or planning for the adult lives of their children with ASD. Regardless of the varying routes participants chose to undertake in embracing their autism journeys, the driving force behind their considerations or conclusive decisions was the thought process.

Furthermore, as there are no traditional routes and shortcuts to successful outcomes, an important theme that emerged from the current study demonstrated parents' constant readjustment of expectations and plans. At adolescence, study participants began to put together fragments of possible plans, which were liable to multiple changes based on their children's current and projected abilities. As they incept these plans, their thought processes went through various stages of adjustments of expectations, as they put together the best possible outcomes for their children's future, which the researcher affirms. As a mother to a 10-year-old son with ASD, findings from this study are nothing short of what the researcher expected, considering she is presently going through the different stages of adjustments of expectations and plans.

Lastly, this academic research was born out of the researcher's insight and the need for a greater understanding of her parenting experiences with an adolescent son with ASD and her peers in similar situations. Undoubtedly, based on the researcher's parenting experiences with ASD, she has recognized the authenticity of study participants' narratives and the vulnerability in speaking about their hopes, fears, worries, acceptances, and denials. The researcher was very aware of the sensitive nature of the current study, considering study participants, in their vulnerability, may be reminded of what could have been a typical parenting experience in the absence of ASD. However, true stories were told with vulnerability, which could mark the beginning of future research for the next generation of parents raising children with ASD. This research is helping to further conversations on parents' lived experiences and the many factors that play multiple roles in the years leading to their children's adult lives, with a goal that the larger community will understand and support the needs of families impacted by autism spectrum disorder.

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Appendix A

Interview Outline

1) Welcome and Introductions
2) Description of Study and Informed Consent
3) Demographic Information Gathering
    - Are you a parent or legal guardian to an adolescent with autism spectrum disorder (ASD)?
    - Does your child have a formal ASD diagnosis?
    - Was the diagnosis given from early childhood?
    - For legal guardians, have you maintained the legal guardian role from the initial ASD diagnosis to date?
    - How old is your child with ASD?
    - Do you reside in Washington State? If no. what state are you currently at?
4) Research Question
    - What are parents' and legal guardians' lived experiences when considering the long-term outcomes of their children with autism spectrum disorder?
5) Subordinate Research Questions
    - How does your child's current functioning impact your thought process when thinking and planning for his/her adult life?
    - How does your child's gender influence your parental experiences when considering adulthood outcomes?
    - In your parenting experience, what are some faith, cultural and personal values that influence your thoughts when considering future plans?

Appendix B

Consent Form

The Thought Process in Planning for the Adult Lives of Adolescents with Autism

Doctoral Dissertation in Psychology, Northwest University

Ifeyinwa Nwangwu

You are warmly invited to participate in a research study conducted by me, a graduate student in the doctoral program in Counseling Psychology at Northwest University**.** The study is being conducted as a class requirement for PSYC 8963/00 – Doctoral Dissertation in Psychology III. The purpose of this study is to understand the thought processes in the lived experiences of parents when considering adult life plans for their children with an autism spectrum disorder.

If you choose to participate in this study, you will engage in a 45 to 60-minute one-on-one virtual interview. I would like to videotape the interviews, but your name would not be stated during the interview, and all information provided will be highly confidential and anonymous. During the interview, I will ask you some questions about your lived experiences raising your child with ASD and your plans for their adult life. As part of my data collection, I would like to take notes about your answers to the questions and my observations during the interview.

There are minimal risks associated with participation. Some individuals may be uncomfortable or embarrassed to answer personal questions about their parenting choices. Some questions asked may also raise emotional feelings about the future. The benefit of taking part in this study is the opportunity to contribute to autism research. This study will also offer an opportunity to reflect on the future and how to support your child.

Participation in this study is voluntary. There will not be any negative consequences if you decline participation. If you choose to participate during the interview, you have the right to ask for a question to be rephrased, the right to skip a question if you do not want to respond to it, and the right to end the interview if you no longer want to participate in the study. All responses are confidential and will not be linked to any of your identifying information. By turning in this consent form via Qualtrics, you are giving me permission to include your responses to the study.

The results from this study will be presented at my dissertation defense at Northwest University. Results may also be published in a psychological journal.

If you have any questions about this study, please contact Ifeyinwa Nwangwu at Ifeyinwa.okeke14@northwestu.edu. If you need help with emotional or psychological needs after the interview, please call the 24-hour crisis line at 1866-427-4747 or visit the Psychology Today website (www.psychologytoday.com) for a list of licensed therapists or call customer services at 1-800-234-8361. If you have further questions, please contact my dissertation chair Dr. Kim Lampson, or the faculty advisor Dr. Leihua Edstrom. You may also contact the Chair of the Northwest University IRB, Dr. Molly Quick.

Thank you for your consideration in participating in this study.

Ifeyinwa Nwangwu

Doctoral Student in Counseling Psychology

College of Social and Behavioral Sciences.

Kim Lampson, Ph.D.

Professor of Psychology

College of Social and Behavioral Sciences.

Leihua Edstrom, Ph.D., ABSNP

Associate Professor

College of Social and Behavioral Sciences.

Ifeyinwa Nwangwu 04/25/2021 ______________________________

Principal Investigator Date Participant Date

Appendix C

Recruitment Materials (Email Invite and Facebook Posts)

The Autism Parenting Study

Doctoral Dissertation in Psychology, Northwest University

Ifeyinwa Nwangwu

Email Invite

Dear ABC Family,

My name is Ify, a former ABC parent. I am currently working on my doctoral dissertation, a qualitative study on lived experiences in autism parenting titled “The Thought Process in Planning for the Adult Lives of Adolescents with Autism.”

It will be an honor to recruit my participants from the ABC family, and I am currently seeking 6 to 8 parents raising an adolescent with an autism spectrum disorder. The ideal candidate must be a parent or legal guardian to an adolescent with a prior formal diagnosis of autism spectrum disorder from early childhood.

Consistent with all qualitative studies, study participants will be subjected to a one-on-one interview, which will be done virtually as a safety precaution from COVID-19. The interview is a 45-60 minutes video call on Microsoft Teams.

Interested participants will be provided with an informed consent detailing the research features that protect the participants and the researcher.

Data collected is entirely anonymous, as participants will be represented with code numbers. Interested participants should reply directly to me via this email, indicating their interest or further questions.

I look forward to connecting with families, and I am excited about the possibility of adding to the existing research on our special community.

Ify

Appendix D

Sample Facebook Post

Dear warriors,

My name is Ify – a fellow parent and a member of this Facebook group (Raising Autistic Kids of WA). I am currently working on my doctoral dissertation, a qualitative study on lived experiences in autism parenting, and I am recruiting participants who will like to add to the existing data on our unique parenting journeys.

It will be an honor to recruit some of my participants from this support group, which is an integral component of my parenting journey. The ideal candidate must be a parent or legal guardian to an adolescent with a prior formal diagnosis of autism spectrum disorder from early childhood.

The data collected is entirely anonymous. Interested participants should please send me a private message on Facebook, indicating their interest or further questions related to participating in the research.

I look forward to connecting with families, and I am excited about the possibility of adding to the existing research on our special community.

Ify

Dear warriors,

My name is Ify – a fellow parent and a member of this Facebook group (SCSN). I am currently working on my doctoral dissertation, a qualitative study on lived experiences in autism parenting, and I am recruiting participants who will like to add to the existing data on our unique parenting journeys.

It will be an honor to recruit some of my participants from this support group, with it being an integral component of my parenting journey. The ideal candidate must be a parent or legal guardian to an adolescent with a prior formal diagnosis of autism spectrum disorder from early childhood.

The data collected is entirely anonymous. Interested participants should please send me a private message on Facebook, indicating their interest or further questions related to participating in the research.

I look forward to connecting with families, and I am excited about the possibility of adding to the existing research on our special community.

Ify